Possibilities and Boundaries: Assembling an understanding of transition to adulthood for young people with learning disabilities

Francesca S C Ribenfors

PhD 2021

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Francesca Susannah Claire Ribenfors

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

Department of Social Care and Social Work
Manchester Metropolitan University
2021

Abstract

Transition to adulthood is conceptualised within UK policy as occurring between the ages of 14-25 and is a period when professionals working within education, health and social care, support young people with learning disabilities to prepare for adulthood. Despite a plethora of good practice guidance, policy interventions and research attending to transition, it is a difficult time for young people and their families and remains rooted in exclusionary Western notions of child development and adulthood. This research draws on critical disability studies, new materialism and feminist research to offer an alternative approach to transition whereby transition is reconceptualised as an assemblage. It is proposed that transition be viewed as a time to enable becomings rather than a time to transition people to adulthood.

A reflexive, qualitative approach is adopted with the perspectives of three groups of people drawn upon: young people with learning disabilities, mothers, and professionals. To enhance accessibility, the research design is flexible and different methods are utilised depending on the individual participants. This resulted in three focus groups and 18 interviews taking place with photography, post-it notes and an adapted Talking Mat used to facilitate discussions. The data were analysed using reflexive thematic analysis which resulted in the development of three themes and twelve sub-themes. These themes highlight the complexity of transition demonstrating it to be a multidimensional, interconnected, turbulent time for young people and their mothers.

By focusing on transition as an assemblage and a time to enable becomings, this research bridges the divide between theory and practice. It has the potential to improve individual experiences on a practical level whilst simultaneously acting as a form of conceptual activism and disrupting the normative foundations of transition which position young people with learning disabilities as different.

Acknowledgements

It goes without saying I owe my thanks to the people who took part in this research. They generously gave up their time to share their experiences with me, yet another ‘professional’ entering their lives momentarily and taking so much whilst offering little in return.

So many thanks to my supervisors, Sue Caton, Leanne Rimmer, and, in the beginning, Katherine Runswick-Cole. They seemed to know exactly when to challenge and when to encourage or offer reassurance; they had endless patience and always had time to help. I could not have asked for a better or more supportive team.

David, for your support, encouragement, and confidence in me. For putting up with a partner who you have barely seen and for giving me time and space to study – I could not have reached this point without you.

Joseph, for coming into our lives midway through and bringing so much joy. For enabling me to keep things in perspective and for being such a monumental part of my continual becoming.

Mum, for your love and support over the years and more recently for the hours and hours you have spent in the car. For giving up your tennis and time with your bees on so many weekends to help David and me out. It really did make a difference.

Finally, thanks to Vee and the young people in Farmhouse all those years ago for setting me on this path, and to the bloggers and tweeters whose words I have absorbed, for sharing your experiences and drawing attention to the difficulties encountered and making me a more considerate and conscientious person.

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Part One

Chapter One: Thesis Overview

This thesis explores transition to adulthood (transition) for young people with learning disabilities within Northern England. Transition is conceptualised within UK policy as occurring between the ages of 14-25 and a period when professionals working within education, health and social care, support young people with disabilities to prepare for adulthood (DfE, 2015). It is an area that is rich in good-practice guidelines and policy interventions (e.g. NICE guideline on transition, 2016). Nevertheless, research and anecdotal evidence consistently highlight many failings for people with learning disabilities and their families throughout the transition period (e.g. Beresford, 2004; Moshi, 2017; Codd and Hewitt, 2020). There are no shortages of documents proposing recommendations for addressing these failings, which, as the literature review in Chapter Three demonstrates, tend to focus on improving service delivery. However, whilst this is undoubtedly an important area, as is explained in Chapter Four (page 83), the influence of critical disability studies, an attentiveness to the ethics of research and an initial scoping review have resulted in an awareness of the need to go beyond making more recommendations of a similar ilk. I argue that doing so would risk perpetuating the othering of people with learning disabilities and contribute to their continued position on the fringes of society. The aim of the research is, therefore, necessarily broad: I seek to draw on the perspectives of three groups of people affected by transition, young people with learning disabilities, parents and professionals to see if bringing them together in one study, which is not restricted to exploring one aspect of transition over another, can shed new light on transition. Therefore, the research question is: 'what can an understanding of the perspectives of three different stakeholder groups bring to transition?' In answering the question, I present an alternative approach to transition. I draw on the work of Deleuze and Guattari (2004) to argue that transition would be better understood as an assemblage and a time to enable people's becomings rather than to transition people to adulthood. As is discussed in Chapter Twelve, it is an approach that has both a practical and theoretical application. It can improve experiences on an individual level whilst also contributing to debates that critique and aim to deconstruct the normative discourses that are prevalent within our society. Therefore, in the chapters that follow, I document the steps taken to assemble an understanding of transition and reach this conclusion.

However, before embarking on a project centred on ‘learning disabilities’, it is necessary to address the use and implications of language. Scholarly writing can contribute to stigmatisation (Gernsbacher, 2017) and “failure to consider the conceptions of disability that already inform our engagement with our bodies, minds, senses, comportments, is to risk…no, is to enforce the status quo” (Titchkosky, 2012: 105). Therefore, I address the use of language below. Following this, I draw attention to the structure of the thesis. This includes three aspects of the thesis that require a brief explanation (the inclusion of easy read summaries, valuing all knowledge, and the use of the first person) and an overview of the chapters.

The use of language

Often words are used, but their histories, the implications they hold, images they evoke and the complexities surrounding them are ignored. However, language is not a system of signs with fixed meanings with which everyone agrees, but rather “a site of variation, contention and potential conflict…language is about power relations and politics” (Corker, 1998: 226). Therefore, we must pay attention to the language used to label people, and the language associated with people once they are labelled, as words used in relation to disability impact individual self-perception and other people's beliefs about disability (Haller et al., 2006).

The terms used to label people currently known as having a ‘learning’ or ‘intellectual’ disability are continually changing. This may appear as progress. However, Walmsley (2016: online) urges caution as the frequent changes are akin to laundering, which "serves to mask our discomfort with intellectual impairment, and to distance ourselves from that discomfort". Changing terminology does not necessarily correspond with a change in attitude toward people with learning disabilities (Harris, 1995) and whilst learning disability is currently the most prominent term within the UK, it is not without controversy.

The current label, ‘learning disability’, was introduced through government legislation (McClimers and Richardson, 2010) and is, therefore, steeped in unequal power relations (Grant et al., 2010). Nevertheless, it provides as well as denigrates (Goodley and

Runswick-Cole, 2015) and is thus considered a double-edge sword (Gillman et al., 2000). The label is often sought out as it is tied to resource allocation and provides an explanation for perceived differences as it allows for “the danger of difference to be neutralised by the demarcation of a ‘new’ normal for the abnormal” (Mallett and Runswick-Cole, 2016: 95). Meanwhile, identification with the label also enables collective organisation through the self-advocacy movement (Goodley, 2001). However, simultaneously, the label creates and sustains the perception of difference. It is inextricably linked with medicalised diagnostic systems, which work to naturalise the term positioning the impairment it denotes as a biological certainty distanced from its social and cultural underpinnings (Davis, 2010). This is problematic as the ambiguities attached to diagnostic processes are forgotten, and the impairment labels become an “essentialising, all-encompassing bio-medical ‘truth’” which legitimise difference and “prevent the full acceptance of humanity” (Mallett and Runswick-Cole, 2016: 115).

An alternative term is ‘learning difficulty’, which is often used interchangeably with learning disability within health and social care settings.[1] Whilst this does not escape the problematic labelling of people, it is often favoured by self-advocacy organisations (Chappell et al., 2001). However, there is a danger that a rejection of ‘disability’ in favour of ‘difficulty’ separates people with learning difficulties from the social model of disability and the wider disability movement and locates the ‘problem’ within the individual, rather than disabling systems and processes within society, thus limiting any interventions (Walmsley, 1994; Brechin, 1999).

Carespeak

An additional problem concerning language lies in the language of social care. Neary (2017), a father and prominent blogger, uses the term ‘carespeak’ to encompass the terminology used within social care services to describe the lives of people with learning disabilities. Whilst non-disabled people go out and live in their home, learning disabled people ‘access the community’ and live in a ‘placement’, ‘scheme’ or ‘facility’. Such language creates barriers to understanding (Surviving Safeguarding, 2018; TACT, 2019), pathologises and others people with learning disabilities and contributes to their

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[1] It should be noted that learning difficulty is also used within educational systems in the UK to refer to people who have ‘specific learning difficulties’ (e.g. dyslexia).

marginalisation as their lives are considered less than others (Neary, 2018; Shannon, 2019; Moore, 2020). Neary argues that "language is the first step to turning people into non-human objects" (Neary, 2018: online), and it is an assertion supported by professionals as well those on the receiving end of the terms. For example, one social worker, writing anonymously, describes how the language used acts as a tool to dehumanise, ultimately protecting those who are already more powerful:

> Language protected me from the reality of what I was doing to people caught in the system, lacking power and influence because of their age and disability, unable to square up to professionals like me with our clipboards and our own language[…]I learnt that dehumanising people through my use of the language of the professional made it easier for me to cope. (Guest blogger, 2017: online)

This is similar to the argument put forth by Gillman et al. (1997), whereby the construction of people through dehumanising case records silences the individual and allows professionals to distance themselves from the person psychologically enabling them to be treated as an object and controlled accordingly. Similarly, Shannon (2019: online), an adult social care professional who writes about the problematic nature of social care language, explains how language removes humanity from social care, turning practitioners into “robots operating the social care machine”.

Transition, despite being the focus of this research, is one such problematic term. It is included within Neary’s (2017: online) ‘A to Z of Carespeak’, where it is defined as “that moment when your world is turned upside down”. Similarly, the author of the ‘A Bit Missing’ blog (Anonymous, 2012: online) includes transition when writing about the capacity of language to set people with learning disabilities apart from their non-disabled peers:

> Then there’s transition. Young non-disabled people grow up and they make their choices, go to university, go to work and move on to live their lives as adults. Disabled young people *‘go through transition’.*

Titchkosky (2007: 3) calls for us to ‘watch our watching, to read our readings’ whilst Mallet and Runswick-Cole (2012) argue for the need to pay attention to how participation within the study of disability also creates it. Thus, it must be acknowledged that the very act of researching and writing about transition contributes to its existence.

Navigating language in this thesis

Learning disability, people with learning disabilities and learning-disabled are the terms used within this thesis. As aforementioned, the term learning disability is currently in widespread use within the UK, and it is the term used by Learning Disability England - a charity and membership organisation that brings together a vast number of people with learning disabilities, families, advocacy organisations, housing and support providers and commissioners. As I did not know who my participants would be or where the thesis would end up when I embarked on the research, I wanted to ensure my terminology appealed to a broad spectrum of people. Nevertheless, considering the above debates and the oppressive and limiting potential of labels, its use sits uncomfortably, and it remains a decision of pragmatism above all else.

Whilst I endeavour to avoid the use of Carespeak, this has sometimes proved challenging (see **Box 1,** page 26). This challenge reflects my position as a member of staff working within learning disability services prior to and alongside the PhD and how words have become ingrained and normalised within society making them difficult to avoid. Additionally, participants often used Carespeak terms themselves. This can be viewed as evidence of the normalisation of the terms and a statement about unequal relations of power between professionals and parents as one parent blogger reflects:

> As parents we work with so many professionals, we start using their language. We do this so they treat us as equals, so they don't think we are stupid […] or maybe it just becomes a habit that we all get into without thinking. (Anonymous, 2012: online)

Therefore, to avoid using carespeak terms completely, particularly within the findings chapter, would feel a misrepresentation. Instead, drawing attention to the problem provides opportunities for reflection and growth.

Thesis structure

Easy read summaries

Each chapter ends with an easy read summary. In keeping with the recommendations provided by Manchester People First (2018), the text is kept simple, and pictures are used to support the text. Whilst easy read documents alone are not enough to ensure accessibility, and there is a risk that the complexity of the original message is lost (Walmsley, 2010), they are nevertheless viewed as one way of enhancing accessibility. This is particularly important in learning disability research as one group of self-advocates recently stated in the British Journal of Learning Disabilities:

> We believe that research that talks about the lives of people with a learning disability, autistic people and families should be available in accessible versions so that everyone can understand. (Sunderland People First, 2021)

Therefore, it is intended that the easy read summaries at the end of each chapter provide a clear and concise overview of the chapter's key points. They can also stand alone and, together, form a more accessible version of the thesis.

Valuing all knowledge

Alongside academic journals and books, tweets and blogs by disabled people, carers and allies are drawn upon and woven through the main body of text within this thesis. I believe that doing so recognises the value of different voices, contributes to breaking down knowledge hierarchies and enhances the transparency of the thesis. A more thorough explanation of the rationale for this is provided in Chapter Five, where I consider some of the ethical tensions associated with the research.

The use of the first person

Within the thesis, my writing alternates between first and third person depending on the nature of the section and the depth of my involvement with the content. This follows authors such as Webb (1992) and Mitchell (2017), who, adopting a feminist position, argue for author visibility through the use of the first person to counteract positivist notions of objectivity and enhance the accessibility of writing.

Chapter summaries

Chapter One introduces the thesis. I draw attention to the use of language and outline several key features of the thesis.

Chapter Two provides context to the thesis. I acknowledge the entanglement between the researcher and their research and introduce myself, explaining my position when I embarked on the PhD and my motivations for doing so. I introduce feminist research, critical disability studies and new materialism, three theoretical positions which have shaped the development of the research.

Chapter Three sees me draw on existing literature and government policy to tell a story about what is known about transition. I situate the research within its policy context and explore how transition has been approached within research. The influence of critical disability studies is visible as I examine the normative underpinnings of adulthood and highlight why this poses problems for people with learning disabilities and transition.

Chapter Four explains how I carried out the research. I return to positionality to provide an overview of my philosophical paradigm and explain how the research aim developed. I present the tools used to conduct the research and an overview of the recruitment and analysis processes.

Chapter Five considers research ethics. I discuss the difference between procedural ethics and ethics in practice and draw attention to several ethical tensions which arose during the research.

Chapter Six introduces the people who took part in the research. I aim to convey a sense of who they are and show them to be people, not simply research participants whose stories are reduced to data.

Chapter Seven presents an overview of how the participants understand transition. The lack of shared meaning between participants prevents this chapter from being considered a theme. Nevertheless, it is an integral part of the findings, and I draw upon it alongside the themes within the discussion chapters.

Chapter Eight presents the first theme: The Transition Minefield. This theme relates to mothers and professionals and shows why transition is considered a minefield.

Chapter Nine presents the second theme: Networks of Support. This theme relates to mothers and young people and highlights the importance of relationships, connections made, and losses encountered during transition.

Chapter Ten presents the third theme: The Push and Pull of Adulthood. This theme relates to mothers, young people, and professionals and examines how participants encounter adulthood.

Chapter Eleven is the first of the two discussion chapters. I draw on the preceding four chapters to argue that understanding transition as a two-fold process (i.e., moving from children to adult services and becoming an adult) is unhelpful. It obscures transition as a multidimensional, interconnected, turbulent time.

Chapter Twelve is the second of the two discussion chapters. Here I draw on Deleuze and Guattari (2004) to argue that transition is better understood as an assemblage and a time to 'enable becomings' rather than to transition people to adulthood. I demonstrate how approaching transition in this way has both a practical and theoretical application.

Chapter Thirteen concludes the thesis. I summarise how the research question has been answered, provide an overview of my contribution to knowledge, acknowledge the limitations of the research, and examine how the research has changed me.

Chapter One summary

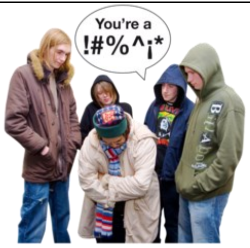
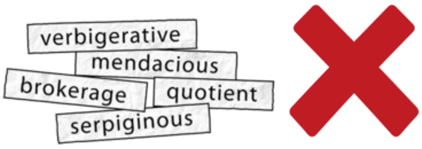
	**Research** is when we try to find things out. This chapter tells you a bit about this **research**.
 	This chapter also talks about language and why there are easy read summaries.

The research

	The research is about transition to adulthood for young people with learning disabilities.
	The research wants to find out more about transition by talking to young people with learning disabilities, parents and professionals.

Language

	It is important to think about the words we use when talking or writing about disability.

	This is because words can hurt people.
	Sometimes the words professionals use make people with learning disabilities seem different.
	This research tries not to use words like this.
	This research uses the term ‘learning disability’ as this is the term most used in the UK.

Easy read summaries

	The easy read summaries tell you about the important bits of the research.
	This is to make it easier for people with learning disabilities to read about the research.

Chapter Two: Introductions

This chapter provides context to the research; I introduce myself as the researcher and provide an overview of three theoretical models that have influenced my thinking, and thus the development of the thesis. I begin the chapter by recognising the influence researchers have over their research and the subsequent creation of knowledge, and I highlight the importance of paying attention to researcher positionality. In light of this, I introduce aspects of my positionality. I weave a path through my personal circumstances, my professional life, and my academic career to elucidate the motivations behind the research and the subsequent form it took, noting that as my positionality evolves and shifts, so too does the research. Following this, I provide a theoretical toolbox. This consists of an introduction to three influential theoretical 'tools': feminist research, critical disability studies, and new materialism. These 'tools' have not only shaped the research and the subsequent thesis, but they have also impacted my identity as both a researcher and someone who works with people with learning disabilities.

The importance of positionality

The concept of positionality stems from feminist scholarship whereby claims of objective, value-free research are questioned, and the myth of the neutral researcher is discredited (Oakley, 1981; Mullings, 1999; Doucet and Mauthner, 2007). Rather than trying to deny the entanglement between the researcher and knowledge production, positionality emerges as a way to encompass the researcher's worldview and their position in relation to the social and political context of the research and highlight the influence this can have on research (Doucet and Mauthner, 2007; Foote and Bartell, 2011; Savin-Baden and Major, 2013; Holmes, 2020). It recognises that researchers are enmeshed within their research as the ontological and epistemological assumptions, values and beliefs, political allegiances, demographic characteristics, and personal experiences of the researcher shape the questions asked, the methodologies used and the results produced (Foote and Bartell, 2011; Rowe, 2014; Holmes, 2020). The extent of the researcher's involvement is highlighted by Denzin (1986: 12) when he states, "interpretative research begins and ends with biography and self of the researcher". As a result, knowledge is viewed as only ever partial as its creation rests within the complex and sometimes contradictory social locations of the creators and the audiences (Women and Geography Group, 1997).

The importance of declaring one's positionality is two-fold. Firstly, it adds to the integrity of the research. The rigour and trustworthiness of research can be enhanced by including the researcher within the research, for example, by clarifying the underpinning values and beliefs and examining how they have influenced the research and engaged in knowledge construction. Providing readers with the opportunity to better understand the interpretations made, meanwhile, enables them to examine the validity of any claims (Etherington, 2004; Watt, 2007; Holmes, 2020). Secondly, there is a political dimension as attending to positionality can expose the power hierarchies that permeate research and affect what one does or does not see (Foote and Bartell, 2011).

Exposing and disrupting power inequalities is a central principle of feminist research (Skeggs, 1994; Doucet and Mauthner, 2007) which, as is highlighted within the theoretical toolbox section of this chapter, has been a guiding school of thought throughout this thesis. However, we cannot attend to external relations of power if we do not first examine our own and situate ourselves within the power dynamics threaded through our research (Ackerly and True, 2008). This is particularly important within disability research, where ethically questionable research practices have perpetuated the oppression and marginalisation of disabled people (Oliver, 1992; Stone and Priestley, 1996; Swain et al., 1998).

It is argued that it is impossible to research oppression, and thus disability, objectively or scientifically (Barnes, 1996; Oliver, 1997). The disability activist Paul Hunt (1981: 42) emphasises the inability of researchers to be impartial when he states:

> Faced with any socially oppressed group, social scientists have a choice of only two alternatives: either a firm commitment to serve the interests of the oppressed group to end their oppression, or a commitment to serve the interests of the oppressors to continue their oppressive practices.

In relation to learning disabilities, research has tended to fall into the latter of these two categories. It has been used to support the segregation and institutionalisation of learning disabled people (e.g. Radford, 1994; Rioux, 1994), it has involved abusive practices (Krugman et al., 1962; Krasse, 2001), and, more often than not, it has simply ignored people with learning disabilities altogether (Walmsley, 1997; Chappell, 1998). Therefore, when approaching disability research, it is important to establish "whose side is the disability researcher on?" (Goodley, 2011: 23). The section that follows, therefore, sets out my position as the researcher. It draws on both my personal and professional life and my academic career to explain who I was when I embarked on the research and how this, and the research, have developed symbiotically during the PhD.

The researcher

I began the PhD following ten years working with people with learning disabilities and their families in various learning disability services. It was a career path I stumbled upon; my undergraduate degree was coming to an end, and I needed a job and a place to live. Scouring the university careers page on the intranet, I found a job advert for a support worker role at Young Epilepsy, a residential college for young people with learning disabilities and epilepsy. Conveniently, not only was staff accommodation provided but the start date tied in with the end of university. Little did I know at this stage just how formative the move would be, turning from simply a 'stop-gap' job into a career in an area and with people I care for deeply. However, whilst I was not, at this stage, driven by a desire to work specifically with people with learning disabilities, I knew I wanted to work with people. My curiosity for understanding people and how society works coupled with a left-leaning family who tended to gravitate towards caring professions had led me to study anthropology for my undergraduate degree. Furthermore, disability was not wholly unfamiliar territory. I have an uncle who is heavily involved in L'Arche, and he would often bring members of his community along with him when he came to visit. I also have two cousins with learning disabilities, and our paths would cross during the school holidays and at large family gatherings. Therefore, disability was an ordinary part of extended family life.

After being offered the support worker job, the following two years were spent, very enjoyably, living in on-site staff accommodation whilst working in 'Farmhouse', home to six young women with learning disabilities who attended the campus college. However, whilst it was great fun, fragments of institutionalisation began to surface and disrupt my naivety. Each morning the young people were required to complete their 'morning jobs' before going to college – a rota of chores that included cleaning the toilets, tidying and hoovering the sitting room and mopping the kitchen floor. With hindsight, this was one of my first encounters with the various discourses acting on young adults with learning disabilities and forcing them to "display a reasonableness which was above-and-beyond” (Slater, 2015: 57). At the time, however, it simply felt bizarre to make people, a similar age to myself, tackle these chores first thing in the morning when I had only leapt out of bed ten minutes previously, leaving my bedroom in a mess, let alone taking the time to mop any floors. Another example of the disruptive encounters relates to the contraceptives the young women were prescribed. Despite not being sexually active, most of the people I supported had been prescribed ‘Depo-Provera’, a contraceptive I had not heard of before I entered Farmhouse, but one I now know is widely over-used with women with learning disabilities (McCarthy, 2009). Although articulate, the young people I supported who were prescribed the contraceptive could not explain what it was or why they were taking it. There was a sense it was prescribed as a matter of routine, and I am still not sure why.

I did not have the confidence to challenge these situations at the time, nor did I know any better, but they, and others, niggled away at me. They contributed to a growing sense of unease, not only at how services were run but also at how people with learning disabilities were positioned within society. I have often reflected upon my time at Farmhouse whilst thinking and writing about adulthood within the context of this thesis. The work of Slater (2015) resonated as they describe how young people with disabilities are pushed into a discourse of adulthood rationality and reasonableness, thereby denying them the opportunity to “live the ‘unreasonableness’ of youth” (Slater 2015: 58).

Several roles related to transition followed my time at Young Epilepsy. I was fuelled with a desire to work with people with learning disabilities during transition, having witnessed the difficulties young people and their families faced when it was time to move on from Farmhouse. Therefore, I first worked within a further education college to support young people with learning disabilities into employment and then as a support broker[2] within a local authority. The feelings of discomfort, which arose whilst working as a support worker, continued to grow. However, reflecting a lack of engagement with matters beyond my immediate role and a limited critical awareness, my focus was predominately on service issues rather than on the social or cultural underpinnings.

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[2] My role as a support broker involved working closely with young people and their families to develop support plans, set up personal budgets, secure funding, establish supported living homes etc.

I became increasingly frustrated by how the local authority treated people with learning disabilities and their families during transition, the unnecessary stress and anxiety caused by a system supposedly designed to help. Keen not to add the issues families faced, I made a point of being open and transparent with the people I was working with and paid particular attention to ensuring I respected their experiences and did not privilege practitioner knowledge (Hodge and Runswick-Cole, 2018). However, whilst I can safely say it never crossed my mind to call parents by anything other than their names[3] and I worked hard to involve people with learning disabilities within the decision-making processes related to their lives, I did little to engage with the broader power dynamics. I had yet to encounter the term ableism, and I struggled to interrogate those feelings of unease relating to the othering of people with learning disabilities and their families that had started to emerge. As a result, I am now ashamed to think about how little attention was paid to the damaging effect of 'carespeak' described in Chapter One; we broke people's lives into 'outcomes' and 'objectives', put 'packages of care' in place and ensured people had 'opportunities to access the community'. Furthermore, securing a family respite provision was viewed only as a positive and something to be grateful for. The enormity of the word and all that it stood for went unacknowledged (Ryan, 2020).

Driven by my experiences, I applied to study part-time for a MA in Intellectual and Developmental Disabilities. It was a course that proved uninspiring as a heavy emphasis was placed on applied behavioural analysis, diagnostic processes and 'challenging behaviour,' all areas outside of my comfort zone. This was further exacerbated by the lack of sessions led by, or at least involving, people with learning disabilities – a somewhat glaring omission. Nevertheless, I enjoyed the opportunity to develop my research skills. Therefore, when, a few years later, the opportunity arose to apply for a funded PhD in an area connected to my work, I seized it. I remained interested in trying to get to grips with my views on disability and stances held by others. I was keen to develop my research skills, deepen my understanding of transition issues and ultimately improve my practice to better support families and young people. It is from this position,

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[3] The campaign 'Don't call me Mum' (https://www.bornattherighttime.com/dont-call-me-mum/) draws attention to how being called 'Mum' or 'Dad' by professionals creates a power-based relationship that fails to recognise or take into consideration parental expertise.

a burgeoning critical awareness coupled with a heavy focus on service issues, I began the PhD.

The above describes who I was at the start of the research. However, it is not who I remained; just as my positionality has affected the research, so too has the research affected me. The section on new materialism in the theoretical toolbox below explains how Deleuze and Guattari's (2004) notion of assemblage is drawn upon within the third part of the thesis. However, my engagement with assemblages also helped me appreciate the research process as a whole, and my changing position within this, as I came to understand research as an assemblage (Fox and Alldred, 2017; Carroll et al., 2020). An assemblage is:

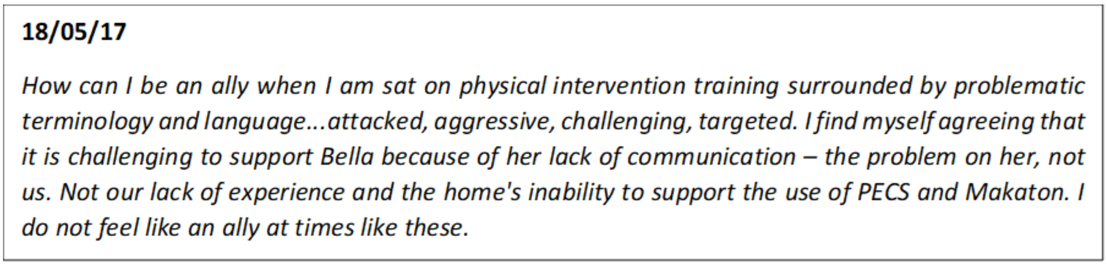
> An emergent, temporarily stable yet continually mutating conglomeration of bodies, properties, things, affects and materialities. Assemblages are not background structures, static situations or stable entities; they are active, always emergent and changing confederations of bodies, objects spaces, affects, forces and desires. (Taylor and Harris-Evans, 2018: 1258)

While this concept is explored further within Chapter Twelve (The Transition Assemblage), its inclusion here draws attention to the shifting, emerging nature of identity and positionality. Treating research as an assemblage, comprising the researcher/s, research participants, supervisors, buildings, books, ideas, technologies, fears, desires, academic standards, discourses and so on, brings forth the complexity and interconnectedness of our endeavours. Thus, as a becoming researcher, our positionality is never fixed as our values and subjectivities change over time, affected by what we encounter and the passing of time (Rowe, 2014).

An example of how the research has affected me can be found in my encountering critical disability studies and feminist research for the first time during the PhD. As is explained in the respective sections of the theoretical toolbox, a growing awareness of these theories has proved illuminating. They have enabled me to begin to unpick the complexity surrounding those niggling thoughts that pervaded my practice, challenge taken for granted notions and become aware of the ableism surrounding us. This has filtered through to the research and helped shape the thesis. It also provided an insight into my behaviour within my professional life and formed part of my becoming. This has, however, not been without its challenges.

For the first couple of years of the PhD, I worked part-time as a support worker in a residential home for children with learning disabilities. It proved unexpectedly conflicting. On the one hand, I was reading and writing about the problematic use of labels and language, the politics of disability studies and the industry built around the othering of people with learning disabilities (Brown, 2021). On the other hand, I was going into work using those problematic terms and expected to encourage young people to conform to developmental norms (Burman, 2008). As the extracts in the two boxes below (**Box 1** and **Box 2**), taken from my diary kept during the research, demonstrate, I felt complicit in their othering.

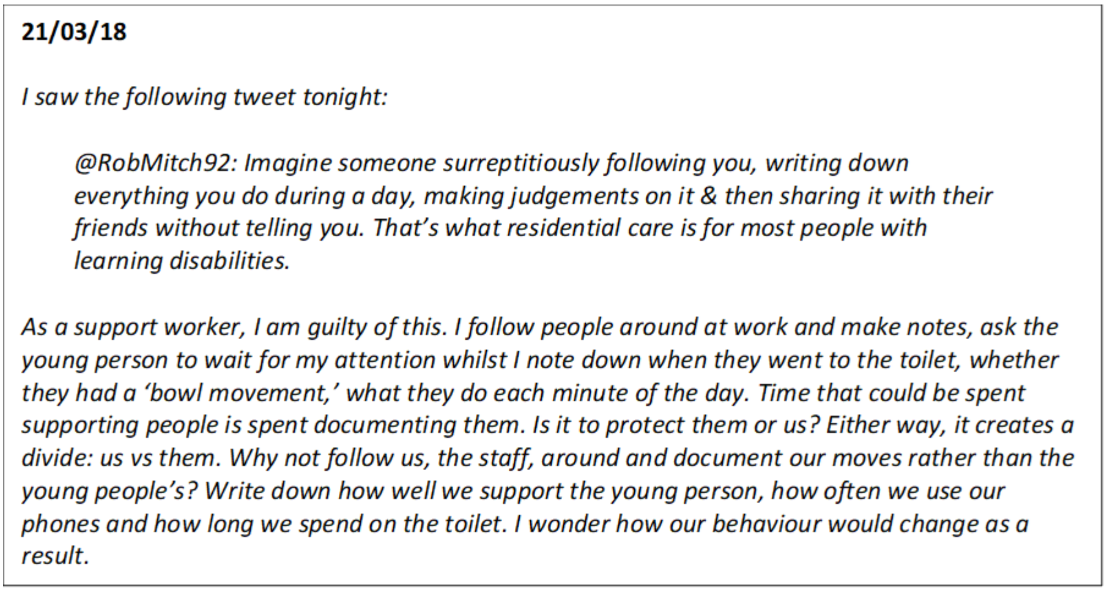
Box 1 Research diary extract 18/05/17



18/05/17

How can I be an ally when I am sat on physical intervention training surrounded by problematic terminology and language...attacked, aggressive, challenging, targeted. I find myself agreeing that it is challenging to support Bella because of her lack of communication – the problem on her, not us. Not our lack of experience and the home's inability to support the use of PECS and Makaton. I do not feel like an ally at times like these.

Box 2 Research diary extract 21/03/18



21/03/18

I saw the following tweet tonight:

> *@RobMitch92: Imagine someone surreptitiously following you, writing down everything you do during a day, making judgements on it & then sharing it with their friends without telling you. That's what residential care is for most people with learning disabilities.*

As a support worker, I am guilty of this. I follow people around at work and make notes, ask the young person to wait for my attention whilst I note down when they went to the toilet, whether they had a 'bowl movement,' what they do each minute of the day. Time that could be spent supporting people is spent documenting them. Is it to protect them or us? Either way, it creates a divide: us vs them. Why not follow us, the staff, around and document our moves rather than the young people's? Write down how well we support the young person, how often we use our phones and how long we spend on the toilet. I wonder how our behaviour would change as a result.

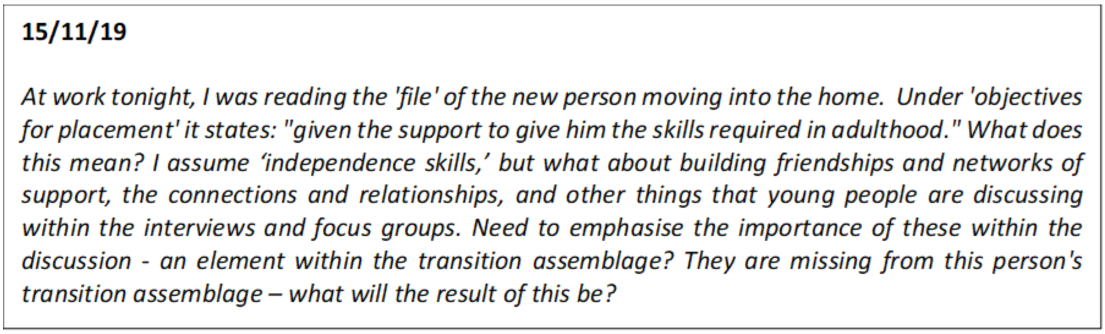
As a result, I struggled with my position; I did not feel I entirely belonged within academia, but I was also no longer content with my role within services. This was further complicated by my awareness that, in relation to the research, I am not an ‘insider’. The role of the non-disabled researcher within disability studies is a contentious one (Oliver, 1992; 1997; Zarb, 1997; Barnes, 2003; Barnes and Sheldon, 2007) and I am not disabled. I was also not a mother at the time of the interviews, and thus, I had not experienced disablism either myself or as a mother of a disabled child (Ryan and Runswick-Cole, 2008). Adopting a feminist approach to the interviews helped overcome the insider/outsider dichotomy. I explain in Chapter Four that the interviews were considered an interactive and creative experience. Thus, at times, I offered up parts of my background and used self-disclosure to position myself closer to an insider to demonstrate an understanding of the topic and highlight a shared sense of injustice (Oakley, 1981; Fontana and Frey, 2008). At other times, however, it felt important to draw attention to my outsider status. For example, when I was asked by a self-advocacy group what my transition to adulthood was like, a conversation about othering ensued.

I use the above, self-advocacy group, example to demonstrate my outsider status. However, it also reveals the unhelpfulness of viewing the researcher’s position as a dichotomy between an emic and etic perspective or insider and outsider status. After all, the group felt comfortable asking the question suggesting they viewed me as something of an insider – young enough to relate to the question. Thus, a more nuanced approach to one’s position is required. Mercer (2007) proposes viewing it as a continuum along which the researcher moves depending on each specific context, whilst Merton (1972: 28) breaks down the dichotomy when he states:

> Sociologically speaking, there is nothing fixed about the boundaries separating Insiders from Outsiders. As situations involving different values arise, different statuses are activated, and the lines of separation shift.

Similarly, Dwyer and Buckle (2009: 60) reframe the dichotomy as ‘insider-outsider’ where the hyphen “acts as a third space, a space between, a space of paradox, ambiguity, and ambivalence, as well as conjunction and disjunction”. My position is thus more akin to the hyphen than any ‘insider’ or ‘outsider’ label. Sitting within the hyphen provided space for the reflections from work to take place. Rather than viewing them as problematic, preventing access to ‘insider’ status or barring my alignment as an ally, they were embraced. I came to view the reflections as evidence of a deeper engagement with ethics and politics and appreciate how they enriched the development of the thesis, as the extract in **Box 3** below demonstrates.

Box 3 Research diary extract 15/11/19



15/11/19

At work tonight, I was reading the 'file' of the new person moving into the home. Under 'objectives for placement' it states: "given the support to give him the skills required in adulthood." What does this mean? I assume ‘independence skills,’ but what about building friendships and networks of support, the connections and relationships, and other things that young people are discussing within the interviews and focus groups. Need to emphasise the importance of these within the discussion - an element within the transition assemblage? They are missing from this person's transition assemblage – what will the result of this be?

Theoretical toolbox

The thesis has developed from my history and experiences working within services, the relationships between myself and my participants, and many other elements. This includes my encounters with different theoretical models. Therefore, the section below outlines three key theoretical developments: feminist research, critical disability studies and new materialism. Together, these theories acted as a theoretical toolbox for the research.

Rather than steadfastly subscribing to one theory over another, the theoretical tools were employed at various stages throughout the research similar to a bricoleur or quilt maker who “uses the aesthetic and material tools to his or her craft, deploying whatever strategies, tools or empirical materials are at hand” (Denzin and Lincoln, 2003a: 6). The metaphor of the bricoleur is borrowed from Levi-Strauss (1966), who uses it in contrast to engineers who follow set procedures using a list of specific tools. Unlike the engineer, the bricoleur has no set way to carry out the research; instead, by adopting a critical approach, drawing on multiple perspectives, theories and methodologies, the research develops and gains depth as it evolves, reflecting the complexity of the lived world (Rogers, 2012). Furthermore, treating the theories in such a way allows for my becoming to be reflected in the research, the research and subsequent thesis developing and evolving as I, the researcher, developed and evolved. It is not a case of a "whatever-goes approach" (Zipf, 2016) but rather a conscious decision to remain open to new ideas and to embrace opportunities that enter into the research assemblage. As a result, however, whilst the research develops, the ultimate destination remains unknown:

> We don't know exactly where we're going, and sometimes we don't even know where we've been, but we do assemble something in the end […] We are not scientists who claim to know where they are going. For us the journey is the inquiry. (Bradley, 2014: 660)

The lack of destination is reflected within the thesis. As explained in the new materialism section below, I did not embark on the research with the transition assemblage in mind; instead, it developed due to my engagement with the different theoretical tools.

Feminist research

The first of the theoretical tools is feminist research. Defining feminist research can prove challenging as a standardised approach fails to exist (Maynard, 1994). Skeggs (1994: 77) argues feminist research is different from non-feminist research because it "begins from the premise that the nature of reality in western society is unequal and hierarchical", whilst Doucet and Mauthner (2007: 36) state that feminist research is:

> The work that feminists do when they take on either qualitative or quantitative research that is driven by, and aimed toward, a desire to challenge multiple hierarchies of inequalities within social life.

Therefore, despite methodological pluralism, it is widely recognised that a core set of values unites feminist researchers. They are values which, as shown in the statements by Skeggs (1994) and Doucet and Mauthner (2007) above, are centred on principles of social change, social justice and the challenging of the power hierarchies permeating society.

The roots of feminist research lie within the exclusion of women from academia and the consequential silencing, misrepresentation and misinterpretation of women's experiences as knowledge creation rested on the male experience (Mulinari and Sandell, 1999). Not only were women often missing as research participants, but because research was focused on problems articulated by men, it failed to take into consideration topics of importance to women or fully reflect women's perspectives

(Saarinen, 1988; Brooks and Hesse-Biber, 2007; Doucet and Mauthner, 2007; Stanley and Wise, 2013). Furthermore, as knowledge relating to women stemmed from men and male perspectives, it was filtered through relationships of power and subordination that prevailed between men and women (Saarinen, 1988). The problematic nature of this is summed up by Harding and Hintikka (1983: X), who explain:

> When […] experience is presumed to be gender free - when male experience is taken to be the human experience - the resulting theories, concepts, methodologies, inquiry goals and knowledge claims distort human social life and human thought.

A growing awareness of this issue led to a call by feminist scholars for sexual (masculine) biases to be exposed, a recognition of the entanglement between power and knowledge creation and for research to be not just about women but for women and with women (Doucet and Mauthner, 2007). Rather than relying on traditional positivist frameworks, feminist scholars advocated for a plurality of methods and methodological approaches to encompass the richness and diversity of human experience. For Oakley (1981: 58), this meant contesting the notion of the objective researcher and welcoming a research-participant relationship because personal involvement “is the condition under which people come to know each other and to admit others into their lives”.

The concern with relations between knowledge and power within feminist research is thus twofold, as attention is drawn to the power exercised through knowledge claims and how power operates within knowledge production. Politics are imbued through every aspect of the research process (Smith, 2012). As a result, a recognition of the wider contexts within which knowledge generation occurs is required alongside an attendance to the power dynamics between researcher and researched as there is a danger “research processes themselves [re]produce power differences” (Harding and Norberg, 2005: 2012). Emphasising the importance of turning attention inwards and addressing the inequalities perpetuated within research processes, Ackerly and True (2008: 694) pose the question, “how can we study power and identify ways to mitigate its abuse in the real world when we […] also participate in the powerful production of knowledge in this world?” Ackerly and True (2008) set out a feminist research ethic to support researchers in this area. They argue that researchers must pay attention to the power dynamics within the epistemologies, boundaries and relationships present within their research. The power of the researcher to silence and marginalise is threaded throughout all stages of the research process, for example, from the inclusion and the exclusion criteria, the prioritising of one research topic over another through to the selection of the methods and the analysis and interpretation of data (Mullings, 1999; Doucet and Mauthner, 2007; Ackerly and True, 2008). Reflecting this, Jenkins et al. (2019: 424) advocate for the selection of methods that "reveal complexity and nuance, with a focus on valuing individuals and ensuring that both the researcher and the research participants retain their human faces and voices". In addition, reflexivity, taken to mean “interpreting one’s own interpretations, looking at one’s own perspectives, and turning a self-critical eye onto one’s own authority as interpreter and author”(Alvesson and Sköldberg, 2000: vii), becomes an integral part of feminist research as it is a tool by which researchers can attend to these issues (Baldwin, 2020; Ackerly and True, 2008).

Feminist research values are drawn upon throughout this study. The research topic is chosen due to the ‘real-world’ issue it presents (Robson, 2011) and knowledge of the structural inequalities and power hierarchies that persist for people with learning disabilities and their families, which posit them on the margins of society. As is outlined in Chapter Four, a desire to understand transition from the perspectives of those who experience it and consideration for the richness and complexity of human experience informs the design of the research; it is a qualitative inquiry, which draws on principles of inclusive research and pays attention to methods and communication to enhance accessibility. Whilst professionals are included as participants within the study, their inclusion is not due to a desire to triangulate the data. Their perspectives are not prioritised, nor is it expected for them to speak definitively on transition. Instead, their inclusion sheds light on the complexity and interconnectedness of transition and allows for examining their power and the implications this has for people with learning disabilities and their families during transition. As is explained within Chapter Five, feminist research and critical disability studies inform the approach taken towards literature within the thesis whereby both academic and non-academic voices are drawn on as attention is paid to silences and boundaries within knowledge production and the question ‘whose knowledge counts?’ posed (Ribenfors, 2020). A concern that the analysis process may lead to participants becoming a series of disembodied quotes (Baldwin, 2020) has led to the inclusion of Chapter Six which, through pen-pictures, situates the participants as people first and foremost rather than data. Finally, a reflexive and transparent approach to knowledge production is adopted and is visible at key junctures within the thesis. This is supported by the use of a reflexive research diary which was kept throughout the research with extracts, such as the ones in the boxes above, included at various points within the thesis to support the main body of text and to expose some of the thought processes lying behind the unfolding of the research and the thesis.

Critical disability studies

The second theoretical tool is critical disability studies (CDS). As explained within 'the researcher' section above, I embarked on the PhD with a desire to develop my critical awareness and explore the underlying feelings of discomfort. A developing engagement with CDS provided the opportunity to do this, supplying the means to begin interrogating the assumptions and beliefs held concerning disability and subsequently work at noticing and disrupting these within my personal and professional life.

As with feminist research, it is helpful to consider the roots of a theory or movement to understand how it has developed and thus how it can be drawn on today. Within disability studies, this means first paying attention to the social model of disability. This model has been revolutionary within the disability movement and fundamentally challenged the way disability has been perceived. Originating from the Union of Physically Impaired Against Segregation (UPIAS, 1976), the social model of disability separates impairment and disability and, in doing so, moves the location of the 'problem' from the individual and their impairment to society. Rather than the focus resting on 'curing' or 'fixing' a 'broken' body, the social model shifts attention to a disabling society and therefore, whilst impairment may be a human constant, disability need not be (Oliver, 1996; Oliver and Barnes, 1998; Barnes, 2012). The result was, for many, liberating (Crow, 1996; Thomas, 1999). So much so that as Shakespeare and Watson (2002: 3) point out, it is now seen as "the ideological litmus test of disability politics in Britain, used […] to distinguish between organisations, policies, laws and ideas which are progressive, and those which are inadequate".

However, the social model is not without criticism, not least for excluding people with learning disabilities (Chappell, 1998; Boxall, 2002; Stalker, 2012) who have remained pathologised and "thrown into the category of naturalised, irrational 'other' […] personal tragedies of their unchangeable 'organic impairments'" (Goodley, 2001: 211). Additionally, despite its original transformative potential, the binary distinction between disability and impairment, and the shift of attention away from impairment, is limiting and the source of much debate since its conception. For example, many disabled feminist scholars, drawing on their personal experience of impairment, have called for more emphasis to be placed on impairment, arguing the effects of impairment, such as pain, can be disabling in their own right (Morris, 1992; French, 1993; Crow, 1996). Crow explains:

> As individuals, most of us simply cannot pretend with any conviction that our impairments are irrelevant because they influence every aspect of our lives […] What we need is to find a way to integrate impairment into our whole experience and sense of our selves for the sake of our own physical and emotional well-being. (Crow, 1996: 58)

Similarly, the nature of impairment has been the focus of attention for critical realists such as Shakespeare and Watson (2002) and Vehmas and Mäkelä (2008) who have argued for the material reality of impairment. For Shakespeare, whilst an accessible environment may minimise the inconvenience of impairment, it does not equalise disabled people with non-disabled people as he states, “my problem is my physical embodiment and my experience of negative symptoms arising from impairment” (Shakespeare, 2014: 65). Others, meanwhile, call for a more nuanced approach that considers the socio-cultural layers surrounding the phenomena (Goodley, 2017). Goodley (2001: 210), for example, argues for “an understanding of ‘learning difficulties’ as a fundamentally, social, cultural, political, historical, discursive and relational phenomenon”.

It is from this backdrop that CDS emerges. CDS remains respectful to the key ideas that emerged with the social model and revealed the structural and material barriers contributing to the oppression and marginalisation of disabled people. However, it seeks to move beyond the model (Meekosha and Shuttleworth, 2009; Goodley, 2013) and aims to:

> Deliberately shake up some of our assumptions about disability and its historical antecedents by employing critique, not just as a way of challenging external forces, but as a method that contests the apparent verities of disability studies itself. (Shildrick, 2012: 33)

In other words, whilst conventional approaches to disability focus on inclusion through the extension and solidification of rights for disabled people, CDS argues that this is not enough. Maintaining a focus on disablism is unhelpful as it often continues to examine and teach disability from the perspective of the Other (Campbell, 2009) and fails to break down the problematic binaries such as disabled/non-disabled, inclusion/exclusion and normal/impaired. Instead, scholars within CDS seek to unsettle entrenched ways of thinking and deconstruct ideas about disability and impairment and, in doing so, understand how and why such definitions are created and contest the normative discourses which underpin them (Shildrick, 2012). As Campbell (2009: 4) states, the challenge is:

> To reverse, to invert this traditional approach, to shift our gaze and concentrate on what the study of disability tells about the production, operation and maintenance of ableism.

Like feminist research, CDS is inherently political. Goodley (2017: 191) explains that "while critical disability studies might start with disability it never ends with it" as it enables consideration for a multiplicity of political, theoretical and practical issues that hold relevance to all. Viewing anomalous bodies through a CDS lens, for example, does not end with those bodies but instead challenges normative assumptions of able bodies and exposes the social, cultural and political conditions which create and sustain such bodies (Goodley, 2013).

New materialism

The final theoretical tool is new materialism. Unlike feminist approaches to research and critical disability studies, new materialism was not influential from the early stages of this study. The research began from a social constructionist perspective, and thematic analysis, rather than assemblage analysis, is utilised; this study is not a new materialist or post-qualitative endeavour (St. Pierre, 2021; 2015). However, remaining open to different theoretical perspectives enabled me to embrace different perspectives when suitable. Therefore, a growing awareness of new materialism, particularly during the analysis stage of the research, and a realisation of the possibilities Deleuze and Guttari's (2004) notion of assemblage held for transition, has very much shaped the discussion in Chapter Eleven and Chapter Twelve. Furthermore, as previously mentioned, it has also significantly impacted my understanding of the research process and has subsequently clarified my role and identity as a researcher. Therefore, an overview of new materialism is included here whilst Deleuze and Guattari's notion of assemblage is addressed in Chapter Eleven and Chapter Twelve.

New materialism is the name given to a collection of theoretical developments which, sharing a re-turn to a focus on matter, arise in response to dissatisfaction with the anthropocentric and logocentric focus of post-modern paradigms (Monforte, 2018). Whilst post-structuralist and social constructionist epistemologies have been beneficial in drawing attention to the relationship between problematic language and the othering of people with disabilities, they have also been viewed as limiting; the emphasis on language is believed to come at the expense of material or non-human forces (Blaise, 2013). Fox and Alldred (2017: 67) sum up the problem when they explain how, "in post-structuralism, texts and textuality become the object of inquiry, while the biological body appeared to recede beyond the analytical purview of the post-structuralist social scientist". Such limitations are particularly pertinent to CDS which has been accused of paying too much attention to texts and discourses whilst overlooking "the ordinary lives of disabled people" (Shakespeare, 2014: 52) and, unlike their critical realist counterpart, ignoring the material reality of impairment and lived experience (Shakespeare, 2014; Vehmas and Watson, 2014). However, Feely (2016) turns attention on the critical realist critics whose approach, he explains, is similarly problematic. Whilst they may indeed engage with the material reality of impairment, they edge perilously close to a return to essentialist understandings of the human body as they perpetuate ideas related to a 'species norm' and fail to contest the discourses which construct people with impairments as different, and less than, others.

It is here that the benefits of new materialism lie as its distinctive ontology enables the discursive and the material to be brought together without a return to essentialism. Post-structuralist and social constructionist insights, which allow for contesting problematic identity categories, are thus entwined with recognition of material reality and embodiment (Feely, 2020; 2016). Described as 'flat' or 'monist', the new materialist ontology breaks down existing dichotomies between natural and social worlds, humans and non-humans, and mind and matter. Furthermore:

> By challenging any distinction between the materiality of the physical world and the social constructs of human thoughts and desires, it opens up the possibility to explore how each affects the other, and how things other than humans […] can be social 'agents', making things happen. (Fox and Alldred, 2017: 7)

It is, therefore, a 'new settlement' rather than a return to Marxist-inspired materialism as matter is viewed neither through an essentialist lens (whereby it is inert and fixed) nor a post-structuralist lens (whereby it is considered as constructed through cultural and linguistic practices) (Monforte, 2018). Instead, both matter and discursive statements are real and mutually affecting. Entities emerge from their relations with each other and, as a result, the world and all that is within it is not static or stable but rather constantly emerging in unpredictable ways "in a kind of chaotic network of habitual and non-habitual connections, always in flux, always reassembling in different ways" (Potts, 2004: 19).

As new materialist approaches do not solely privilege the discursive (and therefore reduce all interventionist critiques of oppression to products of yet further social or cultural constructions), the gap between theory and practice is narrowed (Fox and Alldred, 2019). Therefore, it is a useful paradigm for those looking to research the social world and those wishing to improve it. Fox and Alldred (2019: online) explain:

> The turn to matter offers a re-immersion in the materiality of life and struggle, and the recognition that in a monist world – because there is no 'other level' that makes things do what they do – everything is necessarily relational and contextual rather than essential and absolute.

Furthermore, due to the emphasis on the relational and emergent, social production rather than social construction becomes the focus. Building on the CDS approach outlined above, viewing bodies through this lens opens up new possibilities as Feely (2016: 870), drawing on Deleuze's new materialism, explains:

> We reject the transitional preoccupation with essentialist questions ('What is a body?') and focus instead on its currently actualised, or what Deleuze calls actual,

> capacities (‘What can a body do?’) as well as its potential, or what Deleuze terms virtual, capacities (‘What else could a body do?’).

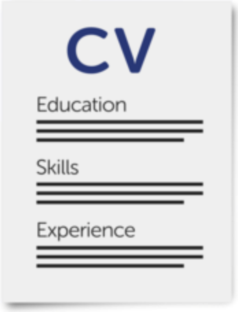
Considering the above possibilities new materialism affords, it is increasingly popular within disability studies, with concepts from a Deleuzoguattarian approach particularly influential. For example, alongside Feely (2016; 2020; 2015), stands Goodley (2007b; 2007a), Simmons et al. (2008), Gibson et al. (2012), Flynn (2017), Gibson et al. (2017), Goodley et al. (2018), Monforte (2018) and Naraian (2020) to name a few. These works, alongside the findings and three key aspects of transition presented in Chapter Eleven, converged to show that assemblage could be a helpful framework for understanding how transition, and those caught within it, currently operates. Although Deleuzoguattarian concepts have been applied to transitions within higher education (Taylor and Harris-Evans, 2018), I am unaware of it being used in relation to transition to adulthood for people with learning disabilities. As aforementioned, the research did not begin as a new materialist endeavour, rather new materialism and the concepts from Deleuze & Guattari (2004) entering into the research assemblage when they did, shaped the emerging thesis. St. Pierre (2015) warns of ontological incoherence occurring when posthumanist Deleuzian concepts are dropped into a humanist qualitative project. Thus, the turn to assemblages within the discussion is, perhaps, a jarring one. To mitigate this, the thesis is split into three parts. Part One is a product of my positionality at the start of this thesis, whilst Part Three reflects where I am now. The results straddle both parts and thus are included in Part Two - a bridge between parts one and three. On the one hand, the results are a product of who I was when I started the research. However, on the other hand, my interpretations are influenced by my growing confidence, my engagement with critical disability studies, and a gradual awareness of new materialism and assemblages. The results, in turn, lead to the embracing of assemblage within the discussion chapter to highlight the complexity and interconnectedness of transition and draw attention to the becomings, which take place throughout transition via the transition assemblage.

Chapter Two summary

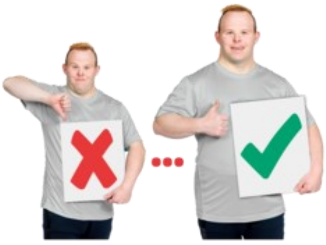
	A **researcher** is someone who finds things out. This chapter tells you about the **researcher** and why they did the research.
	This chapter also tells you about the **theories** that helped the researcher find things out. **Theories** are a set of ideas that help us understand the way things work.

The researcher

	The researcher is called Francesca Ribenfors.
	Francesca is not disabled, but wants to live in a world where everyone is valued and treated fairly.

 	Francesca has lots of experience working with young people with learning disabilities. She has worked with young people and their families during transition - as people leave college and when they move from children to adult services.

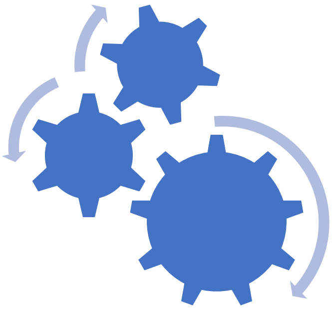
Why Francesca did the research

	Francesca wanted to find out more about transition. She knows it can be a difficult time for people with learning disabilities and their families.
	Francesca wants to help improve transition.

	Francesca wanted to understand why people with learning disabilities are treated differently from people without learning disabilities.

The theories

	There are 3 main **theories** that are used in this research. These are called: Feminist research, Critical disability studies, New materialism.
	Feminist research is about looking at the power some people have over other people.

	Critical disability studies is about looking at how and why disabled people are treated differently and trying to change this.
	New materialism is about looking at how people, objects and words act together to make the world the way it is.
	Learning about these theories helped Francesca decide how to do the research and how to write about what she found out.
	Learning about the theories also helped change the way Francesca thinks about disability and the world around us.

Chapter Three: Literature Review

This chapter examines transition to adulthood, what it means for people with learning disabilities and their families, and why current constructions of adulthood and transition-related policy are problematic. The chapter begins with an introduction to the concept. This is followed by an overview of relevant legislation and policy, before moving into a summary of what should happen during transition. What constitutes a 'successful' transition is then addressed before attention is turned to how previous research has approached transition. This part is split into four sections. The first three sections examine transition research relating to young people, parents, and professionals to demonstrate how the focus of research and individual perspectives differ across the groups. The fourth section provides an overall summary of how transition is experienced. Together, these four sections highlight how experiences fail to meet the criteria required of a successful transition and point to issues associated with the construction of adulthood which is then examined. It is shown why these constructions are problematic, how they are perpetuated within current policy, and why the current focus within policy relevant to transition is flawed.

Transition to adulthood

"We all fear the transition of our child to adulthood" (Moshi, 2017)

"My daughter…is 18 next Jan, so transitions to adult social care. And I am terrified'
(Skemperoony, 2018)

The transition to adulthood has been considered a universal phenomenon as biological changes associated with puberty affect individuals across different societies and historical contexts in similar ways (Hudson, 2006). However, whilst physical changes may be universal, the concepts of adolescence and adulthood are social constructions based upon western notions of child development. Therefore, how the transition to adulthood is experienced depends heavily on individual cultures, societies, and moments in time. The biological changes experienced are only one aspect of the transition as a move into adulthood occurs through "many dimensions of experience, for example biological, legal, social, cultural, emotional and attitudinal" (Mitchell, 1999: 753). Within the UK, whilst the age of majority is reached at 18, adulthood is considered an emergent status realised through the gradual attainment of rights, privileges, and responsibilities. It is heavily associated with a shift from dependence to independence, and age alone is not enough to confer adult status (Scheer and Palkovitz, 1995; Arnett, 1998; Arnett, 2001).

Whilst the changes associated with the move towards adulthood can be difficult for many young people (Heslop et al., 2002), transition to adulthood holds an additional meaning for people with learning disabilities and their carers. It is a meaning which elicits a powerful emotional response, as the tweets from parents of disabled young people at the start of this chapter demonstrate; transition is a time to be feared and a time of immense stress for young people and their parents (Rapanaro et al., 2008; Biswas et al., 2017). This is because transition for young people with learning disabilities is considered a two-fold experience. There are changes experienced in becoming an adult (legally, socially, and physically) and changes related to a move between children and adult health and social care provision (Townsley, 2004). McGinty and Fish (1992: 6) make the distinction between phase and process:

> It is a phase or period of time between the teens and twenties which is broken up educationally and administratively. During the phase, there are changes of responsibility from child to adult services, from school to further and higher education, and from childhood dependence to adult responsibility.
>
> It is a process by which the individual grows through adolescence to adulthood and achieves the balanced state of dependence and independence which a particular community expects of its adult members.

Due to the changes in health and social care provision (the 'phase' aspect of McGinty and Fish's (1992) definition above), transition is a time that is heavily rooted in education, health, and social care policy (Williams, 2013). Current policy captures the phase and process part of transition under the banner ‘preparing for adulthood’, which covers young people between the ages of 14 and 25 (DfE, 2015). It is a time that should involve professionals across education, health, and social care working together with young people with special educational needs or disabilities and their families to:

> Prepare [the young person] for adult life and help them go on to achieve the best outcomes in employment, independent living, health and community participation. (DfE, 2015: 120)

How transition to adulthood is conceptualised within government policy is important. It has implications for how professionals and services work with young people and their families and, therefore, affects the experiences of young people and the support they can access (Yates and Roulstone, 2013; Robinson et al., 2018). However, it is also instrumental in shaping the position people with learning disabilities occupy within society. Within current policy, young people with disabilities are perceived as different from 'normal' children with the ‘problem’ of disability located within the individual (Runswick-Cole and Hodge, 2009). The following extract, taken from the current Special Educational Needs and Disability (SEND) Code of Conduct, exemplifies this as a dichotomy is created between people with learning disabilities and people without:

> A child of compulsory school age or a young person has a learning difficulty or disability if he or she:
>
> • has a significantly greater difficulty in learning than *the majority of others of the same age*, or
>
> • has a disability which prevents or hinders him or her from making use of facilities of a kind generally provided *for others of the same age* in mainstream schools or mainstream post-16 institutions. (DfE, 2015: 15-16 emphasis added)

Given the ramifications of policy, the following section provides an overview of key policies, legislation, and guidance related to transition within the UK. Key features of the different documents are pulled out to demonstrate how transition priorities have evolved within policy since the Warnock Report (DES, 1978).

The legislative and policy context

The origins of transition to adulthood within government policy and the statutory requirement to support young people during this time can be traced back to the Education Act 1981, which first sets out the government's official duty to undertake transition planning. However, the Warnock Report (DES, 1978) laid the foundations for this duty.

In 1974 the Warnock Committee was established to examine educational provision for handicapped children and young people in England, Scotland and Wales and the "arrangements to prepare them for entry into employment" (DES, 1978: 1). The four-year inquiry culminated in the highly influential Warnock Report, which resulted in substantial conceptual, administrative, and practice changes (Lindsay et al., 2020). One of these changes was replacing the 11 categories of handicap within the report with ‘special educational needs’. It was, the report claimed, a “more positive approach” designed to eliminate the categorisation of children, which “perpetuates the sharp distinction between two groups of children: the handicapped and the non-handicapped” (DES, 1978: 43).

Concerning transition, however, the report established the role of education in preparing young people for adulthood. It stated a long-term goal of education was:

> To enable him to enter the world after formal education is over as an active participant in society and a responsible contributor to it, capable of achieving as much independence as possible. (DES, 1978: 5)

Therefore, a chapter within the report was dedicated to the transition from school to adult life where it was acknowledged transition could be a particularly stressful time with many barriers encountered following education:

> The community at large regrettably tends to think of people with obtrusive disabilities as less than human in their emotional and social needs. We cannot over-emphasise the urgency of finding ways of changing attitudes so that such people are accepted as ordinary people who merely have certain special needs. (DES, 1978: 163)

The report suggested that the work achieved throughout the young person's schooling may amount to nothing without adequate support in place. Thus, it emphasised the need for transition planning well before the young person leaves school. Alongside this was the recommendation of a 'Named Person' who could act as the main point of contact for help and advice during transition.

Statements of special educational needs were recommended and were subsequently implemented in the Education Act 1981. These statements, which existed until their replacement with Education, Health and Care Plans (EHCPs) in the Children and Families

Act 2014, constituted a legal contract between the local education authority and the young person's parents. They recorded the child's needs and the provision required to meet those needs. However, significantly for transition, the statement ceased when the young person's education ended and did not include planning for the health or care needs for the young person transitioning to adult services (Robinson et al., 2018).

As is shown in **Table 1**, since the Warnock Report (DES, 1978) and the subsequent Education Act 1981, there has been a plethora of government guidance and policy incorporating transition. Like the Warnock Report, each document acknowledges transition as being a challenging time for young people with disabilities and their carers and sets out ways to manage it to ensure successful transitions.

Table 1 Summary of key legislation, guidance and policy relating to transition since 1978

Legislation, guidance, or policy document	**Summary of the key areas related to transition**
The Warnock Report, 1978	• Recognises the transition from school to adult life as a challenging time. • Introduces the role of education in preparing young people for adulthood. • Emphasises the need for transition planning • Recommends a 'Named Person' to act as a main point of contact for help and advice when navigating transition
Special Educational Needs Code of Practice, 2001	• States that from year nine onwards annual reviews must include transition planning. • Highlights six principles of transition planning: participative, holistic, supportive, evolving, inclusive and collaborative.
Valuing People, 2001	• Transition to adulthood is included as one of 11 problematic areas with problems attributed to a lack of involvement of young people and a lack of co-ordination between agencies. • Has a focus on ensuring continuity of care through transition and enabling as many young people as possible to take part in education, training or employment. • Introduces the Connexions Service, person-centred planning and the appointment of Transition Champions by Learning Disability Partnership Boards.

National Service Framework: Children, Young People and Maternity Services, 2004	• Two standards (four and eight) address transition. • Assessment and planning for transition from child to adult services considered unsatisfactory, with a lack of co-ordination between agencies, and little involvement of young people contributing towards the problems. • Stresses the need for high quality, multi-agency support to maximise the choice and control young people can exert over their lives. • States that responsive, age-appropriate services need to be available during transition.
Improving the Life Chances of Disabled People, 2005	• Transition one of four priority themes. • Recognises problems stemming from poor transition planning and stresses the need for early intervention. • Lists three key ingredients of transition: personalised planning, the removal of the transition 'cliff-edge' and access to a transparent and appropriate menu of opportunities and choices.
Transition: Getting it Right for Young People (2006)	• Focuses on transition between children and adult health services. • Emphasises transition as a process rather than singular event. • States improving transition involves "adequate consultation with professionals and users; flexibility in the timing of transition; a period of preparation for the young person and family; information transfer; monitoring of attendance until the young person is established in the appropriate adult-oriented service." • Also notes developing a young person's communication skills, decision making ability, assertiveness and self-care can contribute to a successful transition.
Aiming High for Disabled Children: Better Support for Families, 2007	• Introduces the 'Transition Support Programme' – a three-year national programme to promote good practice and support service improvement at strategic and operational levels. • Five main areas of the programme: strategic joint-partnership working, participation of young people and their families, personalised approaches, joint assessment processes, realistic post-16 opportunities for living life.
A Transition Guide for all Services, 2007	• Provides an overarching view of the services required to work together to ensure appropriate support for young people in their transition to adulthood.

	• Introduces the implementation of transition pathways which set out the steps involved in transition, who is involved, and options available at each stage. • Discusses the benefits of a keyworker as a single point of contact during transition.
Transition: Moving on Well, 2008	• Stresses transition as a process rather than a singular event. • Notes the importance of forward planning and person-centred approaches. • Establishes a network of health professional champions to promote good transition planning.
Valuing People Now, 2009	• Consolidates and builds on previous reports. • Commits to enabling people to lead fulfilling lives, including paid work and being treated as equal citizens. • Maintains a focus on person-centred approaches. • Sets out an expectation for young people to have a strong voice in review meetings and for them to know what is possible in relation to their futures centring on health, housing, employment, friends, and relationships.
Pathways to Getting a Life, 2011	• Introduces outcome focused pathways to employment, health, housing and social inclusion.
Support and Aspiration: A New Approach to Special Educational Needs and Disability, 2011	• Highlights numerous problems relating to transition including: a disjointed and confusing assessment process, poor planning, lack of choice and opportunities, lack of information and a lack of focus on young people's ambitions for adulthood and how best to help them prepare. • Leads to the establishment of the Preparing for Adulthood (PfA) Programme which is launched in November 2011. PfA provides expertise and support to local authorities to develop good practice and embed preparing for adulthood from the earliest years. PfA outcomes centre on employment, independent living opportunities, good health, friendships, relationships and community inclusion.
Children and Families Act, 2014 Special Educational Needs and Disability Code of Practice, 2015	• Education, Health and Care plans (EHCPs) replace statements and run from birth to 25 years. • From year nine onwards plans must include a focus on preparing for adulthood. • Introduces the Local Offer as a single source of information about the support and services available in

	each local authority. This must include a section on preparing for adulthood. - Recognises high aspirations as crucial to success and states support should centre on young person's aspirations, interests and needs. - Heavy emphasis on working towards clearly defined outcomes in employment, independent living, health and community participation.
The Care Act, 2014	- Overlaps with Children and Families Act 2014. - Outcome focused and emphasises person-centred practice. - The principle of wellbeing is stressed. - Focuses on erasing the transition cliff-edge and ensuring continuity of support until an assessment has taken place and adult care support is in place to take over.
NICE transition guideline, 2016	- Defines transition as "a purposeful and planned process of supporting young people to move from children's to adults' services." - Draws attention to involving young people, parents and carers during transition, early planning, supporting young people to build independence. - Recommends a 'named worker' to coordinate a young person's transition and smooth the transition process.

What should happen at transition

EHCPs are currently the key document for children and young people with special educational needs and disabilities. The document, which replaced statements, brings together a young persons' education, health and care needs, and support in one joined-up record. Unlike statements that could be in place between the ages of three and nineteen, EHCPs can begin before one and follow the young person until the age of 25. Therefore, they can extend beyond the end of education. EHCPs must be reviewed annually, and from year nine onwards this review must include a focus on preparing for adulthood, i.e., transition planning.

Based upon the Children and Families Act 2014 and associated SEND Code of Practice, this planning must be person-centred and based on the young person's aspirations, interests, and needs. It should be outcome-focused and centre on the following four areas:

- **Employment** including training options or support for setting up a business as well as finding work and learning how to do a job.
- **Independent living** including where and with who the young person might want to live in the future, what support will be required and information on local housing options, support available to find a place to live, welfare benefits, and social care support.
- **Participating in society**, including information about social and community activities and support for creating and sustaining friendships and relationships.
- **Being as healthy as possible** including planning with health services to manage the transition from children to adult services, clarifying which health professionals will be involved, and ensuring they understand the young person's needs.

The professionals working with the young person should work together across agencies in a coordinated manner, have high aspirations, understand what support is necessary to help the young person achieve their ambitions, and involve the young person and their parents in decision-making processes.

Under the Care Act 2014, if a child is likely to require support after turning 18, local authorities must carry out a transition assessment for the young person to establish what support the young person will need in adult services.[4] The assessment must take place at the right time for the young person and “include the outcomes, views and wishes that matter to the young person” (2014: 137) and how care and support can contribute to achieving these outcomes with information provided about how their needs and outcomes can be met. To prevent the transition cliff edge, the local authority must continue to provide the young person with existing support until the assessment has taken place and a decision is reached about their need for support from adult services (King, 2017).

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[4] Under the easements within the Coronavirus Act 2020, local authorities are relieved of the duty to undertake assessments of children transitioning to adult social care. However, these easements are due to end imminently (Gov.uk, 2021).

As detailed in **Table 1**, the Children and Families Act 2014 requires local authorities to publish a Local Offer which sets out information and advice for children's social care in the local area. It must include a section on the support available to help children and young people move into adulthood. For example, it must consist of information about preparing for and finding employment, housing, and community participation. The Care Act 2014 places a similar responsibility on local authorities as accessible information and advice must be provided. This should address areas such as housing options, support with employment and training, and access to social opportunities.

What constitutes a successful transition to adulthood?

It is clear within **Table 1** that there are several reoccurring factors considered to contribute to a successful transition to adulthood. These include:

- Personalised and person-centred transition planning that begins well before a young person turns 18.
- A focus on meaningful outcomes relating to employment, independent living, participating in society, and health.
- Professionals working together across agencies, sharing information and delivering coordinated responses.
- The provision of a key worker/'named worker' acting as a single point of contact for families.
- Continuity of provision across child and adult services.
- The involvement of young people and parents/carers in decision-making.
- The availability of information and advice.

Similar factors are identified within transition literature, with an early example being the following statement written by McGinty and Fish (1992: ix):

> Successful transition depends on inter-agency co-operation, collaboration and planning […] Professionals working in education, social services, health, employment and voluntary organisations can make an effective contribution to transition only by working with other professionals, with parents and with the young people themselves.

Existing literature reviews make similar conclusions. For example, Beresford (2004), who conducted a literature review to establish 'what works?' in relation to transition, concluded that timely, person-centred planning that involves young people, their parents, and other advocates is central. Beresford (2004) also stressed the importance of multi-agency approaches to reflect the multi-faceted nature of what young people want and need and the availability of services, facilities, and opportunities for young people post-school. Likewise, a review by Hudson (2003) suggested that individualised, comprehensive transition planning that considers the needs and wishes of young people is required with processes that ensure the continuity of support, provision of information, and maintenance of relationships considered critical for a successful transition. A large mixed-methods study within the UK by Heslop et al. (2002) reported five elements to a good transition. These were termed ‘the five Cs’ and consisted of communication (between all parties involved in transition), coordination (between agencies), comprehensiveness, continuity, and choice.

Several years later and recommendations remain similar. Transmap (undated) cited in Tarleton and Porter (2012: 6) highlighted five key principles to ensure a smooth transition and positive life for young people. These included: comprehensive multi-agency engagement; the full participation of young people and their families; the provision of high-quality information; effective transition planning; and an array of opportunities for living life. Meanwhile, two recent studies from the UK and Canada suggest collaboration between statutory services, the provision of information for parents about the transition process and local services, the involvement of young people and parents within the transition process, and more post-education opportunities are all factors that contribute to a successful transition (Gauthier-Boudreault et al., 2017; Codd and Hewitt, 2020).

However, despite legislation and literature setting out the factors necessary for a successful transition to adult life, what constitutes success is less clear (Leonard et al., 2016). The emphasis on outcomes within the SEND Code of Practice (DfE, 2015: 28) implies success is related to employment, independent living, participating in society and being as healthy as possible as it states:

> With high aspirations, and the right support, the vast majority of children and young people can go on to achieve successful long-term outcomes in adult life. Local authorities, education providers and their partners should work together to help children and young people to realise their ambitions in relation to: higher

> education and/or employment […] independent living […] participating in society […] being as healthy as possible.

These four areas are not dissimilar to early transition literature where employment and economic self-sufficiency, high uptake of post-secondary school education, personal independence and independent living, social participation and the uptake of adult roles are considered markers of success (Thomson et al., 1995; Hudson, 2003). Such outcomes reflect traditional definitions of adulthood where the achievement of developmental tasks and objective 'role transitions' such as finishing school, finding paid employment, and starting a family are the main criteria (Henninger and Taylor, 2014). Within these outcomes and definitions of adulthood, links between childhood dependence and adulthood independence are common. For example, they are visible in the definition of transition to adulthood by McGinty and Fish (1992: 6) and included on page 43**,** where it is suggested a successful transition is one where the individual "achieves the balanced state of dependence and independence which a particular community expects of its adult members". It is a narrative that continues to be reflected in policy today as a dichotomy between dependence and independence is visible (Morris, 2011; Oliver and Barnes, 2012; Burch, 2018; Hodkinson and Burch, 2019).

However, more inclusive and subjective markers of transition success, which incorporate personal or familial wellbeing and security, are also acknowledged within the literature (King et al., 2005; DeZonia, 2008; Neece et al., 2009; Henninger and Taylor, 2014; Gauthier-Boudreault et al., 2017). For example, King et al. (2005: 199) include "greater happiness" in their list of indicators of a successful transition. A more recent study into the criteria for determining a successful transition to adulthood for individuals with disabilities is by Henninger and Taylor (2014: 105), who analysed parents' perspectives within the US. Although the three most dominant themes were aligned with conventional criteria of independence in work, living, and relationships, responses were nuanced and centred on the young person reaching their full potential within these domains. The following participant quote from the study demonstrates this:

> A successful transition would be developing a network of positive relationships with individuals in the community with similar interests as himself. Would also include independent living if this is important to him. Would include maximising

> his academic strengths to fullest and helping him continue to find ways to be happy and secure in his differences.

Similarly, Gauthier-Boudreault et al. (2017) wrote that for transition to be considered successful young people and their families must be given a sense of wellbeing and security. Neece et al. (2009), who examined transition success from parental perspectives, linked it to family wellbeing and the young person's mental health and quality of life rather than adaptive behaviour. However, measuring more subjective criteria can prove challenging. Therefore, Pearson et al. (2020), whose research focused on the experiences of young people with disabilities during transition, explained they were unable to define what constituted a successful transition as the concept is elusive and lacking in metrics. Instead, they summarised the processes and structures necessary to support young people as they embarked on a new phase of their life. These were systems that empowered young people, provided them with autonomy and enabled them to make choices.

However, despite the plethora of policy and outcome-focused Children and Families Act 2014 and Care Act 2014, outcomes for people with learning disabilities are poor. A small single case study into transition, commissioned by one local authority and carried out by Tarleton and Porter (2012), found that seven out of the eight participants entered into time-filling leisure activities following education rather than employment. Furthermore, participants' views of their lives ranged from happy to bored and lonely. The poor employment record reflects the broader picture where the employment rate of working-age adults with learning disabilities stands around 6% (and often part-time), compared to approximately 75% for adults generally (Hatton, 2019).

As a result of the poor outcomes, Williams (2013: 122) questions whether transition is simply a smokescreen, “a slippery term, something that distracts attention from the lack of substance”. The heavy policy emphasis, Williams (2013) states, is simply a sign that the area remains problematic; the focus on systems and processes obscure the reality that it is the provision of better post-education options which is required.

In addition to policy, how research explores transition to adulthood has significant implications for the field. Research design shapes the research findings and, therefore, what is known or not known about transition (Carroll, 2015). Therefore, the following sections aim to ascertain how transition is broached within research. Literature relating to young people, parents, and professionals, both within the UK and internationally, is drawn on to highlight the differing perspectives and approaches. Where research contains more than one group of participants, for example, parents and young people, the themes relating to the specific group of concern are pulled out accordingly. Following these three sections, a general summary of transition experiences is provided.

Young people with learning disabilities

Transition research which involves young people with learning disabilities as participants is growing in popularity (Carroll, 2015) and tends to be focused on adulthood and the end products of transition. For example, how young people develop and conceptualise an adult identity (Murphy et al., 2011; Wilkinson et al., 2015; Salt et al., 2019), social inclusion (Small et al., 2013; MacIntyre, 2014; Merrells et al., 2019), what makes a good life (Scott et al., 2014), and aspirations and transition outcomes (Caton and Kagan, 2007). In addition, some studies examine the factors necessary for a good quality of life for young people with learning disabilities on the brink of adulthood but do so drawing on data obtained via parents (Kraemer et al., 2003; Biggs and Carter, 2016). There are some exceptions to the focus on outcomes. For example, Abbott and Heslop (2009: 53) involved young people in their study exploring transition from residential colleges. Amongst the aims of their research was the desire to understand experiences surrounding transition processes and planning. They found "relationships and continuity" to be the main factors that could improve transition processes from the perspectives of young people. Similarly, Heslop et al.'s (2002: 5) large mixed-method study on transition experiences included a focus on how young people believed transition could be improved. The following areas of importance were identified:

> Having someone independent who they could talk things over with and who would listen to them; having consistent support to enhance their self-confidence and self-esteem; being treated as an individual; others encouraging them to having higher (but not overwhelming) expectations of themselves; being given more responsibility and privacy.

Within research exploring the perspectives of people with learning disabilities, it is not unusual for comparisons to non-disabled people to be made. This is either through the inclusion of non-disabled participants or by comparing findings to 'mainstream' literature (Caton and Kagan, 2007; Forte et al., 2011; MacIntyre, 2014; Scott et al., 2014; Salt et al., 2019). Scott et al. (2014: 1296), for example, in their exploration of quality of life for young adults with Down Syndrome in Australia, highlighted areas of importance to young people as including relationships with friends, family and partners, participation in social and leisure activities, and a desire for autonomy centred on employment, living independently and being in control of their own lives. They concluded the milestones young people desired "are similar to those of their peers, including the rights to the same life opportunities". This echoes a study within the UK where Salt et al. (2019: 908) concluded that "the participants' perspectives were generally very similar to those one might expect to record amongst typically developing young adults". The young adult participants considered themselves to be maturing over time and, although they had some reluctance to take on the roles and responsibilities associated with adulthood, they desired increased autonomy and independent futures.

However, whilst the above two studies find similarities between disabled and non-disabled young people, Forte et al. (2011), who compared the worries of young people with and without learning disabilities during transition, found discrepancies between the two groups of people. Whilst the concerns of young people without learning disabilities centred on employment, finances, failing and decision-making, the concerns of young people with learning disabilities, focused on social relationships (the loss of people they were close to, bullying and making and sustaining friendships) alongside a worry about failing in life. Forte et al. (2011) conclude the differences may be attributed to the different circumstances and histories of the two groups.

Researchers are not alone in making comparisons to non-disabled people; participants within several studies also made comparisons, and the label of learning disabilities appeared problematic in the pursuit of adulthood (Wilkinson et al., 2015; Young-Southward et al., 2017; Merrells et al., 2019; Salt et al., 2019). A study into sexual identity development during transition for four learning disabled participants found the young people to be striving to obtain an "as normal as possible" adult identity and felt defined and constrained by the learning disability identity ascribed to them (Wilkinson et al., 2015: 102). Transition to adulthood was thus perceived as an opportunity to "break free from the 'infantilising' [learning disability] identity by attempting to achieve a highly valued adult identity". Consequently, the young people were under pressure to meet ‘adult’ goals and risked exclusion and being left in limbo as an ‘almost-adult’ when they struggled to reach them. Similarly, in an exploration of social inclusion for young adults with learning disabilities in Australia, participants viewed themselves as different to “mainstream people” and reported feeling isolated and excluded from their community and employment opportunities (Merrells et al., 2019: 18).

Overall, the extant literature which seeks to understand the perspectives of young people with learning disabilities during transition suggests that young people desire and strive for normative goals of adulthood such as independence and employment (MacIntyre, 2014; Scott et al., 2014; Wilkinson et al., 2015; Young-Southward et al., 2017; Salt et al., 2019). These goals are not dissimilar to their non-disabled peers and the four areas of adulthood emphasised in current policy. However, barriers prevent the goals from being achieved. Florian et al. (2000), who drew on data provided by schools to trace transition outcomes for young people with profound and complex learning disabilities, stated social inclusion was a 'hollow promise' with more recent literature suggesting a similar picture. MacIntyre (2014: 868), for example, found young people with learning disabilities "struggle to demonstrate their contribution as active citizens via paid employment in the same way as young people in the general population". Employment rates are low and social inclusion limited (Small et al., 2013; MacIntyre, 2014; Merrells et al., 2019). Furthermore, transition was found to negatively impact young people's psychological wellbeing (Forte et al., 2011; Young-Southward et al., 2017).

Carroll (2015: 347) conducted a review of European transition research involving people with learning disabilities aged 16-30 as participants between 2002 and 2012. They found that research often failed to capture the complexity of transition as a 'deficit approach' tended to be adopted. There was, they proposed, "an over reliance on limited performance data, for example, academic attainment, employment and independent living status", which risks contributing to underdeveloped policy and limiting how professionals and families perceive life for young people with learning disabilities in adulthood. Furthermore, whilst young people are being included within research relating to transition, young people with severe or profound intellectual disabilities tend to be excluded from the research process (Jacobs et al., 2018).

Parents

Parents have been reported to be linchpins during their children’s transition as they manage the multiple different parts of transition (Timmons et al., 2004). As a result, their perspectives must be considered during transition (Gauthier-Boudreault et al., 2017). Correspondingly, parents are regularly included as participants within transition research, either to understand more about the lives of their children (Kraemer et al., 2003; Biggs and Carter, 2016), to document parental experiences of transition (Rapanaro et al., 2008; Neece et al., 2009; Leonard et al., 2016; Gauthier-Boudreault et al., 2017; Codd and Hewitt, 2020), or to elicit their perceptions of their child’s adult status (Docherty and Reid, 2009; Murphy et al., 2011).

Unlike in the literature relating to young people's perceptions, findings in studies that concern parents consistently focus on the transition process and service-related issues. For example, when determining what constitutes a successful transition from parents' perspectives, Neece et al. (2009) found parental involvement in transition planning a core factor of transition satisfaction. For the participants in Codd and Hewitt’s (2020) study, parents experienced worry, uncertainty, and stress related to developmental changes and the move between child and adult services and navigating inadequate support services. Abbott and Heslop (2009: 53), in their discussion of transition and residential colleges, summarised:

> Parents wanted better information; earlier decisions about what would and would not be funded; a back-up plan if things went wrong; and help from professionals who knew what they were doing.

Thus, the majority of challenges experienced by parents during transition, which lead to it being a time to be feared, tend to stem from the services and systems put in place to help rather than the young person's impairment (Duffy and Murray, 2010). In this aspect, transition is much like other areas of social care as demonstrated by one mother who outlined their primary sources of stress in a blog post (Kowalski, 2021). This included: uncertainty surrounding where to go for help and the help one can get; unfairness as basic needs are unmet and ableism blocks access to local communities and wider society; and, echoing Kittay's (1999) notion of dependency work, an unmanageable workload supporting their child whilst also navigating the different systems. Summarising the latter of these difficulties, Kowalski (2021: online) stated:

> The real workload comes from our health, social care, education and welfare systems. The very things that are supposed to support us can very quickly become a full-time job in themselves and keep us feeling stressed and our lives small.

Transition research involving parents tends to result in multiple recommendations to improve the transition process. These recommendations largely reflect those included in **Table 1**, as themes that thread through the research recommendations include knowledge sharing, inter-agency collaboration, young people and parent involvement in transition planning, person-centred approaches, opportunities for young people to reduce social isolation, and the benefits of a transition key worker (Heslop et al., 2002; Abbott and Heslop, 2009; Pallisera et al., 2016; Gauthier-Boudreault et al., 2017; Codd and Hewitt, 2020; Jacobs et al., 2020). Additionally, however, there is a call for emotional support for parents and the facilitation of peer support networks in response to the stress and worry often experienced by parents during this time (Townsley, 2004; Gauthier-Boudreault et al., 2017; Codd and Hewitt, 2020).

As with young people, conceptions of adulthood focus on normative markers such as reducing parental responsibility and accountability, attainment of adult rights, and independence (Docherty and Reid, 2009; Biswas et al., 2017; Codd and Hewitt, 2020). However, this can cause problems as traditional narratives of adulthood contradict individual experiences (Biswas et al., 2017) and lead to the belief that young people occupy a space between childhood and adulthood (Murphy et al., 2011). Furthermore, there can be apprehension about the push for independence, such as moving out of the family home, due to the perceived vulnerabilities of their children (Codd and Hewitt, 2020).

Just as parents are key players within the transition process (Timmons et al., 2004; Biswas et al., 2017; Codd and Hewitt, 2020), they were also fundamental in young adults' attainment of adult status. In response to their research with mothers, Docherty and Reid (2009: 464) draw on Bronfenbrenner's (1979) ecological model to shed light on the lives of young people with learning disabilities as they approach adulthood. A "conceptual adaptation" of the model is proposed with an additional layer, a "layer of influence", believed to surround the young person to reflect the significant role mothers play in their child's attainment of adult status, acting as a buffer between the young person and wider society engaging in processes of both facilitation and gatekeeping.

However, whilst conceptualisations of adulthood focus on normative markers, what constitutes a good quality of adult life is nuanced and extends beyond the four domains of focus within policy (i.e., employment, housing, social participation and health). For example, in DeZonia (2008: 82), mothers also included “personal fulfilment and comfort”, “being surrounded by people who love them” and having “a place in the world where [they are] respected, happy, and loved” as priorities for their adult children alongside notions of productivity and independence.

Professionals

Professionals translate policy into practice. They are critical stakeholders in transition (Jacobs et al., 2020), and their relationships with parents are often problematic (Todd and Jones, 2003; Codd and Hewitt, 2020). Nevertheless, as transition research tends to centre on parents’ perspectives and, increasingly, young people, there are comparatively few studies that include a focus on professionals. This is despite it being recommended to gain a richer picture of transition (Francis et al., 2018), triangulate data on transition experiences and enhance the credibility of transition research (Gauthier-Boudreault et al., 2017), shed light on the complexity of decision-making during transition (Jacobs et al., 2018), and increase the chances of success with transition planning initiatives (Gauthier-Boudreault et al., 2021).

Where studies have included professionals as participants alongside parents and young people, comparisons are often made between the differing perspectives concerning definitions of adulthood (DeZonia, 2008; Murphy et al., 2011) and transition outcomes (Cooney, 2002; Kaehne and Beyer, 2010). For professionals, beliefs surrounding adulthood and the desired outcomes of the transition process have been shown to centre on narrow conceptualisations of adulthood and the importance of young people developing skills to meet those parameters (DeZonia, 2008; Kaehne and Beyer, 2010). Therefore, self-determination and independence are prominent features of adulthood definitions (DeZonia, 2008; Murphy et al., 2011; Jacobs et al., 2021). For example, professionals in DeZonia’s (2008) study saw young people moving out of home as a necessary part of the progression into adulthood, whilst Jacobs et al. (2021) highlighted how perceptions of normality shaped professional views of what a good life should look like. Independent living was viewed as a central aspect of adulthood regardless of whether it suited the young person or what the parent felt was best (DeZonia, 2008; Kaehne and Beyer, 2010).

In comparison to parents who also had subjective priorities for adulthood, DeZonia (2008: 101) noted:

> Teachers were not as concerned about students being loved as they were about students being actively involved in a range of supported activities…teachers feared inactivity more than they feared an absence of affection in the adult lives of students with profound disabilities.

Kaehne and Beyer (2010) also noted that professionals did not appear to consider the wider familial context or the implications of transition on family relationships compared to parents. Likewise, Gauthier-Boudreault (2021) noted a difference between parents and professionals during transition planning was the lack of consideration paid to psychological support for parents, which was, conversely, a need heavily emphasised by parents within their study.

It is important to note, however, that the views of professionals are not homogenous. Murphy et al.'s (2011) study, which included transition coordinators and Connexion workers as participants, found that transition coordinators championed the values set out in Valuing People (DH, 2001); young people were unquestionably seen as adults and any doubt cast on their right to self-determination deemed "morally culpable" (Murphy et al., 2011: 71). Conversely, Connexion workers made comparisons to non-disabled peers. They believed a lack of capacity limited the obtaining of adult status resulting in some young people being suspended between childhood and adulthood (something which echoed the views of parents in the same study). The prominence of disability labels and associated perceived limitations were also evident within Cooney's (2002: 431) research as disability shaped how professionals responded to transition. Here professionals strived to match needs to existing programs, which subsequently limited what young adults could achieve. One teacher within the study, for example, stated: "it's not uncommon for people that are mentally retarded to have a life that is more limited and we have to pretty much comply with what their limitations are".

The discrepancies between parents and professionals within the studies drawn on above have been attributed to the influence of the institutional contexts' professionals work within and the different lenses with which they view young people (DeZonia, 2008; Kaehne and Beyer, 2010). However, given the critical role both parents and professionals play during transition, there is merit in considering both perspectives, alongside the views of young people when researching transition. Not only may this improve decision making (Murphy et al., 2011), but Kaehne and Beyer (2010) suggest the differences may explain some of the challenges experienced when reconciling institutional frameworks of transition with family expectations. That is not to say parent and professional views always differ as overlap exists in relation to obstacles encountered during transition. For example, issues with planning and a lack of post-education opportunities (Abbott and Heslop, 2009; Tarleton and Porter, 2012; Gauthier-Boudreault et al., 2017).

A summary of transition experiences

Overall, experiences of transition appear inadequate, and the picture provided is a bleak one. The focus on transition within policy seems to have failed to significantly improve transition; it remains a difficult period, as initially highlighted within the Warnock Report (DES, 1978). A report by CQC (2014: 2) suggests that the system is not fit for purpose was it states:

> [It] is fragmented, confusing, sometimes frightening and desperately difficult to navigate. Too often, instead of helping young people and their parents, it adds to their despair.

Discontinuity is typical (Smyth and McConkey, 2003; Beresford, 2004; Smart, 2004) and change a continuous experience (Jacobs et al., 2021).

Planning has been non-systematic, lacking coordination and, contrary to guidelines, tends to exclude young people from the process, and post-school options are limited (Morris, 1999; Heslop et al., 2002; Smart, 2004; Raghavan and Pawson, 2008; Small et al., 2013; Gauthier-Boudreault et al., 2017). Despite employment increasing wellbeing it often does not feature prominently in transition planning (Kaehne and Beyer, 2008; Barron et al., 2013; Beyer et al., 2016). There is concern that the introduction of EHCPs within the Children and Families Act 2014 will do little to improve this situation unless systemic barriers that prevent disabled people from gaining work are removed (Hunter et al., 2020). Young people continue to experience social isolation, there is a lack of opportunities for social participation, and friendships often cease at the end of education (Small et al., 2013) despite being a core outcome of transition policy and important to young people (Morris, 1999; Heslop et al., 2002; Smyth and McConkey, 2003).

Although young people and their parents have high aspirations for their futures' (which, as shown above, are not dissimilar to their non-disabled peers), transition planning becomes irrelevant in the absence of meaningful choice. Young people are 'placed' according to the availability of services rather than for attaining long-term individual goals (Kaehne and Beyer, 2008; Raghavan and Pawson, 2008; Small et al., 2013) and the movement from one education and training opportunity to another may not be aimed at gaining employment, "but simply because there is nothing else for them to do" (Abbott and Heslop, 2009: 53). Meanwhile, the available adult day activities tend to be less stimulating than activities available in children's services and are not always considered age-appropriate (Taylor and Seltzer, 2010) and the mental wellbeing of many young people going through transition has been shown to suffer (Rapanaro et al., 2008; Taylor and Seltzer, 2010; Forte et al., 2011; Young-Southward et al., 2017). Additional hurdles are faced by people attending residential colleges as professionals tend to adopt an 'out of sight, out of mind' attitude as young people who remain in the borough consume their time and resources. Consequently, people at residential educational establishments have their transition neglected until they return home or a crisis point is reached. Furthermore, the distance between the school or college and the placing authority, key professionals and close family members results in reviews and planning meetings of variable quality (Abbott and Heslop, 2009).

The transition to adult health services is equally problematic (CQC, 2014). Jacqueline Cornish (2015: online), NHS England's National Clinical Director to Children, Young People and Transition to Adulthood, reported it to be "poorly planned, poorly executed, and poorly experienced" and, similar to social care, parents report a sense of loss, fear and uncertainty as they navigate the process (Davies et al., 2011). The transition is abrupt. A lack of appropriate resources, diminished therapy services, and an absence of health professionals with expertise in learning disabilities results in feelings of abandonment and concern (Barron et al., 2013) and, as with social care, there are cultural changes that can be difficult to traverse (Trachtenberg, 2016). For example, on reaching 18, the young person is often referred back to their GP who may lack disability-specific knowledge and has had little or no involvement in their care until this point. In turn, they may refer to numerous specialists, which results in fragmented and uncoordinated care and the loss of consistency (Foley et al., 2012). Due to the number of different professionals seen at each appointment, the young person or their carers find themselves repeating their story multiple times (Ward et al., 2003). In addition, there are changes in the way appointments are regulated. Within adult health settings, the onus is on the young person or their parents to take full responsibility for appointments, placing further demands on the family compared to children's services where it is customary for regular appointments to be scheduled by the relevant health professionals (CQC, 2014). It is a change that can have a disastrous impact as annual health checks can be missed and health deteriorate (Ward et al., 2003; Trachtenberg, 2016).

Constructions of adulthood

Comparing the above experiences of transition to the factors associated with a successful transition and what should happen during transition demonstrates a gulf between policy and reality as the evidence suggests multiple issues. However, several warning signs within the literature indicate transition is more problematic than simply a service delivery issue. Firstly, frequent comparisons are made between people with learning disabilities and those without as we are told learning disabled people have the same expectations and desires of adulthood as their non-disabled peers (e.g. Scott et al., 2014; Salt et al., 2019). The need to assert they are the same "speaks of the general assumption that to be disabled is to be different" (Slater, 2015: 39). Secondly, the conceptualisations of adulthood perpetuated in policy and incorporated into participant accounts are inherently normative and ableist, leading to the exclusion of people with learning disabilities (Slater, 2015). However, before examining these problems it is necessary to examine how adulthood is currently constructed within Western society.

Adulthood is a social construct contingent on a particular time and place for its meaning (Hammack and Toolis, 2014). The social construction is visible in previous studies, which have exposed variability in the markers of adulthood drawn upon depending on the social and cultural context (Horowitz and Bromnick, 2007; Rankin and Kenyon, 2008). Nevertheless, although definitions of adulthood may vary between cultures or over time, and it can be hard to establish precisely when one arrives (Coles, 1995), there is a mutual understanding and some degree of unanimity as to what constitutes adulthood based upon a society's underlying rules (Thomson et al., 1995; Jordan and Dunlap, 2001).

Within majority Western cultures, there has been a move away from social role transitions characterising adulthood towards individualistic criteria. Whereas once young people moved swiftly from education to marriage and parenthood (Hogan and Astone, 1986), social and economic changes have changed how adulthood is defined (Coles, 1995; Baron et al., 1999; Bynner, 2001). Arnett (2001) draws on anthropological, sociological, and psychological perspectives to propose six possible adulthood criteria. The first of these criteria focuses on 'individualism'. It relates to psychological (e.g., accepting responsibility for one's actions and holding beliefs independent of one's parents) and physical independence (e.g., leaving home and being financially independent). The second category relates to 'family capacities' and the ability to be responsible for others. The third concerns 'norm compliance' and ensuring one's actions are legal and sensible. The fourth category centres on 'biological transitions. The fifth is the legal or chronological transition, which is reaching the age of majority and the associated rights. Whilst the sixth pertains to role transitions, in other words, the end of educations, the beginning of a career and full-time employment and getting married and having children. However, it is the individualistic criteria that rank highest in research with adults across age groups which, Arnett (2001) argues, reflects the individualism of American culture where independence and self-sufficiency are pedestalled.

The move away from social role transitions is captured within Arnett's (1998; 2000) emerging adulthood theory which recognises that the approach to adulthood is more prolonged and nuanced than a transition from school to work would suggest. Emerging adulthood, which covers the ages of 18-25, is a time where one explores the possibilities open to them and "gradually arrive[s] at more enduring choices in love, work and worldviews" (Arnett, 2000: 479). It is also a time where the individualist criteria of adulthood are developed, as the following extract demonstrates:

> During emerging adulthood young people are in the process of developing the capacities, skills, and qualities of character deemed by their culture as necessary for completing the transition to adulthood […] the most important characteristics

> to develop during emerging adulthood are those that confer a sense of becoming an independent, self-sufficient individual. (Arnett, 1998: 312)

Furstenberg et al. (2004) proposed an alternative definition of adulthood. They surveyed almost 1,400 American adults, and concluded the most important milestones are completing education, establishing an independent household, and being employed full-time. It is important to note, however, that Furstenberg's (2004) survey was based on traditional benchmarks of adulthood as respondents were asked how important the following criteria were to being an adult: leaving home, finishing education, getting a full-time job, becoming financially independent from parents, being able to support a family, marrying and becoming a parent. Nevertheless, independence, albeit physical rather than psychological, remains prominent, and independence is viewed as a key factor in today's society as the move into adulthood is considered a move away from a childlike dependence on parents towards an autonomous and independent life. People must take control of their own lives and make their own decisions (McGinty and Fish, 1992; Jones 1997 cited Tisdall, 2001; Shepperdson, 2000).

A recent example of this is Sawyer et al. (2018). Here it is argued that adolescence should be extended to reflect the social and cultural changes which have taken place, resulting in later role transitions. Much like Arnett's (1998; 2000) theory of emerging adulthood, adolescence is described as a time to explore and learn "to acquire the essential assets for the future functioning of the adults of tomorrow" (Sawyer et al., 2018: 228). Although it is not explicitly stated, the implication is that unless you reach specific criteria, you remain an adolescent and cannot be considered an adult.

However, Arnett's theory of emerging adulthood (1998; 2000) has faced several criticisms: doubt is cast over whether emerging adulthood is a new developmental phase, a narrow demographical group of participants are drawn upon, and it is argued he relies too heavily on agency (Bynner, 2005; Shildrick and MacDonald, 2007; Berk, 2014). These areas of criticism are important as they suggest flaws in the definition produced, which, like all social constructs, has real consequences. How adulthood is defined can govern the privileges you can access, the roles you can assume and how others respond to you. Additionally, concepts rooted in developmental psychology, such as the conceptualisations of adulthood outlined above, slip into naturalised prescriptions and gain ratification through scientific claims. So significant are the effects "that they are often imperceptible, taken-for-granted features about our expectations of ourselves, others, parents, children and families" (Burman, 2008: 2).

It is, therefore, a fundamental concern that Arnett's work is based upon the American majority culture, which he describes as:

> The largely white and broadly middle-class majority in American society that sets most of the norms and standards and holds most of the positions of political, economic, and intellectual power. (Arnett, 1998: 286)

Although Arnett acknowledges that this ultimately excludes minority cultures or those outside the 'norm', he does not contest it. Thus, a psychological model of 'developmental stages' which fails to adequately recognise diversity continues to be perpetuated (Bynner, 2005; Shildrick and MacDonald, 2007) in what Goodley and Runswick-Cole (2011: 79) label “the tyranny of developmentalism”.

A narrative of exclusion

The result of the “tyranny of developmentalism” is that people who fall outside of normative narratives and fail to live up to the standards demanded by each particular developmental period are left on the margins (Goodley and Runswick-Cole, 2011). This is evident within the literature where, despite drawing on normative conceptualisations, the participants found their experiences contradicted societal expectations, young people felt they were left occupying a space between childhood and adulthood and excluded from society due to their differences (Wilkinson et al., 2015; Biswas et al., 2017; Merrells et al., 2019). Slater (2015: 39) highlights the problems caused by the preoccupation with normative adulthood by drawing on an account of parenting provided by Ferguson and Ferguson (2001: 87) who encounter difficulties in knowing how best to support their son reach adulthood:

> Do we emphasise his differences and try to avoid the conclusions of inferiority that society has traditionally attached, or do we emphasise his sameness and risk perpetuating the same social rules and expectations that have already unfairly excluded him? Should Ian's adulthood look the same or different from the dominant cultural models, or from any alternative models presented by other parts of the disability community?

Slater (2015) labels the comparison of young people with learning disabilities in relation to adulthood desires and expectations as the 'rhetoric of sameness'. They argue that claiming young disabled people are the same as their non-disabled peers perpetuates the notion that they are different; after all, why would there be the need to assert they are the same if they were. Additionally, it "does not go far enough in addressing dangerous discourses of (neo)liberal adulthood" (Slater, 2015: 50). Tying in with other critical disability studies literature (discussed in Chapter Two), which argues a focus on inclusion does not address the underlying exclusion, Slater (2015: 52) states:

> Arguing disabled young people are no different to anybody else is inadequate, it is not disabled young people's 'sameness' (or lack of it) which is problematic…[the] problem is with the normative imaginary of who this 'everybody else' is […] everybody else can only exist at the expense of those it deems other.

Thus, whilst a 'rhetoric of sameness' and focus on inclusion will lead to some people being included within adulthood, others will remain excluded and part of the population, enabling the continued existence of the 'everybody else' in the quote above. It is a reason why many disability allies, scholars and activists argue people with learning disabilities are not considered fully human, as summed up by Goodley (2021: 34):

> While humanism heralded the celebration of human rationality, single-mindedness, self-sufficiency and autonomy it inevitably dehumanised those who failed to match up to these humanist promises.

Problematic policy

In emphasising the four 'pathways' to adulthood (employment, independent living, social participation and health), transition-related policy is guilty of placing emphasis on normative ways of ''being, becoming and acting like an adult'' (Hamdani cited Kinross, 2017: online). Thus it feeds into the exclusion and oppression of people with learning disabilities whilst simultaneously advocating for their inclusion (MacIntyre, 2014; Slater, 2015). In positioning a successful transition to adulthood within a framework of employment, independent living, participation in society and being healthy, the Children and Families Act 2014 and related SEND Code of Practice reflect the current era of neoliberalism where future citizens, in a display of allegiance to the state and each other, are expected to be employed, independent, active, and healthy autonomous units, responsible for their own lives (Lahelma and Gordon, 2008; Burch, 2018).

In addition, Yates and Roulstone (2013) argue that UK policy takes an individualised approach to transition, which ignores the disablement young people face. They highlight how the focus on self-investment strategies such as raising aspirations, supplying individuals with more information so that they can make informed choices, and initiatives such as the now-defunct Connexions workers which were aimed at supporting young people to overcome barriers to employment, all suggest that it is the young person's deficiencies which are responsible for poor outcomes. However, a continued emphasis on individualisation and the perpetual belief that "opportunities are open to all", as presented through inclusion strategies, can be damaging with individuals blaming themselves for lack of success within education or the labour market (Evans, 2007: 89).

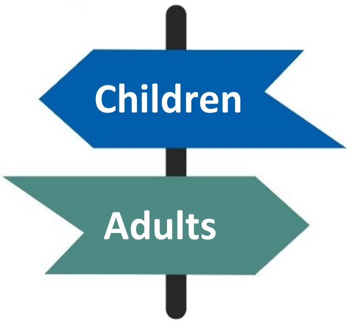
This is similar to one of the criticisms of Arnett's (1997; 1998; 2000; 2001) work mentioned previously. The individualisation of Arnett's approach reflects a growing trend in placing greater importance on the role of personal agency in life outcomes (Giddens, 1991; Beck and Beck-Gernsheim, 2006). However, this is considered problematic by structural perspectives where transitions to adulthood remain deeply class-based, and outcomes are influenced by education, gender, and social and economic status (Banks et al., 1992; Coles, 1995; Bynner, 2001). In a society dominated by individualism, Brannen and Nilsen (2002: 531) questions the extent that everyone is free to be choosers:

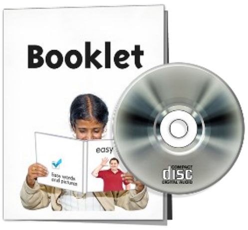
> The 'discourse of choice' is likely to be prominent among particular groups: among the relatively privileged young whose education is likely to lead to better career opportunities, as we found, while in other groups, the old order collectivism prevails.

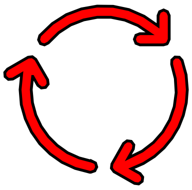
Interventions that concentrate on disabled young individuals and their collective experiences of transition fail to acknowledge broader structural issues and ignore the 'demand side' of employment (Yates and Roulstone, 2013). Instead, incessant calls for inter-agency collaboration and improved planning dominate recommendations (Tisdall, 2001) despite the evidence for transition planning affecting outcomes for young people with learning disabilities concerning housing and employment being scant (Heslop et al., 2002). Alongside young people being excluded from constructs of adulthood as demonstrated previously, it is argued that the main issue with transition lies in the lack of options available to young disabled people (Caton and Kagan, 2007; Barron and Hassiotis, 2008; Davies and Beamish, 2009; Williams, 2013).

Therefore, transition policy ignores the structural issues associated with inadequate opportunities for young people with learning disabilities following education. It fails to use disability to disrupt or challenge the taken-for-granted norms that maintain people with disabilities in an infantilising discourse (Coles, 1995). Instead, transition policy focuses on improving the process of transition to adult services to enhance the attainment of normative adult status and citizenship (Williams, 2013). Indeed, Burch (2018: 108) suggests that it would be more apt to replace the suggestions of a plurality of outcomes within the current SEND Code of Practice with a singular outcome that is "based upon a particularly normative creation of the autonomous, self-regulating, self-correcting subject". However, if efforts within transition remain based on a normative adult discourse and focus on inclusion and solidification of rights (e.g., the right to employment and full adult citizenship), then approaches will fail to shake up law, policy and social relations and dismantle the standards which lead to the exclusion of people with learning disabilities in the first place (Shildrick, 2012: 32). Consequently, there is the danger that young people with learning disabilities will continue to be excluded from society.

Chapter Three summary

	This chapter looks at what we know about transition.
 	Transition for people with learning disabilities is normally described as 2 things: 1) Moving from children to adult services 2) Becoming an adult
 	The government says transition can be a difficult time. It says there are things that can be done to make it better. These things included: • Planning for the young person's transition.

    	• Talking and listening to the young person and their family. • Different services working together. • Making sure people have information and advice about transition. • Transition keyworkers. • Support not stopping when someone turns 18.
	The government have put in place lots of plans to try and make these things happen.

	However, research shows that transition is still a difficult time.
	Young people, parents and professionals say:
	- There are lots of changes.
	- There is not much planning.
	- There is not much for young people to do when they finish college.
	- There is not much information about transition.
	- It is a difficult time for everyone.

	It is good to talk to young people, parents and professionals because sometimes they say different things.
	The way we think about adulthood can be unhelpful.
  	This is because lots of people think being an adult is about being independent and having a job.
 	This can be difficult for people with learning disabilities because sometimes they need support. Sometimes people with learning disabilities are not treated like adults and full members of society.
 	The plans the government have put in place do not help this.

	The government plans try and change the person with learning disabilities.
 ?	The plans try and make people feel included. They do not look at why people are left out in the first place.

Chapter Four: Methodological Overview

This chapter provides a methodological overview of the research. In doing so, I build on the concepts introduced in Chapter Two as I add more ‘tools’, both theoretical and practical, to the research toolbox. The chapter is divided into two sections. In Part One, I explore my philosophical paradigm, revisit positionality as I outline my ontology and epistemology, and explain why a qualitative approach to the research is adopted. In Part Two, I focus on the research design. Firstly, I discuss the scoping phase of the research. I explain how this, alongside the literature review, my background and a consideration of inclusive research approaches influenced the research design. This is followed by a discussion about communication as a sensitivity towards different methods of communication lead to a flexible approach being taken to data collection. I then describe the different data collection tools used within the research before setting out the recruitment procedure and inclusion and exclusion criteria. I conclude the chapter with a detailed explanation of the approach taken towards data analysis. As mentioned in Chapter One (page 15), parts of this chapter are written in first person to bring to the forefront the fundamental role researchers have as decision-makers and thus creators of research.

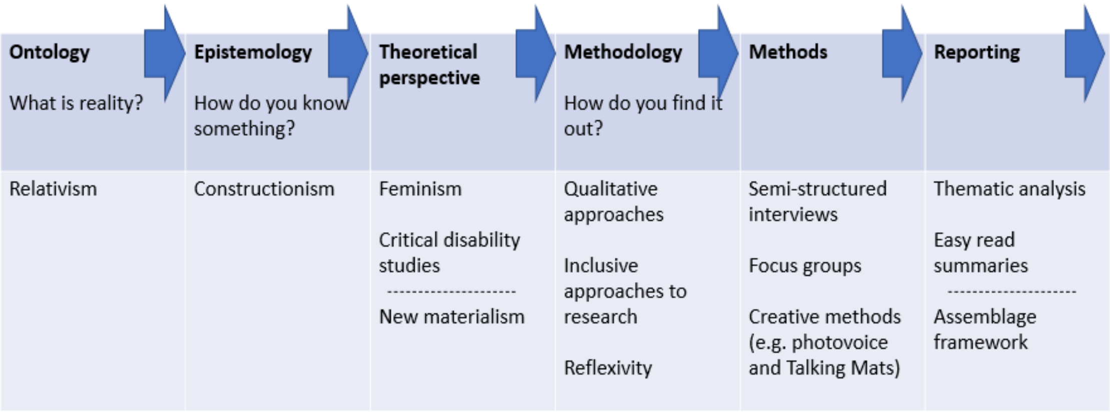
Part One: Philosophical paradigm

In Chapter Two I introduced the importance of paying attention to positionality and highlighted how the researcher’s worldview and social and political context affect their research. The chapter introduced me as the researcher, and located me in relation to the research topic, explaining the motivations behind the study. This section develops this further by drawing attention to my philosophical assumptions. Not only are these assumptions part of my positionality but, as they are affected by my values and beliefs, they are also a result of my positionality (Holmes, 2020).

Creswell (1998: 6) uses the term ‘world view’ to summarise the “general philosophical orientation about the world and nature of research that a researcher brings to the study” and, in doing so, draws attention to the relationship between the researcher and the research. Bringing their philosophical assumptions into the study, the researcher affects the research questions asked and the interpretations made (Denzin and Lincoln, 2003a). Therefore, as Chapter Two explains, if we draw attention to factors that affect the research, research transparency can be enhanced, potential bias exposed, and credibility and rigour improved. In this instance, those factors are the abstract guiding principles contained within my ontology and epistemology.

In the quest to clarify my beliefs and make explicit any implicit assumptions, the work of Crotty (1998) and Denzin and Lincoln (2003b; 2003a; 2008) has been helpful. **Table 2** provides an overview of my position and how it fits into the research process.

Table 2: An overview of the research process. Adapted from Crotty (1998)



Ontology What is reality?	**Epistemology** How do you know something?	**Theoretical perspective**	**Methodology** How do you find it out?	**Methods**	**Reporting**
Relativism	Constructionism	Feminism Critical disability studies -------------------- New materialism	Qualitative approaches Inclusive approaches to research Reflexivity	Semi-structured interviews Focus groups Creative methods (e.g. photovoice and Talking Mats)	Thematic analysis Easy read summaries -------------------- Assemblage framework

Although **Table 2** appears to be neatly arranged, with each box leading on to the next, the reality is different. Most research does not begin with an interrogation of the ontological and epistemological views of the researcher and a topic found in accordance with these. Instead, research typically starts with a ‘real-life’ issue that is to be explored. The selection of the most appropriate methodology and methods then follows. As Crotty (1998: 13) explains, it is only later, when attempting to justify the chosen path, that the process engaged in tends to be addressed and the implicit assumptions that have acted as guiding principles are made explicit. As discussed in Chapter Two, not all the theoretical perspectives listed in **Table 2** were present from the start of the research. This is shown in **Table 2** by the dotted lines, which demonstrate how the influence of new materialism and thus the use of assemblage to report and discuss the findings was a late addition to the research. Therefore, **Table 2** is the end of a messy process which only became apparent as the study developed, and I was able to reflect on why I had taken the steps I had and consider how, and why, I wanted the research to develop in a particular way.

Chapter Two has already addressed the theoretical perspectives listed in the third column in **Table 2** and reflexivity listed in column four. The easy read summaries are addressed in Chapter One, and the assemblage framework used to support the discussion is presented in Chapter Twelve. Therefore, this chapter attends to the remaining sections beginning with my ontology and epistemology.

Ontology

Ontology is the study of being (Crotty, 1998). It is concerned with the nature of what exists (Blaikie, 2007: 13) and asks the question, ‘what is reality?’ Responses to this question typically fall into three categories: realism, critical realism, and relativism (Guba, 1990).

To the realist, reality exists independently of human action (Blaikie, 2007) and our ideas of it (Proctor, 1998). It is driven by immutable natural laws and mechanisms (Guba, 1990) and thus is a standpoint that is often associated with positivism and objectivity. Critical realism also asserts that reality exists and is driven by natural laws. However, it differs from realism in the belief that reality, and its associated natural laws, can only ever be partially understood (Guba, 1990). Thus, critical realism is seen as a rejection of the positivism associated with realism (Proctor, 1998).

I align myself with relativism, which, in contrast to critical realism and realism, is a standpoint whereby the world does not exist independently of our perception (Blaikie, 2007). Realities exist in the form of multiple mental constructions. These are socially and experimentally based, and although there may be shared elements across people and cultures, they are local and specific, "dependent for their form and content on the individual persons or groups holding the constructions” (Guba and Lincoln, 1994: 110-111). It is a stance that often attracts criticism due to a belief it leads to a position where 'anything goes' (Potter 1998 cited Burr, 2015: 107). It is, however, a relativist ontology that underpins this research with the view taken that “declarations of the real operate as conversation stoppers; they establish the limits of what others can say, who can be heard” (Gergen, 2009: 162). Following a relativist ontology, there is no inherent ‘truth’ of disability or impairment. This is not to deny a lived reality of disability (Slater, 2015: 7) but to see it as the qualitative researcher's role to report on the different realities and diversity of interpretations, relying on the voices and interpretations of informants in the process (Creswell, 1998). However, it is important to remember that the different realities are entwined within our society, mediated by discourse and culture (Gergen, 2009). Indeed:

> The moment we begin to articulate what there is – what is truly or objectively the case – we enter a world of discourse, and thus a tradition, a way of life, and a set of value preferences. Even asking whether there is a real world "out there" presumes the Western view of the person, a subjective world "inside" the head and an "objective" world somewhere outside. (Gergen, 2009: 161)

In keeping with this philosophy, it follows that the thesis adheres to a constructionist epistemology (although it should be noted that not all constructionists need be relativists (Crotty, 1998)). This is evident in that the social construction of adulthood is discussed in Chapter Three. Furthermore, it is reflected in the adoption of a qualitative methodology as this methodology is suited to prioritising the voices of people with learning disabilities, their mothers, and professionals to explore and understand their different realities and experiences of transition.

Epistemology

Epistemology is the study of how we acquire knowledge and addresses the question “how do we know what we know?” (Crotty, 1998: 3). As Maynard (1994: 10) states, epistemology centres on providing "a philosophical grounding for deciding what kinds of knowledge are possible and how we can ensure that they are both adequate and legitimate". Epistemology, therefore, plays an integral role within research; it is embedded within the theoretical perspectives adopted and the subsequent methodology (Crotty, 1998).

Crotty (1998) identifies three main epistemologies: objectivism, constructionism, and subjectivism. Within objectivism, “meaning, and therefore meaningful reality, exists as such apart from the operation of any consciousness” (Crotty, 1998: 8). Therefore, as humans, we simply discover the meaning lying in wait for us - an approach familiar to many early ethnographers seeking to discover objective truth. Subjectivism lies at the opposite end of the epistemological spectrum, whereby knowledge and meaning are created from within the mind. The object itself does not contribute to the generation of meaning. Instead, our dreams, religious beliefs, and primordial archetypes within our collective unconscious are drawn upon to create meaning (Crotty, 1998).

Situated somewhere between these two stances lies constructionism. Constructionism holds that there is no objective truth for us to discover as "truth or meaning comes into existence out of our engagement with the realities in our world" (Crotty, 1998: 8). Thus, as with subjectivism, there can be no meaning without mind. However, unlike subjectivism, the mind does not operate in isolation; meaning is constructed as we interact and interpret the world and objects within (Robson, 2011). It is this epistemology to which I, and therefore my research, subscribe.

Somewhat confusingly, the term 'constructionism' is often used interchangeably with that of 'constructivism'. Yet, a critical distinction exists: whilst constructivism tends to focus on how the individual constructs meaning and makes sense of the world, constructionism concerns itself with the group (Crotty, 1998; Robson, 2011).

Burr (2015), following Gergen (1985), asserts that constructionism has several fundamental principles:

Firstly, and of particular pertinence to this thesis, a critical stance is adopted towards taken-for-granted knowledge as "social constructionism cautions us to be ever suspicious of our assumptions about how the world appears to be" (Burr, 2015: 3). For example, the categories we use to order and define the world, such as disability, and the meaning we ascribe such categories are only ever products of social construction rather than ‘real’ divisions. Similarly, Crotty (1998) argues that constructionism ‘fosters the critical spirit’ as it draws attention to the way meaning is inherited from our predecessors and flippantly passed down the generations as ‘truth’ becoming ingrained in how we view the world and thus closing off opportunities for dialogue (Crotty, 1998; Gergen, 2009).

Secondly, Burr (2015) asserts that social constructionism is a relativist account. Any interpretation or creation of meaning which takes place does so within a web of historical and cultural norms (Creswell, 1998; Gergen, 2009).

Thirdly, whilst our understandings may vary historically and culturally, they are sustained by social processes rather than observation of the world. It is through our daily interactions with each other that we 'exchange' or reinforce understandings of the world, and truths become embedded within our society as meanings are passed down through the generations. It is language that is the prime medium for such exchanges and interactions (Darlaston-Jones, 2007; Burr, 2015).

Lastly, and perhaps most importantly, knowledge and social action go hand-in-hand as principal understandings of the world at any one point constrain or promote particular action (Burr, 2015). Power relations are at play as different constructions have implications for how we treat one another and what is legitimate or permissible behaviour. If, for example, we take the construct of 'learning disability', we can examine how values surrounding the category have changed through the years and the implications this has had on how people have been treated. Within this framework, as explained within Chapter One, language is performative. Thus, a questioning or changing of the dominant narrative opens possibilities for social change. This has particular resonance within this thesis whereby critical disability studies is drawn upon, and normative discourses questioned; taken-for-granted terms, such as adulthood, are contested, and a “critical spirit” (Crotty, 1998: 58) fostered in an attempt to challenge current practice and contribute to social change within learning disability services.

This research is situated firmly within its historical and social context in keeping with the above principles of constructionism. The inclusion of **Table 1** in the literature review situates the research in the current political context and it is explained how policy contributes to the solidification and dissemination of dominant narratives within our society and the subsequent impact this can have.

Within a constructionist paradigm, and in alignment with relativism, the researcher's task is to explore some of the multiple social constructions and attempt to understand the meanings others hold about the world. Therefore, qualitative methods are favoured as they allow the researcher to acquire multiple perspectives and explore the nuances of experience (Robson, 2011). Furthermore:

> Qualitative methodologies accept the person and society as co-constructors of his or her reality, and the synergy of person and society is recognised. (Darlaston-Jones, 2007: 25)

As a result, when approaching the analysis, not only were individual situations and realities explored, but common themes were identified to make links to wider societal structures and processes within the discussion chapters.

Methodology: A qualitative inquiry

Methodology is defined as:

> The strategy, plan of action, process or design lying behind the choice and use of particular methods and linking the choice and use of methods to the desired outcome. (Crotty, 1998: 3)

Put simply, the methodology is how the inquirer, or researcher, goes about finding out knowledge. In keeping with the philosophical context outlined above, this is a qualitative study to allow the researcher to explore and acquire multiple perspectives (Robson, 2011). Qualitative research prioritises lived experience and attempts to "document the world from, the point of view of the people studied" (Hammersley, 1992: 165). Such research is often dismissed in favour of quantitative methods as critiques question the reliability and validity of qualitative work (Silverman, 2011). However, qualitative research is designed to provide a rich, contextualised picture of a social phenomenon in which the complexity of a situation is rendered visible (Darlaston-Jones, 2007; Creswell and Creswell, 2014; Mertens, 2015).

There is, however, no one correct way for conducting qualitative research. Indeed, the design often emerges and develops during data collection when multiple techniques may be employed in response to the current situation the research finds itself in (Robson, 2011). Therefore, it is recommended that researchers describe their methodology in detail (Bogdan and Biklen, 1982). Correspondingly, the following sections focus on the research design, describing the motivation behind the design and the subsequent data collection methods employed.

Part Two: Research design

The symbiotic relationship between researchers and their research is a familiar topic, discussed above and in Chapter Two. It is, therefore, no surprise that a discussion on the design of doctoral research involves the researcher. After all, the researcher decides what shape the research should take, who the participants should be, and what methods are used. Thus, this section begins with a return to my positionality and explains why the three stakeholder groups were included as participants and why the research takes the direction it does when it initially began as an exploration of transition in light of Manchester's devolution. As discussed in the opening paragraph of this chapter, the following sections are then discussed in turn: communication; the data collection tools including interviews, focus groups, photography and Talking Mats; the recruitment process; and the analysis process. A description of participants is intentionally omitted from this chapter. This, alongside a rationale for its location, can be found in Chapter Six. However, in short, separating participants from the research design allows space to share more of their stories than might otherwise be possible.

Developing the research aim

As is mentioned in Chapter One, the initial aim of the research was to focus on transition in light of the devolution Manchester agenda, to understand how devolution affected transition for young people and their families and what opportunities devolution presented for improving transition. However, consistent with an emerging design, researchers are encouraged to allow the research aim and associated questions to evolve and change during research (Cresswell 2008) in response to "real-world observations and experiences" and questions raised by people who sit outside of dominant institutions (Ackerly and True 2008: 700). Therefore, the aim of this research changed following a 'scoping phase'. The 'scoping phase' took place over the first few months of the PhD; I began exploring transition literature and learning about different theoretical approaches. At the same time, however, several links were made with local parent carer forums, a disabled people's organisation, a self-advocacy group, several mothers and several professionals working in transition. Informal meetings took place with the different groups of people to discuss the research and learn more about transition and learning disability services more generally in Manchester. During the meetings, it quickly became apparent that devolution was not a concern. Indeed, a common response was 'devolution, what's that?'

Macleur (2010: 282) describes how small fragments of data can catch your attention as they "glimmer" and "glow", taking root in your mind and sparking connections with other thoughts and experiences. Following the informal meetings, three conversations glimmered and lingered as Macleur (2010) described. The first was a discussion with one of the mothers who explained that when approached by the social worker for some dates she would be available for her daughter's transition meeting, she asked why and questioned what her daughter would transition into at the meeting. The second took place at a self-advocacy group where, following a general discussion about 'transition to adulthood', I was asked what my transition was like. The third was a conversation with one of the professionals who spent a long time discussing how parents 'want everything' at transition and how their expectations were too high as it was impossible to meet them. Thus, whilst these conversations were not data per se, they stood out. Connections were made with my own experiences of working in transition, my initial engagement with the literature and my developing awareness of critical disability studies and feminist research (both outlined in Chapter Two). Together, these conversations and the connections they generated moved the aim of the research away from focusing on devolution toward a more general desire to consider what an understanding of the three different perspectives can bring to transition.

I was already keen to include the three different stakeholder groups (i.e., young people, parents and professionals) within the research. It is, of course, imperative to involve people with learning disabilities in research that concerns them. However, as explained within the literature review, transition is known to affect the whole family (Blacher, 2001; Neece et al., 2009; Codd and Hewitt, 2020) and involving parents within transition research is viewed as necessary if any recommendations for improving transition are to be successful (Gauthier-Boudreault et al., 2017). The literature review also highlights that where professionals are included in transition research, differences of opinion can surface between professionals, parents and young people (Cooney, 2002; DeZonia, 2008; Kaehne and Beyer, 2010; Murphy et al., 2011). Additionally, my knowledge of services and the issues young people and their families often encounter during transition meant I was aware of how instrumental professionals can be within these experiences. The parent-professional relationship often a particularly tricky one (Todd and Jones, 2003) and power hierarchies are endemic within learning disability services.

Due to the differing priorities evident across the three groups during the scoping phase, epitomised by the conversation had with one professional about expectations, my desire to include all three groups within the research was cemented. As mentioned in Chapter Two, the inclusion of professionals was not for triangulation purposes but rather to provide a more holistic picture of transition and deepen understanding of transition (Gauthier-Boudreault et al., 2017; Francis et al., 2018).[5] Thus, I wished to explore the complexity of transition, to understand how the young person-parent-professional dynamics unfold during transition and contribute to current experiences.

However, simultaneously, conversation from the scoping-phase meetings pointed to the absurdity of 'transition' and its power to other. This, coupled with my developing interest in critical disability studies and a reflection on the ethics of disability research (see Chapter Five), ensured I was keen to try and avoid perpetuating othering where possible. Thus, unlike other studies that have included the three stakeholder groups to explore a specific aspect of transition (e.g. Murphy et al., 2011; Jacobs et al., 2021), I wished to leave the research open and be led by the participants. Narrowing down the research to focus on a particular aspect of transition (e.g. transition planning or how devolution affected transition), would reinforce transition as a fixed entity. This would do little to break down the boundaries erected between people with learning disabilities who go through ‘transition to adulthood’ and people without disabilities who simply grow older and could risk perpetuating the normative underpinnings of transition highlighted in the literature review (Hamdani et al., 2015). Therefore, I set out with the simple yet complex aim of answering the question, 'what can an understanding of the three different perspectives bring to transition?’

The next sections focus on how I set about answering this question. It discusses the data collection tools used and the recruitment and analysis processes. However, as a sensitivity for different methods of communication heavily influenced the data collection tools, a section on communication acts as a precursor and explains why a flexible approach to data collection was adopted.

Communication

Communication has been described as a particular challenge for researchers working with people with learning disabilities (Lewis and Porter, 2004). Often, the medical model of disability is employed whereby people are viewed in terms of their communication deficits and limitations. Indeed, an inability to communicate verbally or articulate oneself comprehensively has, in the past, proved justification for exclusion from

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[5] This is not a complete picture. As acknowledged within Chapter Thirteen, where the research limitations are examined, fathers and siblings are often neglected within disability research but have the potential to enhance understandings further.

research (Booth and Booth, 1996; Boxall and Ralph, 2011). Approaching communication through a social model lens has the potential to disrupt this narrative; any difficulties relating to the participation of people with learning disabilities within research says more about the unsuitability of the chosen methods rather than the ‘problem of the individual’ (Booth and Booth, 1996; Morris, 2003; Gilbert, 2004; Rabiee et al., 2005). Under the social model, the onus is on the researcher, rather than the researched, to overcome barriers to communication. For example, Booth and Booth (1996: 67) suggest that “researchers should attend more to their deficiencies then to the limitations of their informants”, whilst Argent and Kerrane (1997: 73) point out that the statement 'they don't understand' used in relation to participants often translates as 'I can't think how to explain it to them'. The following statement by a disabled child summarises these issues:

> We are used to people saying we cannot communicate, but of course they are wrong. In fact, we have powerful and effective ways of communicating and we usually have many ways to let you know what it is we have in mind. Yes, we have communication difficulties, and some of those are linked with our impairments. But by far the greater part of our difficulty is caused by ‘speaking’ people not having the experience, time or commitment to try to understand us or to include us in everyday life. (Disabled People Using Scope Services, 2002: 1-2)

Therefore, I was conscious when designing the study and during data collection that any difficulties encountered concerning communication were due to my limitations rather than the participants’. For example, my Makaton not stretching beyond a few basic words. Various documents offer advice and guidance on working with people with learning disabilities (Morris, 2003; Lewis and Porter, 2004; Nind and Vinha, 2013). Easy read information, where explanations are simplified and pictures used to enhance meaning, is advocated for (Bashford et al., 1995; Cameron and Murphy, 2007) and so simplified consent forms (Rodgers, 1999) were handed out alongside easy read information sheets. The consent forms however, acted only as a ‘preliminary guide’ (Durell, 2016) to participants’ decision to take part as consent was viewed as an ongoing process (Morris, 1998; Knox et al., 2000b; Cameron and Murphy, 2007).[6] Furthermore, “making documents accessible is only one aspect of the proper involvement of people

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[6] Consent is explored further in Chapter Five.

with intellectual disabilities in research" (Bashford et al., 1995: 211), and the importance of flexibility in one's approach is crucial. People with learning disabilities are not a homogenous group (Townsley et al., 2003) and should not be treated as such. Therefore, just as methods of communication will vary from person to person, so too must the research tools utilised in order to respond to differing needs, ages and abilities (Booth and Booth, 1996; 2003; Morris, 2003; Rabiee et al., 2005; Nind and Vinha, 2013), and ensure the research remains "reliable, non-threatening and an enjoyable experience" (Rabiee et al., 2005: 388). With this in mind, how the methods and tools were implemented was determined individually and evolved as the study developed (Robson, 2011). In line with the 'researcher as bricoleur' (Denzin and Lincoln, 2003a), introduced in Chapter Two, I allowed myself to be led by the individual participants or the groups, giving them a choice as to how they wished to participate. I responded to participants' suggestions rather than forcing my agenda upon them. This fits with Robson's (2011) flexible design approach whereby the emphasis is on participants views and multiple qualitative data collection techniques are recommended with the design evolving as the study progresses.

The above approach led to the collection of a patchwork of data. This comprised of interviews, pictures, photographs, post-it notes and recordings. The Learning Difficulties Research Team (2006: 85) states:

> There are traditional academic ways of doing research. However, people with learning difficulties are involved better when imaginative and accessible methods are used.

Thus, rather than seeing a patchwork of data as 'mess', it could be viewed as evidence of the flexible design (Robson, 2011) and proof of an attempt to adopt an "imaginative and accessible" approach to methods best suited to individual participants.

Therefore, in light of the above, the sections below provide an overview of the tools used to gather the data: interviews, focus groups, photography and Talking Mats. The first part of each section summarises the method whilst the second part explains the procedure.

Data collection tools

Interviews

Interviews are at the heart of qualitative research (Nind, 2008) and although the validity of interview data has, in the past, been questioned (e.g. Houtkoop-Steenstra, 2000), they provide a flexible and adaptable means of finding things out, and have the potential to provide rich and illuminating data which allows for the complexities of real-life to shine through (Robson, 2011). Interviews can be fully structured whereby the interviewer asks the same set of questions with fixed wording at each interview, semi-structured whereby a topic list acts as a guide for the interviewer but the exact questions asked depend on the flow of the interview and the answers given or unstructured whereby there is a general topic of interest from which the conversation develops (Robson, 2011). It is the latter two approaches that are commonly utilised within flexible designs.

Interviews are widely considered a collaborative process (Järvinen, 2000; Fontana and Frey, 2008; Silverman, 2011). Thus, rather than the interviewee being a passive "vessel waiting to be tapped" (Gubrium and Holstein, 2004: 151), participants are understood to be 'constructors of knowledge' (Järvinen, 2000) with both the interviewee and interviewer active participants (Gubrium and Holstein, 2004). The researcher requires sensitivity to their role within the interview and the control possessed when deciding the questions to ask, the parts of the conversation to follow up and the parts to let fall by the wayside (Rapley, 2004).

Interview procedure

Interviews were the sole method of data collection within this study for participants without learning disabilities. Interviews were semi-structured as a list of prompts acted as a loose guide (see Appendix 7). Movement through the list was dependent on participants' responses (Ayres, 2008) and interviews ranged in length between 32 minutes and 120 minutes. As carers, parents of learning-disabled children often have immense demands placed upon their time (Todd and Shearn, 1996).[7] Therefore, to cause as little inconvenience as possible to participants, interviews took place at a time

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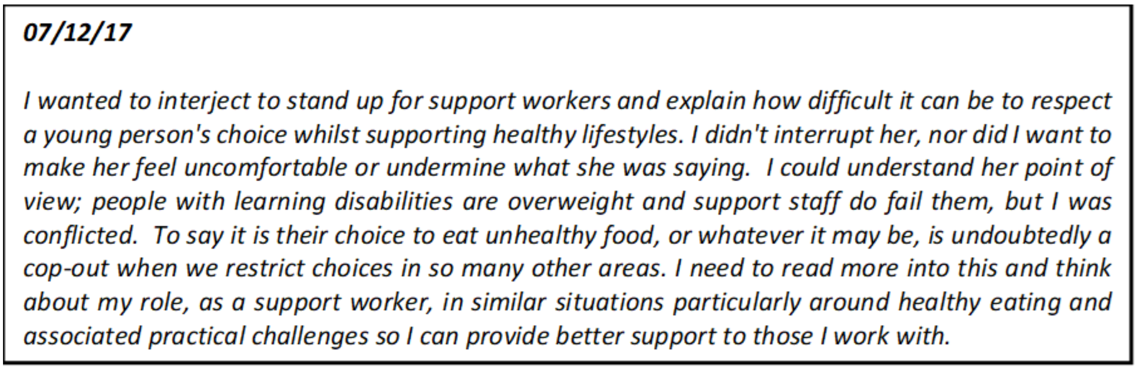
[7] Discussed further in Chapter Five

and location of their choosing.[8] For mothers, this was either at their home or at the parent/carer forum they attended. The interviews with professionals all took place in a meeting room at their place of work. Immediately after each interview I used the research diary to describe how the interview went, and to note any thoughts or feelings that arose during the interview. Scheurich (1995) emphasises how the historical and cultural context behind the researcher shapes their actions. Thus, the diary was also a space to reflect and record the moments I was aware that I directed the flow of conversation in a particular direction, to note when tensions due to my context emerged and, as is explained in Chapter Five, a space to work through other ethically important moments which occurred (Guillemin and Gillam, 2004). The research diary extract in **Box 4** demonstrates how I used the diary to reflect upon the interviews.

Box 4 Research diary extract 07/12/17



07/12/17

I wanted to interject to stand up for support workers and explain how difficult it can be to respect a young person's choice whilst supporting healthy lifestyles. I didn't interrupt her, nor did I want to make her feel uncomfortable or undermine what she was saying. I could understand her point of view; people with learning disabilities are overweight and support staff do fail them, but I was conflicted. To say it is their choice to eat unhealthy food, or whatever it may be, is undoubtedly a cop-out when we restrict choices in so many other areas. I need to read more into this and think about my role, as a support worker, in similar situations particularly around healthy eating and associated practical challenges so I can provide better support to those I work with.

A feminist approach to interviews was adopted whereby the myth of ‘hygienic research’ is challenged (Oakley 1981: 260). Whilst this is explained further in Chapter Five, for the interview to be an interactive experience, the interviewer is encouraged to “bring their personal role into the research relationship by answering participant’s questions, sharing knowledge and experience, and giving support when asked” (Dwyer and Buckle, 2009: 62). This is much in line with the new empathetic approach discussed by Fontana and Frey (2008: 117) whereby an ethical stance, in favour of the individual or group being studied, is taken and “the interviewer becomes an advocate and partner in the study, hoping to be able to use the results to advocate social policies and ameliorate the conditions of the interviewee”. Therefore, during the interviews, I would sympathise

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[8] A telephone interview was suggested by one parent who was stretched for time. However, this failed to materialise.

with participants and reference snippets from my own experiences to show I understood the situation they were explaining and that I shared their sense of injustice, an action that also helped bridge the insider/outsider divide discussed in Chapter Two. The research was also viewed as an 'iterative-inductive' process (O'Reilly, 2009) as I moved freely between "theory and analysis, data and interpretation". The interviews were no exception to this; they were conducted parallel to reading for the literature review and I was often conscious of the two influencing each other. Thoughts or theories encountered within the literature would be raised within the interview where I was keen to explore participants thoughts on a particular topic. Likewise, following interviews I would explore literature relating to comments or thoughts shared by participants. I used the research diary as a space to document these links, forming part of the analysis process (see **Figure 4**).

Focus groups

Focus groups allow researchers to access more than one view at once and benefit from the advantage of a group dynamic and peer support. They can foster confidence within participants and create a safe and comfortable environment to help people with learning disabilities contribute to research (Cambridge and McCarthy, 2001; Fraser and Fraser, 2001; Nind, 2008; LLewellyn, 2009). Furthermore, accessing participants who were already part of established discussion groups, as was the case in this study, can enhance the focus group as participants may be more confident and assertive, happy to share their experiences and thoughts alongside each other and in the presence of a supporter, being well practised in doing so (Llewellyn, 2009).

Focus group procedure

A discussion was held in advance with the facilitators of the groups to share information about the research project, discuss initial ideas of how the group might like to participate and how best to structure the session to suit members' differing needs. For example, in one instance the facilitator requested the interview guide in advance so that one member, who used a communication device, had time to think of their answers and programme them into the device, thus enabling them to contribute on the day. However, the exact structure of the meetings varied from group to group depending on individual needs, existing group dynamics, structures, and routines. I was conscious that members of the groups were often friends and that these meetings might be the only time they had to catch up with each other. Much like with the interviews, whilst there was a loose interview guide, the content of the focus group varied depending on the participants and the stage of the research when the focus group took place. Therefore, the first group I met with discussed how they had enjoyed an event they attended where post-it notes were used to capture key phrases, thoughts, and ideas. These were then grouped to form a bigger picture of the topic much like the 'Diamond 9' technique (Clark, 2012). As the participants had found this a useful way to share their thoughts, I took the idea to the next focus group held and asked whether it would be a useful way to open the discussion. The group liked this idea and so the meeting started with participants writing down, or drawing, with support where necessary, what transition, and consequently adulthood, meant to them as shown in **Figure 1**. These post-it notes then formed the crux of subsequent discussions with the group and acted as a visual prompt if conversation stalled (Clark, 2012). They also enabled those who were less confident in speaking to share their thoughts as supporters could read out what they had written.[9]

Figure 1 Photo taken during a focus group demonstrating the use of post-it notes to facilitate discussion

Photography

The use of imagery and arts-based methods within social research is well recognised as a powerful way to convey meaning (Banks, 2001; Pink, 2006; Boxall and Ralph, 2009). This is particularly so when expressing feelings or thoughts that can be difficult to articulate if only relying on words (Blodgett et al., 2013). The social documentary photographer Lewis Hine sums this up when he states, "If I could tell the story in words,

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[9] The role of supporters is discussed further in Chapter Five.

I wouldn't need to lug a camera" (cited Wang and Burris, 1997: 372). Within learning disability research, however, visual methods have the added advantage of making research more accessible. The focus is moved away from the narrow remit of talk or text and participants can show, rather than discuss, their experiences. In doing so, attention is shifted from incapacity to capacity (Aldridge, 2007; Nind, 2008; Boxall and Ralph, 2011). Photovoice, developed by Wang and Burris (1994; 1997), is one way to do this. Within this method, participants are given a camera so that they can take photographs to illustrate the research topic or question. The photographs then provide a means of "accessing other people's worlds and making those worlds accessible to others" (Booth and Booth, 2003: 431). It is intended to empower participants as it enables them to control both the 'photo' and the 'voice' element of the research (Boxall and Ralph, 2011).

There is also a political dimension to this method as Wang and Burris (1994, 1997) recognise feminist theory as one of the key influences on the development of their work. Knowledge grounded in experience is valued and the conditions are created whereby oppressed groups "can gain power and stimulate positive social change" (Povee et al., 2014: 896). Similarly, Booth and Booth (2003:432) state:

> The process challenges the politics of representation by shifting control over the means for documenting lives from the powerful to the powerless, the expert to the lay-person.

Therefore, due to the political aspect and potential for increased accessibility, I was keen to incorporate photography within my research should participants wish.

Photography procedure

As the flowchart in **Figure 3** (page 97) shows, four participants opted to take photographs as part of their involvement within the research. Therefore, largely in keeping with the stages of photovoice described by Booth and Booth (2003), participants were given a disposable camera alongside an easy read information sheet and consent form asking them to document what is important to them growing up (see Appendix 3 and 5). I collected the cameras when they were 'full' and arranged for two sets of photos to be developed so that both the participants and I had a copy. As dialogue is an important element of photovoice (Boxall and Ralph, 2011) and photos are supplemented by interview data (Povee et al., 2014), I then arranged a meeting with participants to look at the photos together. As with other elements of the research, how these discussions took place was flexible. Therefore, at the request of the participants, I met with one participant on their own and two participants with their mothers. I refrained from looking at the photos before these meetings. This was important ethically as the photos belonged to the participants. Therefore, they should have the opportunity to remove any they did not wish to be included (Booth and Booth, 2003). However, I also did not wish to make any assumptions about what the photos meant.

Talking Mats

Talking Mats involve moving symbols or pictures around on the table or a board to facilitate conversation (Murphy, 1998; Brewster, 2004) and have been used in previous transition studies (Cameron and Murphy, 2000). As with photovoice, their use is intended to supplement interviews and give control to participants over the content of discussion (Bunning and Steel, 2006: 48).

Unlike photovoice where the participant controls the images used (Lewis and Porter, 2004; Boxall and Ralph, 2011), Talking Mats rely on someone else, i.e., the researcher, selecting the images available for use within the interview. This raises the question of whether words are being put in the participants mouth and responses being constrained or pre-determined (Brewster, 2004; Lewis and Porter, 2004; Nind, 2008). However, as one participant was familiar with using PECS (Bondy and Frost, 1994) he and his mother felt the use of pictures, in a form similar to a simplified Talking Mat, rather than photography, would be more meaningful.

Talking Mats procedure

As a frame of reference for picture selection I turned to the Preparing for Adulthood website (www.preparingforadulthood.org.uk) and selected pictures based on the different areas of adult life they suggest: ‘employment’, ‘independent living’, ‘friends, relationships and community’ and ‘good health’ (Preparing for Adulthood: no date). I also included some pictures under the different categories relating to things I knew were important to the young person based on a prior informal meeting with him and a discussion with his mother. As is shown in **Figure 2**, the participant was then able to select pictures and place them under the headings ‘like’, ‘dislike’, and ‘unsure’ to aid discussion. At the end of the session photographs of the ‘mat’ were taken and copies given to the participant. This provided the participant with a tangible record of the session and gave him ownership over what he had said and enabled him to share his participation with others.

Figure 2 Photo taken during an interview with a young person demonstrating the Talking Mat in action

As with two of the participants who used photovoice, this participant was also supported by his mother during the interview. She was able to help interpret his views and Makaton signs and expand on what he communicated.

Recruitment

Separate to those involved in the scoping phase of the research, several parent/carer forums and self-advocacy organisations/speak-up groups for people with learning disabilities were identified across Greater Manchester via internet research and word-of-mouth. These were contacted initially via a brief email inviting them to discuss participation further. Where no response was had, a follow-up phone call was made, and a voicemail message left where possible. If the group failed to make contact following this it was assumed that they did not wish to participate.

Where parent/carer forums responded an informal meeting was arranged with the manager to discuss the research and any potential participation in more depth. At the end of the meeting managers were asked to circulate information about the research to their members. Several parents responded expressing an interest either on their own behalf or on their child's. They were then contacted on an individual basis to arrange an interview or to discuss how the different ways their child could participate. An informal meeting was then arranged to meet with the young person to provide the information and consent forms and, where relevant, a disposable camera.

Where self-advocacy/speak-up groups responded, a discussion was had with the facilitators of the groups, either by email or phone, to find out more about the group and its members and discuss the research. Whilst it was originally intended to recruit individual participants from the self-advocacy/speak-up groups, it quickly became apparent through these discussions that the members would prefer to meet as a group. Applying the 'researcher as bricoleur' metaphor to gathering data (Denzin and Lincoln, 2003a) and with Robson's (2011) flexible design approach in mind, this was embraced and led to the three focus groups discussed above. The group facilitators suggested a suitable time and date for the focus group to take place.

Snowball sampling (Atkinson and Flint, 2004) was also utilised to recruit individuals to the study, particularly professionals working within transition services. In these instances, potential participants were contacted by phone or email to see if they would be interested in participating in the research and an information sheet was provided. If they were interested, an interview was arranged, and a consent form provided at the meeting at a time and location of their choosing.

Figure 3 (page 97) provides a summary of the recruitment procedure discussed above.

Inclusion/exclusion criteria

Participants fell into one of three categories:

1) A young person with a learning disability aged between 14 and 25
2) The parent or carer of a young person with a learning disability aged between 14 and 25
3) Professionals working with young people with learning disabilities and their families during transition.

The age range of 14-25 was chosen for, as explained in Chapter Three, this is considered the transition period within policy and health and social care services.

In an attempt to avoid unnecessary labelling and thus pathologising of people with learning disabilities, information about specific diagnoses was not sought and instead self-identification as having a learning disability or being the parent of a child with a learning disability, was considered enough.

As **Figure 3** shows seven interviews with parents took place (one of whom also worked at the parent/carer forum), five participants with learning disabilities were recruited and interviewed using photovoice or a Talking Mat and three focus groups with people with learning disabilities and their supporters were held. A further five interviews with professionals took place. Overall, this resulted in a total of 21 different data collection sessions, which included a total of 36 people.[10]

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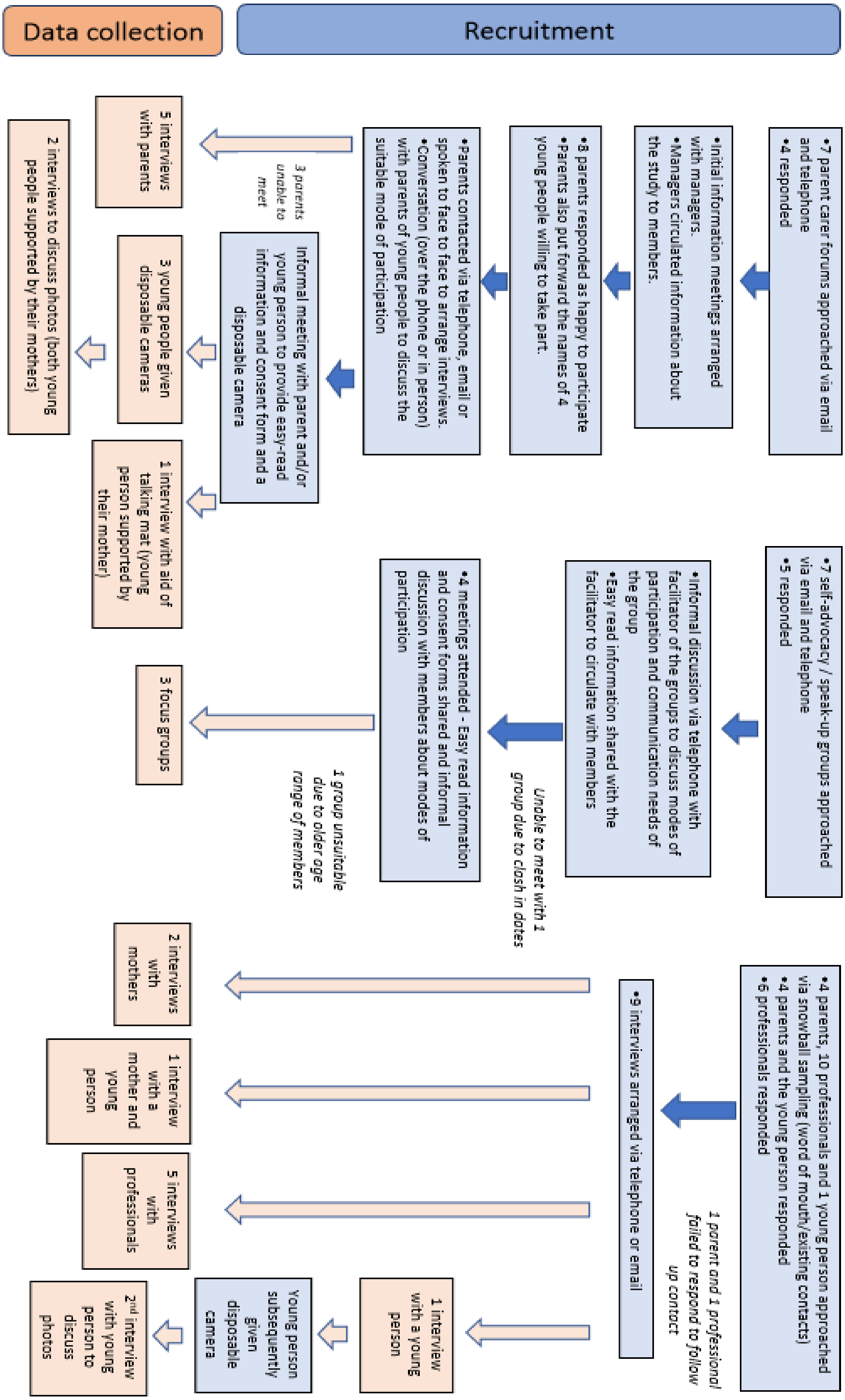
[10] This number excludes supporters who attended the focus groups.

Figure 3 Recruitment and data collection process



- 7 parent carer forums approached via email and telephone
- 4 responded

- Initial information meetings arranged with managers.
- Managers circulated information about the study to members.

- 8 parents responded as happy to participate
- Parents also put forward the names of 4 young people willing to take part.

- Parents contacted via telephone, email or spoken to face to face to arrange interviews.
- Conversation (over the phone or in person) with parents of young people to discuss the suitable mode of participation

3 parents unable to meet

Informal meeting with parent and/or young person to provide easy-read information and consent form and a disposable camera

5 interviews with parents

3 young people given disposable cameras

2 interviews to discuss photos (both young people supported by their mothers)

1 interview with aid of talking mat (young person supported by their mother)

- 7 self-advocacy / speak-up groups approached via email and telephone
- 5 responded

- Informal discussion via telephone with facilitator of the groups to discuss modes of participation and communication needs of the group
- Easy read information shared with the facilitator to circulate with members

Unable to meet with 1 group due to clash in dates

- 4 meetings attended - Easy read information and consent forms shared and informal discussion with members about modes of participation

1 group unsuitable due to older age range of members

3 focus groups

- 4 parents, 10 professionals and 1 young person approached via snowball sampling (word of mouth/existing contacts)
- 4 parents and the young person responded
- 6 professionals responded

1 parent and 1 professional failed to respond to follow up contact

- 9 interviews arranged via telephone or email

2 interviews with mothers

1 interview with a mother and young person

5 interviews with professionals

1 interview with a young person

Young person subsequently given disposable camera

2nd interview with young person to discuss photos

Analysis process

Data analysis is the process of making sense of data and it involves writing, theorising and reading (Coffey and Atkinson, 1996). The researcher organises and reduces their data before shaping it into a story that makes sense in light of the research question guiding the study (LeCompte and Schensul, 2010). There is no single method of analysing qualitative data (Bannister et al., 1999) and, just as each qualitative study is unique, so too are the analytical approaches adopted by the researcher (Miles and Huberman, 1994).

Although conscious that analysis begins in the mind of the researcher (LeCompte and Schensul, 2010) and happens throughout the entire research process (Rice and Ezzy, 2000; Watt, 2007), deciding a formal method with which to approach the data felt like a key juncture in the research process. It was a moment where I, as the researcher, "must determine how best to proceed" (Watt, 2007: 82). Due to how the approach taken would affect the research findings (Guba, 1990; Denzin and Lincoln, 2003b), it felt like an appropriate time to re-examine the epistemological foundations of the research set out earlier in this chapter.

As Part One of this chapter explains, this research falls within a social constructionist paradigm. Social constructionists are encouraged to adopt a critical stance; to question any assumptions about how the world appears to be and pay attention to how 'truths' become ingrained within society as the creation of meaning is deeply embedded within its historical and cultural context (Crotty, 1998; Burr, 2015). Understandings are produced and sustained by social processes rather than inhering within individuals or arising from direct observations of the world (Braun and Clarke, 2006; Burr, 2015) and, therefore, social constructionist are more concerned with the group rather than the individual (Crotty, 1998).

Therefore, when approaching research into 'transition' through a social constructionist lens, there is a desire to understand the social processes and constructs that permeate 'transition'. Exploring the experiences and perceptions of the participants offers a means to do so as their experiences are reflective of the different discourses operating within our society (Braun and Clarke, 2006). As social constructionists "seek to theorise the sociocultural contexts and structural conditions that enable the individual accounts that are provided" (Braun and Clarke, 2006: 84), an analysis method which explores patterns across data sets rather than within individual accounts, is important.

Thematic analysis proved a viable choice as it is:

> A data reduction and analysis strategy by which data are segmented, categorised, summarised, and reconstructed in a way that captures the important concepts within a data set. (Ayres, 2008: 867)

It can be employed by researchers within an essentialist or realist paradigm as well as those taking a more constructionist stance and it can be used in both inductive and deductive approaches to data. Within an inductive approach, data is coded without a pre-existing framework whilst the findings within a deductive approach are more heavily driven by the researcher's particular area of interest. However, it is questionable how inductive one can be. Researchers cannot detangle themselves from their interpretative paradigm leading Braun & Clarke (2006: 84) keen to emphasise that coding does not occur in an "epistemological vacuum". Furthermore, the boundaries between inductive and deductive approaches are blurred as many factors influence how we see and interpret data. Taking engagement with literature, an ongoing process within doctoral study, as one example, and it can be argued that the engagement detracts from the researcher's openness to themes emerging from the data (Tuckett, 2005), after all I discuss previously how my engagement with literature shaped the interviews. Alternatively, however, an awareness of the literature surrounding one's topic can "enhance sensitivity to subtle nuances in data" and later be used to confirm or challenge findings (Strauss and Corbin 1998: 49).

Braun and Clarke's (2006; 2019a; Braun et al., 2019) approach to thematic analysis embraces researcher subjectivity as it is viewed as "a resource rather than potential threat to knowledge production" (Braun and Clarke, 2019a: 591). Their later work, in particular, emphasises how the researcher generates or creates the themes in a complex interplay between the data, the researcher's subjectivity and their positionality. It is an approach I found to be empowering. Taking a step back to remind myself that themes are researcher generated rather than discovered and there is "no one way of making sense of data" (Braun et al., 2019: 12) was liberating. Similarly, embracing my position and reminding myself of the motives for the research alongside my epistemological and theoretical understandings would often give me the confidence to continue. It also helped ensure I remained mindful of one of the criticisms of thematic analysis – that its flexibility can also be its downfall as it can lead to inconsistency and a lack of coherence when developing the themes (Nowell et al., 2017).

Although various suggestions for conducting thematic analysis exist (Attride-Stirling, 2001; Tuckett, 2005; Braun and Clarke, 2006) as with all aspects of qualitative research, there is no one set of rules to guide researchers through the process. Therefore, alongside making our epistemological and other assumptions explicit (Holloway and Todres, 2003) researchers should also disclose the physical steps taken when conducting their analysis (Attride-Stirling, 2001; Tuckett, 2005). Doing so helps demonstrate that the research has been conducted in a "precise, consistent and exhaustive manner…with enough detail to enable the reader to determine whether the process is credible" (Nowell et al., 2017: 1). Braun and Clarke (2006) suggest a six-phase process to thematic analysis which is outlined in **Table 4.** However, they stress that this is a guide rather than a rulebook and interpretation and implementation of the guide rests with the individual researcher. Furthermore, and much like with my epistemological and ontological stance presented in **Table 2**, although the guide is presented as a linear process, it is highly dynamic and iterative (Braun and Clarke, 2019a). It is intended that the researcher goes back and forth between the stages as required and constantly moves between the entire data set, the coded extracts, and their analysis. I outline my implementation of Braun and Clarke's (2006) guide in **Figure 4** (page 103) and provide a definition of the labels used during data analysis in **Table 3.**

Table 3 Labels used during data analysis

Label	**Definition**
Code	A code is the label given to a segment of data to identify what is of interest about that segment of data
Theme	A theme brings multiple codes together to capture something important about the data relating to the research question. (Before the theme is finalised, I have referred to them as tentative themes.)
Sub-theme	A sub-theme draws out and brings attention to a particular aspect of one theme

Table 4 'Phases of Thematic Analysis' Braun and Clarke (2006:87)

Phase	Description of the process
1. Familiarising yourself with your data	Transcribing data, reading and re-reading the data, noting down initial ideas
2. Generating initial codes	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code
3. Searching for themes	Collating codes into potential themes, gathering all data relevant to each potential theme
4. Reviewing themes	Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis
5. Defining and naming themes	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells; generating clear definitions and names for each theme
6. Producing the report	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis

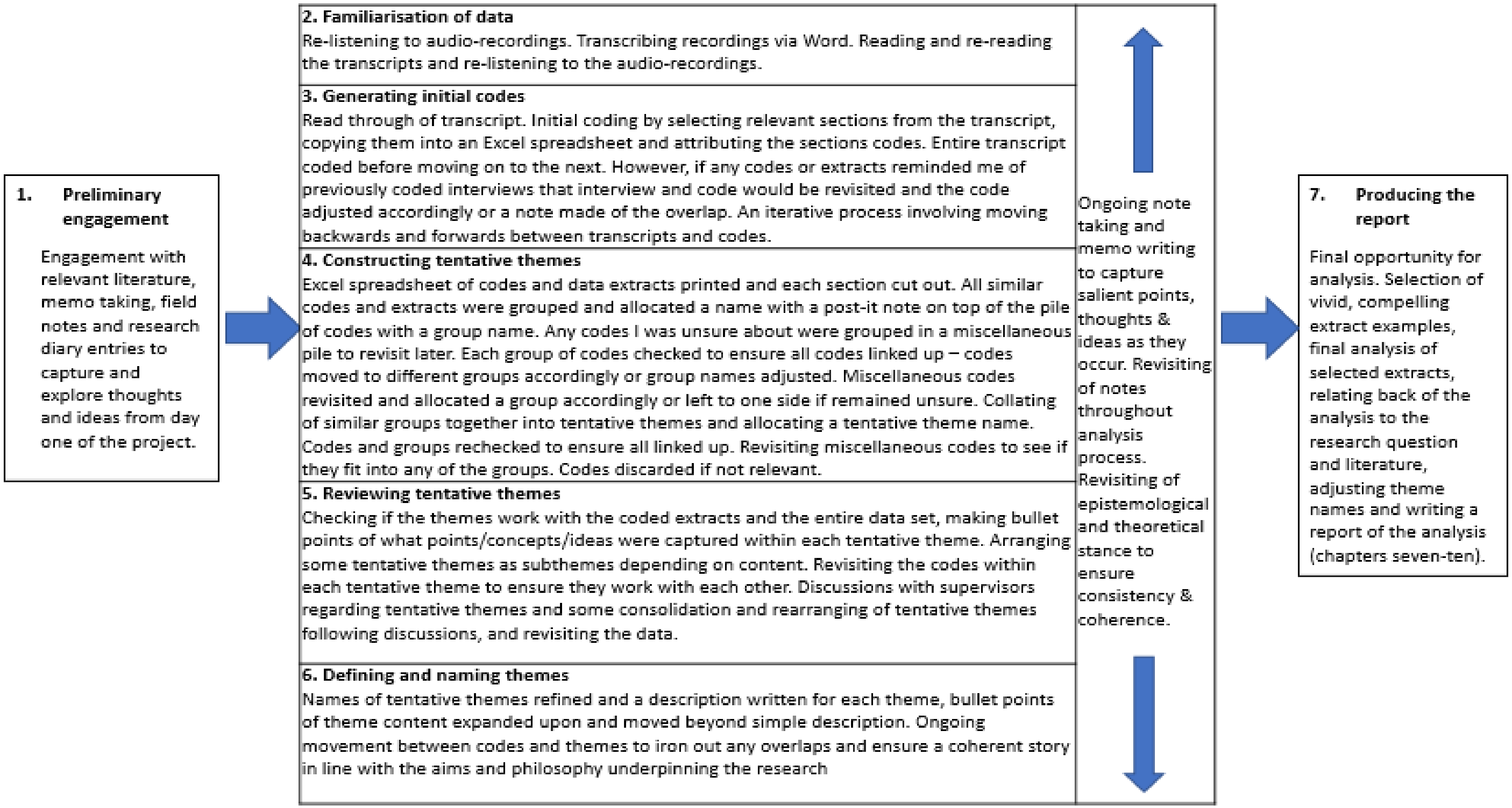
To capture the analysis that occurs before the more formal stages of thematic analysis, I included an extra step in my adaptation of the process. As previously highlighted, analysis happens throughout the research process as ideas are formed through our various encounters with literature and the 'real world'. Keeping a research diary and writing short notes to capture these ideas as they were encountered quickly became one way to manage these analytical beginnings (Watt, 2007). Braun and Clarke (2006: 86) also agree that writing is a central component of analysis stating it should begin in phase one, "with the jotting down of ideas and potential coding schemes and continue right through the entire coding/analysis process". Therefore, during the listening, transcribing and coding of the interviews, I kept a word document open on my computer to keep track of any thoughts, ideas, possible codes or patterns and included these documents in the iterative analysis process.

Originally, I attempted to tackle the coding via NVivo, attracted by its organisational capabilities, the extra element of transparency it can bring to a project, and its potential to save time and effort (Welsh, 2002). However, after coding several interviews I felt distanced from the data and detached from the codes I was producing. This is not uncommon with Creswell (2013: 202) describing how a computer program can put a machine in-between the researcher and their data and cause an “uncomfortable distance between the research and his or her information”. Therefore, I began the process again, reverting to printing the transcripts so a hard copy could be read and annotated before copying sections of the transcript to an Excel spreadsheet and attributing a code to each section. Post-it notes created during the focus groups were also included as data and coded in the same way as the interview transcripts. This ensured that information conveyed by participants who opted to write rather than speak was not lost during the analysis process. Photos, however, although occasionally drawn upon to illustrate the themes in the proceeding chapters, were not coded as they were used to facilitate discussion rather than being treated as data. Once all the transcripts were coded for each set of participants, the spreadsheets were printed and the individual cells containing the codes and data segments cut up. The individual pieces of paper containing the code and data segment were then manually arranged and rearranged into tentative themes (with some adjusting of codes along the way). Although the margin for error felt wider than using NVivo as there was the potential for the individual pieces of paper be mislaid, I felt more immersed within the data, connected via the tangibility of the paper. It was also easier to visualise potential themes and test out different groupings of codes by physically moving the slips of paper around. This process is explained further in **Figure 4** (page 103).

What about ethics and the research participants?

This chapter has outlined my philosophical paradigm, explained the development of the research aim, presented the methods used to conduct the research and described the procedures for recruitment and analysis. It has not discussed the ethical issues which arose during the research or described in detail the research participants. Whilst these are two areas closely linked to research methodology and methods, separating them into separate chapters rather than including them here, reflects the centrality of research ethics to this thesis and ensures the participants are not simply reduced to isolated quotes (Baldwin, 2020). Therefore, the following two chapters supplement this chapter whilst enriching the thesis as a whole as Chapter Five attends to ethics and Chapter Six introduces the participants.

Figure 4 An overview of the analysis process adapted from Braun and Clarke (2006)



1. Preliminary engagement

Engagement with relevant literature, memo taking, field notes and research diary entries to capture and explore thoughts and ideas from day one of the project.

2. Familiarisation of data

Re-listening to audio-recordings. Transcribing recordings via Word. Reading and re-reading the transcripts and re-listening to the audio-recordings.

3. Generating initial codes

Read through of transcript. Initial coding by selecting relevant sections from the transcript, copying them into an Excel spreadsheet and attributing the sections codes. Entire transcript coded before moving on to the next. However, if any codes or extracts reminded me of previously coded interviews that interview and code would be revisited and the code adjusted accordingly or a note made of the overlap. An iterative process involving moving backwards and forwards between transcripts and codes.

4. Constructing tentative themes

Excel spreadsheet of codes and data extracts printed and each section cut out. All similar codes and extracts were grouped and allocated a name with a post-it note on top of the pile of codes with a group name. Any codes I was unsure about were grouped in a miscellaneous pile to revisit later. Each group of codes checked to ensure all codes linked up – codes moved to different groups accordingly or group names adjusted. Miscellaneous codes revisited and allocated a group accordingly or left to one side if remained unsure. Collating of similar groups together into tentative themes and allocating a tentative theme name. Codes and groups rechecked to ensure all linked up. Revisiting miscellaneous codes to see if they fit into any of the groups. Codes discarded if not relevant.

5. Reviewing tentative themes

Checking if the themes work with the coded extracts and the entire data set, making bullet points of what points/concepts/ideas were captured within each tentative theme. Arranging some tentative themes as subthemes depending on content. Revisiting the codes within each tentative theme to ensure they work with each other. Discussions with supervisors regarding tentative themes and some consolidation and rearranging of tentative themes following discussions, and revisiting the data.

6. Defining and naming themes

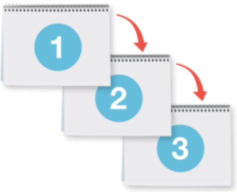
Names of tentative themes refined and a description written for each theme, bullet points of theme content expanded upon and moved beyond simple description. Ongoing movement between codes and themes to iron out any overlaps and ensure a coherent story in line with the aims and philosophy underpinning the research

Ongoing note taking and memo writing to capture salient points, thoughts & ideas as they occur. Revisiting of notes throughout analysis process. Revisiting of epistemological and theoretical stance to ensure consistency & coherence.

7. Producing the report

Final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, adjusting theme names and writing a report of the analysis (chapters seven-ten).

Chapter Four summary

 	This chapter is about how Francesca did the research.

	The research is **qualitative**. This means it is about words**.**
  	Francesca spoke to 3 groups of people. 1. Young people with learning disabilities. 2. Mothers 3. Professionals working in transition

	Francesca found these people by contacting parent carer forums and self-advocacy groups and talking to people
	Young people could choose how they took part. Francesca hoped this would make it easier for them to take part.
	Some people took part in **focus groups**. A focus group is where people come together to talk about something.
 	Some people took photographs of the things that were important to them in their lives and growing up. Francesca and the young person looked at the photos together and talked about what was in them.

	One person used a Talking Mat. This meant they used pictures to show what was important to them.
	Francesca used interviews to find out what mothers and professionals thought about transition.
36	In total Francesca met with 36 people
  	Francesca recorded the meetings so after she had met with everyone, she could write down what they had said. She then looked to see where people had said similar things. This process is called **thematic analysis.**

Chapter Five: Ethical Considerations

Halse and Honey (2007: 336) argue that regulation of ethics regularly leads to research being positioned as "an ordered, linear process", tensions are sanitised, and the principles that guide ethical decision-making are viewed as objective and unambiguous. My experience proved different; the research itself was far from ordered and linear (see, for example, how the research aim developed as discussed in Chapter Four), and there were no overarching objective principles that guided the ethical decision making. Instead, I wrestled with the ethical considerations and tensions throughout the research. Sometimes these considerations presented as a straightforward decision-making process; however, often they appeared as dilemmas encouraging me to reflect on my position both inside and outside the research. What remained constant was the sensitivity, awareness, and interest held regarding ethics throughout the research. As such, including a chapter within the thesis to highlight some of the ethical issues that arose felt a necessary and appropriate step from a personal and academic perspective.

This chapter begins with a return to the ethics of disability research; a topic first broached in Chapter Two when the importance of addressing researcher positionality is raised. Following this, drawing on Guillemin and Gillam (2004), a distinction is made between procedural or institutional ethics and 'ethics in practice', with each addressed in turn. The procedural ethics addresses informed consent, the potential for harm and potential issues relating to anonymity and confidentiality. The ethics in practice, meanwhile, begins with a discussion about the use of a research diary as a space for exploring and documenting ethical issues as they arose. This is followed by three ethical issues: the literature review, the interview process, and the use of proxy respondents/supporters. Extracts from the research diary support the main body of text within this chapter alongside **Table 5** which maps how consideration for ethics threads through the thesis.

The ethics of disability research

Ethics, defined as "moral principles that govern a person's behaviour or the way in which an activity is conducted" (The Compact Oxford English Dictionary, 2005: 341) are part of the everyday practice of doing research (Guillemin and Gillam, 2004: 262). Their consideration "should pervade all professional activity" (British Psychological Society, 2009: 6). As highlighted in Chapter Two, this is of particular significance in relation to disability research due to the potential for research to add to the oppression and marginalisation of disabled people. Therefore, it is considered necessary for researchers to locate themselves in relation to the research (Goodley 2011). Due to my experiences working within social care coupled with a personal desire for social justice, I entered the research allied to disabled people and their families. I was conscious that unless the research outcomes attempted to contribute to improving the lives of young people and their families, it could be considered exploitative. Lewis and Porter (2004) state that as a minimum, researchers should determine the value of the research to people with learning disabilities and question how it contributes to their lives. Likewise, Goodley (2017: 34) states, “one should come to disability studies with a profound desire to understand and change the conditions of contemporary society. If not, why bother?” Having witnessed the challenges faced by young people and their families during transition due to social structures and hurdles established by the systems designed to help (Duffy and Murray, 2010), I was undoubtedly driven by a sense of injustice and a desire to improve the situation.

However, my position in relation to this quickly developed. Due to engaging with transition literature and different theoretical perspectives, reflecting on the three 'glimmering' conversations that emerged during the scoping phase of the research (see Chapter Four) and paying attention to discussions about transition which took place elsewhere, for example on social media, the parameters of what I considered ethical research changed.

Nevertheless, even with the best intentions, research within academia is seldom entirely altruistic. The researcher usually benefits most via career development (Goodley, 2017; Oliver, 1997), particularly when the research forms part of a doctorate. Furthermore, in a set of questions drawn up by Goodley and Lawthom (Goodley, 2017: 28) relating to the ethics of undertaking disability research, they ask: “to what extent do research projects include disabled people as active participants but also as fellow researchers?” It is a question that highlights an ethical shortcoming of this research as young people with disabilities are only included as participants rather than as coproducers or coresearchers. Similarly, as mentioned in Chapter Two, the position of non-disabled researchers researching matters of disability can be troublesome (Oliver, 1992; Oliver, 1997; Zarb, 1997; Barnes, 2003; Barnes and Sheldon, 2007). My non-disabled status could be considered suspicious (Barnes, 2003) and at risk of recreating "the established social relations of research production [which] give rise to inequalities of power between researcher and researched" (Priestley, 1997: 88). Therefore, despite consideration for research ethics throughout the research, tensions relating to my position and the research design arose and it is acknowledged that more could have been done to ensure the research was ethically robust.

Procedural ethics vs "ethics in practice"

Guillemin and Gillam (2004) suggest that ethics within qualitative research comprises two components: procedural ethics and the "ethics in practice." Procedural ethics involve the processes adhered to in the interest of gaining ethical approval from the relevant institution and anticipated before the study commences. In contrast, "ethics in practice" or "microethics" concern the everyday ethical issues that occur when carrying out research.

Procedural ethics

Before starting the research, an application for ethical approval was submitted to Manchester Metropolitan University Academic Ethics Committee. This addressed the proposed aims of the research and the research design. The application also included a copy of the proposed interview framework and copies of the information and consent forms. The main body of the application addressed potential ethical issues which were, at the time, considered to be: consent, the potential of harm to participants, the confidentiality of participants, and the use of photography as a method. Except for photography, which is examined in Chapter Four, the anticipated issues are discussed in turn below.

Informed consent

Historically people with learning disabilities hold less power than their non-disabled peers. Even when people can advocate for themselves, they may be mindful that it is their non-disabled supporters who wield power (Goodley, 2000). Often people with learning disabilities may have little experience in choosing or have choices restricted (Nind, 2008). They may have also experienced problems if making unpopular or inappropriate choices (Harris, 2003). This is in addition to the researcher holding a "special power" due to their position of prestige and influence (Coolican, 2004: 68).

Therefore, it is vital to ensure that participants understand that it is their choice as to whether they take part in the research and do not simply agree due to lack of understanding, fear of saying no, or learnt acquiescence (Stalker, 1998). As a result, although formal consent was gained from each participant before the interviews or focus groups took place, aided by easy read information and consent forms (Cameron and Murphy, 2007), it is recognised that this is not enough. The notion of someone being 'informed' simply via the passing of information from the researcher to the participant is flawed with Swain et al. (1998) raising issues as to whether participation is truly voluntary, given the factors laid out above. Furthermore, it is possible to question how informed participants can be within qualitative research when they do not know the direction conversation may take (Swain et al. 1998). Consent was therefore viewed as an ongoing process and not something only established at the start of research (Morris, 1998; Knox et al., 2000a; Lewis and Porter, 2004; Cameron and Murphy, 2007). I 'checked in' with participants throughout our meetings and remained conscious of both verbal and non-verbal signs from participants indicating that they were uncomfortable and may wish to stop the session.

Potential for harm

In their list of questions to guide ethical research, Lewis and Porter (2004: 5) include the question, "could research participants harmed in any way through involvement?" as beneficence (attending to participant wellbeing) and non-maleficence (protecting participants from harm) are key principles which should guide ethical research (Beauchamp and Childress, 2009). Whilst I did not envisage the research would harm participants, it is impossible to know how participants may feel as "interviews are interventions […] they affect people" (Patton, 1990). Interviews and focus groups are designed to encourage people to open-up. Therefore, to minimise any upset, I ensured participants took the lead and dictated the pace, and I was ready to pause or suggest ending the interview if necessary. In line with on-going consent, participants were regularly reminded that they were free to leave at any point. Furthermore, participants controlled when and where the interview took place as the more control participants have throughout the research process the less likely the research is to infringe on their rights (Swain et al., 1998). I was also mindful that, as a researcher, I may contribute to "the succession of different faces drifting in and out of people's lives' not under their control" (Stalker, 1998: 10). This concern was not unfounded for, in one exchange, when a mother was asked if her son might like to participate is the research, the response was, *"my son won't engage with professionals"* demonstrating a blurring of different professionals and their roles. Therefore, in addition to ensuring I clarified with participants the nature and remit of my role, I also intended to meet with participants during the analysis stage. Discussing the themes with participants whilst they were being developed would provide participants with the power of redress (Nind 2008) and act as closure to the research process. However, unfortunately, as is discussed in Chapter Thirteen, this proved impossible due to the Coronavirus pandemic.

Anonymity and confidentiality

Protecting the anonymity of research participants is another essential aspect of ethical qualitative research (Greaney et al., 2012). However, as Nind (2008: 8) states, "managing it is not always straightforward". I addressed the issues of anonymity within the ethical application as follows:

> *Confidentiality of participants will be preserved throughout the project by using pseudonyms in the written analysis and any outputs resulting from the research. 'Raw' data will be password protected on the researcher's computer.*

However, in keeping with Nind (2008: 8), this was not to a clear-cut process and it highlighted the discrepancies which can exist between 'procedural ethics' and 'ethics in practice' (Guillemin and Gillam, 2004). For example, despite stating participation would be confidential, some participants wished for their own name to be used rather than that of a pseudonym. I responded by explaining to participants the remit of the ethical approval and as such, enforced the use of a pseudonym. However, as participants may wish to own their stories, enforcing anonymity can be considered as denying participants their voice and infringing on their autonomy (Swain et al., 1998; Nind, 2008; Tuffrey-Wijne et al., 2008).

Ethics in Practice

Ethics in practice encompass the everyday ethical issues that occur when undertaking research that are not usually accounted for within the ethics application (Guillemin and Gillam, 2004). As Guillemin and Gillam (2004: 265) explain, the "issues may seem unimportant because they have an 'everyday' sort of quality. However, there is much more to ethics then red-letter dilemmas." Whilst it may seem that there is an obvious way for the researcher to respond in certain situations these moments should still be considered as ethically important as there "is the possibility that a wrong could be done". The research diary was instrumental in exploring these moments, and thus, its use opens this section. The reasoning behind the approach taken to literature follows before two issues that stood out during the data collection process are addressed: the use of interview as a method with parents of children with learning disabilities and the use of supporters and 'proxy respondents'.

The use of a research diary

Reflexivity is regularly evoked in connection with knowledge construction and the ensuring of rigour in relation to this. Indeed, it is in this manner that reflexivity is discussed in Chapter Two. Guillemin and Gillam (2004: 275) sum this up when they state:

> Reflexivity involves critical reflection of how the researcher constructs knowledge from the research process – what sorts of factors influence the researcher's construction of knowledge and how these influences are revealed in the planning, conduct, and writing up of the research.

Following this, keeping a reflexive research diary sheds light on how the researcher constructs knowledge with Watt (2007: 84) explaining that maintaining a diary allows the researcher to establish their knowledge and how they came to know it. However, there is also a connection between reflexivity and ethics as reflexivity allows the researcher to explore the ethical entanglements during the different stages of research (Kleinsasser, 2000; McGraw et al., 2000; Guillemin and Gillam, 2004).

Reflexivity is not just a means of ensuring that rigorous research practice underpins the creation of knowledge, but it also contributes to ensuring ethical research practice. Guillemin and Gillam (2004: 276) explain what utilising reflexivity in this manner involves:

> First, an acknowledgement of microethics, that is, of the ethical dimensions of ordinary, everyday research practice; second, sensitivity to what we call the 'ethically important moments' in research practice, in all their particularities; and

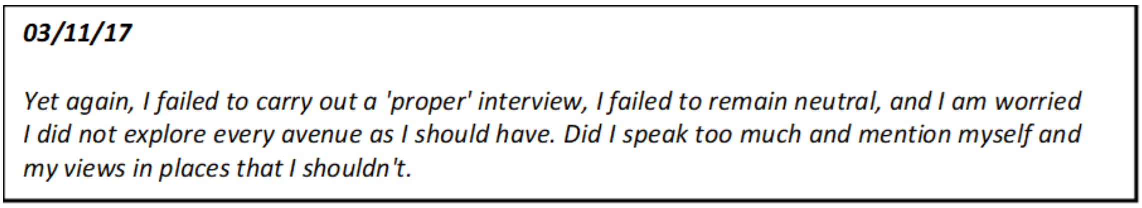
> third, having or being able to develop a means of addressing and responding to ethical concerns if and when they arise in the research.

A research diary thus proved a vital space to document and examine 'ethically important moments' as they arose. For example, through the diary, I came to understand and feel comfortable in my approach to interviews. Multiple diary entries include a concern around the ethics of expecting participants to expose themselves and become vulnerable whilst I, the researcher, remained protected. This is a concern similar to that raised by the anthropologist Behar (1993: 275) when she states:

> We ask for revelations from others, but reveal little or nothing of ourselves; we make others vulnerable, but we ourselves remain invulnerable.

Like Behar, I was concerned that participants "are then left carrying the burden of representations as we hide behind the cloak of alleged neutrality" (Behar 1993: 169). My frustration at being unable to maintain the objective, neutral stance that is encouraged of the researcher (Oakley, 1981) is shown in **Box 5**, and I mistakenly believed I was failing to conduct a 'proper' interview.

Box 5 Research diary extract 03/11/17

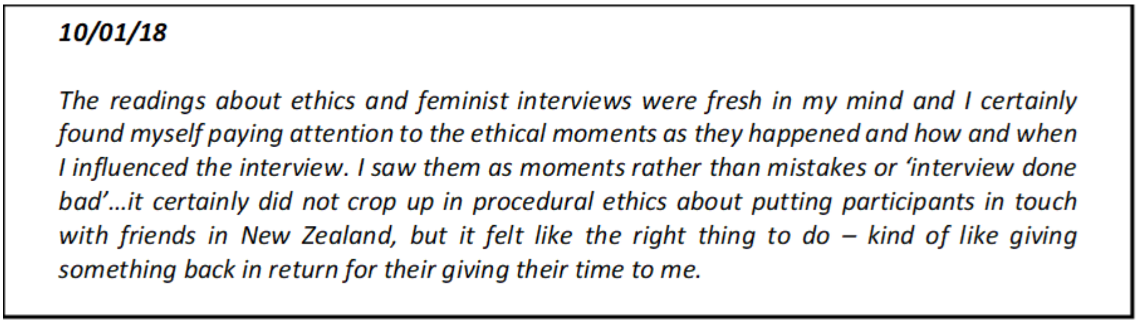


03/11/17

Yet again, I failed to carry out a 'proper' interview, I failed to remain neutral, and I am worried I did not explore every avenue as I should have. Did I speak too much and mention myself and my views in places that I shouldn't.

Acknowledging and articulating my concerns in such a manner made it easier to address them. Drawing on feminist research, I found it reassuring to read of approaches to interviews whereby the 'textbook' researcher and the supposed distance a researcher is meant to maintain is contested (Oakley, 1981; Cotterill, 1992) and, as is shown in **Box 6**, I grew in confidence as a researcher demonstrating the benefits the research diary brought to the research.

Box 6 Research diary extract 10/01/18



10/01/18

The readings about ethics and feminist interviews were fresh in my mind and I certainly found myself paying attention to the ethical moments as they happened and how and when I influenced the interview. I saw them as moments rather than mistakes or 'interview done bad'…it certainly did not crop up in procedural ethics about putting participants in touch with friends in New Zealand, but it felt like the right thing to do – kind of like giving something back in return for their giving their time to me.

Treating literature as a 'community of knowledge'

As introduced in Chapter One, one area where ethical considerations emerged concerned the use of literature to support and develop the research and subsequent thesis as I questioned what kind of knowledge is valued and whose lens is upheld. Drawing on the arguments presented in Ribenfors (2020), this section provides an overview of these considerations and explains the subsequent approach adopted towards literature.

The literature review acts as the foundation to a thesis; it provides the rationale for the research and elucidates the current state of knowledge and is thus a central component of the thesis (Bruce, 1994; Boote and Beile, 2005; Bell, 2010; Ridley, 2012; Machi and McEvoy, 2016). However, traditionally, literature reviews prioritise scholarly knowledge (Boote and Beile, 2005) as opposed to experiential knowledge. Yet it is experimental knowledge, "the possession of knowledge that originates through living an experience or experiences" (Hill Collins, 1990: 233), that is typically valued within emancipatory and participatory approaches to research and prioritised within current disability research. These approaches challenge the traditional dichotomous research relationships of the 'expert' and the 'researched' and advocate that "the quality and relevance of research is improved when disabled people are closely involved in the process" (Stalker, 1998: 6). The value of experimental knowledge is reflected in the rise of coproduced research (Kara, 2017), the presence of "advisory or consultative groups" within research (Tarleton et al., 2004: 75) and even the employment of people with learning disabilities as research associates (Tuffrey-Wijne et al., 2021). Additionally, there is a movement across health and social care more generally to recognise people with learning disabilities and their families as ‘experts by experience’.[11] However, responses to issues of oppression and marginalisation via inclusive and participatory approaches to research are often restricted to the design and data collection phase of research. They do little to contest knowledge hierarchies perpetuated in other parts of the research process, for example, via institutional ethics procedures or literature reviews.

One of the theoretical tools guiding this research is feminist thought which encourages researchers to explore and pay attention to absence and silence, boundaries and marginalisation, and the power of knowledge and epistemology (Ackerly and True, 2008). If a feminist lens is applied to the thesis, then it follows that the literature review should also be mindful of attending to absence and silence or risk recreating dominant discourses and knowledge hierarchies (Beresford, 2003). For instance, it is questionable where the voices of disabled people and their careers are in a literature review containing only knowledge generated through academic scholarship. There is a danger that privileging academic voices and silencing other voices replicates the oppressive power relations experienced when accessing services that are dismantled in other areas of research via participatory approaches.

Beresford (2003) suggests that having lived experience of a problem can lead to accusations of lacking objectivity and thus discreditation due to the lack of distance between the person and the issue. The knowledge of people who draw on health and social care is often viewed with suspicion and therefore dismissed, potentially contributing to the abuse and neglect experienced:

> If you have experience of discrimination and oppression you can expect routinely to face further discrimination and be further marginalised by being seen as having less credibility and being a less reliable source of knowledge. This fundamentally and additionally invalidates people who are already heavily disadvantaged. (Beresford, 2003: 14-15)

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[11] Whilst this is recognised as a positive move there is the danger that it continues to perpetuate an ‘us’/‘them’ dichotomy. People with lived experience continue to be separated from professionals and, instead of valuing all forms of knowledge, consultations tend to draw on a limited number of experts by experiences who are expected to speak for all (Crosbie, 2021).

In contrast to this, social media offers a space where people can speak and be seen as Williams, a disabled person, describes in her blog ‘My Blurred World’; blogging provides the opportunity “to make others realise that we are human, we have a voice and we have opinions that we want heard” (Williams, 2018: online). Blogs, Williams argues, deserve to reach a wider audience because their voice is often denied in contemporary society where fear of judgement restricts expression of opinion (Williams, 2018). Thus, social media provides a platform for people to share their experiences whilst enabling others to gain an insight into issues which might otherwise be hidden. Similarly, Heilferty (2009) describes how health professionals can simultaneously honour patient’s experiences, improve patient-provider relationships and expand nursing’s body of knowledge by using patient narratives shared via blogging to examine and guide practice. Furthermore, academics are increasingly engaging with social media (Mewburn and Thomson, 2013) and therefore routinely coming into contact with different types of knowledge which has the potential to influence thinking and, in turn, shape research.

Therefore, one way to respond to the ethical issues raised due to a reliance on academic texts, is the inclusion of different types of knowledge and marginalised voices within the literature review. For example, by drawing on the tweets and blog posts of disabled people and carers. Firstly, and in line with feminist, emancipatory, and participatory approaches to research which encourage us to contest embedded knowledge hierarchies of expert versus layperson (Stalker, 1998; Porter, 2010), the silencing of disabled people can be addressed and the established hierarchies which reside both in and out of academia can be challenged (Beresford, 2003). Although it is acknowledged that many people with learning disabilities are missing from social media and digital exclusion remains an issue (Caton and Chapman, 2016), drawing upon different sources and including them alongside academic knowledge privileges neither academic nor experiential knowledge. The integration of sources is important as to separate them based on the author’s position could contribute towards an 'us' and 'them' dichotomy. Docherty et al. (2010: 432) sum this up when they discuss the process of co-writing an article when the authors are both learning disabled and non-learning disabled:

> We talked about whether we would have two parts to our article; one part for the learning disabled writers and a ‘professional side’ for the university researchers.

> In the end we decided that if we did two separate sections we wouldn't learn from each other; it would be like 'them' and 'us'. It's better all in one together with everybody helping and learning from each other.

Such an approach acknowledges the value both types of knowledge hold and recognises that together they form the body of knowledge about a topic. Including only one type of knowledge would tell only half the story and thus fail to demonstrate a comprehensive understanding of the current state of knowledge, as is the literature review's purpose (Ridley, 2012; Machi and McEvoy, 2016). Secondly, Beresford (2003: 4) states, "the greater the distance between direct experience and its interpretation, then the more likely resulting knowledge is to be inaccurate, unreliable and distorted." Therefore, drawing directly upon the knowledge of disabled people and their carers provides the opportunity for the research to be situated within contemporary debates without risking distortion. This is likely to enhance the research's relevance to disabled people, a central concern of participatory and emancipatory approaches to research (Stalker, 1998). Lastly, it is argued that the inclusion of different sources contributes to the transparency and integrity of the thesis. It lays bare the different types of information, ideas and opinions encountered throughout the research that have influenced thinking and therefore affected the direction of the research.

Considering the above, the literature review within this thesis should be viewed as a 'community of knowledge'. Utilising the concept of communities of practice (Wenger, 1998; Wenger-Trayner and Wenger-Trayner, 2015), whereby a group of people collaborate for a common cause and, through the sharing of experiences, tools, information and ideas, create an environment of collective learning (Smith, 2003, 2009), the literature review is a space which recognises that multiple individual voices and multiple forms of knowledge together form a body of knowledge. It is an ethos which radiates out to other areas of the thesis. Therefore, alongside academic voices, the literature and references included within this thesis include voices direct from professionals, disabled people, parents, carers, disabled organisations and charities so that it becomes a space in which "everybody [is] helping and learning from each other" (Docherty et al., 2010: 432).

Ethical concerns arising during the interview process

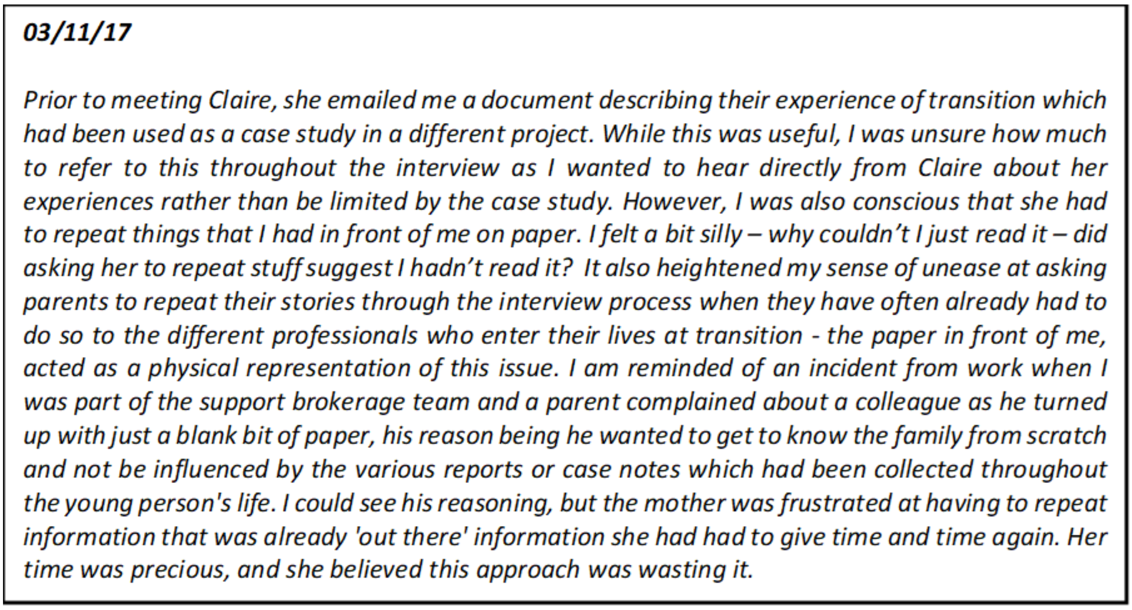
Despite interviews being a popular method of data collection (Fontana and Frey, 2008; Silverman, 2011), Plummer (2001: 41) questions, “who is this sociologist, psychologist or anthropologist who thinks they have the right to ‘seduce’ these stories out of people” and at times I questioned what entitled me to enter people’s lives and request they share their story. Throughout the process I was also acutely aware of the high level of scrutiny people with learning disabilities can face in their lives (Munford et al., 2008a) and that many people accessing services feel the burden of having to engage with multiple professionals and repeat their stories countless times as demonstrated by the comments below:

> At last count my son and I have since interacted with 25 medical teams, 8 hospitals, and 6 educational settings […] Each referral is a dread, a worry, something else to research, another appointment in a diary, something else to follow up, to remind someone about, to fight for […] we are exhausted. We find it somewhat difficult to remain positive with our professional relationships. (Wraparound Partnership Blog., 2018: online)

> I wish they all had access to exactly the same information to avoid constant repetition of information that I have done for the last 22 years for my son. (AIM Mediation Ltd., 2018: online)

Transition can be a challenging time for this as professionals and agencies change in the move between services placing extra demands on parents’ time and mental wellbeing. **Box 7** demonstrates it is an issue I reflected upon within the research diary. Despite approaching participants from a position of wanting to change the system I was unavoidably contributing to it by being “yet another person interested in seeking answers to questions about their lives” (Munford et al., 2008b: 339). I subjected them to my ‘gaze’ (Allan, 1996) without being able to offer much in return (Munford et al., 2008a). Although ensuring the interviews took place at a time and location suited to the participant went some way to mitigate any inconvenience, I felt uneasy about the process and felt the need to acknowledge the irony of the situation at the start of each interview and to apologise for my role.

Box 7 Research diary extract 03/11/17



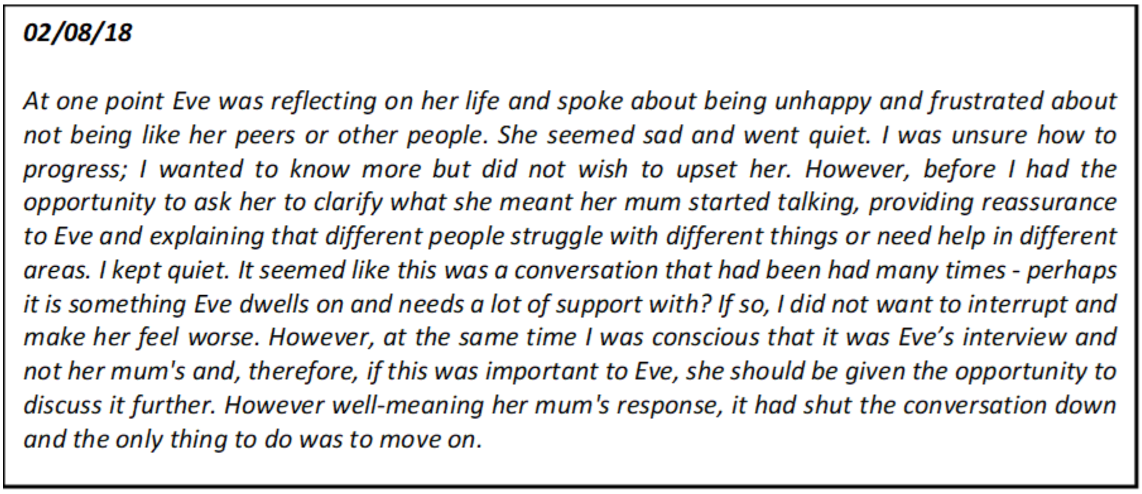
03/11/17

Prior to meeting Claire, she emailed me a document describing their experience of transition which had been used as a case study in a different project. While this was useful, I was unsure how much to refer to this throughout the interview as I wanted to hear directly from Claire about her experiences rather than be limited by the case study. However, I was also conscious that she had to repeat things that I had in front of me on paper. I felt a bit silly – why couldn't I just read it – did asking her to repeat stuff suggest I hadn't read it? It also heightened my sense of unease at asking parents to repeat their stories through the interview process when they have often already had to do so to the different professionals who enter their lives at transition - the paper in front of me, acted as a physical representation of this issue. I am reminded of an incident from work when I was part of the support brokerage team and a parent complained about a colleague as he turned up with just a blank bit of paper, his reason being he wanted to get to know the family from scratch and not be influenced by the various reports or case notes which had been collected throughout the young person's life. I could see his reasoning, but the mother was frustrated at having to repeat information that was already 'out there' information she had had to give time and time again. Her time was precious, and she believed this approach was wasting it.

The use of supporters and 'proxy respondents' during data collection

The use of 'proxy respondents' (Stancliffe, 1999), someone who has an established relationship with the participant and is able to interpret their communication or behaviours (Boxall and Ralph, 2009), can be helpful within research where participants may have more profound disabilities (Nind, 2008). Although the participants within this study did not have profound disabilities, there were sometimes issues with communication, for example, my limited Makaton and difficulties in understanding some speech (due to limited time to get to know participants). As a result, as discussed in the methods outlined in Chapter Four, in four instances mothers also supported their sons/daughters in the interviews (in addition to the use of Talking Mats and photography) and were able to act as interpreters when I struggled to understand what the young person was saying. However, involving supporters can be considered controversial as there is a risk the interpreters assign meaning to the communication based on their own hopes, fears and desires rather than the participants (Grove et al., 1999; Cummins, 2002). One way of addressing the potential issues of supporters is giving them the opportunity to express their views separately to that of the participant they are supporting (Clegg, 2003 cited Nind, 2008) and in three out of the four interviews where mothers supported their sons/daughters the mothers were also interviewed separately. Nevertheless, it proved a difficult dynamic to manage and gave rise to several ‘ethically important moments’ as **Box 8** demonstrates.

Box 8 Research diary extract 02/08/18



02/08/18

At one point Eve was reflecting on her life and spoke about being unhappy and frustrated about not being like her peers or other people. She seemed sad and went quiet. I was unsure how to progress; I wanted to know more but did not wish to upset her. However, before I had the opportunity to ask her to clarify what she meant her mum started talking, providing reassurance to Eve and explaining that different people struggle with different things or need help in different areas. I kept quiet. It seemed like this was a conversation that had been had many times - perhaps it is something Eve dwells on and needs a lot of support with? If so, I did not want to interrupt and make her feel worse. However, at the same time I was conscious that it was Eve’s interview and not her mum's and, therefore, if this was important to Eve, she should be given the opportunity to discuss it further. However well-meaning her mum's response, it had shut the conversation down and the only thing to do was to move on.

Similar risks are associated with the use of supporters within focus groups due to the possibility of contamination of the data and the risks of enforced ‘censoring’ and ‘conformity’ (Carey, 1994; Alty and Rodham, 1998; LLewellyn, 2009). However, like with Llewellyn (2009) and Durell (2016) the role of supporters were crucial within the focus groups. Not only did they assist in creating a supportive and encouraging atmosphere, but they also knew the individual participants and were able to step in and assist when necessary, whether it be in helping someone to articulate their thoughts, providing crucial background information, or in helping with more practical tasks such as supporting someone to the bathroom.

Ethical considerations throughout the thesis

This chapter has drawn attention to the importance of ethics and discussed how ethical issues were encountered at different stages of the research process, from the procedural ethics through to ethical tensions during data collection and when writing the thesis and deciding what literature to include. Therefore, this chapter ends with **Table 5** which provides a summary of how an appreciation for ethics threads through the thesis.

Table 5: Ethical considerations throughout the thesis

Chapter	Ethical concern	How it was addressed
Chapter One (the use of language)	The language used within the thesis has the potential to other and perpetuate the them/us dichotomy.	• I discuss this issue at the beginning of the thesis and pay attention to my use of language throughout the thesis. • I engage with blogs/twitter etc and regularly discuss language with people both in and outside academia to keep abreast of language developments. • I use the research diary to document and explore tensions as they emerged.
Chapter Two (positionality)	My role as a support worker within a residential children's home and previous roles within local authority creates tensions as I feel complicit in practices which are in opposition to views of participants, disability activists and allies (for example the discourse surrounding 'challenging behaviour').	• I use of research diary to examine dilemmas as they occurred. • I consider the dichotomy of insider/outsider unhelpful and instead occupy a 'space between.' • I endeavour to be transparent and acknowledge my position throughout the thesis and research and adopt a feminist approach to interviews.
Chapter Three (the literature review)	Prioritising academic knowledge can perpetuate the marginalisation of some voices.	• I consider the literature review (and literature drawn on in general) as a 'community of knowledge' and thus draw upon unconventional sources of literature.
Chapter Two and Four (theoretical approaches guiding the research and the research's methodology)	Social research should aim to draw attention to voices which are "hindered" and strive "to bring awareness through ideas and experiences not commonly heard" (Lietz et al., 2006: 456).	• I draw on critical disability studies and feminist theory. • I adopt a qualitative methodology and include parents and young people as participants alongside professionals.
Chapter Four (methods)	Potential for research to be inaccessible to people with learning disabilities.	• I use a 'toolbox' of data collection methods and remain flexible to respond to individual participants.

	Interviews demand vulnerability from participants whilst the researcher remains protected and interviews place demands on participants similar to professionals who expect participants to repeat their stories multiple times. The use of photovoice as method raises concerns in relation to ownership of the images and confidentiality of people in the photos.	• Where possible, and appropriate, I discuss communication strategies and suitability of methods with a key individual in advance of the interview. • I approach communication through a social model lens and recognise the problem lies in my limitations of understanding not the participants deficit. • I draw on feminist approaches to interviews and make use of a research diary to expose myself and make myself vulnerable as I interrogate my professional practice in light of the research. • I draw attention issues associated with interviews with participants at the start of the interview and express thanks for their time. I also ensure all meetings were at a time and place to suit participants. • I had two copies of the photos printed to enable participants to keep a copy. I do not use any identifying images within the thesis or any research outputs.
Chapter Seven-Twelve (analysis and discussion)	Distortion of voices. Analysis is the researcher's interpretation and therefore individual voices can be lost.	• I intended to return to participants to discuss findings with them. However, due to COVID-19 this was not possible. Therefore, this is raised as a limitation of the study in chapter thirteen. • I adopt a reflexive, iterative approach to the analysis and I am transparent about issues encountered during the analysis process as discussed at the start of chapter twelve. • I include chapter six to ensure participants are not simply reduced to data or quotes.

Dissemination	Research findings must be accessible to people with learning disabilities	• I include easy-read summaries of each chapter throughout the thesis which can be shared with participants and stakeholders to support the dissemination of the research.

Chapter Five summary

	This chapter talks about the **research ethics**. **Research ethics** means making sure no one gets hurt or upset.
 	There were **two** ways Francesca made sure the research did not hurt or upset anyone: 1) Before the research started Francesca made sure the design of the research was ok. This is called the **procedural ethics**. 2) Once the research started Francesca looked out for any problems. This is called **ethics in practice.**

The procedural ethics

	Francesca had to tell the university what she was going to do to make sure the research was ok.
  	Francesca said: • She would make sure people could choose if they wanted to take part in the research. • She would make sure people were ok when she talked to them. People did not have to answer all the questions if they did not want to. • She would keep what people said private. She would not use real names when she writes about the research.

	The university said it was ok for the research to go ahead.

Ethics in practice

	During the research Francesca was careful to make sure she looked out for any problems.
	Francesca kept a diary so she could write down what the problems were and work out how to solve them.
	These are some of the problems: 1) Interviews can take a lot of time. Sometimes people were telling Francesca the same things they had said to professionals lots of times. People might find this annoying.

2) Some young people were supported in their interviews and focus groups by their mothers or a member of staff.

   Francesca had to be careful to listen to what the young person was saying and not just the supporter.

3) When writing about the research it is good to use things written by other people.

   Sometimes it is easy for researchers to only use things written by other researchers.

   Francesca did not think this was very fair.

   She wanted to make sure she also used things that disabled people, families or carers had written.

Chapter Six: The Participants

This chapter introduces the participants via pen-pictures. These aim to capture the essence of the participants by drawing attention to key aspects of their stories.[12] The reason for doing so is two-fold. Firstly, participants were keen to share their stories and experiences, yet the analysis process breaks up these stories and reduces their experiences to 'data' and a series of isolated codes. Such deconstruction is necessary as it allows for the separate fragments of experience, which may be meaningless on their own, to be brought together to understand the collective experience (Aronson, 1994). However, a danger with this is that participants and their stories can become lost within the research, existing only as disembodied quotes encased within the researcher's interpretations and analysis (Baldwin, 2020). Should this happen, the research could be seen as bearing hallmarks of the dehumanising diagnosis and assessment processes that pervades much of adult social care (Gillman et al., 1997; Carey, 2019). Therefore, making the participants visible via pen-pictures is an attempt to mitigate this (although it is acknowledged that, as the pen-pictures were not drawn up with the participants themselves, they too are a product of the researcher). Secondly, it is hoped the pen-pictures share a little of the 'mess' of lived experience conveyed by mothers during the interviews and reflected upon within the research diary, an extract of which is shared in **Box 9** below. Thus, the pen-pictures provide context to the findings.

Box 9 Research diary extract 13/12/17

13/12/17

Coming away from each interview with the mothers and I am struck by the mess and chaos of each transition. Their stories are hard to follow, so much chopping and changing, false starts and broken promises, and many different elements impacting and shaping their experiences – mothers pulled in multiple directions. The timelines are unclear (I wonder if mapping them out together on paper would have been a helpful exercise and sparked different conversations?) There is no sense of any stability or space to relax. I am struck by the comment Janet made in her interview that even though their experience of transition appears relatively straightforward, reflecting on it, she realised it was not - just 'no big dramas' but still plenty of problems and issues to navigate and enormous stress and anxiety for them as a family.

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[12] Little has been written to guide the construction of pen-pictures in this context. Therefore, principles from 'Listening for plot' (Woodcock, 2016) were drawn upon, and the interview transcripts, recordings and diary notes revisited to pull out important elements of participants' stories paying particular attention to emotional resonance, language, repetition and information or comments which stood out.

Whilst the pen-pictures are designed to complement and aid understanding, they can also stand alone and tell a story about transition in their own right. Including pen-pictures at the start of the results chapter, rather than relegating them to the appendix or including them as a table within the methodology chapter, ensures the reader begins the analysis with the human in mind. The names given to participants and focus groups are pseudonyms, although this was not without issue, as discussed within the ethics chapter (Chapter Five).

Young people

Stewart, 25. Stewart had left college several years previously. He lived at home with his parents and was involved in providing ad hoc learning disability training sessions for which he was paid expenses. He had a PA who he went out with for a few hours a week but said otherwise he spent his time following around after his mum, who also looked after his young niece. Stewart wanted to settle down, find a girlfriend and get a ‘proper job’ – he was desperate to fit in, dress appropriately and be like other people his age. This desire to fit in meant that sometimes he got into trouble as he was too trusting of people. He was also worried about change and having to move out of the family home in the future. Stewart had one interview and then decided he would like to use photos. Therefore, he was given a camera, and we meet a second time to discuss the photos he had taken.

Gary, 21. Gary was leaving college in a couple of months, and whilst he did not know what he would be doing next, he had his sights set on the airport – he loved planes and spent many hours at the airport watching the planes take off and land. Gary lived at home with his parents and younger sister, although he wanted to move out of home in the future. Gary was very careful at the interview to make sure I signed in correctly to the building we met. He kept a careful eye on the clock throughout the interview and set the alarm on his phone as he did not want to be late for lunch – he liked to eat his lunch at the same time each day. Gary’s mum supported him during the interview and, at times, expanded on what he said. Gary used photos to facilitate discussions, but his mother said she did not know what he had taken photos of before the interview. Gary’s mum was also a participant in the research.

Eve, 25. Eve attended a social enterprise one day a week and a college course one day a week. However, the college course was coming to an end shortly, and she had nothing lined up to replace it. Eve lived at home with her mum and spent a lot of time alone in her bedroom. She wanted to make more friends but didn't have the opportunities or confidence to do so. Eve was relatively subdued during the interview, and there was a sense of sadness when she spoke. The topic was difficult for her as it reminded her of things she didn't have - she said she felt 'behind' other people her age. Eve used photos in her interview and was supported by her mum as she said she is not very confident talking. Eve's mum was also a participant in the research.

Sam, 22. Sam lived at home with his parents and loved guitars and going to the pub. He enjoyed spending time at the parent carer forum where his mum volunteered and liked taking part in a sing and sign group there. Sam was very chatty with other people at the centre and kept jumping up throughout the interview to go and tell other people what was happening. He was in his final year of college and said he wanted to stay living at home with his parents. Sam has ten hours of PA support a week and used it to go out in the evening or at the weekend without his parents. Sam used pictures in his interview to facilitate discussions as well as Makaton and lots of gestures and actions. He was supported by his mum, who occasionally expanded on what Sam said or chipped in with her thoughts. She also interpreted Sam's Makaton signs for me. Sam's mum was also a participant in the research.

Michael, 23. Michael lived on his own in a flat which was part of a block of supported living flats. Michael had support from staff to cook meals and go shopping, and there were shared communal areas where Michael liked to hang out with his mates. He had a varied week of activities that his mum had set up for him, and he loved having a drink and socialising. Michael enjoyed being able to decide for himself what he did with his time and how he dressed. However, sometimes this caused conflict with his parents who were worried about him getting into difficult situations, not least because he liked to go out dressed as a famous singer. Michael liked sharing funny stories in his interview where he or other people had been silly. Michael and his mum, who was also a participant in the research, were interviewed together in Michael's flat, although Michael was quick to point out when he disagreed with her.

Focus groups

You Can. You Can is a youth voice forum for young people with learning disabilities aged 11-21. The council funds it, and the forum aims to work with the council and other agencies to try and make a difference for young people in the local area. Six young people aged between 17 and 21 attended the focus group, which took place one evening in place of their usual monthly meeting. All the young people who attended the focus group were still in full-time education. They described themselves as friends, and there was lots of banter amongst the members before and after the discussions. One young person who was present decided he didn't want to take part and took himself off to a separate part of the room to do something different. The focus group was supported by two staff members who facilitated the forum, and one young person also had their own PA with them.

Ace. Ace is a self-advocacy group for people aged 18-25. It is attached to a local charity that offers a range of services to people with learning disabilities and their families including advocacy, information and advice and social activities. Eight young people between the ages of 18 and 25 attended the focus group and they were supported by one member of staff from the charity. Two young people who attend the focus group had PAs with them, and one of the PAs was also the mother of a different young person who attended the group. The focus group took place one lunchtime in place of their usual monthly meeting.

Shout-out. Shout-out is a group of young people aged 13-25, and their supporters, who have special educational needs and disabilities. They come together to share their views and experiences of using services to feed into the design, development, and delivery of local services. The group is organised by a local parent carer forum and funded by the council. Four young people aged between 18 and 22 and two parents attended the focus group as well as the member of staff who facilitated the sessions. The focus group took place in place of their usual weekly evening meeting.

Mothers

Anne. Anne was mother and primary carer for her daughter, Eve, 25, who was also a participant in the research. Anne did not work and described her time as being split across Eve and her four other children, two of whom misused alcohol and one who had epilepsy. She had a lot on her plate and could not always give transition the attention it needed. Anne expected Eve would move out in the future, although she was happy for her to remain living at home - she worried a lot about Eve's safety as Eve had previously been in some difficult situations. They had been waiting two years for mental health support to help Eve process these situations. Anne explained that Eve had started and stopped several different day activities and work experience opportunities as the tasks were not suitable and/or transport too tricky. At the time of the interview, she was looking for something more for Eve as she thought she spent too much time at home by herself - she thought Eve would benefit from doing things that are not just disability specific. Anne enjoyed spending time at her local parent carer forum and had made lots of friends through it.

Jackie. Jackie was mother and primary carer for her son, Gary, 21. Gary was also a participant in the research. Gary only had a few months left at college, and they did not know what he would be doing when it came to an end. Jackie was hoping to get him onto a part-time college course and then onto an apprenticeship at the airport, although she was worried as they had not been to visit the college and did not know what support would be in place. She also worried about the apprenticeship as when they looked around the staff did not seem to know much about disability. Jackie worked part-time at her local parent-carer forum and believed this had been invaluable in helping her navigate the system and find out about things for her son. Jackie hoped her son would move into supported living in a few years and talked openly about this with Gary – they used his budget to pay for respite with his PA to prepare him for moving out of home. However, it was not easy getting this agreed with social services.

Janet. Janet was mother and primary carer to her daughter, Emma, 24 (Emma was not a participant in the research). Emma had spent three years at residential college, following the end of school, and Janet and her husband were able to enjoy a little freedom, doing things spontaneously for once. However, Emma was once again living at home whilst waiting for a suitable supported living opportunity to become available. Janet would have liked for Emma to move straight from college into supported living, but this did not happen despite pushing for it, and several plans for supported living had since fallen through. Janet was a nurse but had to give up work when Emma was 17 as she found it too difficult to manage a career alongside her caring responsibilities as her husband worked away during the week. Emma attended a community interest company five days a week; however, Janet said the social worker was not happy with this and would have preferred Emma to split her time between the CIC and 'going out in the community' with a PA. Janet worried a lot about her daughter's health and how well the staff supported her, both now and in the future. The worry was regularly exacerbated by staff losing Emma's possessions or not paying close attention to her hygiene and appearance. Emma was an only child and Janet and her husband had very little family support and no family who would be able to look out for Emma should something happen to them. This, too, was a worry for Janet.

Frances. Frances is mother of Michael who was also a participant in the research - they were interviewed together. Michael lived in a supported living flat which Frances had been very involved in setting up. Although Michael was settled in his flat, Frances was still heavily involved in his life and ensured Michael had a full and varied week of activities that included voluntary work. She worried about what would happen if she did not oversee his support and activities. Frances tried to give her son as much freedom as possible but at times felt the need to step in and set boundaries as she worried his choices would put him at risk (particularly in relation to alcohol and how Michael liked to dress). Frances was very aware that she was 'stricter' with Michael than the staff were. Frances was a special educational needs teacher and had one younger son still living at home and an older son at university.

Jean. Jean was mother and primary carer to Sean who was 22 (Sean was not a participant in the research). Sean was in his last year of college, which he attended four days a week. Sean was happy and settled at college and was sad it was coming to an end in a couple of months. Jean was trying to find something to replace college, although she would prefer for college to continue - she was worried her son would end up sitting at home not doing anything. Jean was also worried the change would unsettle him as he liked his routine. Sean had 15 hours of PA support a week and used this to go out without his parents and participate in sports activities he loved; otherwise, his spare time was spent watching television at home. Jean wanted her son to stay living at home forever - she said she was a private person and did not trust other people to look after her son.

Cath. Cath was mother and primary carer for her son, Sam, who was 23 years old and also a participant in the research. Sam lived at home with Cath and her husband, Sam's dad. Sam was in his final year at college, but they did not know what would be happening next. They had reluctantly been to visit a couple of different day centres but were not sure how many days they would be able to afford within Sam's personal budget. Cath was very vocal about how angry she was with the council, mainly how people with learning disabilities are treated. Visiting the day centres was an excellent example of this as Cath felt that people with learning disabilities were shoved together in day centres because the council did not know what else to do with them. Cath volunteered at her local parent carer forum and was a member of a parent steering group at her son's hospital. Sam was an only child and had epilepsy. Cath wanted her son to stay living at home for as long as possible.

Sandra. Sandra was mother and primary caregiver to her son, Tom, who was 21. Tom, who was not a participant in the research, spent one day a week doing work experience at a football club. He also had ten hours of PA support a week and attended a part-time college course for a couple of hours a week, having been suspended, and then expelled, from full-time college the previous year because of his behaviour. Sandra thought Tom was set up to fail by the college as he was put in a class with someone they knew he did not get on with, and Sandra was not listened to when she voiced her concerns. Sandra had some issues with her health which, at times, detracted from the amount of support she could provide her son, and she was currently fighting for adaptations to be made to her house. Tom had not been able to go to the part-time college course for several weeks as the tutor had been off sick. It was also shortly coming to an end, but Sandra was hopeful her son could start an animation course she had found, although many details still needed to be worked out. Sandra had been told the course could lead to a job, and she hoped this was the case as he had taken part in various work experiences in the past, which he had enjoyed, but they had never led on to anything else. Sandra would like Tom to stay at home as long as possible as she did not trust services to take care of him. If something happened to her, Sandra had two daughters who had said they would take care of Tom. Sandra was sad that Tom did not have a group of friends he could spend time with.

Claire. Claire was mother and primary carer to her son, Andrew, who was 22 and an only child. Andrew, who was not a participant in the research, had left college two and a half years previously and was settled in a routine of going out five days a week with his PAs. However, they had a turbulent time getting to this stage, including a lot of difficult behaviour, emotional upheaval, and disruption. Claire does not know how she survived the last few years as she has also had her health problems and family ill health to contend with alongside transition. She was relieved to be out on the other side of transition but was aware she could not be complacent. Whilst Claire hoped to get to the stage where her son’s support and budget ran itself she felt this was still a good few years away. Claire had taken early retirement and was heavily involved in a parent participation group with her local authority. She had built a strong network of peer support around her.

Professionals

Sarah. Sarah was a learning disability advocate in a local community benefit society. She worked with young people age 16+ and their parents and carers. Sarah provided both formal (i.e. advocacy under the Care Act) and informal advocacy. Whilst Sarah advocated for young people and their families, she remained realistic about what was and was not possible and was cynical of the various reforms and multiple pathways introduced over the years.

Colette. Colette was a learning disability transition social worker working with young people aged 17 and 18 as they moved into adult social care. A local authority employed Colette. Colette loved her job but struggled with the workload and felt her department was constantly restructured and reorganised. Colette believed transition did not work as well as it could do and that many families were not receiving support when they wanted it.

Katy. Katy had worked for local authorities for over 40 years. She trained initially as a social worker and had held various roles across children's and adult's social care but was currently working in a managerial role, which involved improving the transition journey. Therefore, she was currently reviewing the transition pathway and worked hard to produce many different resources aimed at people in transition. Whilst she was passionate about improving transition, she also felt it was important to be realistic and understand what was out of their control.

Alice. Alice ran a learning disability charity that provided a range of advice and support to parents and young people with learning disabilities. Alice was also a mother to a young teen with learning disabilities and was involved in a local government health and social care advisory group. Alice was highly knowledgeable about all things SEND and spent much time ensuring she understood the relevant legislation and guidelines to use it to her advantage when advocating for her daughter and others.

Peter. Peter had a managerial position within a local charity and had a sibling with learning disabilities. He was passionate about changing things. He was cynical about learning disability services and believed we had gone backwards regarding how people with learning disabilities are supported. Peter's ideal was for there to be no need for separate learning disability services as everyone would be included within society. Therefore, he found it heart-breaking that large-scale services exclusively for people with learning disabilities continuously crop up. Peter was slightly apprehensive about being recorded as he thought a lot of what he believed went against what parents want.

Chapter Six summary

	This chapter tells you about the **participants**. These are the people who took part in the research.
	The names used are not the participants' real names.
 5	Francesca interviewed 5 young people.
21 - 25	They were aged 21-25
	4 people lived with their parents. 1 person lived in their own flat.
	2 people were at college full-time.
	No one had a paid job

 3	Francesca had 3 focus groups.
	The people who came to the focus groups were all members of youth groups or self-advocacy groups.
18	18 young people came to the focus groups.
17-25	They were aged 17-25
	Some people were still at college and some people had finished.
	7 members of staff and 2 mothers came to the focus groups.
 8	Francesca interviewed 8 mothers.
	All the mothers were very worried about their children’s futures.

 5	Francesca interviewed 5 professionals.
	The professionals all worked with people during transition.

Part Two

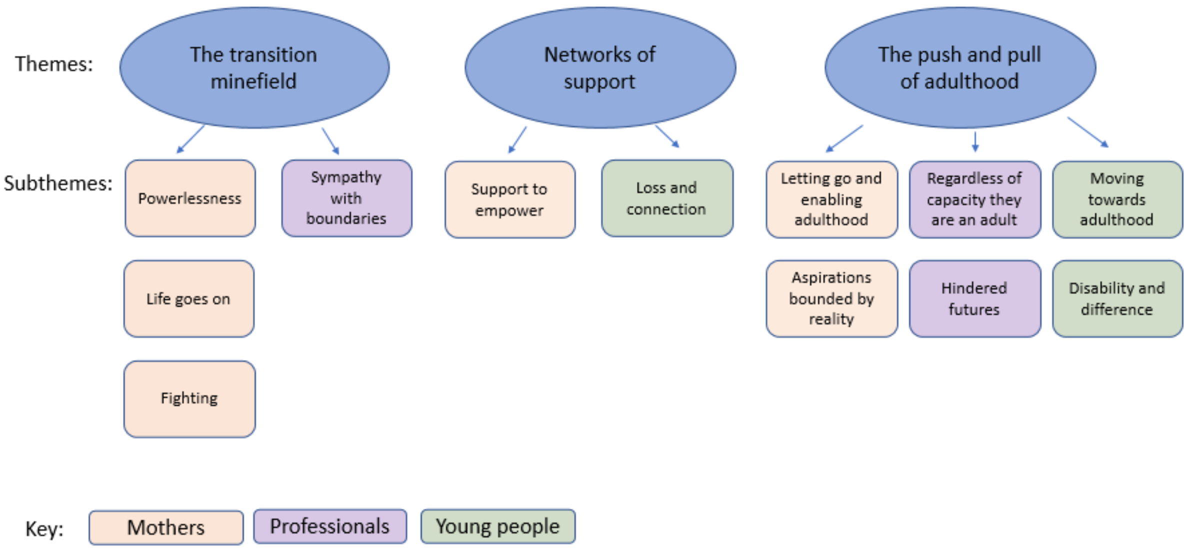
Chapter Seven: An Introduction to the Themes

The analysis process described in Chapter Four led to the generation of three themes:

- The Transition Minefield,
- Networks of Support,
- The Push and Pull of Adulthood.

Each theme contains several subthemes related to the individual stakeholder groups. The themes and corresponding subthemes are summarised in **Figure 5**. Here the subthemes are colour coordinated to show the distinctions between the three stakeholder groups. As **Figure 5** shows, only the theme 'The Push and Pull of Adulthood' was relevant to all three groups. Chapters Eight, Nine and Ten, address each of the themes in turn.

Figure 5 A summary of the themes and subthemes generated through the analysis process



In addition to the themes and sub-themes summarised in **Figure 5**, it was apparent during the data collection and analysis process that how the three groups interpreted transition varied depending on what group they belonged to. This was not a surprise given the variation between the groups explored within the literature review and visible in the scoping phase of the research (discussed in Chapter Three and Chapter Four respectively). Nevertheless, although the different interpretations of transition cannot be considered a theme due to the diversity of meaning,[13] they provide context to the themes which follow. Therefore, this chapter examines the differences. However, first, there is a brief note on how participants are addressed within this chapter and the chapters which follow.

A stylistic note

In all discussions about the data, the participants I met with on an individual basis are referred to by their names. However, participants who took part via focus groups are not named. Instead, they tend to be referred to more generically (e.g., ‘one young person’ or ‘one mother’). This is partly due to the difficulty distinguishing between different voices on the audio recordings and, in part, to make the text easier to follow. Additionally, although the subthemes are separated into three different groups, some quotes or information provided by mothers or supporters are included within subthemes relating to the young people. This is where mothers or supporters have been present during the meetings with young people and have provided clarification or expanded on what the young person was saying to ensure the meaning of what the young person was saying was conveyed.

Transition, what’s that?

For all participants, 'transition' was understood to encapsulate a period in which a series of changes occurred. However, as **Figure 6** shows, the catalytic events and changes of significance that formed 'transition' varied depending on the participant group. Therefore, whilst for young people transition referred to growing up and becoming an adult, health service changes and leaving college, mothers were mainly concerned with their child leaving college and the health service changes. For both these groups of participants, transition was also a period that was wrapped in worry and unease. In contrast to this, however, professionals working within social services were focused on transition as the young person's move between children’s and adult services. This is not to say they did not acknowledge how mothers and young people experienced transition, but instead, this did not form part of the service definition of transition they were working within. As a result of the discrepancies, not only was transition seen to occur at

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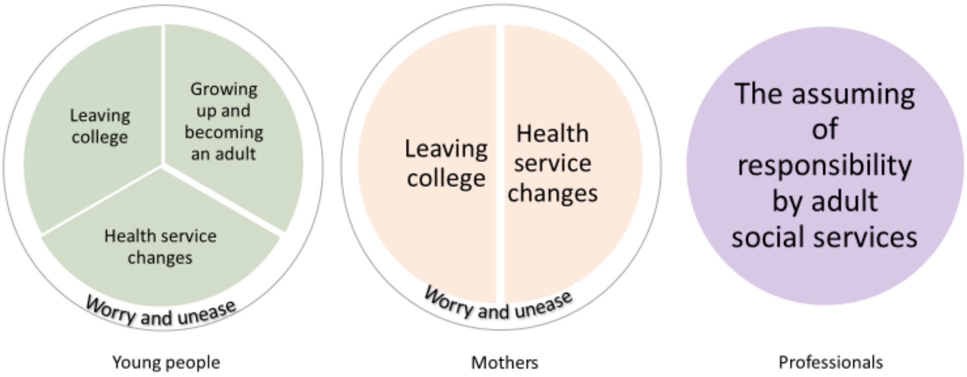
[13] Braun and Clarke (2019) describe how themes must contain shared meaning. If there is a shared topic but not meaning, Braun and Clarke label it a 'domain summary.' These, they explain, help capture the diversity of meaning surrounding a topic.

a different time for professionals than it did for young people and mothers, the length of time participants believed it should last also differed between the groups.

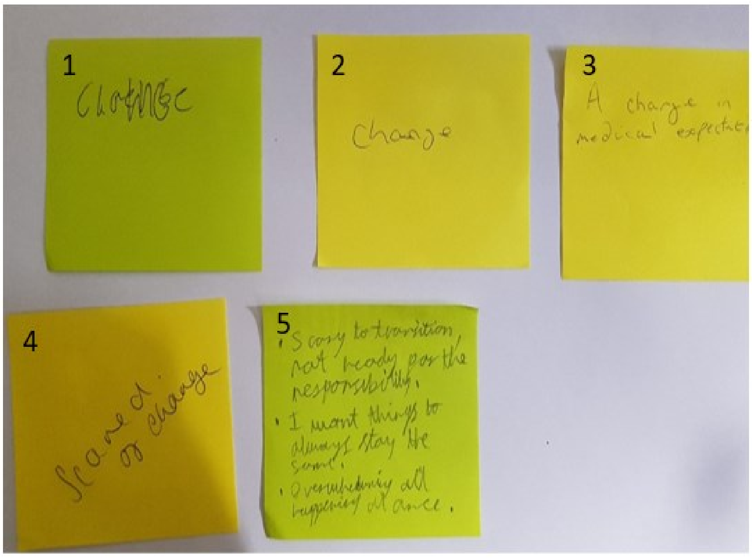
Figure 6 An overview of the different aspects of transition for each participant group



Young people

As a starting point for discussions within the focus groups, young people were asked what ‘transition to adulthood’ meant. As **Figure 7** demonstrates, it was understood to be a period of change within their lives. This was then explored further with participants, and there was a consensus that the change occurred in three interconnected areas: leaving college, growing up and becoming an adult and changing healthcare provision.

Figure 7 Post-it notes from the focus groups demonstrating transition meant change



Post-it note transcription:

1. *Change*
2. *Change*
3. *A change in medical expectations*
4. *Scared of change*
5. *Scary to transition, not ready for the responsibility.* ***I want things to always stay the same.*** *Overwhelming all happening at once.*

Leaving college

For participants in both the interviews and focus groups, leaving college was at the heart of the changes which occurred, and was therefore central to transition. The end of college was viewed as a significant event on the path to adulthood. For example, one young person who, when describing how things change as they grow up during transition, included *"[leaving] college and school and that"* in their list of examples. Another participant, Eve, when discussing transition, explained how she was disappointed that college had finished, *"I'm just a bit disappointed that the college has gone really",* demonstrating her association of the end of college with transition. Stewart, meanwhile, explained he *"weren't ready for it [transition], a job"*, and a member of a focus group described transition as *"going from college into the community and CICs and having PAs to go out to do activities".* Therefore, although for some people the post-college destinations were different, the end of college marked the next phase in their lives, and transition was understood to be the period that encompassed this change. As a result, there was a belief that whilst for some young people transition may be fairly quick, for others, it could be a long, drawn-out process as they hunted for a job or tested out different day services. Stewart, for example, explained how he felt like he was still in transition as he continued to struggle with new experiences and had not yet found a stable opportunity:

> *Well, I'm still in that [transition] now really because I left the Link Centre a year ago, so doing this voluntary and things, and that felt a bit overwhelming. Like I couldn't cope with going to different places out my comfort zone.*

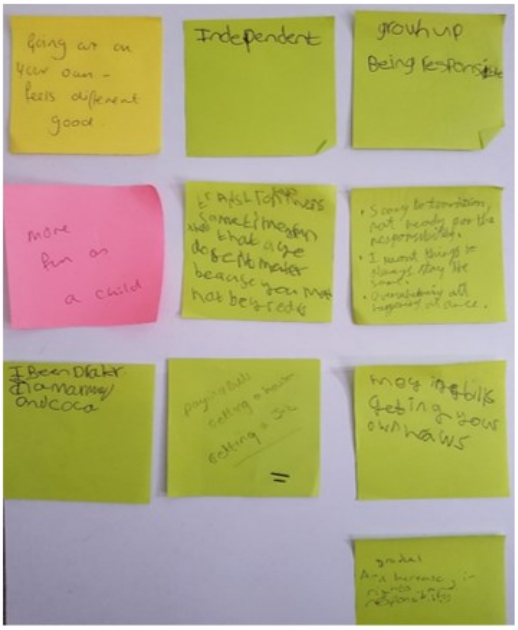
Growing up and becoming an adult

Alongside leaving college, transition was also understood to relate to growing up and becoming an adult. This involved both tangible markers of adulthood such as the gaining of rights and responsibilities as one turned 18, as well as a change in behaviour and status with one young person commenting that transition felt good as they were *"growing up, being a young woman, being a lady, not being a little girl anymore."* Whilst adulthood is explored further in the theme 'The Push and Pull of Adulthood', **Figure 8** introduces some of the changes participants believed occurred during transition concerning 'growing up'. Turning 18 was significant in that it marked the start of this process with young people, encouraged by their parents, taking on more responsibilities at home via involvement in chores as the young person below illustrates:

> *[I'm] also just getting a little bit more responsibility at home as well, like already my mum is getting me to do everything. She is saying you are nearly 18 so you need to do this and this. (You Can member)*

However, just as the amount of time required to find stability following the end of college was seen as specific to the individual, so too was the time taken to 'grow up', as one young person commented in a focus group, *"people grow up at different rates".* Furthermore, another young person wrote on a post-it note, *"transition means sometimes age doesn't matter because you may not be ready".* This suggests that imposing a time-frame on transition is meaningless as how long it lasts is dependent on the individual concerned.

Figure 8 Post-it notes from the focus groups demonstrating transition as 'growing up.'



Post-it note transcription:

1. *Going out on your own feels different, good.*
2. *Independent*
3. *Grown up. Being responsible*
4. *More fun as a child*
5. *Transition means sometimes age doesn't matter because you may not be ready.*
6. *Scary to transition, not ready for the responsibility. I want things to always stay the same. Overwhelming all happening at once.*
7. *I been drinking Tia Maria and cola*
8. *Paying bills. Getting a house. Getting a job*
9. *Paying bills, getting your own house*
10. *A gradual increase in rights and responsibilities.*

<u>Health service changes</u>

The final element of transition for young people related to health service changes. However, this was only relevant to young people who required input from health services. In the You Can focus group, one young person wrote on a post-it note that transition meant *"a change in medical expectations"* (see **Figure 7**) and, when asked to expand on this, stated:

> *A change in expectations and what the service can provide…you can expect different responses from clinicians and clinicians can expect you to have slightly greater knowledge.*

Whilst these examples relate to the young person maturing as they grow older and, therefore, having a different relationship with clinicians, for other young people, the changes were more tangible and directly linked to their movement between children's and adult health services. For example, one young person discussed how they were going to have to switch hospitals once they had had an upcoming operation:

> *Now I am at the children's hospital but after the operation I will no longer be there. I will then go into adult services […] apparently the hospital won't keep hold of you.*

Likewise, a member of the Speak-Out focus group recalled how she was no longer able to receive the same mental health support when she turned 18:

> *When I was 16 or 17 I started getting some support from CAMHS […] and as soon as it come to my 18th birthday […] he was just like ok because of your age now, we need to start wrapping things up and we will make this your second to last session.*

Mothers

Mothers echoed the views of young people as both the end of college and changes to health care provision were raised as significant. However, whilst for the young people the end of college was significant as it marked the start of the next phase of their life, for mothers, it was significant as it marked the start of a long and tiring battle navigating services (discussed further in the theme 'The Transition Minefield').

Leaving college

Although adult social care assume responsibility around the age of 18, it was not until the young person left full-time education that families felt the full impact of these changes. Subsequently, it was the end of college, either the local college or residential college, that was significant. Janet's daughter, for example, received funding to attend a residential college once her education at their local college ceased and thus continued in full-time education for several more years. As a result, Janet did not feel transition begun until the end of residential college:

> *Somebody I know said that you are just delaying it and you are. It's delaying the choices and things you have got to do.*

Other mothers, whose children did not attend residential college, experienced transition sooner, as shown by Cath, whose son, younger than Janet's daughter, was coming to the end of his time at their local college:

> *We are going through transition at the moment aren't we […] Sam is going to be leaving college and we are having to look at day services.*

The enormity of the end of college to the lives of young people and mothers, and thus the significance of transition, was evident within the interviews with mothers. Jackie, for example, explained that although her son would encounter many changes in his life, none would be *"as big as the big transition [leaving college] when everything changes"* whilst another mother, Claire, stated that the end of college was the point *"their whole lives are turned upside down".*

Like with young people, there was the view that transition continued until the changes experienced following the end of education had been overcome and the young person was settled in their new way of life. The age at which this was achieved depended on the individual circumstances, as the following extracts from the interviews with Anne and Claire illustrate*:*

> *I think a lot more understanding to the parent in transition […] right up to when the person is settled in some kind of permanent placing and whatever age that might be. (Anne)*
>
> *I think as far as families are concerned they should be told 'we will support you through this transition' obviously it's not going to be forever and some families need more support than others, but to reassure the family they should be told 'we will support you through transition' and then it will depend how long that takes. (Claire)*

Accordingly, Janet believed her family was still in transition as her daughter had not yet received the support necessary to establish herself following the end of college, *"we are still learning […] we are still going through it [transition] even after all these years".*

Health service changes

The movement between children and adult health services was also highlighted as a key aspect of transition. For the two mothers below, this meant a change in the hospital(s) their children accessed:

> *It was when she was under the children's hospital and that's when she went into transition […] when she was going to adults. (Anne)*
>
> *It was very poor […] going from […] hospitals to the different hospitals. (Cath)*

However, as with the young people above, the change in health provision was only significant for mothers whose children required ongoing input from health professionals, as the quote below demonstrates:

> *We sort of think of transition […] as when they are going from children's to adults […] because we haven't got all the medical side of it, we haven't had to swap doctors and things like that, so for me it is just really the service end of it all. (Janet)*

As Janet's daughter did not have any significant issues with her health, transition between health services was not a concern. Instead, she was focused on the 'service end of it all'. In other words, the changes that occurred within social care provision.

Professionals

A third and contrasting interpretation of transition was evident in the interviews with two professionals who worked within transition services. For these two participants, the focus was on the move between children's and adult social care, which occurred when the young person turned 18.

The assuming of responsibility by adult social care

Both Colette and Katy worked within adult social care, albeit within different boroughs, and viewed transition to be a highly structured, time-limited process centred on the movement between children's and adult services. This interpretation of transition is reflected in the description Colette gave of her role as a transition social worker and the explanation of transition Katy provided:

> *So, we do the assessment, care plan, everything, put that into place for when the person turns 18. Then we review and then, at 18 and three months, we would either close if everything is working out and there are no issues, or we would transfer over to long term adult social workers. (Colette)*
>
> *Once they have been screened, yes they are eligible, no they are not. If they are eligible, they will go through to have a long-term support assessment and support plan put in place and then they will be allocated […] to the adult learning disability team. (Katy)*

It is clear from these examples that within social care, transition is viewed as a practical, time-limited, and mechanistic process that ends shortly after the young person turns 18. Therefore, this conceptualisation of transition fails to encompass both the young person's changing status (other than 18 signifying the age at which adult services assume responsibility) and the end of college, which typically happened a few years after the person turned 18. As a result, this understanding of transition also fails to address the worry and unease wrapped around young people's and mother's understandings of transition related to the changes that occurred as the young person left college.

This is not to say that professionals did not recognise that these elements were important aspects of transition, simply they did not form part of the definition of transition the professionals were working within. Colette, for example, was frustrated that the narrow remit of transition as it meant specialist transition support was not targeted at a time families needed it most. She acknowledged the discrepancies between how transition was viewed by social care and those they supported, as the following quotes from Colette demonstrate:

> *[We] are concentrating on the 17-18 […] and parents are not happy. They don't see that 17-18 as transition in their eyes. The main transition, what's meaningful for them, is when they leave college. It really is.*
>
> *Some might not have had any services in children's so they do get a few hours here and there, but they are in school all the time, or college, so they don't really need*

> *much. It's when they leave that the whole thing changes so that's when they need the support.*

Similarly, Katy alluded to the discrepancies when she stated:

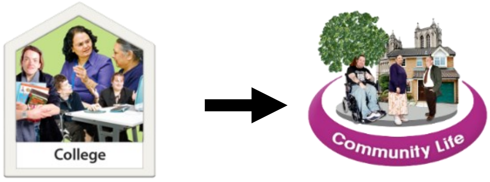
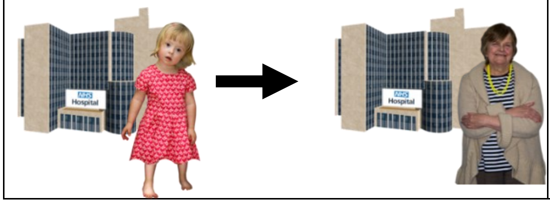
> *If we had the capacity, what we would like for transition is for transition social workers to stay involved until they have left education. But, because we haven't got the capacity, we have to hand them over to a long-term team once the support plan is in place.*

Katy's desire for transition social workers to be involved longer suggests she believed families' experiences of transition would be improved should they have access to specialist transition support when the young person left college. However, heavy workloads and limited capacity within the transition team prevented this from happening and meant they remained working within the narrow remit of transition evident in the examples above. Therefore, transition within social services remained focused on when the young person turned 18 and moved to adult services.

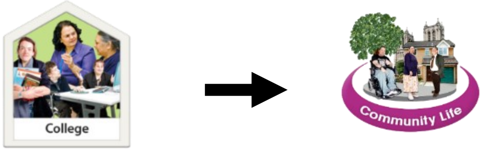
Setting the scene for the themes

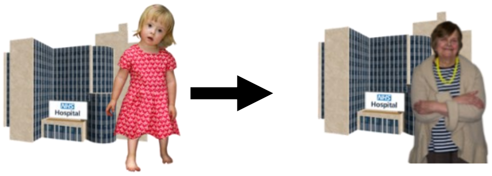
The above sections demonstrates that transition holds different meanings for different people. This sets the scene for the following themes, for whilst transition is a term that is widely used within services for people with learning disabilities, it is not an absolute concept. The presentation of the discrepancies between how the term is interpreted serves to highlight just how problematic transition can be; as people approach it from different starting points, it seems likely that difficulties will be encountered. Indeed, the themes which follow draw attention to an array of difficulties experienced. For example, Chapter Eight, 'The Transition Minefield', shows transition to be a minefield and Chapter Nine, 'Networks of Support', whilst highlighting the importance of relationships demonstrates some of the losses young people experience during transition. Chapter Ten meanwhile, 'The Push and Pull of Adulthood', shows adulthood for young people to be both enabled and constrained by others around them.

Chapter Seven summary

	This chapter explains what transition meant to the people who took part in the research
	Transition meant **change**.
	Different changes were important to different people.
3   	For **people with learning disabilities** there were **3** big changes. 1. The end of college. 2. Growing up and becoming an adult 3. Changes in health services

2



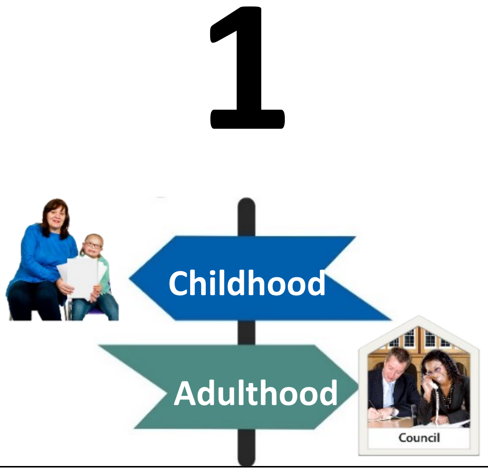


For **mothers** there were **2** big changes.

1. The end of college.

2. Changes in health services

1

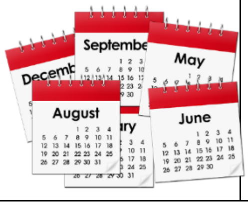


For **professionals** there was **1** big change.

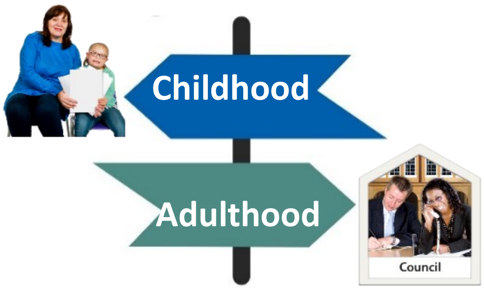
1. Young people moving from children to adult services.

Young people and mothers said transition can take a long time.

This is because some people can take a long time to grow up and find things they want to do.



Professionals did not think transition took a long time.

	This is because they were thinking about young people moving from children to adult services.

Chapter Eight: Theme One, The Transition Minefield

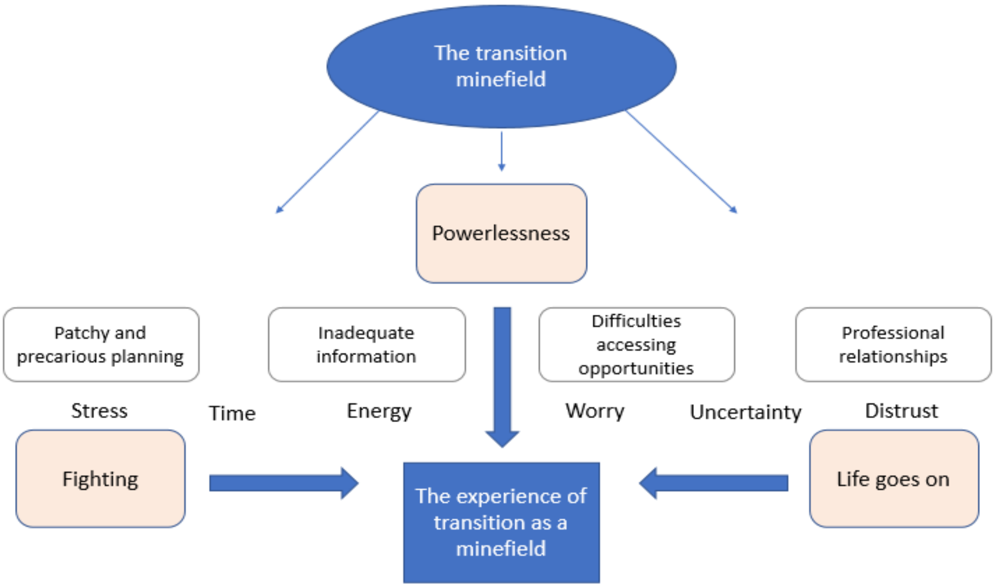
This theme presents the difficulties experienced by mothers during transition as they interacted with adult social care to try and establish a life for their child following the end of full-time education. The chapter is split into two parts; Part A which addresses mothers' views, and Part B which concerns professionals.

Part A contains three subthemes: Powerlessness, Fighting, and Life Goes On. Whilst each of these subthemes presents a particular set of difficulties encountered by mothers during transition, together the subthemes, and the issues within them, led to transition being experienced as a minefield.

Part B contains one sub-theme: Sympathy with Boundaries. The sense of transition as a minefield was also conveyed by professionals who were understanding of some of the issues experienced by families during transition. There was an acknowledgement that some aspects of transition could be improved and sympathy for how difficult transition could be. However, the tight funding restrictions professionals worked under appeared to influence their views. There was a sense that parental expectations were often too high and that parents needed to take some responsibility for the situation by adjusting their expectations. This implied that there was a limit to the sympathy available.

Young people are absent within this theme. This is not to say transition was not a challenging time for them but rather the themes stemming from the interviews and focus groups held with young people predominately related to growing older and adulthood rather than the bureaucratic and health and social care processes and hurdles associated with transition.

Figure 9 How mothers experience transition as a minefield



A. Mothers

Powerlessness

Several factors contributed to mothers' negative experiences of transition as shown in **Figure 9**: patchy and precarious planning; inadequate information; difficulties accessing opportunities; and complicated relationships with professionals. However, due to the close entanglement of the issues with services, remedial action remained outside of mothers' control. Consequently, despite an awareness of the issues and the investment of time and energy in overcoming them, both before and after they were encountered, mothers remained largely powerless and unable to improve transition for themselves and their children.

Patchy and precarious planning

All mothers in this study believed planning for their child's transition was vital if a smooth transition out of college was to be achieved. However, despite such a belief, mothers were uncertain about what their child would be doing once college ended, suggesting existing strategies for transition planning were ineffective.[14] Attempts by mothers to push for support with planning appeared fruitless as Janet expressed, "*We tried to get it done earlier, we tried to get planning, we tried to get things sorted out.*"

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[14] As explained in Chapter Three, transition planning should form part of the EHCP review from year nine onwards.

The emphatic use of 'we tried' in the quote above illustrates the time and energy spent pushing for action and the subsequent frustration and powerlessness experienced when it failed to make a difference. The only support with planning the mother in the above example recalled taking place was a *"scantily put together"* transition review which she felt led to no tangible outcomes:

> *As far as the borough were concerned, she was out of borough until she came back so absolutely nothing, despite me ranting on at various people, got done until she came home. (Janet)*

Similarly, another mother, Jackie, recounted *"two brief meetings"* which had taken place to support her son's transition. However, she fared little better than Janet and, despite the end of college rapidly approaching, Jackie did not know what would happen, suggesting a lack of clear outcomes arising from the meetings:

> *I've had two brief meetings, one to say it's time to look at whether we are going to fund him for another year and then they said no he definitely needs to move on this year […] then we had one in February and then from February to now there has been no communication about how this transition is going to develop. (Jackie)*

Jean was also unaware what her son would be doing once college ended shortly:

> *He's at college and he should be leaving in June. I'm not quite sure what happens after that.*

These examples demonstrate the uncertainty surrounding what would happen once college ended and suggest the absence of any clear plan, backed by adult social care, to guide the family through the changes. For the people who were leaving college imminently, there was a sense that mothers, and thus their children, were rapidly hurtling towards a post-education void. This was epitomised in the following statement by Cath, who declared the lack of plan meant they were on their own:

> *It was statements at the time, I mean they're finished now aren't they? They're not worth the paper they're wrote on now, so we've got no other plan. It's down to […] us now to find out what's available to him.*

As a result, mothers were having to search for opportunities themselves as one mother explained: *"we're all in the same boat, looking for things, thinking what's out there* *next".* That all mothers were considered in the same boat suggests these experiences were the norm rather than the exception. The lack of a plan or guide meant that mothers were understandably worried about what the future held for their children. However, due to restrictive funding decisions and the time-limited nature of many opportunities available to people with learning disabilities, there was a sense that even if something were found, it would only offer a short-term reprieve from the void and the associated anxiety. The lack of planning put people with learning disabilities in a precarious situation following the end of college. Stability was out of reach, and consequently, the worry for mothers was relentless:

> *It's just a minefield that you have to get through step by step and it's frightening [pause] frightening yeah frightening. Just not knowing what is going to happen, you know the years ahead if he gets something, like I say, for the twelve months, what happens after the twelve months? (Sandra)*

Where plans had been made, previous disappointments due to the local authority reversing decisions or failing to adhere to the plan had taught mothers to be wary and subsequently they could not rely on those plans. For example, Janet was in the process of moving her daughter into supported living. However, due to past experiences of decisions made in conjunction with the local authority being overturned, she had little faith that what she had been told would materialise. As a result, she was left in a state of uncertainty and unable to prepare herself or her daughter for possible changes ahead:

> *I don't actually trust it will happen. That's another thing you don't actually trust that it might happen because things can change instantly and if they decide they need to put somebody else in then they can probably do that. And that's another thing, they just override everything all the time. You can't plan anything and even if you do plan it they say 'oh well no we are not doing that anymore'.*

The inability to rely on professionals following through on decisions was also evident in the interview with Jackie, who, due to past experiences, felt that unless something was in writing, it could not be relied upon, "*we've not had it in writing to say yeah that's definitely going to happen".*

Jackie was in a similar situation to Janet in that she was unable to prepare her son for the changes which would be occurring at the end of college, "*how can I explain it to him if I don't know myself properly?"* This was particularly problematic as parents expressed how important routine and structure were to their children as Claire highlighted:

> *It's very important to him to have a structure. He has a timeline, he has a diary, he has to know what is going on […] consistency is most important to him.*

Therefore, there was a sense that young people were being set up to fail with the inability to prepare the young person for the forthcoming disruption seen as a contributing factor in post-college placements breaking down. Janet alluded to this when she stated, *"Yeah, she doesn't do well not knowing what's going on or if you spring it on her that's not good."*

The result of the lack of planning and inability to rely on plans when they were in place was thus two-fold. Firstly, it created a sense of uncertainty with young people put in precarious positions leading to increased worry for mothers. Secondly, it meant that mothers were unable to prepare their children for the upcoming changes and limit any distress caused by the changes to their routine.

Inadequate information

The availability of good, clear information was important to mothers. This was particularly the case due to the lack of support with planning and subsequent requirement for parents to take on many of the planning tasks. Unfortunately, however, all mothers drew attention to issues surrounding the availability and delivery of information and the role they felt it played in their poor experiences of transition.

Mothers described a lack of clarity surrounding what happened, or what should be happening, during the transition period. As a result, they were sometimes taken aback by some of the changes which occurred when their child turned 18 and the differences between children's and adult social care. There was a belief that being better informed about transition, in advance of it happening, would help prepare them for the changes and remove some of the frustration, worry and anxiety experienced during this period. For example, whilst one mother stated, "*the information wasn't really out there to explain things*", another explained how *"just knowing a bit more"* would make transition easier. A lack of information was perceived as contributing to difficulties experienced during transition:

> *Transition, as I say, it's quite daunting but I don't think you get a really lot of support in transition to be honest. It's not really explained. (Anne)*

The absence of information perpetuated the notion of transition as a void with Anne describing it as being *"dropped in a hole".* As with the issues relating to planning above however, the consequences were not limited to the mothers. Anne, for example, described how her daughter Eve was impacted, "*Eve was a little bit worried because the information wasn't readily out there to explain things".*

Mothers were critical of the Local Offer,[15] believing it had failed to serve its purpose. It was found to be unhelpful with words such as "*dismal*", "*terrible*", and "*meaningless*" used to describe it. It was challenging to access, hard to navigate and information was reported to be out of date. Further issues were highlighted relating to gaps in the list of services and information provided and a belief that key professionals who should be signposting families to the tool were unaware of its existence. Indeed, far from finding it helpful, one mother described how she felt it had the potential to exacerbate issues rather than ease them:

> *It's user unfriendly, it's not visually friendly, it's terrible. Legally it has to be there on the website, legally it has to be all the right wording […] but if you are a family who is stressed, and you are sat at home and you want to find some information [pause]. (Claire)*

Claire's statement above suggests she believed the Local Offer was a 'tick-box' exercise which failed to consider the needs of the families it was intended to help. People required easy-to-access, straightforward information, particularly when stressed, and this was not something Claire felt the Local Offer provided.

Furthermore, Claire's statement implies that for the information to be empowering, professionals and services must pay attention to how information is delivered; information needs to be 'user-friendly', simply providing information is not enough. Janet drew attention to this when recalling her experience of attending a transition

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[15] The Local Offer is discussed on page 51 of the literature review.

information event. Janet highlighted how, just as too little information was problematic, so too was too much information and the use of jargon:

> *There is all this lingo […] if you are a brand-new parent […] it is totally overwhelming. You don't know what to ask, you don't really know what's expected from you and you are wondering around trying to find things out, but you don't really know what you are trying to find out.*

Another mother, meanwhile, drew attention to how the emotional toll of transition sometimes limited their ability to understand and retain the information they were given. As a result, meetings could be overwhelming and counterproductive, implying a sensitivity from professionals towards how mothers were feeling would be helpful:

> *When you are in meetings as a parent [there's] the emotional side – you don't necessarily take on everything that was said, or you might forget what has been said or you get a bit frustrated. (Jackie)*

Mothers described finding things out from each other via *"word of mouth"* rather than a central source of information, further highlighting the Local Offer's failure. Information about the different opportunities available to young people after college was scarce and haphazard, as one mother in a focus group explained, *"you don't know enough what's out there for these young people".*

When mothers did hear about something, there was a sense that it was down to being in the right place at the right time, as illustrated below:

> *One of the mothers here her daughter was on it and I was asking her about it and she gave me the phone number. (Sandra)*
>
> *I'm fortunate because working in a place like this you get to know about a lot of different things which helps. (Jackie)*

These examples imply that if other mothers did not have the connections the mothers above had forged, they, and therefore their children, may miss out.

Difficulties accessing opportunities

Communication surrounding existing opportunities for young people following the end of education has been identified as one of the problems above. In addition to this however, all mothers in the study believed there was not enough for their children to do once full-time education ended and reported struggling to find appropriate opportunities:

> *Especially with all the cuts, there is nothing out there for them. (Cath)*
>
> *There's not enough out there for them, definitely not. (Sandra)*
>
> *We were trying to find somewhere but they didn't really have any appropriate places for her to go. (Janet)*
>
> *We didn't really find a lot. (Claire)*
>
> *I still think once you leave college there's not a lot, not a lot going on. (Frances)*

As a result, the mothers whose children were still in college were worried about what there was for their children to do once college ended, an issue not helped by the lack of planning detailed previously. Sandra was one mother who expressed her worry about this, stating, *"there is every chance he could be sat at home for the rest of his life".* That Sandra referred to *"the rest of his life"* emphasises a belief that the lack of opportunities for people with learning disabilities was not simply a short-term problem but somewhat reflective of the situation facing all adults with learning disabilities regardless of their age.

One mother's description of a review meeting she attended suggests mothers were misled about what was available with the meetings providing an inaccurate picture of reality:

> *They are great the review meeting, they like to big themselves up and say they've done this and they've done that, but obviously there is nothing out there.*

The lack of opportunities alongside poor experiences of planning and the absence of information left mothers feeling abandoned and alone:

> *There's nothing at all for them from 16-25. Nothing […] who comes knocking on their doors when they become an adult in transition…who comes knocking on their doors? No one comes knocking on my door for him. (Cath)*

Finding something suitable for their child to do following the end of college was, however, only the beginning of a long and bumpy road as mothers described a multitude of challenges experienced once something had been found. For example, difficulties with transport jeopardised attendance alongside support failing to materialise and tasks not suited to the individual's needs. Mothers described their children having to try numerous different places, each bringing new angst and disruption, before finding one that worked. Funding decisions surrounding changes to the use of personal budgets or in connection to new services were not straightforward, and this brought an extra layer of uncertainty to transition. Mothers within one focus group described waiting tirelessly for decisions to be made, unable to make alternative arrangements in the meantime:

> *I mean this funding; it's been going on since last February.*
>
> *You are waiting, waiting, waiting […] so he could be sat at home all the time waiting for that to take off or anything.*

As a result, mothers and young people were left in limbo, not knowing how to move forward. Sandra was one such mother waiting for a decision regarding whether her son would receive funding to attend a course she had found. Due to the long wait for answers, she had to take a gamble on how best to proceed:

> *He could do about twenty days at this place with the money what's in the account. So, he can start it but you know [pause].*

Sandra could use the surplus money in her son's budget to enable him to commence the course but risked disrupting her son further should funding not be granted.

However, like the inability to rely on plans once made as mentioned previously, even when something was found, funding secured, and the young person was settled in a new routine, mothers were acutely aware that their child was in a precarious position:

> *You are just worrying really, even when things are going smoothly you can't take your eye off the ball because if you do [pause]. (Janet)*
>
> *Even now, although he is living independently, I don't know, it still feels quite fragile. It feels like it needs an awful lot of support and input to keep it going. (Frances)*

There was a belief that issues could arise at any stage, causing everything to unravel. Thus, mothers were unable to relax, and, as the quotes above demonstrate, they were on edge, waiting for the next problem to manifest. Their ongoing involvement was crucial to the success of an opportunity.

Professional relationships

Mothers described dealing with people working within adult social care as a source of tension, often increasing their stress and frustration rather than relieving it. Two areas contributed to the tension experienced and clouded the interactions mothers had with services. Firstly, there was an underlying belief that professionals viewed families through a financial lens and thus failed to recognise the individual and appreciate their broader context. Secondly, there were day-to-day challenges of communicating with professionals within the local authority.

The financial pressures services were under were viewed by mothers as shaping the relationship professionals had with families. Mothers were made to feel like their children were simply numbers in the council's eyes and were thus positioned as a financial burden with the difficulties faced by families unappreciated. Cath was one mother who was vocal on this matter and explained that her son had *"always been a number on form and now he's money".* She stated:

> *I'm sick of people promising things, like promising something from college that is similar and then letting you down at the last bit because it all revolves around money. (Cath)*

Mothers felt pressure to justify and defend themselves when asking for support. They believed they were perceived as greedy and treated with suspicion when they were, in fact, desperate. One mother in one of the focus groups felt the need to refute this within the focus group emphatically stating, *"we're not all greedy, we're not all greedy",* whilst another mother, Claire, highlighted a belief that families were treated with suspicion when she stated:

> *The families who never ask, when it comes to transition it's like 'well you've managed all this time, what's the problem now?'*

Claire further drew attention to how the financial lens professionals viewed families through created a divide between families and adult social care when she explained how, in her experience, the desperation and complexity of emotions surrounding requests for help were ignored:

> *When somebody rings up and asks for support, I said they are desperate, desperate and all it seems they hear is 'can I have some money', 'parents are always asking for money' [...] that first time I rang that social worker's number and said, 'I need some help' […] you can't imagine what it's like.*

In addition to this divide were the day-to-day interactions between mothers and services, which proved to be a persistent source of tension. These interactions were a series of smaller 'mines' in the transition minefield which required time and effort to overcome.

Mothers described how they were "*lucky*" if they got hold of a social worker. They used verbs such as "*chasing*", "*ringing*", "*mithering*", "*pestering*", and "*waiting*" to describe the nature of their relationship and the labour involved as phone calls were left unanswered and messages were lost. Once more, life was described as being *"on hold"* whilst waiting for phone calls to be returned:

> *Life gets so stressful at times and if you can't get hold of someone to speak to for a week and you're told they will right you back, ring you back, ring you back, you can't describe to anybody that feeling. Your life is on hold waiting for that phone call. (Claire)*

These difficulties contributed to the diminishing sense of trust in professionals, with mothers advising each other to email *"so there is a trace" (Jackie)* and to take copies of all letters in case they get lost. It also contributed to parent-professional relationships breaking down and had an emotional impact on mothers as the cumulative stress became too much. For example, one mother, Sandra, explained how she was reduced to shouting at her social worker out of sheer frustration when she constantly struggled to get hold of them, "*It just leaves you frustrated and you're shouting and balling but you have to get it out your system".*

Meanwhile, Cath highlighted how the way some professionals lacked respect when speaking with her making her feel degraded:

> *I won't be degraded by the way they spoke to me, I'm not something off the bottom of their shoe.*

The number of different professionals encountered during transition and the subsequent volume of communication, number of meetings taking place and lack of coordination between professionals, placed a burden a physical and mental burden upon mothers:

> *There is always somebody writing to you or ringing you and saying well I have to get this report filled in by such a date so I have to come and see you and…there is umpteen other people coming to see me as well. As a professional you are dealing with your bit but they don't realise how many other people are involved, how many other professionals we are seeing as well.* (Claire)

This extract further alludes to a lack of appreciation and understanding from professionals for the position families were in. It suggests that if different professionals worked closer together, they might be aware of the broader demands placed on families and adjust their demands accordingly.

Anne, who also had to navigate her daughter's transition within health services due to a *"leaky heart",* also drew attention to a lack of coordination between health professionals. In children's health services, Anne's daughter, Eve, had been seen by a core group of health professionals who knew Eve and her medical history:

> The only ones I dealt with were the paediatric and the cardiac nurse – she was lovely Linda, we had been with her for a long long time.

However, since moving to adult services, Anne described a chaotic timeline of numerous professionals, different hospitals, cancelled appointments and a lack of one person overseeing the care. As a result, the burden was on Anne to coordinate the care - to chase professionals, to follow up missed appointments and fill in gaps in her daughter's medical history leading to frustration with the professionals encountered:

> I took her to the doctors and the GP didn't know half of what Rachel had and that's my family GP. Oh she has got so and so, heart problems and I go yes, yes they didn't know anything because she had never been to the doctors.

Fighting

In light of the powerlessness experienced above, mothers seized opportunities to fight for their children when they could. In addition, some mothers were driven to fight at a systemic level motivated by a desire to change the experience of transition for others.

Individual battles – fighting for their children

Having a child with learning disabilities was, for the mothers within this study, synonymous with fighting. It was a fight that began in childhood and continued through transition and into adulthood, as demonstrated by the comment below:

> *When you have a person with a learning disability, I say to parents, from when they are young you have a fight on your hands because you are fighting and begging all the time until they are older. (Cath)*

Cath's poignant use of "*begging*" alongside "*fighting*" indicates the level of desperation and powerlessness mothers felt. On the one hand, they did everything they could to 'fight' decisions to get their child what was needed, yet, on the other hand, all too often they remained at the mercy of services and thus felt as if they had to beg for support.

Even before a decision had been reached, parents were ready to challenge the outcome:

> *We were ready to sort of put our case forward if we had to. (Janet)*

> *If they say no, I mean obviously I will appeal. (Sandra)*

This demonstrates just how ingrained the need to fight for support was. Families expected a poor outcome, and a struggle to get what was required is shown to be the norm rather than the exception. Words such as "*fighting*", "*battle*", and "*winning*" were regularly employed when discussing past experiences and interactions with both health and social care services.

Mothers were acutely aware that their child was unable to appeal decisions for themselves, and if they did not fight for their children, no one else would:

> *At the end of the day he can't fight for himself and if that's what we've got to do, then that's what we have got to do. (Cath)*

This further emphasises the sense of aloneness mothers experienced during transition. Professionals and services could not be relied on to ensure young people had the help and support they required. As a result, the quality of a young person's life was precarious as it depended on their parents' ability to advocate for them. As is shown in the quote below, questions arose as to what would happen when mothers were no longer around to advocate or fight for their child:

> *They will put her somewhere, but like I say the council will get reorganised or they get spread even more thin and then you are thinking well when I am not here they will do what they want at the end of the day if I haven't found a way to stop them so I don't know. (Janet)*

Despite the necessity of challenging decisions and 'fighting back,' gaining the ability to do so was, however, a journey. Knowledge was considered empowering, but it came with time as mothers described learning and growing in confidence from their own experiences and the knowledge gained from speaking with other parents and attending workshops and events. Comments from both Janet and Claire illustrate this. Whilst Janet explained that she felt "*in a better position now to move forward because you learn",* Claire explained that due to the knowledge she had gained over the previous few years, she was in a stronger position to respond to a disappointing letter:

> *Three years before that, I would have got the letter sat down and cried and thought there is nothing I can do about this. But, because of the journey I had been on with those other parents, I felt empowered to appeal the decision. I thought 'I'm not having this' and they upheld it.*

Systemic battles – fighting for others

Alongside the individual advocacy mothers provided for their children, there was a desire to challenge and change the broader system. Mothers did not wish for others to experience the same difficulties they had, and mothers were concerned for young people whose parents were unable to advocate for their children, for example, if parents were not proactive or if parents were not equipped with the knowledge and skills required. This was a concern that often factored in mothers' decisions to challenge the broader system as there was a worry that these parents would *"just have to go along with what has been said",* as highlighted in the following comments:

> *I’m on the ball with Sam […] but what about our other parents who can’t read and write? Who can’t fight? Who’s helping them? They are just falling and falling through the loop. (Cath)*

> *You have to have a good parent there to get the child sorted and there are some children who don’t have that so they are just left. (Sandra)*

How mothers approached the systemic fight was varied. It included individual and collective action as well as formal and informal routes. For example, Claire described wanting to share her story with anyone who would listen:

> *All we can do […] speak to anybody who will listen and then they will have a glimmer of understanding of what it’s like. And the more people who can express that about transition and things like that.*

Whilst mothers in one of the focus groups expressed a desire to get their local MP “*to come down and sit with us in these meetings”* so that they could hear their stories first-hand and presumably be prompted to act.

At other times the action was more formalised. Cath, for example, explained how she had been driven to take on new roles in the hope that she may be able to contribute to change:

> *I’m on a lot of boards at the hospital, trying to fight for young people with disabilities because I think the transition is really really bad.*

Life Goes On

Transition did not occur in a vacuum. Therefore, whilst families were spending time and energy navigating the disruption and challenges that occurred during transition period, trying to fill the void left by the end of college and advocating for their children to access support, they were also having to contend with 'life carrying on'. For many families, this meant managing additional difficulties and other sources of stress or worry, which, whilst not directly related to transition or learning disability services, affected individual resilience and their ability to whether the transition-specific difficulties encountered. This is summed up in the extract below:

> *Life goes on, life goes on even though you are going through transition. You want to stop the world when you are going through transition. You want to say give me*

> *a break, don’t let the washing machine break down, don’t let the car break, don’t let [there be] any health issues, just let me concentrate on this. But you can’t because life doesn’t work that way. (Claire)*

Although a washing machine breaking down might ordinarily be considered a relatively minor issue, its inclusion in the list above highlights the enormity of transition. It is shown to be all-consuming, leaving little energy or emotional resilience left to deal with the everyday problems life can throw up. There was little room to manage other problems, no matter how trivial they might otherwise be. Thus, there was a desire for life to be put on hold so efforts could be poured into navigating transition and managing the problems faced during this period.

For Claire, the participant quoted above, life carrying on during transition meant contending with a breast cancer diagnosis and her father's death. The emotional and physical toll this took subsequently affected her ability to cope with the issues which arose during transition:

> *I get that letter and the day before I had just been told that I probably had breast cancer, that was, believe it or not, it was the letter from the council that broke the camel’s back. I was dealing with everything until that letter came and I could have punched somebody. (Claire)*

The letter Claire received one Saturday morning announcing the reduction in her son's personal budget was the straw that broke the camel's back. The cumulative stress of the various challenges faced during transition became too much to manage with the statement *"I could have punched someone*" highlighting the impact of decisions on mothers' emotions and the anger and frustration experienced by events outside of their control.

Claire was, however, not alone in her experience and other mothers reported similar situations in their own lives, which subsequently affected their wellbeing and ability to advocate for their child during transition. For example, Sandra, was also dealing with health issues. These issues coincided with her son experiencing difficulties in his last year of college. Consequently, she could not dedicate as much time or energy to tackling her son's problems as she might have otherwise. As a result, she felt guilt at her son's suspension:

> *I has been in the hospital and it was the day after I came out and they phoned me up. I said, 'I'm not well to come up, I've just come out hospital, I'm not well enough.' So anyway, they suspended him altogether and at the time as I say, I wasn't well enough to fight back and it's only later I thought I should have done more.*

Similarly, Anne felt unable to dedicate as much time as she would like to sort things out for her daughter during transition due to the impact of her other caring roles:

> *There is so much in my own background that I have to manoeuvre things round. I have got two daughters that suffer with alcohol abuse and I have another daughter who has seizures really really bad […] I can't always give 100% at doing things for Eve.*

The ill-health or death of relatives also affected families during transition. As mentioned above, Claire had recently lost her father whilst Janet explained how her parents could no longer support her in looking after her daughter, their grandchild, due to a deterioration in their health. As a result, the pressures on these mothers increased and, in addition to the emotional impact of losing a relative or having to come to terms with a relative's declining health, they also lost a valuable source of informal respite. Unsurprisingly, this had a knock-on effect on their wellbeing.

Janet also reported a decrease in the amount of time her daughter was able to socialise with her cousins as they reached adulthood, stating, *"they have grown up enjoying university life and things now so yeah she doesn't really see them a lot now".* The paths the cousins were taking were different to her daughter's, and, for Janet, this contributed to a sense of difference and isolation. Whilst Janet described similar feelings throughout her daughter's childhood, it became heightened during transition when her daughter and the cousins entered adulthood, their paths diverged, and Janet lost the support of her family.

Therefore, whilst the above events and the competing demands placed on mothers were not directly related to transition, as many of them were age-related, they were more likely to occur during the transition period. Not only were these issues difficult to manage at the best of times, but they detracted from the amount of time and energy mothers had to dedicate to transition.

B. Professionals

Sympathy with Boundaries.

Professionals were understanding of many of the challenges faced by families during transition and, mirroring the interviews with mothers, acknowledged that several areas were particularly problematic. However, there appeared to be a limit on the sympathy and understanding available due to the financial restrictions influencing their views.

Inadequate information and limited opportunities were two areas highlighted as troublesome and believed to affect families negatively during transition. Issues with communication were also raised. However, unlike mothers who focused on issues they experienced when communicating with professionals, professionals focused solely on their relationships with other professionals and the lack of joint working. For example, the sharing of information between teams was believed to be limited, and there was a belief that individual professionals lacked understanding of sectors outside their own, resulting in misinformation being given to families:

> *Health team don't know enough about education and education don't know enough about health […] so there is a lot of work to do with both teams so they understand each other better.* (*Alice*)

> *Education services do give a wrong impression of the bigger picture to families.* (*Sarah*)

One reason given for difficulties in joint working were administrative differences with different sectors having different systems and procedures in place communicating and documenting information:

> *I'm finding that emails to teachers aren't like emails to members of staff here […] they just work differently to us and you need a different approach as a result. (Colette)*

> *They all use different computer systems, there is an issue around the sharing of information. (Sarah)*

Furthermore, a difference in priorities between children's and adult services hindered the two departments from working closer together. Professionals interviewed suggested that those in children's services did not view transition with the same importance as they did. Instead, children's services were viewed as focusing on the *“here and now”* as they had more pressing issues to manage, such as child protection and safeguarding. Therefore, professionals believed that children's services did not have the time nor inclination to place a greater focus on the young people's future as they took a short-term approach and would no longer be responsible for them. This translated into a lack of forward planning for the young person and parents being insufficiently prepared for the changes. Colette, the social worker, summed up these issues when she stated:

> *Somebody having to tell their story over and over again, where if they just told it once and maybe recorded it and then everybody had access to that who needs to obviously, that might help…when we get the referrals and we work together I think that’s probably when we have our best transitions. Things are identified well in time and the person’s transition can go really smoothly.*

As is evident above, Colette believed professionals sharing information in a timely manner would reduce the burden on parents and contribute towards a smoother transition experience. There was, therefore, an awareness that transition did not currently work as well as it could, and the attribution of the problems to the way professionals worked suggests some acceptance of responsibility for difficulties faced by families.

As aforementioned, professionals, like parents, believed the provision of information to families regarding transition to be inadequate. Again, as with mothers, knowledge was viewed as empowering, and, as a result, there was an understanding that the lack of information disempowered families. Professionals were sympathetic to the position this placed families in. Colette, for example, acknowledged that families often did not get the support they could have as, *"a lot of people just don't know what to do or what to ask for,"* whilst Alice explained how vital knowledge was for both parents and professionals alike in order to successfully navigate the system and achieve positive outcomes:

> *Knowledge is power at the end of the day and I am sometimes able to say to people who don’t know the system as well as I do, ‘well you can’t make that decision because this is happening at a Greater Manchester level and that will influence*

> *what you are doing.' And because they don't know that, they panic and then I will say 'well go and read it' or I will say to them 'well what happens if I don't sign that?'*

Being knowledgeable enabled Alice to challenge decisions confidently, arguing from a position of power due to her intricate knowledge of how things worked.

Consequently, parents were recognised as being disadvantaged, and transition was understood to be a confusing and overwhelming time, as the following quotes illustrate:

> *One of the key things for me was the fact that parents were saying they didn't know where to get any information from, they didn't understand who they needed to approach for a transition assessment or whatever. (Katy)*

> *People don't understand the process, they don't understand what happens in adult services. (Sarah)*

In Sarah's eyes, parents were set up to fail as they were *"expected to know an awful lot about the system"* but did not have the necessary information to do so. Furthermore, there was a belief that parents had been insufficiently prepared for transition-related changes resulting in feelings of frustration and anger from parents:

> *That's another thing, the financial contribution. Because in adults everyone is expected to have a financial assessment and contribute towards their services and they are like 'what do you mean we have to pay? We didn't have to pay in children's, why do we have to pay?' (Colette)*

Echoing the views of mothers, there was an awareness that the delivery of information was also important. Jargon was viewed as a barrier, and there was an appreciation that it was necessary to tailor information to individuals in order to make it meaningful, as the following two extracts demonstrate:

> *I think language again is an important thing. You can see it sometimes when parents are in the same room as staff and the staff are continuing to use this very jargon-y terminology. It doesn't help and that again increases the anxiety. (Alice)*

> *All sorts of things will change…you know it is huge really and I think for people to just go to a review say and expect parents to walk away from that not thinking 'oh*

> *my god.' I think a lot more emphasis on giving information out to people on an individual basis…some parents love all that, some parents haven't got the time or can't be bothered. (Sarah)*

Demonstrating a recognition that professionals and services could do better in this area and alleviate some of the problems experienced, examples were given of initiatives that had been, or were being, introduced in an attempt to tackle the problem. For example, Alice, who was both the parent of a teenager with a learning disability and the manager of a charity that supported families, was exploring using 'vlogs' to share information on the different processes and roles within social services, explaining the rationale behind this:

> *I think actually having it visually and spoken for most parents is quicker and easier than doing lots of reading […] We are only going to do three or four minutes per thing because that's all it needs really.*

Katy, meanwhile, discussed how her borough was introducing a range of leaflets to give information on the various aspects of transition, and Peter explained how their local authority now had 'community knowledge officers' and a transition fair for parents to attend to gather information on transition and the different services available.

Thus, it was recognised that the availability and presentation of information was an area that required improvement and that services and those working with families were the ones responsible for tackling this problem.

Further issues were identified concerning a lack of opportunities for young people once they leave college. For example, Sarah described transition as *"a bit of a black hole as to what are they going to do every day, particularly for parents who are working"* and, again mirroring the views of parents, there was an awareness that parents felt that they had to fight to access support:

> *Parents talk about needing to fight all the time and I find that really disheartening. I am sure that is how it must feel to them. (Katy)*

Indeed, several professionals indicated that families could not rely on services to ensure their needs were met, "*if parents aren't the ones fighting their corner for them then who is?" (Peter)*

Positive outcomes were viewed as contingent on *“the tenacity of parents”,* and there was a belief that those who 'shouted the loudest' were the ones who got what they needed:

> *The people I know who have had really kind of positive experiences have had really strong advocates fighting their corner. (Peter)*

> *I probably have more [parents] who are not on the ball than who are to be fair, and then you think their child isn’t getting as good a service and they are not, because their parents are not shouting out for it. (Colette)*

However, whilst this appears to be an acknowledgement that the system was failing and it was those who did not have knowledgeable or articulate parents to advocate for them who were disproportionately affected, there is also a danger that it shifts responsibility from services to families. After all, a system where positive outcomes depend on parents' tenacity also implies a system where parents can be blamed should a young person's transition not go as well as it could.

The position parents were in was further complicated by the pressure professionals were under to reduce spending, the pressure evident in the extract below:

> *It can be quite difficult saying you know ‘do you really need an extra hour at the weekend’ and it’s really hard. I think ‘oh gosh, of course you need it’, but when you look at what the absolute minimum amount of support you need to manage on [pause]. (Colette)*

Whilst Colette spoke with empathy when describing how difficult it was to limit support, the decisions being made were viewed as out of the council's control due to *“finite resources.”* Furthermore, funding restrictions were also shown to impact professionals who were viewed as being put in a precarious position:

> *If you think about it from the professionals’ point of view if the Local Authority or CCG is going through a restructure, they are worried about their jobs and I have professionals who have said to me personally, that they know their job is safe because they are saving the local authority the equivalent in their salary but not providing services to young people. (Alice)*

In Alice's opinion, the precarious position staff were placed in affected their ability to be better allies as interactions with families were clouded by a personal fear. However, rather than explicitly relating the difficulties caused to a lack of funding and the product of an unjust system, there was a suggestion that mothers were the ones who needed to change. They were positioned as unreasonable in their expectations:

> *The questions the parent was asking, they clearly do not understand the restrictions that we are working within so I think sometimes their expectations are higher that what we can give them. (Katy)*

> *The parent has unrealistic expectations of what their son or daughter is entitled to. (Sarah)*

Katy suggested increased transparency with families would go some way to mitigate against the restrictions:

> *With all the will in the world we would like to give them everything they want but we only have finite resources […] realistically some of these things are out of our control…so we have to be realistic and we have to be honest with parents but at the same time we have to say well it is important that you get this information, that you are involved in the planning and the parents help the young person take some control over what is going on.*

However, whilst suggesting increased transparency, Katy also indicates that parents and young people need to *"take some control over what is going on",* one more suggesting a further transferring of responsibility from the local authority to the family.

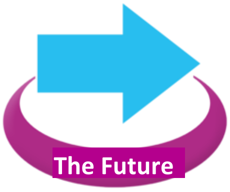
Sympathy for families, therefore, only seemed to run so far. Whilst responsibility was accepted for the easier to remedy issues, such as the availability of information and better communication between professionals, issues arising from a lack of funding placed families in an impossible position. On the one hand, they were being told to take more control over the situation, that they *"must speak up, speak up and ask for what you want or what your son or daughter needs"* (Colette), but on the other hand they must speak too loud or risk being positioned as unreasonable.

Chapter Eight summary

	A **minefield** is an area where there are lots of small bombs on the ground waiting to explode.
	This chapter explains how lots of difficult things made transition feel scary and a bit like a minefield.

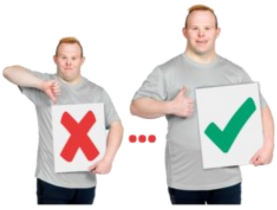
Mothers

   	The difficult things included: • Poor transition planning • Not much information • Not many things for young people to do after college. • Difficult relationships with professionals.

	Mothers said they had to do a lot of fighting to get what they needed.
  	Sometimes other things went wrong in their lives. This included family members getting ill or dying. This also made transition difficult.
 	Mothers were worried about their children's futures and they wanted things to be different.

Professionals

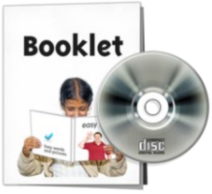
	Professionals knew transition could be a difficult time for families.



They said there were some things which they could do to improve transition.

This included:

- Professionals working together and sharing information.

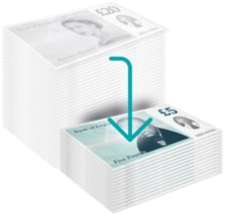
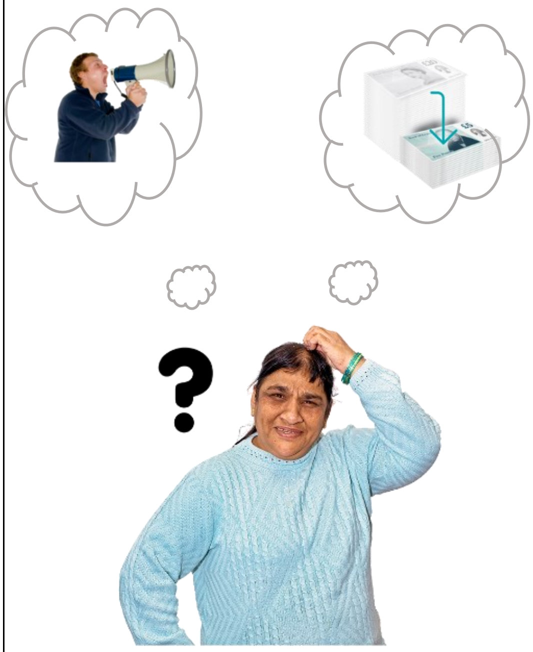


- More information for families.

- More things for young people to do after college

Professionals knew parents had to fight for support.

They said sometimes it is the parents who shout the loudest who get listened to.

 	However, professionals also said there was not much money. They thought parents needed to change how much they wanted.
	This meant parents were in a difficult place. They were told to speak-up and ask for help. But they were also told not to ask for too much.

Chapter Nine: Theme Two, Networks of Support

Connections with other people were important to mothers and young people alike during transition as both groups described benefiting from forging positive relationships and building networks of support. Practical and emotional support from peers and family members empowered mothers and enabled them to withstand many of the challenges encountered during transition. Meanwhile, for young people, the changing dynamics of relations between them, their parents and personal assistants fed into conceptualisations of adulthood and increased the sense of choice and control they had over their lives. However, the end of college also saw the unwelcome breaking of connections as young people lost touch with staff and friends leading to feelings of loneliness and isolation during transition. Therefore, this theme is split into two parts. Part A addresses mothers' views and contains one sub-theme, 'Support to Empower', whilst Part B addresses young people and contains the sub-theme 'Loss and Connection'. This theme was not an area that was raised by professionals, and therefore they are not included in this chapter.

A. Mothers

Support to Empower

Help and support from other people were invaluable to mothers during transition due to the multiple difficulties experienced as one mother, Claire, stated, *“you can’t do it on your own”.* However, in the absence of formal support, it was in family members and other parents of children with learning disabilities that mothers found support. Not only were other parents and family members a crucial source of practical help, but the emotional support and sense of solidarity gained through the relationships contributed to the building of resilience and enabled mothers to “*survive*” transition.

The practical help gained was varied. Mothers shared information and filled in gaps in knowledge as Sandra described, “*we all natter together, and we find things out and think ‘oh yeah’*”.

In this way, mothers learnt about the systems and processes in place and about opportunities available. Parents were viewed as a more trustworthy source of information than professionals:

> *Lots of families won't listen to professionals […] The social worker is ringing up, 'I'm coming to see you' and your first thought is 'what are you going to take off me?' (Jackie)*

As a result, other parents were often the first port of call, particularly for those who believed services intended to cut support and could not be trusted to give impartial information. A lack of trust in services also meant mothers utilised family for respite rather than seeking more formal arrangements, as in the case of Cath below:

> *He always stays with his mum and dad, he doesn't stay out, don't have respite only with my sister if she comes over from America.*

Other parents meanwhile described the practical support they benefited from when they were able to do things as a group rather than as individuals:

> *We supported each other, and we are all friends fortunately, we all went to see different services together as a group. (Janet)*

Sandra described being able to draw on her daughter for support during a difficult meeting:

> *I phoned my other daughter and she said right […] I'll take you up […] to see what's going on.*

Anne, meanwhile, explained how she benefited from her other children's support when they had a tricky, but timely, conversation with her daughter that alleviated some of her worries:

> *My other daughters have had a talk with her and said you know Eve and they have explained what happens and so forth which I thought phew, so she knows.*

However, besides providing help with practical tasks, the friendships forged with other parents positively impacted emotional wellbeing. Sandra described how the parent carer forum she attended was a *"godsend",* explaining she *"would be lost without it definitely",* emphasising the importance of peer support to surviving transition. Whilst Claire described "*meeting up with other like-minded parents"* as empowering:

> *Three years before that I would have got that letter, sat down and cried and thought, there is nothing I can do about this. But because of the journey I had been*

> *on with those other parents I felt empowered to appeal that decision. I thought 'I'm not having this' and they upheld it.*

Therefore, for Claire, the friendships she formed gave her the confidence to appeal a decision that she would have otherwise accepted without question. The positive impact was visible in the outcome of the decision and the emotional resilience displayed; when faced with a difficult situation, Claire now had the strength to tackle it rather than feeling defeated.

Claire's use of "like-minded" parents was significant. Not only did it highlight the importance of peer support, but it suggests a sense of solidarity could be found in the sharing of one's experiences with people who are in the same situation. This was also evident in the following two statements from Janet and Cath:

> *Support from other families has been a godsend because they are the ones who really get it. You are sort of addressing it together. (Janet)*

> *We should all stand by each other and that's what we should do. (Cath)*

It was a comfort for mothers to find other people in the same position as them, to be able to share their hopes and fears, and consequently reduce the sense of isolation experienced. For example, Claire described how *"fear"* had brought her group of friends together as they were all *"really scared for [their] kids futures*". Another mother knew she could always turn to her local parent carer forum for help should she need it, thus reducing her sense of isolation, *"I could come here if I needed".*

In light of the positive experiences of peer support experienced above, mothers also expressed a desire to empower others alongside feeling empowered themselves. They were keen to share what knowledge they had with other parents, particularly those with younger children, hoping that they might have an easier transition. Cath, for example, explained how, now she had been through transition, she could *"pass that information on*" to others. Another mother was pleased other parents with younger children had joined their friendship group:

> *Because they are in at the very beginning so they will have the chance to get all that information and experience and knowledge in order to help their young people.*

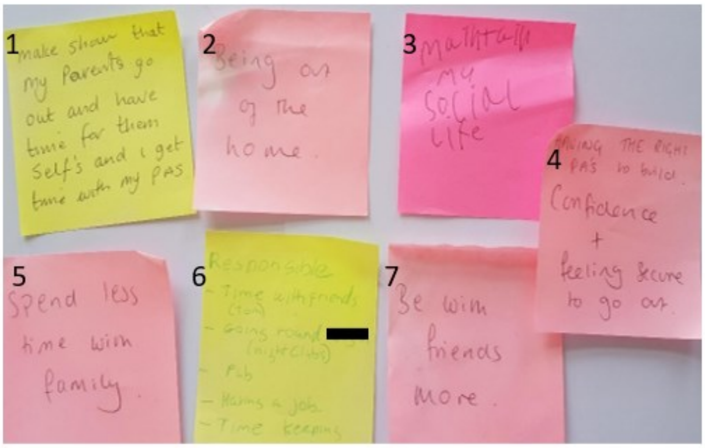
B. Young people

Loss and Connection

As with mothers, relationships with other people during transition were important for young people. However, rather than being framed as a source of support during a difficult time, relationships for young people were often framed within a discourse of independence and adulthood. Existing dynamics changed, and young people expressed a desire to branch out beyond their immediate family. For example, several young people spoke of spending less time with their parents as they grew older, as the following comment from one of the focus groups illustrates, *"you spend less time with family as you get older […] it's just something which happens".* (Ace member)

Gradual separation from parents was therefore viewed as an inevitable part of growing up. However, far from this meaning the lessening of connections young people had with others as they moved towards independence, young people spoke of increasing and building connections and networks of support; they envisioned spending a greater amount of time with friends and personal assistants (PAs) as the post-it notes in **Figure 10** demonstrate.

Figure 10 Post-it notes from the focus groups related to relationships changing



Post-it note transcription:

1. *Make sure that my parents go out and have time for themselves and I get time with my PAs*
2. *Being out of the home*
3. *Maintain my social life*
4. *Having the right PAs to build confidence and feeling secure to go out*
5. *Spend less time with family*
6. *Responsible, **time with friends**, going round nightclubs, pub, having a job, time keeping.*
7. *Be with friends more*

PAs were thus an integral part of young people becoming adults. Not only did they enable young people to take part in a broader range of activities and allow for new experiences to take place but, in doing so, PAs helped develop the young person's sense of personhood and adult identity. They built confidence and gave the young person a greater sense of choice and control over their lives and were therefore viewed in a positive light. For example, one young person explained how the support they had from their PA enabled them to go to places of their choosing:

> *It's not holding me back because when I go with these people I can go anywhere I want to really.* (Stewart)

Figure 11 Gary's photo of the airport

For Gary, support from his PA meant he could go to the airport and watch the planes take off and land (**Figure 11**). This was his favourite activity and was evident in the many photos he had taken at the airport and the numerous airport-related conversations the photos prompted as a result. It had also led to him wanting a job at the airport pub.

However, whilst new connections with PAs were made and existing ones strengthened, some connections were also broken during transition, and young people experienced the loss of both support staff and friends as college came to an end.

Like PAs, college staff were viewed in a positive light. They enabled the young person to do things they otherwise might not have been able to and facilitated the young person taking part in new and different activities. This was the case for Michael, who explained his favourite work experience was due to the "girl there". Michael's mother, who supported him during the interview, expanded on this, explaining that he was referring to the staff member who supported him to use the various cleaning equipment which he had enjoyed:

> *When he worked at the gym there was a woman he worked with who helped him do the cleaning and he used to use the big cleaning things, the floor cleaners…and she was great with Michael and loved him.* (Frances – Michael's mother)

Eve, who had taken several photos of her college support worker, spoke with sadness when she explained his role and how she would miss him:

> *This guy here who is sat next to me is my support worker. He helps me do my work. I'm going to miss him really because I have been with him two years now.*

In addition to college staff, however, young people were concerned about losing friendships during transition. Despite a desire to spend more time with friends, believing this was something which should happen as you grow older and spend less time with your parents (see **Figure 10**), it was by no means certain that this would happen. The end of college meant young people ceased to see friends daily, and social media use to stay in touch with them was limited. Furthermore, support was sometimes required to mediate friendships but was not always available. Stewart, for example, explained how his desire to make new friends and to *“be with the in crowd”* led him to trust the wrong people:

> *I’m easily led, and I’ve been like if you’re my friend I’m your friend and so even if they are a bad influence. I’m not really a good judge of character. I think the world is all nice and rosy and then people see me and take advantage.*

Whilst Eve explained she was lonely since the end of college. She had few opportunities to socialise and, due to falling out with friends on social media in the past, she no longer used it to connect with people. The importance of friendships to Eve was evident in the number of photos Eve had taken of people at a group she attended weekly. When looking at the photos, Eve explained how the group enabled her to get out of the house and see people, “*it’s what I need really as I don’t really go out much”.*

The loss Eve experienced at the end of college meant transition was a difficult time. Despite desiring more friendships, stating again at a later point, *“it’s what I need really”,* she required structured opportunities to make them. The group she attended was only once a week, and, as a result, she spent much time feeling lonely and isolated at home.

Chapter Nine summary

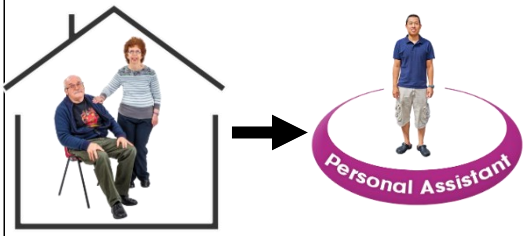
	This chapter explains how **networks of support** were important to mothers and young people.

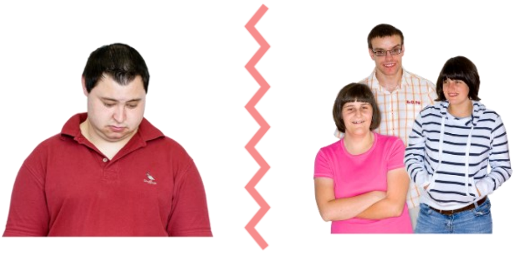
Mothers

	Mothers needed support during transition.
  	They got support from other parents who had children with learning disabilities. The support included: • Finding things out by talking to each other. • Talking with each other about their lives.
	This support made mothers feel less alone and more confident.

  	Mothers also got support from family members. This included: • Help looking after their children. • Someone going with them to meetings. .

Young people

 	Connections with other people were important to young people. But the connections young people had with other people changed a lot during transition.
	Young people said they would spend less time with their parents as they got older.

	They said they would spend more time with their PAs and friends.
 	PAs helped young people to take part in different activities and to do things they liked. This made young people feel more in control of their lives.
	Some young people were sad when they left college. They lost their friends and missed the staff.
  	This made people feel lonely. They wanted to make new friends but needed support to do this. Social groups are important as they help people to make friends.

Chapter Ten: Theme Three, The Push and Pull of Adulthood

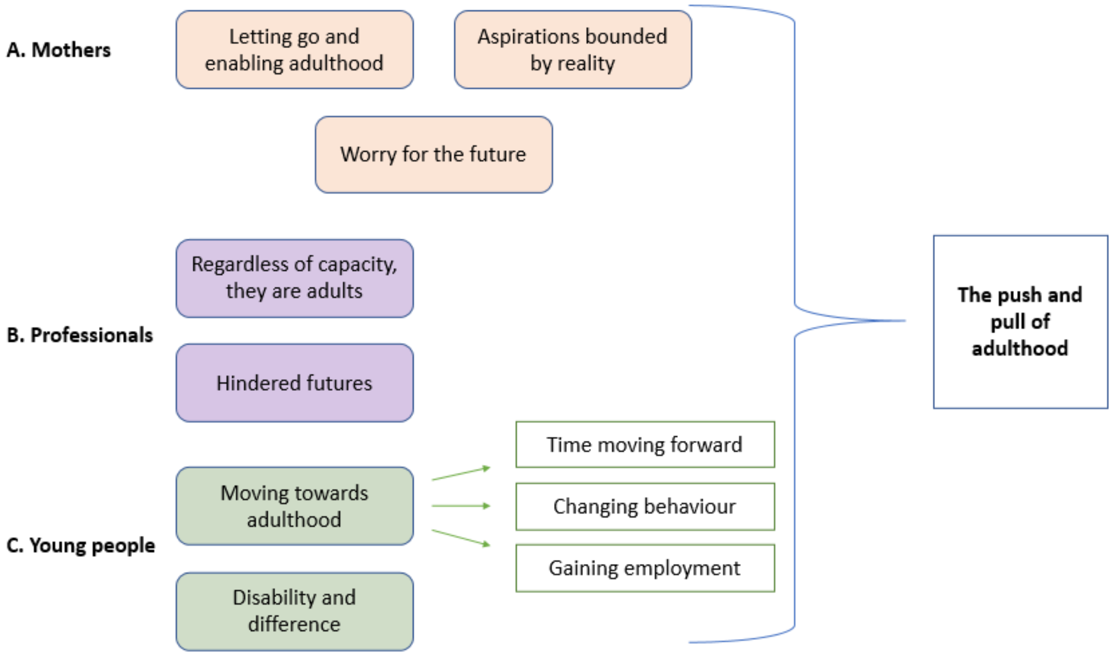
This theme captures how participants conceptualised adulthood and the different challenges encountered on the way as young people became adults. As is shown in **Figure 12** the theme is split into three parts, A, B and C.

Part A presents mothers' views. It contains three subthemes: 'Letting Go and Enabling Adulthood', 'Aspirations Bounded by Reality', and 'Worry for the Future'. These subthemes demonstrate that whilst mothers recognised their child's changing status, held aspirations for their future and enabled them to develop their independence and adult identity, difficulties were encountered. Concerns about safety, together with employment-related barriers were seen to place limitations upon what young people could do. Furthermore, for mothers, underlying transition and discussions about the future and adulthood was a continuous worry about what would happen when they were no longer around to care for their children.

Part B focuses on professionals. It contains two subthemes: 'Regardless of Capacity, They Are Adults', and 'Hindered Futures'. The first subtheme captures the emphasis professionals placed on the legal changes at 18. The second presents how professionals believed young people's futures were shaped (and limited) by society.

Part C presents the views of young people. Here the interviews generated two subthemes: 'Moving Towards Adulthood', and 'Disability and Difference'. **Figure 12** shows that there are three strands to the subtheme 'Moving Towards Adulthood' to reflect the different areas of importance to young people as they grew older. 'Disability and Difference' highlights how young people felt their lives were impacted by disability and how they were, at times, prevented from reaching the milestones raised as desirable in 'Moving Towards Adulthood'.

Figure 12 A summary of the theme 'The Push and Pull of adulthood'



A. Mothers

Letting Go and Enabling Adulthood

Mothers drew attention to how they recognised and respected their child's changing status. However, concern for their child's safety meant they often acted as gatekeepers to the young person's autonomy and independence and thus played a role in enabling or restricting the development of their child's adult identity.

Mothers drew on cultural norms to frame the young person’s behaviour, and their responses, within a discourse of age-appropriateness. For example, mothers discussed respecting their child’s autonomy due to their age:

> *You can’t force him you know he’s 21. I can try and talk him into it, but I mean I can’t physically force him to go. (Sandra)*

> *He wants to be on his own and who doesn’t at that age? You know, ‘you go out mum’ and I will come in here so he has the living room and I am thinking ‘hang on a minute’ but that’s him growing up [...] And that’s what I did when I was that age. (Claire)*

Reiterating the age-appropriate discourse, Jackie highlighted how, as her son was now an adult, he could drink alcohol:

> *When we go out to parties he is allowed, if he wants to buy an alcoholic drink he can do, he is an adult so [pause].*

Jackie described an incident that occurred on an all-inclusive holiday when her son was given a child's wrist band preventing him from ordering alcoholic drinks. Jackie recalled challenging this decision to ensure her son was given a wristband in accordance with his age:

> *I said that's a child band and we questioned it at the hotel and they went 'oh well we put a child band on him because of the bar'. And we went, 'well actually if he wants an alcoholic drink he is old enough and we accept that he is old enough and it is his right if he wants one. So, put him an adult band'. So, we made them change it to an adult band. They didn't even ask if we wanted them to do it.*

Although Jackie is advocating for her son's adult status to be recognised, stating it was her son's right to drink alcohol, the use of words such as "*allowed*" and *"we accept"* alongside the assumptions made by the member of staff, suggest that other people ultimately maintain authority over young adults with learning disabilities and act as gatekeepers to what they can or cannot do. In other words, regardless of their age or adult status, the young person's ability to exercise their rights is dependent on what other people decide.

It was easier for mothers to recognise and advocate for their child's adult status when age-related markers of adulthood and cultural norms associated with adulthood were relevant or meaningful to their child. For Janet, discrepancies between her daughter's age and her behaviour and support needs were ever-present, bringing ambiguity to an adult identity:

> *I think you can do age-appropriate things but at the end of the day Emma still watches Teletubbies so adulthood […] I think it needs to be monitored and careful because you can't suddenly say 'oh they're adults' because they are sort of not really. I don't know. I think it's very hard and I think with Emma you can try and get her to be grown up but as I said, she isn't really.*

Mothers described encountering difficulties when they, or their child, made comparisons to other non-disabled young people:

> *[…] he’s saying I can do this myself and he can’t he’s just thinking he can because his friend does it. So that makes life a little bit hard because he’s not fully understanding that he can’t do it. He thinks it’s me holding him back. (Jean)*

Jean’s son was frustrated at not doing the same things as his peers and blamed his mother, believing she was restricting his freedom. A disparity between peers as they grew older was also visible elsewhere. Jackie described her son's desire to drive after watching his sister learn as "*heart-breaking*", as she believed he would never be able to do the same.

For all mothers, the notion of independence was prominent within understandings of adulthood as an increase in independence was viewed as a marker of growing up. Therefore, encouraging their child's independence was one-way mothers could acknowledge their child's adult identity and support their children to realise their adult status in a way they felt suitable. As a result, mothers played a part in both creating and shaping their child's adult identity. Cath, for example, echoing the views of young people in theme two, focused on building a bigger network for her son to enable him to spend time apart from her and her husband. Whilst she felt this would be beneficial to her son, she also felt it appropriate given his age and status as *“a young man”:*

> *He’s coming now when he’s a young man and he’s needing more than what me and my husband can […] he needs a bit of life […] and to be with people his own age or mixing. He doesn’t always want to be with mum and dad you know.*

As is shown in Cath's comment above, there was a belief that growing up included a gradual separation from parents. However, while this happened for people without learning disabilities when they started to stay away overnight with friends, people with learning disabilities did not get such opportunities. One mother poignantly stated, *“kids like ours don’t get invited for sleepovers” (Claire).* Therefore, mothers had to create these experiences and turned to respite or residential college to fill the gap. This was particularly important to mothers who envisaged their child’s future as including a move out of the family home, as spending time apart from parents overnight was considered vital preparation for supported living and an important step on the path to adulthood:

> *It was good he had the experience of the college [respite] because I feel like that was a resemblance if he was to go into supported housing to kind of get that sense of feeling and that kind of environment. (Jackie)*

> *It just seemed like a good experience perhaps to just try out how she would be, being away from home. She has done a few nights but she has not done any respite […] she hasn't really been away. (Janet)*

In addition to spending time apart from parents and developing networks of support (in line with the views of young people in theme two), independence was also linked to the ability to take part in self-care tasks and participate in practical everyday chores. For example, Sandra stated her son was, "*quite independent you know, personal hygiene and that"* and explained that, as her son was now older, he had *"started doing jobs in the house".*

However, for all mothers, there were challenges attached to 'letting go'. As much as independence and the development of their child's adult identity were encouraged, it brought with it a particular set of difficulties and was a source of worry. Mothers had to balance their child's desire for more freedom and their desire to develop their independence with their safety. Therefore, once more, parents acted as gatekeepers: "*It's just weighing up taking those risks. Is it worth taking those risks or shall I just keep them safe?" (Frances)*

This was *"not easy",* and mothers described being placed in an impossible position, fearing their child's safety on the one hand versus guilt of holding them back on the other: "*I sometimes think that I am quite selfish in that I don't let her do an awful lot as I can see the danger"* (Anne). Anne explained how she required encouragement from her other children to 'let go':

> *We don't live far from the shops, but I live on a very busy road and they said, 'mum please just let her go to the shop, mum let her go to the shop'.*

Anne's response to her daughter's desire for more freedom was complicated by an awareness of her daughter's adult status and the subsequent belief that she should be respecting her autonomy:

> *I did find out she had got the tram on her own and gone to Oldham […] I said, 'you must never do that again unless Alex is with you'. She said, 'oh but I just wanted to try' but I thought well I can't say 'well you can't do this and you can't do that'. So, it is very hard.*

It was difficult for mothers to know the extent young people's autonomy should be respected:

> *There are a lot of things that I found around Michael making adult decisions that can be a bit tricky really. (Frances)*

However, whilst mothers erred on the side of safety, they believed support workers prioritised adult status:

> *There is a difference between a parent and a staff as well […] I have certain expectations of Michael, but staff are very much 'well he's an adult.' (Frances)*

There was a scepticism attached to the focus on adult status staff had and a sense that staff were taking a laissez-faire attitude towards support, perhaps using the young person's adult status to avoid navigating a tricky situation:

> *They do that thing where 'she's an adult now she doesn't want to do that' and you think oh well it might not be the best idea […] she was coming home, and she would have eaten rubbish. (Janet)*

Frances mentioned a situation where she was cross with staff who had allowed her son to buy, and go running in, a bright pink Lycra outfit. Concerned her son might be bullied, Frances challenged the staff who, she recalled, responded with, *"'well he's an adult, it's his money, he makes a choice'".* However, for Frances, the situation was not straightforward:

> [My son] *still needs guidance around what's socially appropriate, what's expected and what you need to do in private and I think he probably always will so it's just getting that balance around independent adult decisions and support and guidance.*

For both Janet and Frances, simply stating their children were adults ignored the nuances of their adult identity and oversimplified the situation. A similar view was evident in attitudes towards the legal changes which occurred once their child turned 18 and mothers lost parental responsibility. These changes came as a shock as the following quote from Claire illustrates:

> *When you have a young person with a severe learning disability, you think you are always going to be able to do what is best for them, but legally, once they are 18, you can't. You are going 'what? He's my child! He can't sign for himself!*

Reactions to the changes highlight the complexity surrounding mothers' conceptualisations of adulthood for young people with learning disabilities. Whilst there was an acknowledgement that the changes should take place due to their age, the loss of control was described as *"scary"* and *"frightening".* There was a sense of disbelief attached to the changes as the young person's support needs had not changed. Mothers remained the ones overseeing their child's health and wellbeing, and thus the changes seemed somewhat arbitrary - they failed to consider the individual situation of the young person. Furthermore, the changes were reported to introduce an extra layer of bureaucracy which proved frustrating for mothers. Organising a GP appointment, for example, was described as, *"a lot of effort for no gain"* by one mother, with this point further emphasised in the comments below*:*

> *As soon as they are adults you can't make any decisions like at the doctors they want them to be there all the time […] and for us to go to the doctor we have got to take her out of her routine and then she is getting wound up and they can't talk to her so it all seems a bit ridiculous really. (Janet)*

> *The GP surgery will phone up and say 'can I speak to Gary' […] and well no you can't speak to him because he can't speak on the phone! And they will say 'well it's confidential' or whatever and I say, 'you have to tell me as I am his parent so if he needs something happening I am the one who has to put it into place' and they could turn around and say well 'I can't tell you'. (Jackie)*

Aspirations Bounded by Reality

All mothers held aspirations for their children's future which were connected to employment or work-related activities. Reflecting cultural norms of adulthood, mothers emphasised 'meaningful' activities. They expressed a desire for their children to take part in something more than leisure activities as Janet and a mother from the Speak-Out focus group highlighted:

> *A lot of the people we know they sort of go out and they will just be hanging around or going around the shops because they have to be out but I don't want it to be like that for her. (Janet)*
>
> *I didn't want him at a day centre, I want him out doing a little bit of work and things like that. (Mother in Speak-Out focus group)*

In the absence of any formal plans, as highlighted in theme one, mothers described trying to pursue work for their child in an area in which the young person was interested. For example, whilst Gary's mum was exploring internships at the airport, another mother tried to support her son to build a dog walking business. Similarly, Sandra had found her son an animation course which was both something her son wanted to do and something which had the possibility of leading on to paid work:

> *I'm hoping that, you know he does get on with doing this animation thing and get a job […] I'm hoping that it works out like how they say it does, goes on to paid work.*

It was, however, apparent that the aspirations mothers had for their children were tempered by reality, and expectations were lowered in light of the limited opportunities discussed in theme one. As a result, despite expressing a desire for paid work, the need for routine following the end of full-time education, coupled with a desire that their child was occupied and not simply sat at home, *"he's a young man, you know what I mean? The thought of him sitting at home doing nothing it's not…I don't want it to be an option." (Jean),* meant that, for the short-term at least, anything was better than nothing regardless of whether it was aligned with long-term aspirations. This was alluded to by Jean and Sandra when discussing what their sons would do following education. Whilst Jean stated her son just needed *"a couple of hours to break up his day",* Sandra explained how she was keeping her son enrolled on a part-time course *"because it's giving him another day doing something".* Similarly, Anne described how she look*ed* for opportunities for her daughter as she *"need[ed] something more".* However, she had to base the search on what was practical in terms of travel, rather than anything else:

> *I live across the road from [the] hospital and I'm hoping to see if I can get her in like going in for a day helping around the wards and things […] or the airport because my other daughter works at the airport so she could travel in with her.*

Mothers also identified multiple barriers rooted in discriminatory attitudes of wider society and narrow approaches within local authorities, which prevented aspirations from becoming a reality.

Barriers from wider society

Mothers believed their children were disadvantaged in the employment market due to discrimination faced by people with learning disabilities. Sandra, for example, explained that because her son needed support, *"a lot of people wouldn't take him on".* She reported hearing from other parents *"that a lot of places are not taking our type of children on because […] health and safety, it's not cost effective*" and later, when asked if anything would make transition more manageable, stated:

> *More companies taking our types of children on. I mean that sounds bad 'our types of children' but they can't just walk into a job. They have to have a support network around them, the company has to be prepared for that, a lot of them aren't willing to put the staff in.*

Sandra's repeated use of *"our types of children"* was moving. It reflected how she felt her son and other young people with learning disabilities were othered by society, treated differently and thus, their options were limited.

Sadly, Sandra was not alone in thinking this as another mother stated:

> *[…] they don't treat people with disabilities the same as you or I and employers are the same…It's down to the management in the shop and they are only interested in the fast turnover and their profit. (Mother in Ace focus group)*

Barriers from local authorities

In addition to the difficulties mothers faced from services and local authorities during transition, as explained in theme one, a particular set of challenges were experienced relating to the low aspirations mothers believed local authorities held for their child and their perceived narrow way of working. A failure from professionals to think creatively or work in a person-centred manner was believed to limit what the young person could achieve. Several mothers, for example, described how a 'one size fits all' approach was adopted following the end of education as they were encouraged to explore day centres for their child regardless of what they, or their child, wanted:

> *Social services just gave me a list of day centres and stuff like. (Mother in Speak-Out focus group)*

> *Different ones have said you know there’s day centres. (Sandra)*

Rather than the young person being given support to explore their goals or do something ‘meaningful', there was a belief that professionals within the council did not care what the young person did once education finished, *“no one seems bothered, you know once they leave school they’re not bothered”.* Mothers felt that their children were being written off and were understandably frustrated and angry as a result:

> *I say he’s not going in any day centres. No, he’s capable of more. He’s got his problem’s but he is capable of more than a day centre. (Sandra)*

This was particularly the case for mothers whose children required higher levels of support as Cath and a member of the Speak-Out focus group believed their sons to be problematic in the eyes of the council:

> *I think what they were thinking, they have the severity of the disability it’s ‘oh he can’t do that’ so they aren’t bothered so what we’ll do, we’ll just give him the two days here, he can do that here and then simple. (Cath)*

As day centres were presented as the only viable option, the local authority appeared to be treating people with learning disabilities as one homogenous group with little attention paid to the differing ages, needs, interests and potential of the young people. Mothers expressed unease at this and did not feel it reflected the life stage their child was at:

> *It’s sending him into places that are, I’m not being funny, but a lot of older men, older people like 50s and 60s. Not being funny but I don’t want my 23-year-old son mixing with people that age as it’s just not right. (Jean)*

A lack of creativity and person-centeredness was also seen to limit what one mother believed her son could achieve. This mother explained how her son was keen to work as a dog-walker. She felt this was more than achievable with the right support and therefore had proposed to the local authority that her son uses some of his personal budget to pay for support from a PA to establish a dog-walking business. However, the local authority disregarded the young person's wishes and responded by encouraging them to apply for a supported internship:

> *He was asked in his social assessment 'what do you want to do?' and he said, 'get a job'. So then give him some extra hours so he can explore that! Maybe if he had a PA he could help with his dog walking business but 'oh no we can't do that we have to go down this route and that and then supported internship' […] when it could just be simple and long term save money. The red tape holds people back. (Mother in Ace focus group)*

Both Jackie and Cath expressed a similar view believing the local authority failed to work in a person-centred manner and, unlike parents, based decisions on budgets rather than the individual:

> *As a parent you want it to be the right place where you know your child is going to be happy and suit their needs not just because it fits into the council's budget.* (*Jackie*)

> *They just don't understand, they want to cut people's budgets down and don't want to listen and they just don't want to listen to parents. They just want to cut the people's budgets. They are not a bit person centred. (Cath)*

There was a concern that this would ultimately prevent young people with learning disabilities from being able to lead fulfilling lives, "*without the financial help there they are not going to be able to achieve anything". (Mother in Ace focus group)* As a result, Cath, who said she would be *"200% behind"* her son getting a voluntary job, conceded that, *"at this moment in time, things have not worked out for us that way […] and we are having to look at day services".*

Worry for the Future

Mothers were worried about their children's future. They feared they would be stuck at home or in a day-centre unable to reach their full potential and worried that the hard work the young people had put into college and the skills they had gained during their education would go to waste:

> *He has been out over a year and done nothing. I'm worried that he is going to lose these skills that he has gained. (mother in Speak-Out focus group)*
>
> *Nothing. Nothing. To go to a day service, so all the good work that they had put in, they just wanted him to go to a day service. (Cath - mother)*

These concerns fed into a deep-rooted worry about what would happen when parents were no longer around, a worry which had been ever-present:

> *From being born you have a lifelong worry. There isn't a day which goes by without your emotions being there so every decision you are making you are fearful for the future and it's always 'what's going to happen when I'm not here?' (Claire)*

Transition and the young person growing older and leaving the safety net of college only amplified these emotions as it forced mothers to *"face things that you don't want to face" (Claire).* The acknowledgement of their child's adult status was a reminder that they were growing older and were *"not going to be around for ever"* as Janet commented*, "you start thinking about things like that and start thinking about well what happens if we are not here?"*

Intensifying this concern was an awareness of various high-profile failings within adult social care, "*you hear all the horror stories in the papers about residential places and stuff". (Janet)*

Knowledge of such scandals coupled with the difficulties experienced during transition outlined in theme one, 'The Transition Minefield', together eroded confidence in the adult social care system:

> *I'm not being funny you know but you read it and listen to it on the news and that and it's nought can be trusted like that.* (*Sandra*)

For example, Janet, whose daughter had attended residential college, was disappointed that staff did not always pick up on small but essential matters of her daughter's care. This made Janet realise that *"adult social care isn't going to be a bed of roses",* and she was understandably worried:

> *You do wonder […] what happens if and you know they don't quite notice things the same if they are in care […] you have got to wonder, what, what might happen in the future and you know if she is ill are they going to deal with it and things so yeah it's scary. It's definitely scary.*

As a result of the fear, mothers were trying to put in place measures to safeguard their child's future wellbeing. For example, Anne was working to allay her fears by *"trying to put things in place now"* so that she knew her daughter *"has got a life"* when she was no longer around. Jackie was exploring deputyship to protect her son against the possibility of devastating decisions by others:

> *The way I see how I will protect him long term would be for me to get deputyship for him to try and have a voice for him* and *to protect his finances and that and for medical […] it's scary because say like medically as well he has a heart condition, the doctors could turn around and quite easily say they are not going to resuscitate him where as if I had deputyship I could say well actually I want you to resuscitate him, I want you to give him every chance you know.*

The fact that mothers felt the need to put in place such measures further emphasises a lack of faith in services and an inability to rely on society and the current adult social care system to ensure the wellbeing of their children.

Knowing that the council had a duty of care to their children as adults offered little comfort as Janet explained, "*although the council do have a duty of care to do it, it's all the little things really isn't it? It's really scary".*

There was a scepticism surrounding just how much caring was involved in the duty of care. Janet, for example, did not feel it covered the *"little things",* yet it was the little things and attention to detail that signified to her that people looked out for, and cared about, her daughter. As a result, Janet was desperate for reassurance from the council for the future beyond the obligatory duty of care:

> *Just anybody saying they will care will be good.*
>
> *You sort of want somebody to say to you 'look it's ok, we will look after her' and nobody is prepared to do that. I've sort of asked could we have it in writing or could we have a charter or could we just have a promise 'we will endeavour to do our*

> *best to look after her as you would want her to be looked after' and nobody seems to want to take me up on this point and I do think 'well why not?' because even if they are just saying it, it's reassurance.*

The fact that no offers of reassurance were forthcoming in response to Janet's plea was alarming and only served to exacerbate the worry she had for her daughter's future.

B. Professionals

Regardless of Capacity, They Are Adults

Professionals recognised young people with learning disabilities as adults. However, their concerns centred on the legal implications of the young person's adult status and the subsequent implications this had for parents. It was the loss of parental responsibility that was at the forefront of discussions about adulthood as Sarah, the advocate, summed up, *"it's about understanding that in adults your son or daughter, regardless of their capacity, is an adult".*

Professionals drew attention to the complexity surrounding the loss of parental control, particularly for parents whose children had high support needs. They believed it was difficult for some parents to accept the change in status quo due to the juxtaposition of the young person being dependent on their parents on the one hand, and parents no longer being able to consent for them on the other:

> *Trying to explain about capacity, and they've not changed. Just because they have gone from 17 to 18, you know, they are not suddenly like, 'oh right, I'm all right now. I'm 18. I can make my own decisions.' They struggle that they can't sign on their behalf or consent on their behalf. (Colette)*

There was the suggestion that, as autonomy was part of adulthood, parents struggled to recognise their child as an adult when the young person's capacity to make decisions was limited:

> *That's a tricky one particularly where a young person has a complex learning disability because in their parents eyes they are never really going to be able to make a lot of decisions for themselves and that so it is difficult for them to see them as an adult I think. (Sarah)*

Furthermore, there was a concern that some young people were not given adequate support to make their own decisions and, due to the influence of parents throughout their childhood, found it difficult to assert themselves:

> *A lot of the time the voice of the parent is the one which they look up to all their life so they don't really like going against that. (Peter)*

Thus, there was a belief that young people with learning disabilities were not in an equitable position to their non-disabled peers and lacked self-determination:

> *If they [a non-disabled person] were told 'right your mum now is going to make every decision for the rest of your life they are going to tell you what to do, oh you are not marrying him, you have to do this' there would be uproar.* (Peter)

When discussing some of the difficulties' parents experienced, the 2005 Mental Capacity Act was evoked or alluded to multiple times. For example, Sarah drew attention to best interest decisions, *"obviously there is an emphasis on capacity and best interests and that kind of process*", whilst Colette emphasised the right for young people to make unwise decisions. Again, there was the suggestion that parents struggled to accept or understand aspects of the Mental Capacity Act, something which in turn created a sense of division between knowing professionals on the one hand and unknowing mothers on the other:

> *The hardest thing as well, one of the harder ones, is about the unwise choices. That even though it might not be a good choice, it's a bad choice, but that's their prerogative just like it is for us if we make a bad choice. (Colette)*

Supporting parents to understand the changes was described as, *"a little bit of a minefield".* Professionals wanted to maintain good relationships with parents whilst at the same time ensuring both they and parents were acting in accordance with the Mental Capacity Act.

Professionals were, however, mindful that parents were not at fault for the difficulties experienced in this area as they were simply *"doing, usually doing, their best with what they have got" (Sarah).* Mirroring the views of mothers (see page 195), the legal changes regarding responsibility were seen to come as a surprise to parents, and professionals appreciated why parents might question them:

> *I think it comes as a shock to a lot of parents as I think they feel like they are being pushed away and they are thinking well I have looked after my son or daughter all their lives and I know what is best for them and now you are telling me that I don't have parental rights.* (Sarah)

Again, as highlighted in theme one, information was seen as crucial, and there was the suggestion that if parents had more information about the legal implications of their child turning 18 prior to it happening, they would be better equipped to manage it when the time came:

> *I suppose it is scary because I don't think people are given enough information about the differences when your child turns 18 and actually their rights change quite a lot.* (Peter)

Hindered Futures

There was a sense amongst some professionals that young people's futures were limited. Current attitudes and failings from the local authority and wider society were seen as hindering what young people could achieve as they were pushed down uninspiring paths and did not have support to reach their full potential.

Like with mothers, there was a sense of sadness that there was not much for young people to move onto and a belief that skills learnt at college were going to waste:

> *There has certainly be times when it comes to the end of the school year and there has still been nothing found for them and it is really sad as they have worked so hard. Picked up all these life skills. (Staff member in Speak-Out focus group)*

Sarah, who worked as an advocate, suggested that equipping young people with skills they were then unable to use was setting them up to fail:

> *What they are going to do in the day. Where they are going to live and what they are going to do in the day. They are the massive things that they have been set up at colleges to be independent…and it feels almost like you are setting people up to fail.*

As shown in theme one, professionals acknowledged the lack of opportunities available to young people with learning disabilities after college and this was believed to impact young people and their families' immediate experiences of transition (as presented in theme one). However, it was also believed to shape what young people could achieve in the longer term and whether they could reach their full potential. Discriminatory attitudes from employers, and thus wider society, were viewed as playing a part in this. For example, the staff member in the Speak-Out focus group spoke with incredulity as she shared her experiences of companies being reluctant to work with people with learning disabilities and the implicit othering which took place as companies declared, *"we don't do that"*:

> *It is so so hard to find them work. Places that will accept people. The amount of phone calls I have where they are like 'oh no we don't do that' like that's a thing in the first place! So, it is really hard to find jobs.*

Katy, who worked within transition services for a local authority, felt that nationally employers did not have enough of an incentive to employ people with learning disabilities over someone without a disability, as the following comment illustrates:

> *I suppose at the end of the day what I have heard employers say is well if we can do this job without that level of support and that is what happens.*

For Peter, issues arising from the attitudes within wider society to people with learning disabilities had further ramifications for young people. He believed the lack of prominence of people with learning disabilities within society influenced young people's thinking. For example, ambitions were restricted due to the lack of positive and varied role models:

> *If they haven't had any different experiences or they don't know what their options are it's difficult isn't it? They don't know what to ask for.*

Furthermore, how society treated people with learning disabilities was, in turn, seen to shape people's attitudes towards themselves. Peter used the example of a young person he had worked with to explain his point, suggesting that, as a society, we segregate people with learning disabilities from a young age through the special education system. This then teaches them to view themselves as different and not as capable as others which subsequently affects their long-term prospects:

> *I said, 'do you not see yourself as working when you get older' and she said 'no I couldn't manage in mainstream education I'm disabled I've got to be there' and*

> *then you ask young people what they see in themselves and it's obviously enforced in them that they are disabled and have a disability. (Peter)*

Added to this was a belief that the council were limited in their approach and prevented young people from achieving meaningful outcomes related to their personal goals or ambitions. Echoing the views of mothers, one professional believed that the council ignored the individual and prioritised finances:

> *I know the councils have their budgets and stuff, but they are always working within their budget. The amount of meetings we seem to be having which supports what a young person would want then we get it back saying 'oh well we can't afford that' and it is almost like we are not putting that person first, we are putting all the other restrictions in place before hand. (Staff member in Speak-Out focus group)*

Whilst Peter believed limited planning, again something highlighted as an issue in theme one, meant that young people were pushed down uninspiring paths and unable to reach their full potential. Once more echoing the views of mothers above, the need to simply put something in place to ensure the young person was not left without anything reduced the ability to seek out something more creative and tailored to the individual:

> *If we know at 14 that someone wants something different then we can start to make that happen whereas if you only start at 17 or 18 there is not really much at that point you can change as you are just going down the same path as everyone else. (Peter)*

Thus, both the council and wider society were seen as hindering what young people could achieve as adults. Rather than being supported to build on their interests, develop individual goals and take risks, perhaps and do things slightly differently, young people were encouraged to travel down a well-trodden path:

> *I don't really see aspirations being raised. Some people might tell me I am wrong with that but I've not seen any evidence and I've not seen any evidence in the community of people doing different things, you just see people going in the same direction. (Peter)*

C. Young people.

Moving Towards Adulthood

‘Moving Towards Adulthood’ brings together three different aspects of adulthood that young people drew attention to, time moving forward, changing behaviour, and gaining employment. It highlights how young people were influenced by normative conceptions of adulthood and believed there were key milestones and changes in behaviour one must experience to be considered an adult. The three components of this subtheme are addressed in turn below.

Time moving forward

Becoming an adult was closely associated with chronological age and the subsequent gaining of age-related rights. The prospect of ageing was welcomed as young people enjoyed the rights they were afforded as they grew older. Gary, for example, had proudly taken a photograph of his birthday card and agreed with his mother when, looking at the photo, she explained it meant he was grown up:

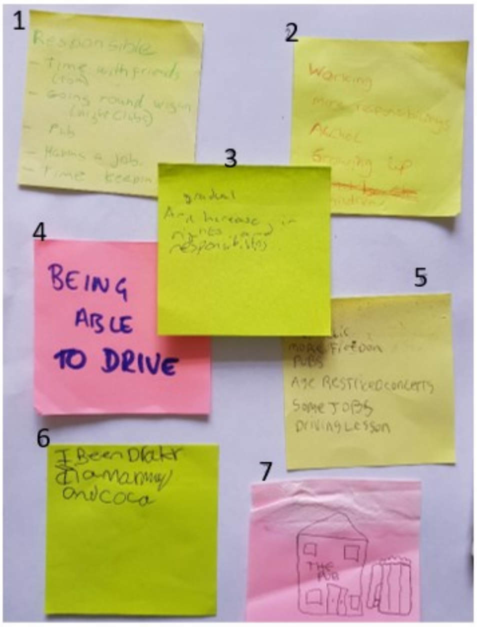
> *Mother: What's the next photo? 21 this year, so you had a party, didn't you, and that means you are all grown up or growing up.*
> *Gary: Yeah.*

Another participant meanwhile explained how she felt good growing up and, amongst other things, associated it with being able to have a drink:

> *Researcher: What does adulthood mean?*
> *Speak-out member: Growing up, being responsible, having a drink of Tia Maria and cola.*
> *Researcher: And you have written ‘I feel good’?*
> *Speak-out member: Yeah.*
> *Researcher: What do you feel good about?*
> *Speak-out member: Being growing up, being a young woman, being a lady. Not being a little girl anymore.*

Figure 13 shows that attending nightclubs and age-restricted concerts, learning to drive, and voting were all listed as markers of adulthood and things one could do as one grew older. However, it was being able to buy and drink alcohol and go to pubs that held the most meaning for young people. It was accessible and enjoyable for all participants, and thus an easy demonstration of adult status. Indeed, whilst one young person, Sam, who used the adapted Talking Mat in his interview, placed the picture of voting under the unhappy face on the table as he did not know what it meant, he placed the picture of the pub under the happy face as he enjoyed going there with his parents.

Figure 13: Focus group post-it notes demonstrating age-related markers of adulthood



Post-it notes transcription (age-related sections in bold):

1. *Responsible; time with friends;* ***going round nightclubs; pub****; having a job; time keeping.*
2. *Working; more responsibility;* ***alcohol****; children*
3. ***A gradual increase in rights*** *and responsibilities*
4. ***Being able to drive.***
5. *More freedom;* ***pubs; age-restricted concerts; some jobs; driving lessons***
6. ***I been drinking Tia Maria and Cola***
7. ***The pub***

For one young person, the pub was a symbol of the freedom and independence that they associated with adulthood. They explained how they were frustrated at still having to be at home with their mum and wished instead to be at the pub:

> *I don't like being at home when my mum is at home. I don't like it so much. My mum I just do not like in being in the house on my own. I just want to go to the pub up the road. (Ace member)*

For Michael, meanwhile, being able to buy alcohol and go to the pub demonstrated his adult status and it was one way he could exercise choice and control over his life. Michael spoke with a sense of pride when he mentioned he was able to drink. He enjoyed being able to buy a bottle of vodka when he did his food shop, as well as going to the pub for a drink with his dad. However, this was also a cause of conflict between Michael and his mother as his mother worried he sometimes drunk too much. As a result, she had decided to limit where and when he could drink. Michael felt this was unfair and drew on his age to assert himself and support his argument:

> *Mother: It's hard to know, isn't it with vodka how much is too much, and I've just said to him you do not drink in your flat. You can have a drink if you go out, we know how much you are getting then as there is someone with you…You had too much to drink, and you weren't well with it, so I'm afraid that's my rule now, and I've just told them, and you expect that now don't you?*
> *Michael: I do. I don't agree with Frances.*
> *Mother: The other thing which happened was, because he had a drink here, one of the other residents kept calling around and drinking it with him.*
> *Michael: I don't agree, I don't agree.*
> *Mother: It's great he has his play-station, he has two controls they can have a drink and play a game and [cut off by Michael].*
> *Michael: I don't agree with Frances. Not now, but I am 18.*

Mirroring elements of the sub-theme 'Letting Go and Enabling Adulthood', Michael's mother acted as a gatekeeper despite his age. She balanced his wellbeing with his autonomy and ultimately remained in control of how much freedom her son had. It was a similar situation for Sam, who, as mentioned earlier, also enjoyed going to the pub:

> *Mother: The pub? Oh my god, the pub. What happens in the pub?*
> *Sam: Drink.*
> *Mother: And what do you have?*
> *Sam: One beer.*
> *Mother: No one [cut off by Sam].*
> *Sam: Larger.*
> *Mother: No one lemon [cut off by Sam].*
> *Sam: One lemon cider.*
> *Mother: No one lemonade! Sam doesn't drink because of the choice we have made...Sam has a lot of anti-epileptic drugs, but he has lemonade, and Sam can drink all the lemonade.*

Like Michael's mother, Sam's mother was also balancing his wellbeing with his autonomy and had, in this instance, decided that the need to protect his health was more important than his freedom to choose an alcoholic drink.

Alongside enjoying some of the tangible benefits growing older brought, there was, however, also a sense of apprehension attached to the prospect of ageing as one focus group member explained:

> *You Can member: She brings it up a lot […] me being 18 in two days. She has scared me a little bit because for the last month or so, every time I check, it's significantly closer. Last month it was a month to go, obviously, but it didn't feel like it, but then I checked what seemed like the next day, and it was two weeks away, and the day after that, it was two days away.*
> *Researcher: So, is turning 18 a big deal?*
> *You Can member: It's just [pause] it has sort of given me a perspective on how fast time moves really, as it is a date I am looking up to but also at the same time scared of it happening. It's weird.*

This young person felt time was passing too fast and turning 18 was a reminder of the changes they would encounter. They were daunted by exams at the end of college and felt increased pressure from their mother to take more responsibility at home due to their age. Thus, they expressed a desire to remain as they were:

> *In an ideal world, every day would be the same and I don't want where I am now to ever end […] also thoughts of getting good enough results in exams and things like that and also just getting you know a little bit more responsibility at home as well. Like already my mum is getting me to do everything. She is saying 'you are nearly 18 so you need to do this and this and this'.*

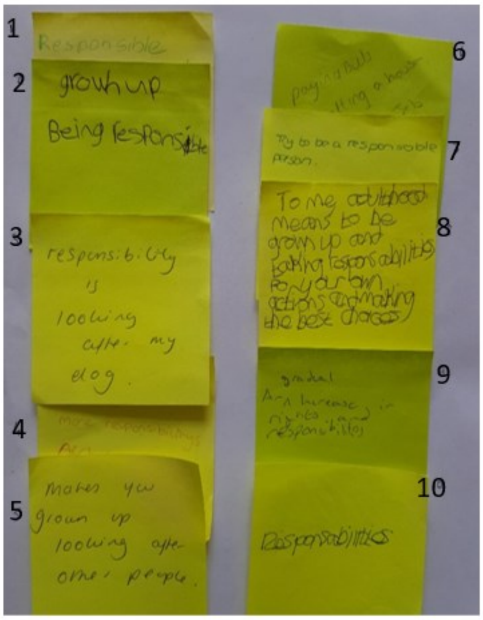
Stewart expressed similar feelings. He, too, did not like change and therefore growing older was troublesome as he believed changes linked to his parents' age were inevitable:

> *Stewart: My dad wants to retire in a year, and he wants to move away, maybe abroad. But my mum still has to work so wherever they move to my mum still has to work. And then you have like what do I do?*
> *Researcher: What would you like to do?*
> *Stewart: I don't know. I don't like change. Change is a big thing for me, but they say it should be your best friend. Everything is always changing. That's what they say, though, isn't it – everything's always changing; nothing stays the same. But a lot of people like stuff to stay the same.*

Changing behaviour

In addition to the markers of adulthood evoked above, adulthood also included a change in behaviour for all participants. Adults acted differently to children, "*when you are a child you can have more fun and when you are an adult you can't"* (Ace member). As shown in **Figure 14** below, young people believed that they must gain responsibility and independence as they become adults. When young people expanded on what responsibility meant, responses were two-fold and included looking after oneself and others and a need to act responsibly or sensibly. Post-it note 8, for example, in **Figure 14** states, *"to me adulthood means to be grown up and taking responsibility for your own actions and making the best choices".* For this young person, whilst adulthood was about taking responsibility for themselves and not relying on others, it was also about making the "*best*" choices. In other words, whilst they gained autonomy, they had to be sensible in their choices. Other examples from the focus groups of behaviour changing in relation to being sensible related to paying bills and timekeeping, *"pay bills as an adult, pay your phone bill" and "you are always on time and never late. Like I'm more responsible now".*

Figure 14 Focus group post-it notes demonstrating adulthood as responsibility



Post-it notes transcription:

1. *Responsible*
2. *Grown up; being responsible*
3. *Responsibility is looking after my dog*
4. *More responsibility*
5. *Makes you grown up looking after other people*
6. *Paying bills*
7. *Try to be a responsible person*
8. *To me adulthood means to be grown up and taking responsibility for your own actions and making the best choices.*
9. *A gradual increase in rights and responsibilities*
10. *Responsibilities*

Being responsible also involved a shift in dynamics and a movement from being the recipient of care to the giver of care. For example, in the post-it notes in **Figure 14**, one person had support to write, *"responsibility is looking after my dog"* and another, *"makes you grown up looking after other people."* The shift in dynamics was also reiterated in the discussions which accompanied the post-it notes with one young person commenting that adulthood was *"being responsible, spending time with my friends and spending time with my nieces basically me looking after them"* and another *"I think it means being grown up so looking after others not just myself."*

The second element to the behaviour change associated with adulthood is related to independence, as the following participant indicated:

> *Obviously when you are older, in your 30s you aren't going 'right let's get you some education' obviously it is more about life skills and being independent and stuff like that.* (Speak-out member)

What independence looked like was varied and relative to the individual participants. However, it included 'independence skills' (participants taking part in everyday tasks), a greater sense of freedom as participants spent an increased amount of time apart from family, and autonomy (i.e., the ability to make one's own decisions).

As with Sam and Michael's experience with alcohol detailed in the previous section, and mirroring interviews with mothers, other people were shown to shape young people's experiences of independence and enable or hinder its development. However, alongside other people, objects were also shown to play a role. As shown in **Figure 15** and F**igure 16**, Gary took photographs of his mobile phone and items in his kitchen.

Figure 16 Gary's photo of his mobile phone

Figure 15 Gary's photo of items in the kitchen

When looking at the photo in **Figure 16**, Gary explained how he would *"butter toast and sugar in the tea. Stir it."* Whilst he and his mother explained the phone in **Figure 15** enabled Gary to stay in touch with his parents, and thus, he was more confident at spending time apart from them. When discussing the photos, Gary spoke with a sense of pride and achievement that he could now do these things, suggesting an entanglement between the objects and the development of independence and between the objects and Gary's self-esteem and adult identity.

Figure 17 Stewart's belongings

Similarly, as shown in **Figure 17** to the left, Stewart had taken photos of various possessions. This included his alarm clock, shoes, bag and shower gel. He explained that the alarm clock helped him wake up on his own and be on time places, whilst the other items made him look presentable. For Stewart, looking presentable was important as he grew older. It signified taking responsibility for himself, but he also felt others would take him more seriously, as the following extracts demonstrate:

> *Stewart: My bag is important to me. Fashion [….] shoes. I have to look smart for volunteering.*
> *Researcher: Do they tell you how to dress, or is that you?*
> *Stewart: Personal preference. I want to look smart.*
> *Researcher: Why is that?*
> *Stewart: I want to impress.*

> *Stewart: My alarm clock is important to me to wake me up on time. Being clean and fashion here.*
> *Researcher: So, being clean kind of goes with fashion?*
> *Stewart: Yeah, presentable sort of stuff. Presentable because I want a girlfriend.*

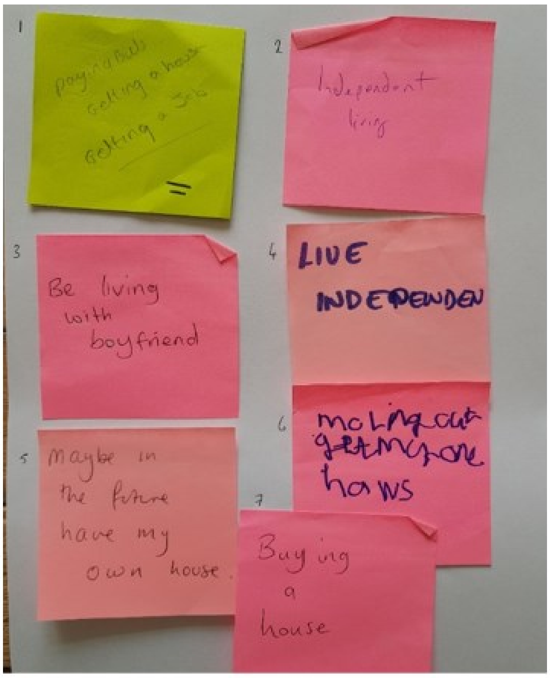
Elsewhere participants reported how family members supported them to develop their independence, as in the example of the young person below where their mum and grandma encouraged them to go into the shop on their own:

> *I was with my mum and grandma they gave me £3. My brothers were in the back of the car but my grandma said, 'go on your own, if you can't reach the food just ask someone' and I did that. I went and reach it and pay with my own money. I*

> *come back and my grandma says, 'see that's not hard is it?' It's being more independent. (You Can member)*

When it came to moving out of home, however, young people were conflicted. As shown in **Figure 18** below, it was considered a part of adulthood and therefore was assumed to be something they would eventually achieve.

Figure 18 Focus group post-it notes focusing on moving out of home



Post-it notes transcription:

1. *Paying bills;* ***getting a house;*** *getting a job*
2. *Independent living*
3. *Be living with boyfriend*
4. *Live independent*
5. *Maybe in the future have my own house*
6. *Moving out get my own house*
7. *Buying a house*

However, in contrast, people were apprehensive. They were unsure about how or when it could happen and what form it would take, suggesting a disconnect between normative models of adulthood young people were influenced by and their current situations. Eve, for example, said she *"would like one day to live on my own"* but later in the interview stated she would like to stay living with her mum:

> *I would like to live with my mum forever […] I wouldn't want to live on my own. It wouldn't be the same. I would like to live with my mum though. I would find it very hard to if I lived on my own […] I wouldn't know what to do.*

Another young person meanwhile stated, *“I want to live independently”* but when asked to expand on this, he responded, *"I don't know yet",* and was unable to visualise anything further. Similarly, a third young person explained that they were unsure about it despite aspiring to live apart from their parents. They were concerned they were not yet ready for it and were unsure how it might look:

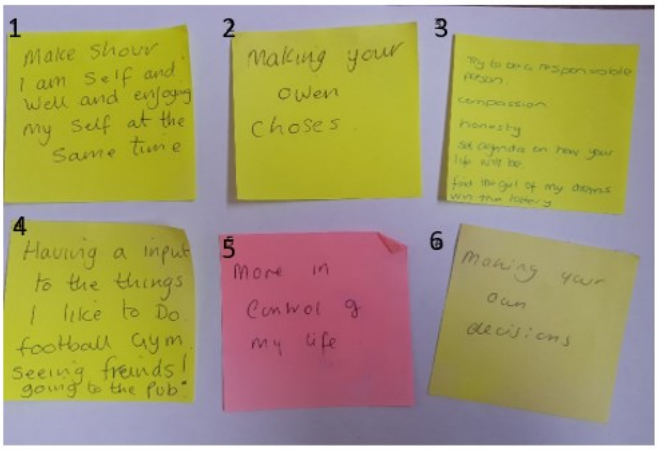
> *I don’t want to stay with my mum and dad […] I don’t know maybe by myself. In the future it was yeah, not right now, but definitely in the future. I’m in the process of moving out but I’m not ready for it yet […] I’m just not ready for it yet. (ACE member)*

In contrast to these three young people, was the participant who drew on social care terminology and wrote, *"independent living"* on post-it note 2 in **Figure 18** when discussing adulthood. This suggests this young person had an awareness of the different models of support and housing available. It also highlights a gap in knowledge between different young people and their understandings of what moving out of the family home would entail and what support could be available.

Although moving out of the family home was a desire for many participants and a key element of their conceptualisations of adult life, it was not for everyone. Sam, when looking at a picture of ‘home,’ said he was “happy.” He placed the picture under the happy face on the table and indicated that he would like to stay “with mum and dad”.

Figure 19 shows a final behaviour change young people considered important as they became adults and gained independence related to autonomy: making decisions for themselves and having greater control over their lives. The areas in which autonomy was exercised, were again, relative to their individual contexts. For example, whilst Stewart said that independence meant “being in control of your own life […] having the life you want”, the example he gave to accompany this was *“not being told or pushed into things, like stay up late”.* In another case, a member of the Ace focus group explained that now they were an adult and had left college their support was *“more flexible and working around me”.* A supporter in the focus group reiterated this point by stating, *“you are definitely more relaxed and happy then when you were in school and college. You feel more in control of your life”.*

Figure 19 Focus group post-it notes demonstrating decision making and control



1 Make shour I am self and well and enjoying my self at the same time

2 Making your owen choses

3 Try to be a responsible person. compassion honesty set agenda on how your life will be find the girl of my dreams win the lottery

4 Having a input to the things I like to Do football gym seeing freinds! going to the pub"

5 More in control of my life

6 Making your own decisions

Post-it notes transcription:

1. *Make sure I am safe and well and enjoy myself at the same time*
2. *Making your own choices*
3. *Try to be a responsible person; compassion; honesty;* ***set agenda on how your life will be****; find the girl of my dreams; win the lottery.*
4. *Having an input to the things I like to do. Football, gym, seeing friends! Going to the pub*
5. *More in control of my life*
6. *Making your own decisions*

An increase in autonomy was central to Michael's adult identity as he explained that now that he was 18, he no longer had to agree with his mother. He gave several examples, such as the one below, throughout the interview where he would assert himself despite his parents disagreeing. The repetition of the *"my choice"* highlights just how important this was to him:

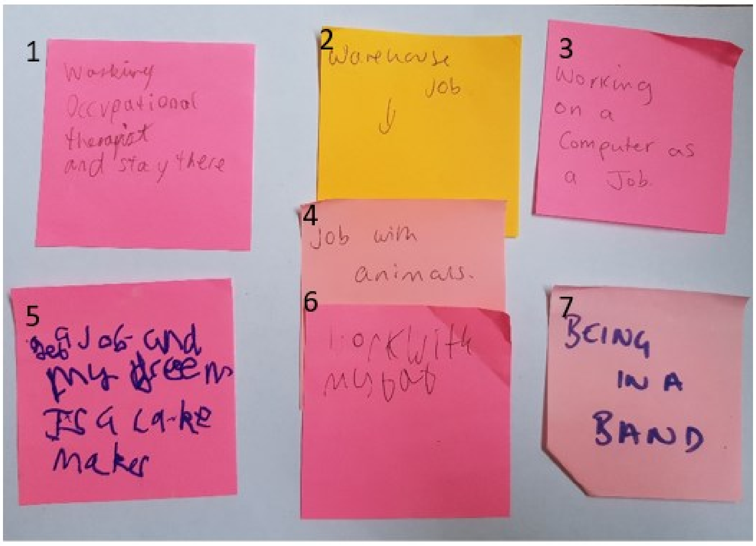
> *Dad don't like me painting my nails. That's my choice though. I painted my nails at youth club like Michael Jackson – my choice. Dad don't agree with it. I told him it's my choice.*

Gaining employment

The third component of adulthood for young people in this study, alongside chronological age and behaviour changes, centred on work, the importance of which was implied both implicitly and explicitly. When discussing adulthood, many participants referred to "*working*" or *"getting a job".* When one participant was asked if anything had changed for them since they became an adult, they replied, *"I started doing a supported internship".* Similarly, Michael spoke about how, rather than attending a drama group as a participant, he now volunteered as he was now an adult, *"I help, I'm an adult."* Furthermore, as shown in **Figure 20** below, when discussing what young people would like their future to look like, most responses included work. Gary, for example, who, as mentioned previously (see page 184) had taken numerous pictures of planes, explained he wanted to work *"in the pub behind the bar"* at the airport whilst

Sam said he wanted to help with security at a local festival and acted out how he would stand with his hands on his hips to look for any “*naughtiness*”.

Figure 20 Focus group post-it notes demonstrating work-related aspirations



Post-it notes transcription:

1. *Working occupational therapist and stay there*
2. *Warehouse job*
3. *Working on a computer as a job*
4. *Job with animals*
5. *Get a job, and my dream is a cake maker*
6. *Work with my dad*
7. *Being in a band*

Whilst work was embedded in young people’s visions of the future, demonstrating how central it was to understandings of adulthood, it was also considered important due to the latent benefits it brought. Namely, it was a way to meet people and something to fill time. For example, Gary wanted to work in the airport pub as he enjoyed seeing the planes, and it would mean he could *“chat to girls*” whilst in Michael's interview, his mother, Frances, explained that Michael liked working as he enjoyed *“seeing people […] and feeling appreciated”.* On the other hand, Eve wanted “*to do a little job like voluntary work to get me out and about",* and Stewart had a foot in both camps when he explained he liked work *“for the sociable aspect, it got me out and stuff*”.

However, whilst young people envisaged working in the future, most participants were unsure about this would become a reality. Young people did not know how they would get support to get a job or onto a supported employment scheme. Everyone in one focus group responded "*no”* when a supporter asked if anyone knew anything about supported employment. In another focus group, one young person who wanted to work as a police officer or a firefighter explained that, despite having this ambition, he had not been supported to work towards it or explore associated options. When asked if he had spoken about it with the college staff, he replied, *"I told some people yeah […] they didn't say anything about it",* and when asked what he had studied at college, his response was:

> *I can't remember now. Just some random course […] if I had known about a public service course, I would have gone on that.*

Like moving out of the family home, there was a disconnect between the normative discourses of adulthood that shaped and influenced young people's expectations of adulthood and their visions of their future and their current situation. Despite viewing work as the next step after college and central to adult life, a lack of practical support and information prevented young people from knowing how they would achieve this. This is summed up by one young person who, despite wanting work, stated, *"we don't know what we are doing after education" (You Can member).*

There were two notable exceptions in relation to young people being supported to pursue their desired careers, both of which have been mentioned previously. One young person in the Speak-Out focus group who liked animals was being supported by his mum to try and build a dog walking business whilst Gary's mum, who was supporting him in his interview, explained how they were trying to make his dream of working at the airport a reality by enrolling him on to a part-time further education course which would help prepare him for a possible internship at the airport.

Disability and Difference

Young people expressed a belief that they were different to their peers and felt restricted by their disability. They reported struggling to fit in with their non-disabled peers and experienced difficulties reaching some of the markers of adulthood presented within 'Moving Towards Adulthood'. Disability was internalised, and rather than view the problem as lying with disablist attitudes within society and ableist conceptions of adulthood, young people believed they were part of the problem. For example, Eve believed her life was *"different to everyone else"* and, when asked why said, *"I'm quite far behind my age".* Despite expressing a desire to live alone, she believed she could not do so as she could not do things for herself:

> *To be honest I would be a bit scared to live on my own as I wouldn't know what to do. I can't cook, I can't really use the oven – that's something I would be scared of*.

Similarly, Stewart explained that he compared himself to others which made him realise what he was missing out on, stating, *"I just look at other people who do it, like do jobs and go to the gym and stuff and it's a big thing".* Whilst Stewart acknowledged people with learning disabilities were often treated differently to their peers, which limited what they could achieve, *"just being disabled people stigmatised a lot, oh just stick, just let him go to college",* he also expressed a desire to change himself to fit in with those around and to stand a better chance at achieving his goals:

> *See I'm always looking inwards me because I want to change. I don't fit in so I want to change so I can get a girlfriend, try and get a job. I don't know if the problem is me but at least I'm willing to try. If there is a problem, well if people tell me, I'm willing to change. I'm not stubborn.*

In another instance, a young person attributed the reason they would find it difficult to get a job to their communication when they stated:

> *Because of the way I am, because of the way my speech and language is I will struggle getting a job. (You Can member)*

Whilst another stated they *"hadn't got the confidence"* to begin a work experience programme *"because of the way things are at the minute".* Despite feeling grown-up, they believed they would struggle due to their needs and consequently were reluctant to take up a possible opportunity:

> *Well, they said in year 13 maybe. Because of the way I am so grown up and looking to the future and I am so grown up about it, maybe year 13. But at the minute, the way my needs are and everything it's not worth trying. (You Can member)*

Thus, except for Stewart, who mentioned stigmatisation disabled people faced, rather than considering wider society to be at fault due to a lack of support or suitable opportunities, the young people above considered it was 'the way they were' which held them back, preventing them from getting work or moving out of the family home.

Chapter Ten summary

	This theme tells you what participants thought about young people becoming adults.

Mothers

	Some mothers found it difficult to think about their children being adults. This is because their children still needed a lot of support.
	Mothers wanted their children to be more independent, but they also wanted to keep them safe.
  	Mothers wanted their children to work but lots of things stopped this from happening. This included: • Companies not employing people with learning disabilities.

	- Professionals not doing enough to help young people.
	Mothers worried about their children’s futures. They worried their children would be stuck at home not doing anything.

Professionals

 	Professionals believed young people were adults when they turned 18. Professionals said sometimes it was difficult explaining this to parents.

  	Professionals thought lots of things stopped young people being independent and getting jobs. This included: • People not employing people with learning disabilities. • Professionals not doing enough to help young people.

Young people

    	Young people thought three different things made you an adult. These included: • Turning 18 and being able to do things like drink alcohol and vote. • Acting differently to children (becoming more independent, being sensible and responsible)

	• Getting a job
 	Some young people thought their disability made them different to other people They thought their disability stopped them from doing things like getting a job or moving out of home.

Part Three

Chapter Eleven: Multidimensional, Interconnected, Turbulent Transition

Transition to adulthood is a highly challenging and emotionally turbulent time, characterised by change and uncertainty. Bringing the three stakeholder groups together demonstrates the complexity of transition as all three groups approach transition from a different standpoint, and consequently, differing priorities are evident within the themes. Maintaining a focus on the transition binary, whereby transition is explained as a move between services and a move to adulthood, over-simplifies transition and obscures the nature of recent experiences, which are, instead, an entangled web of constantly mutating connections between many different elements. This chapter, the first of the two discussion chapters, opens by drawing attention to an issue encountered during the analysis stage of the research. Although an unconventional start as this issue is related to the research design rather than transition itself, understanding the problem and how it was addressed provides context to the discussion chapters and enhances the overall transparency of the research. Following this, the findings are drawn on to highlight three salient aspects of transition: transition as multidimensional, transition as interconnected and transition as a period of turbulence. These three aspects of transition provide the rationale for then drawing on Deleuze and Guattari’s (2004) notion of assemblage to present an alternative view of transition, that of the transition assemblage which is introduced in the concluding section, ‘Towards the transition assemblage’, and expanded upon in Chapter Twelve.

The shaping of the analysis

As discussed in Chapter Four, thematic analysis is a creative endeavour. Themes are constructed through an intricate interplay between the research participants, the data, and the researcher’s subjectivities and positionality (Braun and Clarke, 2019a; Braun et al., 2019). Therefore, knowledge construction is imbued with power hierarchies, not least the interpretation, analysis and presentation stages of research which often takes place away from the participants (Mullings, 1999; Doucet and Mauthner, 2007). Despite a desire to construct the themes with more involvement from participants, this was not the case.[16] Thus, as Chapter Two highlights, a reflexive and transparent approach to knowledge construction is vital if “accountable and responsible knowing” (Doucet and Mauthner, 2007: 7) is achieved. Drawing attention to a challenge encountered during the analysis stage of the research and exposing some of the ‘workings out’ that lead to the development of the subsequent discussion chapters is part of this process. Highlighting where decisions made have affected knowledge construction aids understanding of the construction of the themes, the subsequent creation of the transition assemblage and contributes to the overall transparency and rigour of the thesis.

This research aimed to develop understandings of transition based on the experiences of three key stakeholder groups. Therefore, the analysis process is central to this endeavour as it is the process that brings the three groups together. Although it is acknowledged that analysis is a continuous and iterative process (Rice and Ezzy, 2000; Watt, 2007; Braun et al., 2019), it is within the main analysis stage that the interviews are reduced to data, fragmented and categorised before being reconstructed to tell a collective story, the story the researcher chooses to tell. Alvesson and Sköldberg (2018: 12) sum this up when they state:

> The research process constitutes a (re)construction of the social reality in which researchers both interact with the agents researched and, actively interpreting, continually create images for themselves and for others: images which selectively highlight certain claims as to how conditions and processes – experiences, situations, relations – can be understood, thus suppressing alternative interpretations.

How the three groups came together within this stage, how their stories were broken apart and reconstructed together thus has implications for the subsequent story that is told.

The steps taken during the analysis are presented within **Figure 4** (page 103), which emphasises the iterative and reflexive approach taken. However, **Figure 4** fails to capture the ‘mess’ between steps three and four; in other words, what happened

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[16] Chapter Thirteen explains how a period of maternity leave followed by coronavirus restrictions and time limitations meant it was impossible to return to participants following the initial data collection.

between ‘generating initial codes’ and ‘constructing tentative themes’ to lead to the groups being brought together within themes whilst separated via subthemes as shown in **Figure 5** (page 140). To emphasise the active role the researcher plays within the analysis and during the creation and resolving of the ‘mess’ identified below, the next part of this section is written in the first person.

I approached the thematic analysis mindful that I was undertaking one piece of research, not three separate studies. I was keen to bring participants together to see how areas of convergence and divergence could aid understandings of transition. As a result, once the individual interviews had been broken down into codes, I attempted to piece together the themes whilst merging the groups into one dataset. I believed this would prevent me from ending up with multiple disconnected themes.[17] Additionally, I naïvely thought that blurring the distinctions between the groups would demonstrate a sense of equity between participants and make a statement about erasing traditional hierarchies between ‘professionals’, ‘service-users’ and ‘mums.’ Instead, I found myself creating chaotic, messy themes and simultaneously reproducing the power imbalances I was keen to avoid.

Trying to do justice to all three groups whilst treating the data as one dataset proved challenging. The interviews with mothers and professionals were lengthy as they spoke in-depth on many topics. Thus, the quantity of data yielded from their interviews was greater than that from the interviews and focus groups with young people, and I found myself drawing on this data to shape a theme or illustrate a point. On the surface, a quote from a mother or professional succinctly conveyed more than the exchanges with young people where responses were often monosyllabic and required much probing to unpick meaning. As a result, the themes that I was developing were imbalanced. They did not prioritise the voices of young people which, as a result, were in danger of being lost. If I was to continue in this manner, any discussion born out of the themes and corresponding ‘knowledge constructed’ would be driven by the concerns of mothers and professionals, thus recreating the silences and boundaries that, as researchers, we should pay attention to and work to avoid (Ackerly and True, 2008). Harding and

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[17] Although there are no set criteria for the ideal number of themes in thematic analysis, Braun and Clarke (2019b) recommend between two and six themes for a single journal article, an undergraduate or Masters dissertation or a single analytic chapter in a doctoral thesis.

Norberg (2005: 2012) warn that “research processes themselves [re]produce power differences”. Similarly, my analysis was bearing stark similarities to the ‘real world’ where young people’s plans are often driven by the concerns of those around them (Leonard et al., 2016; Hunter et al., 2020), the views of professionals and family shaping the transition agenda (Kaehne and Beyer, 2009) and where person-centred planning is in danger of being a paper exercise reflecting a “paternalistic steering process” from service staff (Claes et al., 2010: 448). Indeed, as is included on page 203 of Chapter Ten, somewhat ironically, one participant drew attention to the silencing of young people with learning disabilities when they stated:

> *If they [a non-disabled person] were told ‘right your mum now is going to make every decision for the rest of your life they are going to tell you what to do, oh you are not marrying him, you have to do this’ there would be uproar.*

Furthermore, and unsurprisingly given the different standpoints of participants, areas of tension and conflict between the groups was evident. The areas of divergence that I was keen to explore rendered the themes messy and incoherent. Central to Braun and Clarke’s (2006) conceptualisation of themes is a central organising concept (i.e., an area of shared meaning). Domain summaries, meanwhile, are the label they assign to pseudo-themes where the 'theme' collates everything participants said on a topic but fails to capture a sense of shared meaning. However, the themes I was producing were more akin to domain summaries than themes, and thus trying to unite the groups within the themes was counterproductive.

Therefore, driven by both an ethical responsibility and the need to demonstrate academic competence, it was clear that the approach I was taking towards the analysis had to change. Different ways of drawing attention to young people within the themes were explored. However, due to the irresolvable tensions across groups, the data was ultimately separated back out into the three stakeholder groups. Tentative themes were then constructed within the individual groups rather than across them and, concurrently attention was paid to areas of shared meaning across the groups. As a result, the tentative themes became subthemes, brought together within three main themes to capture the overall area of shared meaning. Therefore, whilst the three main themes draw attention to a general area of convergence, the subthemes show how meaning and priorities within this diverged across the groups. The group identities remain, and the voices of mothers and professionals do not engulf the voices of young people.

Transition as multidimensional

Bringing the three participant groups together in one study shows transition to be multidimensional, as there are many different parts to transition, for example, different events, people and experiences. As starkly displayed in Chapter Seven a singular definition of transition, or period to which all participants ascribed, fails to exist. Therefore, alongside adult services assuming responsibility for the young person and the young person growing up and becoming an adult, an important, but under-emphasised, aspect of transition within services is the end of full-time college.

Hudson (2006) draws attention to two transitions that occur, labelling them the visible and invisible transition. Whilst the visible transition occurs between the ages of 18 or 19 as the young person moves between school and college, the invisible transition occurs a few years later when the young person moves from college to a post-college destination. It is labelled invisible due to the lack of law or guidance surrounding this transition and informing what happens. Although written in 2006, the division of transition into a visible and invisible transition holds resonance for the findings of this study.

The findings demonstrate professionals were predominately concerned with the visible transition. Although this is not necessarily the transition between school and college as in Hudson's study, it is the 'legal' transition that was the focus (where adult social services assume responsibility for the young person due to their chronological age). As a result, a short-term view of transition was apparent, whereby adult social care professionals aimed to cease their involvement as soon as possible after the transfer to adult services. Subsequently, they were no longer involved when young people and mothers believed they fully entered transition (i.e., the end of college). Health transitions can also be seen as being encompassed within the visible transition. Like social care, the health transition relates to a movement between specific services and the assuming of responsibility by adult health services, as one of the young people drew attention to in Chapter Seven (page 145). However, whilst this transition was not relevant to everyone, despite being part of the visible transition, it was also imbued with difficulties as Anne's experiences (page 164) and the literature review demonstrate

(Davies et al., 2011; Foley et al., 2012; Barron et al., 2013; CQC, 2014; Trachtenberg, 2016). The focus of the visible transition is not necessarily on supporting with transition to adulthood, but rather simply the transition between services. As one participant explained (page 145), far from enabling her to have a positive start to adulthood, the transition to adult health services was detrimental to her mental health as support suddenly stopped.

As transition services are time-limited they are no longer in place when the young person seeks to attain aspects of adult status (Beresford, 2004). For the young people and mothers in this study, this was following the end of full-time college. As a result, the transition at the end of college can be considered the invisible transition. The end of college was the pivotal event that marked the beginning of a difficult time for mothers as they tried to establish a life for their children without full-time education. Meanwhile, for young people, the end of college signified a significant step on the path to adulthood. The labelling of this transition as invisible is apt; despite growth in policy and guidance meant to incorporate this transition,[18] a lack of planning, information and opportunities continues to persist for both participants within this study and elsewhere (Abbott and Heslop, 2009; Small et al., 2013; Biswas et al., 2017; Gauthier-Boudreault et al., 2017; Jacobs et al., 2021). This leaves parents feeling abandoned with a lack of clarity surrounding how young people would meet their aspirations and achieve some of the markers of adulthood they deemed important such as getting a job and moving out of the family home.

The difference between the visible and invisible transitions, and thus the multidimensional aspect of transition, threads throughout the themes. For example, theme one (Chapter Eight) captures the difficulties mothers encountered and the lack of support following college. Meanwhile, theme three (Chapter Ten) demonstrates the focus young people had on the association between transition and changes encountered when becoming an adult, including behavioural changes and employment alongside legal changes. However, professionals within theme three were primarily concerned with the legal distinctions between childhood and adulthood, evoking the 2005 Mental

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[18] As explained within Chapter Three, EHCPs, introduced via the Children and Families Act (2014), are meant to focus on ‘preparing for adulthood’ across the four domains of employment, independence, community involvement and health (DfE, 2015).

Capacity Act and the right to make decisions that others may consider unwise (SCIE, 2020). This ties in with Murphy et al.'s (2011) study discussed within the literature review, whereby professionals positioned young people unequivocally as adults. Within Murphy et al.'s (2011) study, any erosion of young people's right to self-determination was morally questionable, and the nuances of adulthood encountered by mothers when their child's support needs failed to change in line with their chronological age and status (as was the case for mothers within this study) were largely ignored.

In order to capture the multidimensional aspects of transition, other reports have described transition as 'layered' (Jindal-Snape, 2016; Johnston et al., 2016; The ALLIANCE, 2017), referring to the other health, social, psychological and relational strands of change which also occur in peaks and troughs alongside and beyond any move between services. Whilst the findings support this, it is also important to highlight the multifarious elements which contributed to participants experiences of transition and the changes encountered. They too require attention when thinking about transition, as changing any of these elements can potentially improve, or worsen, individual experiences.

Exploring the components of transition presented within the previous four chapters reveals how support networks, finances (both participants' own and social care budgets), opportunities, relationships, people, objects, information, policies, and normative discourses are all elements, which were drawn upon when young people, mothers and professionals discuss transition. Transition is, therefore, more than just a process or an event. The interaction between these elements creates current experiences of transition, and it is this which is the focus of the next section, which explores the elements and their relations in more depth.

Transition as interconnected

The findings demonstrate that relationships with other people are a key element within transition. These relationships threaded through each theme and form the foundations for viewing transition as interconnected. However, the significance of connections during transition goes beyond interpersonal relationships. As explored below, connections between the array of elements detailed above are both present and active during transition and contribute to creating the current experiences of transition.

Perhaps the most significant connections during transition, for participants within this study, are the connections between mothers and young people. Transition is a significant time in young people's lives. What they do during the day changes as college ends, some friendships are lost, and relationships young people have with others can change. Furthermore, as is shown in theme three, young people also navigate a changing identity as they gain privileges, are encouraged to develop their independence, and take on more responsibilities. However, in keeping with other research (Blacher, 2001; Davies and Beamish, 2009; Biswas et al., 2017; Codd and Hewitt, 2020), this study shows that transition does not just affect young people as mothers were, heavily involved in their child's transition. Like Timmons et al. (2004), mothers can be considered linchpins, holding together the many elements of complex service systems encountered during transition. Both mothers and professionals within this study believed successful outcomes during transition depended on the parents' ability to advocate for their child. The policy section within Chapter Three highlights how parental views should be considered during transition. This study supports this as understanding the connections between mothers and young people and an appreciation for the central role mothers play needs to be incorporated into understandings and conceptualisations of transition. This is to ensure a comprehensive picture of transition is presented if any interventions, such as transition planning or strategies to improve transition, are to stand a chance of success (Gauthier-Boudreault et al., 2017; The ALLIANCE, 2017).

The entanglement of people during transition and prominence of relationships goes beyond mothers acting as linchpins. This is unsurprising given our capacity to be in relationships with others is central to conceptions of personhood: "being a person means having the capacity to be in certain relationships with other persons, to sustain contact with other persons, to shape one's own world and the world of others, and to have a life that another person can conceive of as an imaginative possibility for him- or herself" (Kittay, 2001: 568). However, what was significant was the extent to which other people shaped experiences of transition; how, in the words of Kittay (2001: 568) relationships with others "shape[d] one's own world and the world of others". How young people encountered adulthood is a prime example of this.

Growing older and becoming an adult was a central component in young people's conceptualisations of transition. However, other people are shown to enable and constrain the development of an adult identity (Morris, 2004; Midjo and Aune, 2018). A change in behaviour and increased responsibility and independence was viewed as one part of becoming an adult. However, this required interactions with other people, be it family members encouraging the young person to go to the shops alone, an expectation from parents of the young person becoming more involved in household chores, or the young person being provided with opportunities to care for others. For example, when discussing responsibility, one participant described looking after their nieces or nephews, whilst another young person discussed caring for their dog. In keeping with other research (Murray, 2002), personal assistants were looked upon favourably by young people as they enabled them to broaden their experiences and have more choice and control over how they spent their time. Emphasising the interconnectedness of transition based on experiences of adulthood as described above ties in with Slater's (2015: 63) assertion:

> Rather than think about youth-as-becoming-independent-adult, we should think about it as a time of dynamic and increasing relations of interdependency, within which autonomy is at times enabled and at other times denied.

However, the findings within this study concerning adulthood are also a reminder of the power other people can exert on people with learning disabilities. Being able to drink alcohol was a marker of adult status and something young people welcomed. However, one mother explained how her son was automatically allocated a child's wristband when on holiday, thus removing this privilege, demonstrating how, whilst adult status can be encouraged, it can also be restricted. It is also an example that highlights the ongoing infantilisation of people with disabilities (Robey et al., 2006). Similarly, gaining autonomy, making decisions for oneself, and having a greater sense of control over how they spent their time were viewed by young people as an important part of adulthood. However, the extent to which they could do this was also in the control of people around them. Consequently, parents are often positioned as oppressors over their disabled children (Ryan and Runswick-Cole, 2008). However, the findings highlight the difficult position mothers are in, constantly balancing enabling greater freedoms with risk management. Discussions with mothers revealed a concern that always prioritising values associated with adulthood, such as the freedom to make one's own choices, was short-sighted. The longer-term ramifications also had to be considered. For example, if a short-term approach was taken and all choices respected despite the negative impact choices might have on their health, it would affect what the young person could do in the future. This suggests a distinction can be made between short and long-term interests. Thus, decisions made based on respecting and protecting a person’s long-term autonomy could be justified even if it means impinging on self-determination in the short term (Horne, 1987; Preston-Shoot, 2001).

Jindal-Snape (2016) draws attention to connections between people during times of transition within their Multiple and Multidimensional Transition model. Comparing transition to a Rubik’s cube, they argue that significant others will also experience a change when one person goes through transition, although not necessarily the same one. Each colour of the Rubik’s cube denotes one individual and their interactions with others. Thus, if something relating to one individual changes, their colour on the Rubik’s cube moves and it produces a ripple effect across the whole cube, affecting the colours, or lives, of those around them. For example, transition affected mothers as, in the absence of help and support, they had to take on many planning tasks or risk their child ending up with nothing. This feat had a tremendous impact on their wellbeing. However, the ripple effect of transition extends beyond simply the taking on of practical tasks, for whilst young people were grappling with their changing identities, mothers too experienced change. As is suggested above, mothers had to renegotiate their role as a mother to an adult rather than a mother of a child, letting go to enable their child’s independence to develop whilst establishing new boundaries and levels of acceptable risk (Almack et al., 2009; Pownall et al., 2011). In contrast to parents of children without learning disabilities, caring responsibilities often increased as education no longer filled much of the young person’s week. As shown in other studies, it is at this point that mothers sometimes need to reduce their work hours if not give it up entirely (Davies and Beamish, 2009; Dyke et al., 2013; Jacobs et al., 2021).

As mentioned in the introductory paragraph to this section, connections that shaped or influenced experiences of transition extended beyond the immediate parent-child dynamic. As the subtheme ‘Life Goes On’ demonstrates, transition does not occur in a vacuum. All mothers within the study drew attention to factors outside of transition that affected their resilience to transition and the amount of energy and time they could funnel into supporting or advocating for their child. This, in turn, had a ripple effect on what the young person was able to do or achieve. This ties in with other research both in the UK and internationally. Scotland's Health and Social Care Alliance report (2017) draws attention to how the connections between young people and those close to them evolve. The needs of adult children can become more complex whilst the energies of their family carers, on whom they depend, may lessen as they have their own support needs, responsibilities, and losses to contend with, which impact their ability to provide care. Dyke et al. (2013) highlights the timing of transition, with the loss of informal support being a concern for parents. Thus, there is a need to consider the wider contexts and the networks within which young people and parents belong. The Health and Social Care Alliance Scotland (2017) states that professional definitions of transition to adult services and adult life are inadequate if they do not consider the evolving connections between individuals and those to whom they are closest.

Similarly, just as the wider contexts of mothers and young people need to be considered, so do the wider contexts professionals operate within. Professionals are not neutral, objective beings. They too are shaped by the elements and discourses around them. The roles they hold influence their values and beliefs, which in turn affects how they work. As Chapter Six highlights, one of the professionals, Alice, was also a mother of a disabled teenager and another, Peter, had a learning-disabled brother. This heavily shaped their approach. Alice was highly knowledgeable about children's and adult social care systems as she was motivated by a desire to ensure her daughter received appropriate support. As a result, she understood and was empathetic towards mothers' experiences whilst also aware of factors that shaped how other professionals acted, such as job precarity, as discussed on page 174-175.

Jacobs et al. (2021) found that the support available to professionals influenced the support they could provide to families. They explain how professionals appeared caught between supporting families and acting as gatekeepers of resources– limited in what they could offer and how they could act by the systems around them. This appears the case for professionals within this study. The definition of transition they were operating under was different to that of mothers and young people. Furthermore, despite an awareness of the discrepancies between the visible and invisible transition, and despite a desire for it to be different, they were unable to change the way they worked. Financial restrictions, heavy caseloads, and job precarity were all suggested as reasons for this. In addition, the mother-professional relationship was a particularly prominent connection for mothers within this study; mothers drew attention to how these relationships affected them emotionally and, in turn, shaped their behaviour.

The experiences of mothers within this study suggest that successfully navigating transition requires resilience. Resilience literature stresses how internal attributes and support networks, of which professionals are part, contribute to building resilience (Jindal-Snape, 2016). However, consistent with other evidence, both within research (Todd and Jones, 2003; Ryan and Quinlan, 2018) and elsewhere (Kowalski 2021; Nimmo 2019), epitomised in the 'Don't call me Mum campaign,[19] relationships with professionals were problematic. Encounters were often marred with conflict and liaising with service professionals placed considerable demand on mothers' time and energy. Whilst they struggled to get hold of the necessary person, they were also often overwhelmed by the number of professionals involved the lack of coordination between them and by repetitive and excessive paperwork (Schrag and Schrag, 2004; Ryan and Quinlan, 2018). These relationships were thus seen as a source of stress rather than support (Burke and Hodapp, 2014; Ryan and Quinlan, 2018) and mothers recalled multiple examples of problematic interactions which had left them feeling alone, angry, frustrated, disrespected and, at times, reduced to tears. Emotions were therefore very present within mothers' stories of transition. The emotions experienced were also affective as they generated action. Jasper (1998) suggests that emotions are central to social movements as they provide motivation and goal within social action. Beresford et al. (2008), meanwhile, draws attention to the role emotions play within decision making as the feelings people have about decisions, and expectations about feelings that may arise from particular decisions, guide the choices made. These arguments are corroborated within this study; for example, fear for their children's futures together with a sense of anger and injustice led mothers to fight back. For some, this was solely at an individual level as they advocated for their child, challenged decisions and tried to ensure their child had a decent life for when they were no longer around. However, for others, the advocacy extended beyond their immediate child as they were motivated by a desire to change how other families would experience transition. This ties in with Ryan and Runswick-Cole's (2009) notion of an internal activist continuum which encompasses

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[19] https://www.bornattherighttime.com/dont-call-me-mum/

the variety of advocacy behaviours assumed by mothers of children on the autism spectrum. They argue that mothers, motivated by their individual children, undertook a range of enhanced advocacy as they fought for their children, battled professionals, and lobbied their local MP – advocacy which is akin to a form of internal activism. However, whilst some mothers remain at this stage of advocacy, for others it is a precursor to broader, external activism where there is a shift from fighting for the individual to campaigning for change outside of the family, with some mothers moving backwards and forwards along the continuum depending on their circumstances.

Multifarious connections

In keeping with other research (Salt et al., 2019), young people had clear ideas about how they were meant to change and develop over time which, alongside particular milestones or privileges, contributed to the attainment of adult status. There were aspirations for work, to move out of the family home and an increase in independence and responsibility played a prominent role, something not dissimilar to typically developing young adults (Hendey and Pascall, 2002; Slater, 2015; Nelson and Luster, 2016; Salt et al., 2019). As is discussed within Chapter Three, young people with learning disabilities are exposed to the same normative, neoliberal images of adulthood as people without disabilities (Slater, 2015). Images, which Chapter Three highlights, also thread their way through the latest SEND reforms (Burch, 2018; Hodkinson and Burch, 2019). However, echoing the experiences of participants within Wilkinson et al.'s (2015) study where young people desired a 'normal' adult identity and felt constrained by their disabled status, despite participants within this study having 'the same aspirations as everyone else', some young people believed it was their impairments which were holding them back rather than a lack of suitable opportunities or support. Self-esteem and confidence suffered as a result which impacted what they did, thus whilst one young person expressed a desire to change, to fit in with their peers, another wanted to wait until their 'condition' had improved before they felt they were able to take up a new opportunity. This suggests the internalising of their oppression (Reeve, 2004) and a reflection of the continued dominance of the individual deficit model of disability within society and, in particular, within the education system (Oliver and Barnes, 2012) whereby the 'special education needs' language of current policy accentuates difference based on individual deficits (Runswick-Cole and Hodge, 2009).

Other connections present within the findings are more subtle. For example, how the connections young people had with particular objects shaped their becoming. As discussed in theme three (page 213), one young person took a photo of their mobile phone and explained how it meant they could do more by themselves as they could stay in touch with their parents. Another young person highlighted how they dressed (e.g. a bottle of shower gel and a pair of shoes) affected how they felt and how they believed others perceived them. Similarly, captured within theme one and the subtheme 'Aspirations Bounded by Reality' (theme three) are examples of how transport, finances, and where people lived affected what the young person could do and the ongoing success of any opportunities. Finances, meanwhile, and limited resources also impact how mothers felt they were perceived by local authorities and shaped how professionals within the study framed their views. Thus, a narrative of mothers having to manage their expectations surfaced within the accounts of professionals whilst mothers believed due to the budgetary constraints and pressures professionals were under, a divide existed between them and professionals affecting their relationships and subsequently their and young people's experiences of transition.

Turbulence

The third and final aspect of transition described within this chapter relates to change. Indeed, the word transition, by definition, refers to change (Oxford English Dictionary, 2020). Within the transition literature produced by services for families and young people, the notion of change is synonymous with a sense of forward motion and progression. I.e., a positive movement into adulthood whereby several steps are taken to support the young person in getting a job, living independently, participating within the community, and leading a healthy life (Preparing for Adulthood, no date). This is further emphasised by the imagery which often accompanies the transition literature produced by local authorities and third sector organisations as pathways and journeys are often drawn upon as advised in transition guidance (see **Table 1**, page 46). However, these images do not convey how much change and disruption occurs during transition and the difficulties this brings. Far from being an a clear path along which people travel, change is continuous, transition messy and a time of discontinuity and uncertainty as routines, services, finances, support networks, education provision, relationships all change, if not fall away altogether (Hudson, 2006; Jacobs et al., 2021).

Therefore, considering transition within a multidimensional and interconnected framework helps draw attention to the continuity of change as each element within transition is continuously affected by its multiple connections (other people - professionals, family members, personal assistants - as well as objects, budgets, and discourses). These connections continuously break and reconnect, shaped by the wider sphere within which each person or thing operates. Returning to the Rubik's cube imagery and we are reminded how, should one person or thing in their life change, there are ripple effects for others (Jindal-Snape, 2016). Jacobs et al. (2021) draw attention to the ripple effect when explaining how professionals often took on the role of advocate and facilitated a sense of belonging. However, these relationships were dependent on the wider service provision context they were operating within and thus vulnerable to changes in funding, recruitment, and restructuring, which placed the relationships at risk of being suddenly cut off and discontinued. These findings bear similarities to the experiences of participants within this study. Young people, for example, experienced the loss of friendships both with peers and support staff at the end of college, feeling lonely and isolated as a result. Mothers touched upon how professionals change during transition leading to confusion over whom the right person to contact is when help is required. This is a particular issue within health services, often resulting in the loss of knowledge about the young person’s medical history, fragmented care, and the need for mothers, and young people, to have to recount their histories multiple times (Ward et al., 2003; Foley et al., 2012).

In contrast to the pathway imagery, young people within this study did not always have something to move onto after college. Employment opportunities were scarce, as is well documented elsewhere (Beyer and Kaehne, 2008; Beyer et al., 2016; Hatton, 2016), and far from continually progressing into adulthood and a sense of moving forward, there was a fear from mothers that young people would lose skills they had learnt and take ‘a step back’ due to the lack of opportunities after college. When young people did have the opportunity to move onto something, it depended on several factors aligning such as having the right support and transport. Thus, opportunities often collapsed. This, alongside the time-limited nature of many opportunities and a dependence on funding from local authorities, meant stability was elusive and future uncertainty rife (Jacobs et al., 2021), with mothers believing decisions could, at any stage, be overturned and funding withdrawn thus causing further disruption to the young person and their family. The title of theme one, 'The Transition Minefield,' captures the numerous hurdles, the change and disruption encountered during transition and stands in stark contrast to the 'transition pathway' espoused elsewhere.

As discussed previously, whilst the young person experienced changes connected to their changing child-adult status, mothers also experienced change as they renegotiated their role as a parent of an adult child as well as moved up and down the internal activist continuum (Ryan and Runswick-Cole, 2009), sometimes taking on new 'activist' roles within the community. Like young people, their changing identity was a continuous, but not necessarily linear, process with no beginning or end. For example, whilst there was a sense that empowerment developed as mothers gained experience and knowledge and built support networks during transition, the notion of empowerment is imbued with a sense that power is given and thus can be taken away. Therefore, although mothers' knowledge of transition increased and they gained in confidence to challenge decisions, there was a sense that they could, at any time, encounter a different process, hurdle or system and not be equipped with the knowledge or information to traverse the issue, resulting in further experiences of powerlessness and disempowerment.

Static turbulence

Together, the multiple connections and elements within transition alongside the changes and lack of stability create an image of transition as a highly dynamic and disruptive period. Juxtaposed with this image is the lack of change surrounding transition. Despite numerous policy changes (not least the introduction of the Children and Families Act and the Care Act in 2014 and corresponding SEND CoP (DfE, 2015)), the only thing that does not change during transition is the overall experience of the period. In other words, although transition is a turbulent time, the turbulence is static as it does not go away despite the policy interventions outlined in Chapter Three. This is demonstrated by the numerous similarities between the findings of this study and those from research spanning the previous two decades and drawn on within Chapter Three (e.g. Morris, 1999; Beresford, 2004; Townsley, 2004; Abbott and Heslop, 2009). Transition continues to be a difficult time; the transition cliff-edge persists, opportunities and information are scarce. Despite guidance setting out the importance of transition planning, it appears elusive with young people and their mothers, unsure what will happen following college. A disconnect appears to continue to exist between policy and best practice guidance and implementation. As Chapter Three explains, the policy reforms of 2014 were heralded as the biggest reforms within education and social care policy for decades (DH, 2014). However, this appears to have had little impact on the participants' experiences of transition within this study. To understand why this is the case, it is helpful to look beyond individual participants and unravel some of the connections between them and the other elements that shape transition.

Far from being the radical intervention that was promised (DfE, 2011), the Send Code of practice is instead old ideology in a new format and remains constrained by Conservative ideological history, which continues to centre productivity and create an unhelpful dichotomy of “disabled bodies as un-productive and ‘in need’ of support against a mythical being that is non-disabled, docile, independent and productive” (Hodkinson and Burch, 2019: 165). Although employment and independent living are espoused, the reasons are economically orientated, bound to the wider ambitions of reducing welfare expenditure. Furthermore, it fails to explain what happens to young people left behind by their framing of neoliberal ableist adulthood (Burch, 2018). The dominance of individualism within neoliberal policy described in Chapter Three places a heavy emphasis on individuals’ human capital, aspirations and self-investments (Yates and Roulstone, 2013). This is problematic for several reasons. Firstly, focusing on changing or improving individuals attributes the ‘problem’ to them rather than to society. Secondly, locating the focus of the change with the individual fails to grasp the complexity surrounding such issues and shapes individual beliefs and actions.

Therefore, despite the mothers and young people within this study having aspirations about work, mothers remained having to make decisions based on what was available and practical, which limited what the young person was able to achieve, the need to plan for the short term limiting long term possibilities (Pearson et al., 2020). Work was viewed as a key aspect of adulthood by young people with many of the young people able to vocalise what they wanted to do in the future both in relation to work and, for some, independent living. However, there was a lack of discussion about how they might achieve their goals and the practical steps being taken to reach them. It remained unclear what they would be doing when college finished, with those who had finished experiencing a fragmented mix of activities and support. Professionals within this study espoused similar views as shown within the sub-theme 'Hindered Futures'. There was a belief that discriminatory attitudes alongside a lack of opportunities limited what young people could achieve post-education. Together, these experiences suggest that focusing on raising individual aspirations is not enough. More opportunities and greater inclusion within employment markets of people with learning disabilities are required with Oliver and Barnes (2012: 129) arguing that attempts to make disabled workers more attractive to employers reinforces the idea that there is something different with them:

> By packaging and selling workers with impairments as a special case, the idea that there is something different and 'wrong' with them is reinforced and can lead to exclusion rather than inclusion.

Additionally, the findings reflect concerns raised within other research concerning person-centred planning (Claes et al., 2010; Small et al., 2013; Kaehne and Beyer, 2014; Jacobs et al., 2021), whereby there is a danger that young people are only prepared "for transition into existing services in a person-centred way, not plan a person centred service" (Small et al., 2013: 285). This is perhaps best epitomised within this study by the experiences of mothers feeling their children were being encouraged to go to day-centres following college and the example one participant gave where their attempts to establish a dog-walking business were thwarted by social care professionals who instead encouraged them to explore existing supported internship opportunities. Like the narrative visible within the social care reforms, the focus on personalisation and person-centred planning during transition fails to address structural change or address the needs of those who fall outside of the ideal neoliberal adult citizen (Burch, 2018; Hodkinson and Burch, 2019; Pearson et al., 2020).

Person et al. (2020) argue that if a shift to personalisation within social care is to be successful, the availability of vibrant and diverse services is required to enable people to make choices and meet their needs (Baxter et al., 2011; Pearson et al., 2020). Similarly, if mothers have to 'pick up the pieces' and plan for their child's transition without support or effective planning, access to information and opportunities is paramount. To support their argument, Pearson et al. (2020) draw on Furlong and Cartmel's (2007) notion of 'epistemological fallacy' to suggest that a focus on personalisation within policies places too much emphasis on young people's individual ability to secure opportunities and direct their futures:

> There is an overemphasis on agency and individual choice, with a failure to address the root causes and disadvantage; the barriers that disabled people face and the structures that exclude them remain unchallenged and unchanged. The choices and services available are constrained […]. (Pearson et al., 2020: 13)

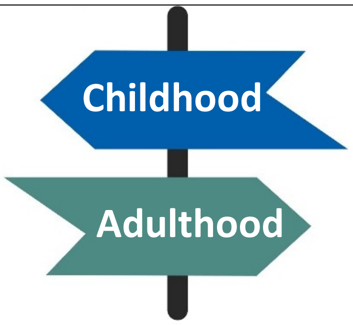
Similarly, I would argue that when addressing transition, the multidimensional and interconnected aspects must be considered. Looking only at the young person neglects the multiple, interconnected factors which work together to produce current experiences of transition, not least influential policies which continue to position those who are unable to live up to the neoliberal ideals, remain on the margins of society - falling off a cliff edge at transition when support and opportunities fail to materialise.

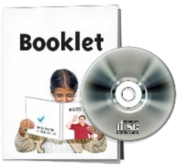
Towards the transition assemblage

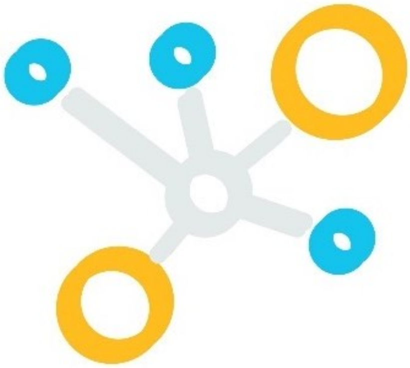
As shown in this study, transition has a different meaning depending on who is using the term and their experiences, roles or responsibilities, and a single definition fails to exist. Although some services or people may emphasise the young person transferring between services or the move to adult life, transition is a complex, dynamic time where experiences of transition are shaped by the entanglement of multiple different elements and actors. Thus, a more nuanced and intricate approach to transition is required. The elements touched upon above have included, but are not limited to, the different stakeholders, events, objects, emotions, budgets, policies and dominant discourses. Each person brings to transition their own experiences, values, beliefs and standpoint, which shape not only their experiences of transition but those with whom they connect (Jindal-Snape, 2016). Change has shown to be a continuous experience as different elements move into, or alter, in people's lives. Furthermore, young people and mothers are constantly becoming, their position shifting depending on the interplay between elements surrounding them and the connections which continually develop and break. Thus, adulthood is both enabled and constrained by the elements at play. While some elements that contribute to transition experiences, such as individual contexts and relationships, are unique to individuals, others, such as the end of full-time education and the construction of normative neoliberal citizens within policy, thread through all experiences. However, approaches to transition will remain inadequate if they do not consider the whole family and the evolving relationships within this over time (Jindal-Snape, 2016; The ALLIANCE, 2017) and the multiplicity of elements and connections which create individual experiences of transition. For these reasons, attention is now turned to the assemblage, a web-like entanglement of heterogeneous elements, both material and non-material, which temporarily work together to produce a particular understanding, activity or entity (Feely, 2016). As explained within the theoretical toolbox presented in Chapter Two, this is not a post-qualitative piece of work, or an assemblage analysis, rather in light of the aspects of transition identified above, the assemblage is a helpful model by which to understand and draw attention to the intricacies of transition. It allows for a consideration of the multiple elements which connect and work together to create transition in its current guise, elements that may otherwise be relegated to the periphery and encourages a creative approach to transition by exploring what the possibilities are when elements are added or removed.

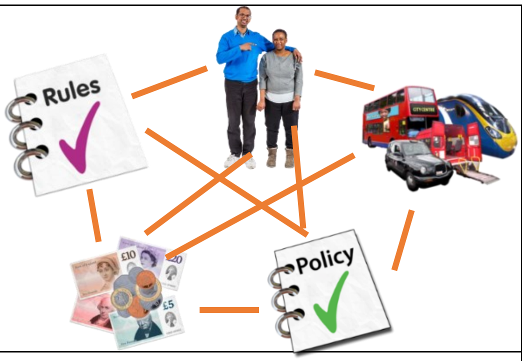
Chapter Eleven summary

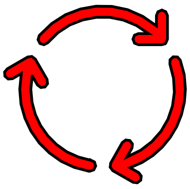
	This chapter tells you what the results say about transition.
3	There are three main points.

	1. The results showed that transition is **multidimensional.** **Multidimensional** means there are lots of different parts to something.
 	Transition is normally described as two things. 1) Moving from children to adult services. 2) Becoming an adult.

	However, transition is not this simple.
       	Transition is made up of lots of different things. This includes things we can see and touch like money, objects, people, events, and information. It also includes things we cannot see or touch but impact what people think or behave.

	2. The results also showed that transition is **interconnected.** **Interconnected** means things are connected to each other.

	The different parts of transition are all connected. They all affect each other.
	This means that when one part changes, it can make other parts of transition change.

	3. The results showed that lots of things **change** during transition.
	There might be changes in routines, relationships, budgets, education, support and services.
	These changes are not always good. They can make things difficult for young people and their families.

	People have been saying transition is difficult for a long time, but things have not got better.

Chapter Twelve: The Transition Assemblage

The previous chapter draws attention to the complexity of transition. In light of the findings, it is argued that transition is multidimensional, interconnected and a time of static turbulence. Previously, transition has often been looked at from an ecological systems perspective. However, it is argued this fails to capture the complexity of transition. Instead, drawing on Deleuze and Guattari (2004), this chapter argues that transition is better understood as an assemblage. The transition assemblage reflects current experiences of transition; it encompasses the three prominent aspects of transition presented in the previous chapter and accounts for the emerging and changing identities of young people and their mothers who are caught up within the transition assemblage. However, reflecting the influence of critical disability studies, one of the guiding theoretical tools presented in Chapter Two, approaching transition through the conceptual lens of the assemblage also serves to disrupt dominant notions of an independent adult and destabilise transition as a fixed naturalised concept.

Therefore, the chapter begins by examining the ecological systems theory often drawn upon within transition literature. The shortcomings of this model are discussed, and the advantages of a Deleuzoguattarian approach are highlighted. The introduction to new materialism presented in Chapter Two is then built upon to provide an overview of Deleuze and Guattari's (2004) concept of assemblage. It is demonstrated how this can be applied to transition focusing on two areas: lines of affect and becoming. The section 'Destabilising transition: enabling becomings' then turns attention to the utility of the model. It is argued the model has a practical application to transition in the mapping out of one's assemblage whilst also acting as a form of conceptual activism. The chapter concludes by proposing that, rather than transition, we should consider this period as a time to enable becomings.

An ecological systems approach to transition

Bronfenbrenner's (1977; 1979) ecological systems theory is a common theoretical approach within transition literature (e.g. Small et al., 2013; Hirano et al., 2018; Jacobs et al., 2020). Bronfenbrenner (1977; 1979) suggests that child development is best understood using a framework that considers the wider environments the individual is located within to account for the multifaceted influences on their development. The subsequent framework sees the child at the centre of five different systems wrapped around them in concentric layers: the microsystem, the mesosystem, the exosystem, the macrosystem and the chronosystem. These systems pertain to the person's immediate setting (e.g., family, peers, school, or work), the interrelations between the major settings in the person's life (e.g., the interactions between family, school, and peer group), the social structures which affect the person, the societal 'blueprints' (e.g., the overarching beliefs, values, laws, regulations and political systems which govern the way society works) and finally time (e.g., the changes which occur over time).

It is an attractive model for transition research as it provides a way to identify and discuss the numerous barriers encountered by a young person during transition. For example, Small et al. (2013: 297) propose its use as an alternative to person-centred planning, which is, they state, "an exosystem activity determined by a macrosystem adherence to the shibboleth of individualism". A more recent study (Jacobs et al., 2020)) uses the model as a framework for data collection and analysis and to distinguish between a 'practical transition' which occurs in the mesosystem (e.g. the transition between school and a new setting) and an 'organisational transition' which occurs in the exosystem (e.g. processes related to transition such as decisions surrounding funding and the availability of services). Like Small et al. (2013), they then use the model to illuminate barriers experienced within the different systems in relation to family and young people's involvement in decision-making during transition. This is not dissimilar to Hirano et al. (2018), where the model acts as a framework for barriers experienced in relation to family involvement in transition planning.

As Hirano et al. (2018) argue, Bronfenbrenner's (1977; 1979) model is helpful in that it moves the focus away from addressing individual familial deficiencies to exposing wider issues that pose barriers to families during transition; as the individual is part of wider systems and larger societal social structures (Jindal-Snape, 2016), there are multiple factors which influence how their transition unfolds. As a result, it can be argued, there is much in common with the assemblage approach proposed within this chapter as both models emphasise that a young person's transition to adulthood does not occur within a vacuum. Many influential elements need to be considered when working with young people and their families during transition. Mapping out the systems surrounding a young person during transition planning, as recommended by Small et al. (2013), serves a similar function to mapping a young person's assemblage proposed later within this section.

However, Bronfenbrenner’s (1977; 1979) model presents a neat and ordered vision of development. When applied to transition, although it emphasises the various factors affecting an individual’s development, it lacks flexibility and dynamism (Price-Robertson and Duff, 2019). The turbulence, the multiple changes and experiences of discontinuity people experience during transition are not visible within the model. The child at the centre of the model is also problematic for, as argued in Chapter Eleven, it is imperative that family members are also considered. Although the model shows how they affect the young person, it does not make visible their contexts, and it suggests the different systems have equal amounts of influence over the individual (Docherty and Reid 2009). Reflecting this, Docherty and Reid (2009: 464), who draw on the model, propose an adaption to demonstrate how mothers act as a “layer of influence” surrounding the young person gatekeeping and facilitating their interactions with wider society.

Nevertheless, the model is rooted in traditional developmental theory, which rests on notions of humans having a normative trajectory. Deviations from this trajectory are viewed as abnormal, and therefore those who deviate are afforded less status (Amorim, 2017). It does little to query the person at the centre of the model (Price-Robertson and Duff, 2019) and the fixed identities ascribed to them. Whilst development (i.e., the normative trajectory) may be constrained by the wider systems surrounding the individual, the model does not challenge the underlying normative assumptions guiding the individuals' supposed trajectory. In other words, whilst it may be useful in highlighting the barriers affecting a young person's transition to adulthood, as in the examples drawn upon above, it does little to question the concept of adulthood or transition itself. It is here that Bronfenbrenner’s model and assemblage differ as Bronfenbrenner's (1977; 1979) model remains a theory of development rather than “a form of conceptual social activism” (Hickey-Moody and Malins, 2007: 2).

A Deleuzoguattarian approach to transition

As was mentioned in Chapter Two, inserting a posthumanist framework into an otherwise conventional humanist qualitative project can be problematic (St Pierre, 2015). We are warned that care that must be taken when working with different paradigms for "as we try to set aside a system of thought, an order of things, that is so powerful we can slip back into it with a single, tell-tale word" (St. Pierre, 2013: 655). However, embracing the ethos of doctoral study where the student is positioned as a researcher in training learning about both thought and method (Petre and Rugg, 2010) and recognising that the thesis unfolds as the researcher does, comfort is drawn from the words of Lennon (2017). Rather than any slippages between paradigms serving to delegitimise thinking, Lennon (2017: 538) writes they should instead be viewed as:

> One would the language practices of foreign nationals who sporadically slip back into their mother tongue when the words of their newly adopted language fail them. Instead of denouncing my slippages as aberrant and/or non-sense, I ask that they be reframed as a folding together of my past and present paradigmatic allegiances.

Therefore, the encountering of new materialist philosophy (Fox and Alldred, 2017) and the work of Deleuze and Guattari (2004) during the research is not shied away from due to the benefits it can bring to transition. A Deleuzoguattarian assemblage approach encompasses the benefits of Bronfenbrenner's (1977; 1979) model whilst encouraging a more fundamental change and disruption to the normative order. In other words, not only does an assemblage bring into focus the wider factors influencing a young person and, as is discussed below, have a practical application when transition planning, but it also challenges reliance on normative discourses and contests the fixed identity categories and narrow ways of being that people are shoehorned into.

However, it is important to note that the theoretical contribution the model offers transition is not simply theory for theories sake, an accusation often levied against critical disability studies (Goodley and Runswick-Cole, 2016). For Deleuze and Guattari (2004:161), theory and practice are heavily entwined, and experimentation is welcomed as Feely (2016: 879) states when discussing assemblage analysis:

> Assemblage analysis is not simply an academic attempt to describe the phenomenon, it is also a form of activism that may open up new ways of intervening in, affecting and changing the phenomenon in a positive way.

To understand how the assemblage model can be applied to transition, however, it is helpful first to examine what an assemblage is.

What is an assemblage?

Deleuze and Guattari (2004) use the assemblage to describe how every aspect of life is produced. Rather than the different entities that comprise the world having their own ontological status and an inherent essence, they are produced when a multiplicity of heterogenous elements temporarily combine to form a machine-like assemblage, which often operates without our noticing (Ballantyne 2007: 27). The multifarious elements can be both living and non-living (Shildrick, 2015) and, therefore, the assemblage brings together "semiotic, material and social flows simultaneously" (Deleuze and Guattari, 2004: 24) as Deleuze and Guattari (2004: 102-103) sum up:

> An assemblage comprises two segments, one of content, the other of expression. On the one hand it is a *machinic assemblage* of bodies, of actions and passions, an intermingling of bodies reacting to one another; on the other hand it is a *collective assemblage of enunciation*, of acts and statements, of incorporeal transformations attributed to bodies.

Each element within the assemblage has the capacity to affect and be affected, that is, the capacity to produce change and be changed. The change, which might be physical, psychological, biological, social, political, emotional, or economic (for example, the gaining of knowledge, the experience of a kiss or a hit, feelings of empowerment, anger or frustration), is dependent on the context for the form it might take (Fox and Alldred, 2017). Due to this capacity to affect and be affected, although assemblages may appear stable, they are highly dynamic and constantly in motion. The elements are continually changing, or about to change; as they come into contact with each other their capacity to affect other elements alters in the process. As the changes occur, existing connections between the components can break, and new ones take form. This results in some elements falling out of the assemblage and others being drawn in:

> Assemblages are thus never stable or closed systems, but rather temporary entanglements that continually come together and then break apart, forming different machines with other elements that can produce different effects (Gibson et al. (2017: 449).

As a result, an assemblage is neither fixed or confined to official borders (Wiley et al., 2012: 188). Rather, it is composed of all elements that contribute to sustaining the core purpose of the assemblage (Huff and Cotte, 2016). In turn, the assemblage lacks an intrinsic identity or essence as it is instead "just a set of contingent relations that evolve and change over time" (Shildrick, 2015: 21).

The transition assemblage

Applying the concept of assemblage to transition, therefore, sees transition as a temporary creation brought into existence when young people with learning disabilities and their families are drawn into a complex network of diverse elements that temporarily work together and affect each other, to create this significant occasion in young people's (and their families) lives which has been labelled transition. While the common conceptualisation of transition may explain it as moving from children to adult services and moving from childhood to adulthood (see Chapter Three), the transition assemblage breaks down this boundary. It opens up transition to include all of the context-dependent elements contributing to creating and sustaining transition in its current guise. Therefore, whilst the move between services may be part of transition, it is just one element of many. In addition to this event, the transition assemblage also includes other events, people, objects, policies, budgets, institutions, technologies and places alongside discourses, social and cultural conceptions (such as childhood and adulthood and indeed learning disability), desires and emotions – all factors the previous chapters have highlighted as contributing to and thus creating current experiences of transition.

Within the transition assemblage, neither the material nor the discursive is privileged (Feely, 2016). Instead, they are brought alongside each other, functioning together to form the assemblage. Not only is this a key aspect of new materialism's flat ontology (Fox and Alldred, 2017) and Deleuze and Guattari's concept of assemblage (2004), but it is reflective of the findings. Marrying theoretical and discursive concerns with the material reality was a tension that surfaced during the interview process. Critical disability studies encourages seeking out and contesting normative discourses and deconstructing binaries that see people labelled abnormal or normal, disabled or non-disabled (Shildrick, 2012). However, participants were predominately focused on the material reality of transition and the impact of impairment within the interviews. They were not explicitly concerned with policy or the discourses behind it – the social construction of disability or the ableism of adulthood, for example. Therefore, privileging the discursive and focusing primarily on social and cultural constructions within the thesis would feel insincere to participants. However, to ignore it would only present half the picture for, as is shown in the previous chapter, discourse mattered; how adulthood is constructed and presented to young people understandably shapes their understanding of adulthood and renders some on the inside whilst others are excluded (Slater, 2015).

The transition assemblage, like all assemblages, is highly dynamic. It is an affective economy whereby relations between elements (the lines of affect) form and break, morph and mutate, the elements within altered accordingly. As a result, the transition assemblage is always in process and never stable. It is, for this reason, we are encouraged away from focusing on the essence or identity of an assemblage (Feely, 2020), defining what is included or excluded, and instead, we are encouraged to explore how "apparently inchoate elements come together to form a particular whole" (Youdell, 2011: 46). That is to examine the lines of affect which connect the elements sustaining or disrupting the assemblage and enabling or constraining the elements (and people) within the assemblage.

Tracing lines of affect

Affect within an assemblage is the force that connects the elements, draws them into the assemblage and temporarily holds them together to create the assemblage and produce the entity. Therefore, it is the lines of affect within assemblages that is how lives, societies, and history transpire (Fox and Alldred, 2019). Affects are the changes produced (which within transition could be the empowerment, the loss of trust, the lack of confidence, the anger or experience of adult status, for example). They are also "projectiles" (Deleuze and Guattari, 2004: 466) as they produce further affects. Fox (2015: 306) explains this process:

> As one affect produces capacities of relations to do, desire or…feel, these capacities in turn create subsequent affective flows.

This can be seen within the transition assemblage in relation to the emotions mothers described and their role in generating action. For example, the relationships with professionals gave rise to feelings of anger, frustration and upset and, in turn, these emotions lead to action such as fighting back, challenging decisions, or taking on new roles to change transition for both their child and others, as shown in the subtheme 'Fighting'. Similarly, various events and experiences led to feelings of disappointment, of being let down and the erosion of trust, which then affected the way mothers approached or perceived situations.

To describe how affect moves, and thus how the assemblage works, Deleuze and Guattari (2004) draw on the rhizome, which, as explained by Feely (2016: 874), is, "a complex subterranean tangle of interconnected root-like sprouts which spreads in a horizontal fashion and has no centre". Rather than stemming from one root, the rhizome moves horizontally as it "ceaselessly establishes connections" (Deleuze and Guattari, 2004: 6) and throws out multiple roots and stems in all directions "branching, reversing, coalescing and rupturing" in the process (Fox, 2015: 306-307). When fractured or broken, the rhizome progresses, reconnects or travels in an alternative direction of growth (Cluley, 2020). Such imagery, and the focus on tracing the multitude of lines of affect working within an assemblage, stands in opposition to the neat and ordered linear pathway often evoked when presenting an image of transition. Along this pathway, people are meant to travel as they move from one state to another, from childhood to adulthood, yet it is an image already troubled in the previous chapter.

The emphasis on tracing lines of affect reflects both the multidimensional and interconnected aspects of transition explained in the previous chapter. It ensures that all elements that are active within the transition assemblage are taken into consideration. Therefore, it enables lines to be drawn between material elements and discursive factors, which have already been highlighted as important, and lines can be traced between family members, professionals, and other people who are caught up in transition. As predefined boundaries do not restrict assemblages, mothers can be incorporated into understandings of transition alongside the young person. This is an important and necessary consideration if any strategies to improve current experiences of transition on both an individual and wider level are to be successful (Gauthier-Boudreault et al., 2017). Similarly, as "subjects are caught up, simultaneously, in multiple assemblages" (Wiley et al., 2012: 188) and elements within an assemblage can consist of many smaller assemblages in a manner akin to Russian dolls (Feely, 2016), tracing lines of affect exposes the multiple different aspects of life acting on individuals concurrently to their involvement with the transition assemblage. The findings highlight that transition does not occur in a vacuum as 'life goes on.' Therefore, whilst transition may be part of the larger special educational need assemblage, young people, mothers and professionals may be part of their family assemblages, employment or education assemblages and so on. Reflective of the interconnectedness of transition, when one element or relation within each of these assemblages shifts or changes (for example, grandparents becoming ill, family members dying, new staff at college, redundancies at work), there is the potential for it to have a knock-on effect and alter elements within the transition assemblage. It is a process that draws attention to the context-dependent nature of components within the assemblage. It thus has the potential to encourage a more nuanced and individualised approach to transition.

The example of illness during transition explains this further. When someone is unwell or has problems with their health, as was the case for two mothers in the study and several young people, they become part of an ill-health assemblage that draws transition into its orbit. The ill-health assemblage does not simply restrict illness to the mother's or the young person's body solely a matter of physiology, but it is part of an affective economy composed of physical and psychological relations alongside social and cultural (Fox and Alldred, 2017). Rather, as Fox and Alldred (2017: 135) suggest, it can contain:

> Respiratory tract – virus – immune system – inflammation – pharmacist – pharmaceutical compound – theories of infection and inflammation – daily responsibilities – family members – social networks.

The ill-health assemblage impacts what the body can do, and thus in the case of mothers during transition, it can limit the amount of support they can provide to their child. It may limit their ability to drive their child to an activity or job and thus limit what opportunities are available to the young person or, in the case of a mother within the study, affect their ability to contest their son's suspension from college, which in turn affected how the mother's emotions as feelings of guilt or regret emerged. Similarly, a young person caught up in an ill-health assemblage sees other elements drawn into the transition assemblage, children and adult hospitals and the movement between the two, and the various professionals encountered. Likewise, their becoming, a concept explored further in the next section, may be constrained, or altered. For example, the presence of epilepsy may stop them from going out alone or taking part in particular activities.

The previous chapter has shown that whilst change, disruption and discontinuity were common features of transition, the overall experiences of transition changed very little. To understand this within the context of the assemblage, Deleuze and Guattari's concept of territorialisation (reterritorialisation and deterritorialisation) proves helpful. It provides “an explanatory framework for how the forces of the social impinge on individuals or cultures, from the stratification of class, gender and ethnicity through to the construction of subjectivities, for instance as ‘women’, ‘husbands’, ‘patients’ and ‘risk takers’” (Fox, 2002: 353).

The assemblage is a territory produced and disrupted by the relations of affect. It has “both *territorial sides,* or reterritorialised sides, which stabilise it, *and cutting edges of deterritorialisation*, which carry it away” (Deleuze and Guattari, 2004: 103). Therefore, whilst some flows of affect work to territorialise or reterritorialise, specify the assemblage, stabilise it and constrain what can be achieved (Feely, 2016), other affects work to destabilise or deterritorialise it “re-shaping the possibilities and limits of what a body can do, continuously and unendingly” (Fox and Alldred, 2017: 32). Thus, whilst reterritorialising forces maintain order and keep the assemblage in its current guise, deterritorialising forces are lines of flight that serve to disrupt and disassemble the assemblage to “carry it away” (Deleuze and Guattari, 2004: 103).

Therefore, amongst all the disruption and change experienced at an individual level, reterritorialisation forces ensure transition continues as it does, that change remains a constant. Professionals are territorialised and reterritorialised by their employment as budget cuts, time pressures and heavy caseloads limit what they can do and restrict their ability to think or act creatively. This, in turn, specifies and territorialises young people and limits what they can become. Take, for example, the young person wanting to start their dog walking business who had their suggestion rejected by staff. Instead, they were steered in the direction of a supported internship scheme, a pre-existing path ‘suitable’ for people with learning disabilities. This would mean the young person would remain coded by their learning disability and in a precarious position. Whilst the dog walking business had the potential to continue indefinitely, the supported internship was for a set time, suggesting further change and disruption would lie ahead for the young person. Similarly, the lack of information, limited personal budgets, and the absence of planning, all worked to ensure mothers and young people were kept in a state of uncertainty.

The Send Code of Practice (DfE, 2015) highlighted in the previous chapter as being shaped by individualist neoliberal ideology (Burch, 2018; Hodkinson and Burch, 2019) alongside the normative conceptions of adulthood (Slater, 2015), could be viewed as other forces of territorialisation as they promote a particular, ableist, way of being - an adulthood which is centred on self-sufficiency and narrow definitions of independence (Arnett, 1998). These forces can be seen as producing molar affects (Deleuze and Guattari, 2004) which Fox and Alldred (2017) rename aggregate affects to make the terminology more accessible. In contrast to molecular or singular affects which only produce singular outcomes "with no significance beyond itself" (Fox and Alldred, 2017: 32), molar or aggregating affects "act similarly on multiple bodies, organising or categorising them to create converging identities or capacities" (Fox and Alldred, 2017: 32). Thus, normative discourses of adulthood shape young people and influence their desire to pursue a trajectory of nondifference (Gibson et al., 2014). They are norms that are reiterated by services, professionals and research that promotes what Slater (2015) names a 'rhetoric of sameness' and lead to the territorialisation of young people with learning disabilities who fail to live up to these norms as other, on the fringes of society as Slater (2015: 50) explains:

> Although an argument of 'sameness' may mean some disabled young people are (reasonably and often partially) included in the textbook of adulthood, many are rendered unreasonable. Any exclusion or marginalisation they face is therefore rendered reasonable and they are left as part of the disposable population.

However, whilst such territorialising forces may constrain young people and amplify marginalisation (Gibson et al., 2014; Hamdani et al., 2015; Slater, 2015; Slater et al., 2018), the concept of becoming offers the opportunity to resist such over-coding (Deleuze and Guattari, 2004) and leave open the doors to who people can become.

Becoming bodies: becoming adult; becoming mother

Preparing for adulthood is a key part of transition from both current policy perspectives (DfE, 2015) and for young people within this study. It is an adulthood that moulds people into a particular way of being and thinking, centred on individual qualities of character such as independent decision making, taking responsibility for oneself, and becoming financially self-sufficient (Arnett, 1998). Its social construction appears forgotten as the impact of traditional developmental psychology sees a normative narrative of developmentalism become ingrained within society, drawn upon unquestionably and unproblematically (Burman, 2008). The dichotomy between childhood as dependence and adulthood as independence is reproduced and reinforced within welfare policy (Coles, 1995) and underpins transition policy (Hamdani et al., 2015). As a result, transition practice is focused on moving people along a linear trajectory which reproduces dominant narratives of what constitutes a ‘good’ or ‘successful’ adulthood as Hamdani et al. (2015: 1147) explain:

> The ideal outcome of transitions best practices is the acquisition of particular characteristics, abilities and responsibilities aligned with a ‘normal’ adult life, such as increasing independence for managing health and activities of daily living, moving out of the family home, participating in work or post-secondary training, and forming intimate relationships […] A normal social developmental trajectory is taken for granted as the ‘right’ or only way to guide transitions best practices. No mention is made of other paths or perspectives […].

However, the ableist construction of adulthood and binary modes of thinking such as child/adult, independence/dependence, normal/abnormal which pervade it imposes limitations on what young people can or cannot be (Hamdani et al., 2015; Slater et al., 2018) and, as aforementioned, they become territorialised as different or other. Some parents were conflicted by their child’s status, particularly where the age-appropriate discourse did not resonate with their experiences. Their children were viewed as not-a-child-but-not-an-adult as they failed to meet normative markers of adulthood as they remained dependent, reliant on others to meet their support needs. Elsewhere, the narrative of people with learning disabilities as eternal children is an all too familiar one with other studies suggesting that, as a result of this position, there is a belief people with learning disabilities do not deserve the same rights as other adults (Priestley, 2000; Starke et al., 2016). Meanwhile, as discussed in the previous chapter, some young people felt left out or left behind. Differences were internalised, and they blamed themselves for not living up to the norm despite a desire to do so. Furthermore, echoing Gibson et al. (2014) study concerning the emerging adulthood of young men with

Duchenne muscular dystrophy where limited fields of work and independence were accessed or drawn upon, discussions about different ways of experiencing or entering adulthood, a desire to travel or to rebel, were absent.

The dominant conceptualisations of adulthood are, in Deleuzoguattarian terms, akin to arborescent or tree-like thought that grows from a singular root in a hierarchical nature (Deleuze and Guattari, 2004). The term is used to characterise the type of thinking that dominates and organises society and promotes "grand narratives" (Goodley, 2007b: 148) which territorialise people, restrict creativity and growth, constrain knowledge and limit what people can become (Goodley, 2007b; Youdell, 2011; Feely, 2016).

Challenging such conventional knowledge and normative, structured ways of being (Goodley, 2007b), Deleuze and Guattari (Deleuze and Guattari, 2004: 26) call for us to "make rhizomes, not roots, never plant! Don't sow, grow offshoots! Don't be one or multiple, be multiplicities! Run lines, never plot a point!" The assemblage and its parts exist as rhizomes without beginning or end but "always in the middle, between things, interbeing, *intermezzo"* (Deleuze and Guattari, 2004: 26), a factor which moves the focus away from being and what a body or thing is to becoming and what it can do (Fox, 2015) for, as Cluley (2020: 289), explains "being pertains to the logic of the one and becoming pertains to the multiple". Rather than having an essential identity, impossible to escape, the notion of becoming encompasses the idea that assemblages and their component parts are only momentary stable as they are always morphing into something else (Taylor and Harris-Evans, 2018). Becoming is a process that is "creative rather than regressive or progressive" (Cluley, 2020: 289) and produces nothing but itself (Goodley, 2007b).

Viewing people as becoming within an affective economy of the transition assemblage deprivileges human agency as attention is shifted from agency to affect, the relations between the elements (Fox and Alldred, 2014; 2017). It is another aspect of Deleuzoguattarian philosophy that resonates with the interconnectedness of transition discussed in the previous chapter. Adult status was not a stable identity that one gained through a linear process. Instead, it was in constant flux, negotiated continuously as it was enabled or constrained by people, things, and objects around them. Having a phone, for example, enabled a young person to spend less time with their parents, a wristband on the arm of one young person prevented him from being able to drink alcohol, and a dog meant a young person was able to take responsibility for something else. Similarly, within the assemblage, rhizomes face barriers limiting one's becoming (Goodley, 2007b). Whilst escaping these can prove difficult, there were examples of young people and their mothers challenging the barriers and finding ways around them, deterritorialising their position and re-opening their becoming. Therefore, whilst striving for independence, the dominant narrative of adulthood which excludes and marginalises people with learning disabilities, young people embraced networks of interdependence as they welcomed their relationships with their PAs and thus challenged the dominant narrative. Parents meanwhile resisted their children being pushed into day centres, spoke out about budgetary decisions that limited what was possible, and took on roles to try and transform transition practice. However, as with the parents in Goodley's (2007b: 151) study, "to hit a line of flight means challenging, not totally escaping, disabling strata of society"/ Furthermore, the lines of flight taken described within mothers' stories reflect the shifting nature of their becoming. In some instances, mothers fought to break down the barriers that constrained them and their children. However, in other instances, they did not, and thus, they moved up and down the internal activist continuum as they responded to factors around them (Ryan and Runswick-Cole, 2009).

Destabilising transition: enabling becomings

The above sections have introduced Deleuze and Guattari's (2004) notion of assemblage and drawn on the findings to demonstrate how the concept can be applied to transition. It argues that transition is better understood as an assemblage: an intricate context-dependent network of components and their relations, which are constantly in motion and in which people are always becoming. This section attends to the model's utility and demonstrates how it is helpful beyond simply producing a detailed description of transition. A practical application of the transition assemblage is presented, and it is shown how the model extends from theory into practice with the transformative potential of viewing transition as a time to enable becomings highlighted.

Mapping out the assemblage

Chapter Seven and the discussion of the findings in Chapter Eleven demonstrate how priorities during transition differed from person to person. Whilst viewing transition as an assemblage acknowledges this, physically mapping out an individual's transition assemblage during the transition period (i.e., 14-25) would provide the young person, their family and professionals an opportunity to explore the myriad of elements affecting the young person's becoming whilst ensuring the young person is not viewed in isolation from their wider family context. The importance of appreciating the family has been discussed in the previous chapter (e.g., page 232), with the findings highlighting how mothers' situations and the differing demands placed upon them both physically and mentally (see, for example, the subtheme 'Life Goes on') have a knock-on effect on the young person. Similarly, within Ryan (2020: 159), professionals are cautioned, "don't atomise the child or children; think about the family. Stresses, strains and challenges can fluctuate over time". Mapping out the assemblage and tracing the relations between elements would thus help identify relations or elements that may be problematic and those that are (positively) productive and should be encouraged. This includes components and relations within other assemblages the young person or their family members may belong to. For the mothers in this study (see, for example, Anne, Sandra and Claire on pages 167-169 within the subtheme 'Life Goes On'), this could lead to discussions about the impact of other caring commitments on the amount of support they can provide their children during transition and the explorations of strategies to fill any gaps. Alternatively, attending to the family context and the differing assemblages one is part of might mean ensuring any communication from professionals is sensitive to wider difficulties being experienced by the family. This could lead to a greater focus on providing mothers with emotional support and opportunities to access peer support, to share their experiences with other likeminded people as shown to be important for the mothers in this study as presented in the subtheme 'Support to Empower' in Chapter Nine and recommended in other studies (Townsley, 2004; Gauthier-Boudreault et al., 2017; Codd and Hewitt, 2020).

Although responses from professionals may ultimately be limited by budgetary constraints (a reterritorialising force as discussed earlier in this chapter), mapping out the assemblage would draw attention to their role within the assemblage. This could provide an opportunity to reflect on practice and consider the lines of affect which flow from them to other elements within the assemblage. How they shape the experiences and becomings of young people and their families. Difficulties in the mother-professional relationship was a common experience for mothers within this study, captured within the sub-theme 'Powerlessness' and a key element of theme one presented in Chapter Eight ('The Transition Minefield'). Frustration and anger at empty promises and lack of contact, feeling the need to justify the desperation experienced for fear of being perceived as greedy, and a belief that their child was seen as a number rather than a person, are just some examples taken from the findings to illustrate the effect of relationships with professionals. Whilst the assemblage is not an automatic cure for these problems, professionals viewing themselves as an element within the affective economy and mapping out the flows would draw attention to the power of communication and the effects of problematic interactions. Similarly, it would highlight the power kindness has to influence wellbeing and increase relationship satisfaction as “gentle and thoughtful interactions, support, and assistance are more likely to benefit both the recipient and the purveyor of kindness, and these may flow onto and into the approach and actions of others” (Cleary and Horsfall, 2016: 207). It may encourage more acts of micro-kindness - a term used by Runswick-Cole (2019) on Twitter to describe the tiny, yet powerful, actions of professionals which families remember for many years to come. They are acts that prove a welcome experience "in a sea of micro and macro aggressions" (Runswick-Cole, 2019: online).

Likewise, in relation to the mother-professional relationship, the focus on affect rather than agency when mapping out an assemblage has the potential to change attitudes towards mothers. The ‘challenging-parent’ narrative (Corby, 2018) can be reframed as parents, who stand up for their child, argue decisions and fight for a fair outcome (a draining but necessary process as presented in the sub-theme 'Fighting'), are viewed within the relevant context. Thus, the experiences discussed on pages 165-167), which may unintentionally antagonise professionals as they fail to respond with the desired deference (Ryan, 2020), would be viewed as a result of the many lines of affect flowing within this assemblage and others over the years and not simply a "default approach to interactions with school" (Corby, 2018: online).

To return to the young person, mapping out their assemblage opens up the scope to explore their desires for their future and think creatively about bringing elements into the assemblage to encourage and enable these desires to take shape whilst simultaneously pay attention to lines of affect of elements which might pose as barriers. Some of the desires may be related to the attainment of markers of adulthood, such as the young people in **Figure 20** of Chapter Ten who discussed their aspirations in relation to employment. However, as with mothers, the focus on affect rather than agency reframes the young person as it removes the focus on individual responsibility in relation to the attainment of adulthood and inclusion within society. Therefore, rather than professionals trying to change the young person to fit into existing services or structures (a particular issue when it comes to employment strategies (Yates and Roulstone, 2013) as discussed on page 69 in Chapter Three), the focus becomes on changing the flows of affect and "helping persons to live well through making and breaking connections" (Gibson et al., 2012: 1897). This may include, for example, exploring how services and employers can adapt to suit the individual, "reformulating assumptions of what constitutes 'ability' and create working environments in which we can all contribute" (Ryan, 2020: 125). It could also see other elements brought into the assemblage as had happened for the two young people in **Figure 14** who discussed how looking after their dog and their nieces facilitated a sense of responsibility – another desired marker of adulthood. This is a particularly important consideration for people, who despite desiring work, are not provided with that opportunity. Within the assemblage approach, professionals working with the young person can explore what else could be done to support, not limit, the young person’s becoming in the absence of employment.

Thus, mapping out the young person's assemblage will also show any gaps where elements have been removed or are expected to be removed. Whilst employment may be one missing element, the loss of college is another obvious example. Drawing the lines of affect from college to the other elements will expose other losses or disruptions experienced due to this event. Eve, for example, on page 185, discusses the loneliness she experiences due to the loss of her friends at the end of college and the lack of opportunities to replace the missing social interaction. Highlighting such gaps is necessary for professionals, young people and their families to begin to look at ways of addressing them as all too often, friendships are lacking from transition planning (Small et al., 2013). In the previous chapter (page 233), Slater (2015) was drawn upon to describe how youth should be a time of increasing connections rather than reducing them. Therefore, an assemblage approach, which already emphasises interconnectedness, could see professionals focusing on how to increase relations of interdependency – a strategy that may also work to alleviate a fraction of the worry experienced by mothers in relation to their children's futures. The addition of a circle of support to the young person's assemblage is perhaps a prime example of how relations of interdependencies can be increased with a multitude of positive lines of affect flowing out of the circle (e.g. Franklin and Sanderson, 2014). Another example of bringing a new element into the assemblage to introduce positive lines of affect and remove other, more problematic, flows is that of a keyworker. The keyworker is a named professional whose role is to guide the young person and their family through the transition period, not simply the transition to adult services, as recommended elsewhere (Gauthier-Boudreault et al., 2017). The addition of their role has the potential to bring much needed information to the assemblage. The information could be delivered in a personalised way and embedded in the context of the family and their specific requirements as shown desirable by the examples provided in theme one (pages 158-159) as well as within the literature (e.g. Townsley, 2004; Biswas et al., 2017; Gauthier-Boudreault et al., 2017; Ryan, 2020). Having one designated point of contact and not needing to search out information and support could help reduce the 'dependency work' mothers necessarily undertake in relation to their disabled children. The term dependency work was coined by Kitty (1999) to describe the tasks parents of disabled children must undertake in addition to the usual parenting role as Ryan (2020: 98) describes: “it is everyday life as a parent with a ton of stuff on top” with experiences of such work threading their way through the themes.

Theory to Practice

Examples of how the theory extends into practice can be found in other studies that have drawn upon the notion of assemblage. Taylor and Harris-Evans (2018: 12), who draw on assemblage to reimagine transition to higher education, explain how universities can open spaces for students becomings and "pay heed to the immanence of students' experiences and their rhizomic connectivities in multiple directions". This led to the formation of a staff/student choir, poetry workshops and field trips that were not subject-based. However, whilst encouraging others to similarly experiment, they warn that it is impossible to predict what form the experiments may take or what the outcomes may be as "specificities of context, singularities of events and the in-situ emergence of particular assemblages prohibit that" (Taylor and Harris-Evans, 2018: 11). Thus, whilst it is impossible to predict the outcomes, several examples from the findings illustrate the transformative potential ‘enabling becomings’ offers.

The first example is that of independent living. It is held as a pinnacle of transition and one of the four cornerstones of transition emphasised in the policy section in Chapter Three. For some mothers and young people within this study, independent living was indeed the goal. However, this was not the case for everyone. Several mothers did not wish for the child to move out of home and neither did Sam, whilst Eve, as shown on page 215, was conflicted. Under the lens of enabling becomings, however, independent living is taken off its pedestal and recognised that it is instead just one of many ways to live. Each arrangement can constrain or enable depending on individual context (Gibson et al., 2012). Remaining living at home, thus need not be the failure Eve sees it to be but simply one way of living which enables and supports her becoming at that particular time. If mapping out her assemblage, however, Eve could be supported to explore how and where dependencies and connections could be made that may empower her, break down the belief that she could not move out of the family home, and open new possibilities for her should she so wish.

The second example is work, another one of the four cornerstones of transition highlighted in Chapter Three. The mapping out the assemblage section discussed how the emphasis on affect rather than agency has the potential to remove responsibility for failing to live up to the expected norms of adulthood from the individual. Enabling becomings has the potential to extend this further as a focus on multiplicity removes the emphasis on getting work as the main way to 'do' adulthood. However, this is not intended to deny young people the very normal desires they have, as young people within the study have shown they want to work. However, it would open up possibilities that there are other ways of becoming alongside this and foster an approach that looks at all aspects of ones becoming and ways to meet or encourage this - not just through the limited handful of opportunities currently on offer to mothers and young people within this research. The desire for a young person to set up their dog walking business is a prime example of how things can be done differently. Trying to fit the young person into existing services by encouraging them to explore a supported internship rather than the dog walking idea, constrains and territorialises. However, were the professionals focused on enabling becomings, they would see the possibilities the dog walking business brings to the young person. The young person and their family would be supported to develop this idea further, and thus, the doors to their becoming left open to unfold through the new experiences on offer. In a similar vein, the focus on enabling becomings would bring professionals in line with parents in relation to day centres and view them as the parents in the study do (see Chapter Ten page 198) as limiting the young person's potential and their capacity to become.

The final example is that of personal budgets. This section does not attempt to understand the decision-making processes undergone in relation to budgets. Local authority funding is a complex matter made even more so within the context of austerity, where the impact on disabled people has been devastating (Ryan, 2019). However, regardless of the size of personal budgets, the management of them has over the years become encased in bureaucracy and stress (Mark Neary's blog[20] providing a detailed account of the level of work involved). As is shown on page 161, changes to budgets were not straightforward, people lived in fear of cuts, and there were long waits for decisions leaving young people and their families in limbo. This contrasts their "potentially revolutionary redistribution of power and resources, and recognition of a strengthened social and cultural status for disabled people and others" (Hall, 2009: 46) as originally envisaged. The focus on enabling becomings has the potential to regain some of this potential and remove the ambiguity and inconsistency surrounding what budgets can and can't be used for (Turnpenny et al., 2020). A more holistic vision would be encouraged in line with removing such a heavy emphasis on independent living and work as discussed in the two examples above. With a goal of removing reterritorialising forces, the emphasis would be put back on creativity and the budget holder being in control, given the freedom to utilise the budgets to meet the individual needs, enable their becomings, and being allowed to respond to the shifting or changing nature of these.

Conceptual activism

The potential of the assemblage model extends beyond simply mapping out the elements and lines of affect, however, for, as suggested above, it is a form of social activism (Hickey-Moody and Malins, 2007) as the assemblage destabilises transition and brings into question its normative underpinnings. Conceptions of transition which position it as a move from children to adult services and a time when young people are 'prepared for adulthood' feed into a normative discourse and perpetuates adulthood as

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[20] https://markneary1dotcom1.wordpress.com/

being seen as a natural state of development, a fixed way of being in which one is included or excluded (Hamdani et al., 2015). In its current guise, transition perpetuates the othering of people with learning disabilities and separates them from their non-disabled peers, as is highlighted in Chapter One and by the following:

> ‘Transition.’ A word that works to separate out the expectations and aspirations experienced by most children from those who are denied this. Talking about 'transition' creates a different space to leave childhood with a differently shaped adulthood to enter (Ryan, 2020: 113).

However, approaching transition as an assemblage can disrupt this as it stops transition from being viewed as a neutral description of an inevitable, naturalised process. Instead, it sees transition as created and maintained by the territorialising and reterritorialising forces which flow between the components. The assemblage’s absence of a fixed identity and lack of eternal essence (Feely, 2020), whilst reflecting the individualised experiences of transition and thus encouraging similarly individualised responses, opens up the possibility for transition to change, to be carried away on lines of flight as it does not have to exist as it does.

Furthermore, the connectivity of elements within the assemblage is a reminder of the connected nature of humans, for as Goodley (2021: 67) states, "to survive and thrive in the world relies on the input of others". However, such an emphasis on connectivity troubles the pedestaled ideal of the self-sufficient individual - a central aspect of the normative adult that dominates society (Arnett, 1998). Of course, for disabled people, this is not new. As the young people within this research have shown, assistance from others is often perceived as positive and enabling (e.g., page 183-184 and page 233 in the previous chapter). Disability, Goodley (2021: 66) writes, “shines a particular light upon human dependency not least because many disabled people hold close to them many intimate dependencies”. However, in a society where independence is held up as the goal of adulthood, “to be considered ‘adult’ is to be considered ‘able’ – ‘able’ to be financially self-sufficient, ‘able’ to be independent” (Slater et al., 2018: 416), those who require assistance to go about their day-to-day life are perceived as different. A conspicuous dependence limits one’s entry into adulthood as violations of the normative developmental trajectory “can fix a body at a particular stage, such as child or adolescent” (Skott-Myhre, 2009: 43). An ambiguity over adult status because of dependence and deviation from the 'norm' is reflected in the accounts of both mothers and young people (see, for example, pages 190-195 and 219-220 within the findings chapters). However, as assemblages "trace and celebrate the multiple dependencies that constitute all our lives" (Gibson et al., 2017: 508), within them, young people are no longer considered lacking. Dependence is not automatically negative, a barrier to adulthood, but rather it is just one of many ways of achieving and doing-in-the-world (Gibson et al., 2012).

That there is a right or wrong way to be, a certain type of adulthood which one must reach, is further broken down within the assemblage by the notion of becoming – a concept which acts as an antidote to a preoccupation with being and identity (Stagoll, 2010). Fixed identities are replaced with multiplicity as becoming "is identity-in-motion…a process not a way of being" (Gibson et al., 2012: 1896). Becoming "invites variations, discrepancies, other ways of knowing and being" (Amorim, 2017: 43) and under this lens, the goal becomes not one of supporting young people to develop and live as normally as possible but rather one where we are encouraged to explore different ways of being and becoming.

As Deleuze and Guattari (2004: 8) state, "the point is that a rhizome or multiplicity never allows itself to be over-coded". One way to reduce the over-coding people with learning disabilities are subjected to would be to remove 'transition' from the 'carespeak' dictionary (as introduced in Chapter One). Instead, the time leading up to and after the end of education could be viewed as a time to 'enable becomings', with professionals treating it "as a space of potential possibilities" (Ryan, 2020: 114). Of course, the becomings enabled in this period are simply part of the continued becoming of life (Slater, 2015) and thus allocating this period a label, no matter how nice the label may be, still jars.

Replacing 'transition' with 'enabling becomings' and discussing how the assemblage can disrupt normative assumptions is, however, not simply an academic endeavour. Rather changes in thought are entwined with changes in practice as Hickey-Moody and Malins (2007: 3) state, "the way in which we imagine the world, and other bodies around us, impacts upon what is possible". A group of families within Ryan (2020: 159) request that professionals "leave the window of possibilities, aspirations and imagination well and truly open and always see the human". It is a powerful yet simple request which costs little in respect of time or money, but rather it demands a shift in attitude. It is this shift in attitude which a focus on becomings and the mapping out of a young person's assemblage has the potential to bring about. Meanwhile, the focus on ‘enabling,’ acts as a reminder that, as Lord Justice Munby (2013) stated: “the local authority is a servant, not a master, a truth which on occasions is too easily overlooked.”

The assemblage encourages more nuanced approaches from professionals that consider the multiplicity of components and the relations between them. Creativity is encouraged as one can explore what is possible for young people and their families when the assemblage has elements added or removed, connections made or broken. At the same time, relabelling transition as ‘enabling becomings’ captures the disruptions the assemblage brings to taken-for-granted concepts and encourages a shift from trying to fit people into narrow conceptions of adulthood to embracing and supporting different ways of becoming. In this process, the othering potential of transition is removed. Young people are recognised as being steeped in possibility and potential but remain susceptible to relations that establish boundaries and limit what one can do and become. The role of people around the young person is thus one of supporting the unfolding of their becoming and, in this manner, the theory, the concept of becoming is lifted off the paper and filters into practice.

Chapter Twelve summary

	This chapter tells you about a different way of looking at transition.
	It says that transition is like an **assemblage**.
	An **assemblage** is where lots of different things are connected to each other and impact each other.
	When professionals work with young people and their families, they should think about the different things in the young person's transition **assemblage**.
	This means looking at the things that matter to the person during transition.

 	This chapter also says we need to stop thinking about adulthood as being independent and having a job.
	Thinking about adulthood like this is unhelpful as not everyone can be like this and not everyone wants to be like this.
Transition ✗ Enabling becomings ✓	To help change this we could call transition to adulthood ‘**enabling becomings.**’
	‘**Enabling becomings’** means helping people to be what they want to be. It means thinking about all the different ways people can live their lives.

	This would help people get the support they need to do different things. It could help people to stop doing things they don’t want to like going to a day-centre.

Chapter Thirteen: Conclusion

Following an initial introduction, I began the thesis by introducing myself and the theories which have shaped this research: critical disability studies, feminist research and new materialism. I then examined existing literature and policy related to transition and presented an overview of the research methodology and methods drawn upon. I highlighted the ethical considerations that threaded through the research and introduced the participants. I then presented the research findings, which consist of three themes and an overview of the different meaning transition held. Following this, I drew on the themes to demonstrate that transition is a multidimensional, interconnected time of turbulence. In turn, this led to the use of Deleuze and Guattari (2004) to argue that transition should be understood as an assemblage and a time to enable becomings rather than a time to 'transition people to adulthood'. This chapter concludes the thesis. In it, I draw together the preceding twelve chapters by summarising how I answered the research question and explaining my original contribution to knowledge. I also reflect on the development of the research and the thesis as part of a research assemblage. In doing so, I draw attention to some of the limitations of the research which then form the basis of suggestions for the future development of the research and reflect on my role as a becoming researcher.

Answering the research question

The central question to this thesis is 'what can an understanding of the perspectives of young people with learning disabilities, parents and professionals bring to transition?' It is an unusually broad question for doctoral research as it does not include a set of sub-questions (Creswell and Creswell, 2014). However, I considered this necessary to try and avoid reinforcing the status quo of transition and its normative foundations about what constitutes a proper adulthood (Priestley, 2003; Hamdani et al., 2015). To answer the question, I adopted a qualitative methodology and took a flexible approach to the design and methods (Booth and Booth, 2003; Robson, 2011; Nind and Vinha, 2013). This meant I could respond to differing needs and preferences of participants to enhance the accessibility of the research and strive for an unintimidating, enjoyable experience (Rabiee et al., 2005). As a result, people with a range of communication styles were able to participate, and interviews and focus groups were carried out with young people, mothers and professionals using photography, post-it notes, and an adapted Talking Mat (Murphy, 1998) to facilitate discussions.

Thematic analysis led to the construction of three themes, and Chapter Seven which provides contexts to the findings highlighting how transition is approached from different starting points and the meaning of transition varies across the three participant groups. The three themes, 'The Transition Minefield', 'Networks of Support', and 'The Push and Pull of Adulthood' are presented in Chapter Eight, Nine and Ten, respectively.

The research demonstrates that transition continues to be a challenging time, with issues attributed to a lack of information, poor planning, a lack of suitable opportunities, difficult parent-professional relationships and, the loss of friendships for young people. Despite young people having aspirations for their future, it was unclear how these aspirations would be met, and mothers and professionals reported numerous barriers that they believed prevented young people from flourishing in adulthood. This suggests that previous recommendations for a successful transition remain relevant. For example, early planning focused on the needs and wishes of the young person and the availability of information and advice (as examined in Chapter Three).

However, as I argue in Chapter Eleven, professionals supporting young people during transition need to consider young people's, and their families' wider contexts as parents have competing demands on their time and energy which impact the support they are able to provide the young person. Similarly, the findings suggest that professionals need to pay attention to interpersonal relationships and emotional wellbeing during transition. This includes maintaining young people's social networks, how professional-parental relationships develop, and the opportunities available for parental peer support. Whilst attending to these areas has been highlighted as necessary elsewhere (Townsley, 2004; Small et al., 2013; Gauthier-Boudreault et al., 2017; Codd and Hewitt, 2020), bringing the three participant groups together suggests that interpersonal relationships is not a key area of concern for professionals due to the absence of professionals from the theme 'Networks of Support.' Although they acknowledge difficult conversations with parents related to the young person being an adult, they did not draw attention to the difficulties expressed by parents in relation to their relationships with professionals nor did they discuss the importance of peer support or young people's friendships.

However, whilst proposing recommendations to improve transition may lead to a smoother transition, it does little to disrupt the normative underpinnings of transition and problematic constructions of adulthood outlined in Chapter Three. The dominant discourse of adulthood as independence (Arnett, 2001) is reflected in the themes concerning young people. Young people viewed themselves on a developmental trajectory as they moved towards adulthood with a prescribed way of being and a set of objectives to achieve, including changing relationship dynamics, employment, independence, behaving responsibly, and moving out of the family home. Whilst this is not surprising (Slater, 2015), the literature review has examined why it is problematic. Young people who fail to live up to the ideal norms are excluded, considered different, and positioned on the fringes of society. Some mothers expressed difficulty in viewing their children as adults due to the nature of their support needs. Some young people considered themselves different, left behind others of the same age, and other people's attitudes were seen as preventing the full inclusion of young people within society and thus limiting what young people could achieve.

As my research question did not restrict me to focusing on one particular area of transition over another, I was able to look across the themes and examine what bringing the three groups together revealed about transition. In doing so, I expose the complexity of transition, showing it to be a multidimensional, interconnected period of turbulence that is not captured within existing transition frameworks. Remaining open to different theories and treating them as tools to be used to advance the research as necessary led me to make connections with the work of Deleuze and Guattari (2004) and reconsider transition as an assemblage; an intricate network of context-dependent heterogeneous elements that constantly affect each other, limiting and enabling what is possible and shaping people's becomings. In light of this, I argue that transition should be perceived as a time to enable becomings with young people steeped in potential and no right way to be.

Thus, drawing on the perspectives of the three participant groups has contributed to understandings of transition by making visible the complexity of transition, and offering an alternative approach. It is an approach that has the potential to improve current experiences of transition and address the problems raised by participants, and in the extant literature, whilst also serving to disrupt the normative discourses that position people with learning disabilities as different. It is within this approach that my original contribution to knowledge lies.

My contribution to knowledge

Whilst other research within transition has brought the three participant groups together, it is usually done to examine a particular aspect of transition (see Chapter Three). Therefore, this study was different due to the attempt to examine the perspectives of the three groups without a specific aspect of transition in mind. In doing so, I am able to offer a new approach to transition, which has the potential to improve current experiences of transition in a practical manner whilst also acting as a form of conceptual activism (Hickey-Moody and Malins, 2007) and contributing to the dismantling of normative discourses which perpetuate the othering of people with learning disabilities. I argue that attending to a young person's assemblage encourages a more nuanced approach to transition, which reveals the complexity and draws attention to the multiple elements and lines of affect surrounding the young person and their wider contexts. In doing so, the issues raised by parents and young people within the findings would be exposed, and a creative approach is encouraged with experimentation welcomed to explore what might happen if elements are added or removed, lines of affect created or broken (Feely, 2016; Gibson et al., 2017). An assemblage framework draws attention to all elements' interconnectedness and thus deprivileges independence and agency (Fox and Alldred, 2014; 2017). It demonstrates how people are shaped and constrained by the connections surrounding them and encourages us to be sensitive to our role within this. In this manner, the assemblage both reflects and attends to current experiences. However, at the same time, as assemblages are constantly mutating and changing, they lack a fixed identity (Feely, 2020), and thus the assemblage stops transition from being viewed as an inevitable, naturalised process that people with learning disabilities have to go through. My proposal to relabel transition as a time to enable becomings moves away from focusing on narrow conceptualisations of adulthood, which people with learning disabilities are 'transitioned' into. Instead, we are all continually becoming, and the support young people might require to enable their becomings at this stage is, as stated in Chapter Twelve, simply part of the continued becoming of life (Slater, 2015). As a result of my approach, this thesis not only contributes to what is known about transition and the existing transition literature but also contributes to critical disability studies; I do not limit my proposals to calls for inclusion but seek to remove the problematic constructions which lead to exclusion in the first place.

The research assemblage

Encountering new materialism and, in particular, the work of Deleuze and Guattari (2004) has been instrumental in the arguments I developed as a result of the findings. However, it has also contributed to my development as a researcher. Understanding research as an assemblage (Fox and Alldred, 2017) brought clarity to my role and gave me confidence in my approach. The research assemblage brings forth the complexity and interconnectedness of research. Doctoral research is an entanglement of the researcher, their participants and supervisors, the institution they are working within and its buildings, books, ideas, technologies, locations, ideas, fears and desires. The thesis is the product of these different elements coming together. The initial design of my thesis reflects the research assemblage and who I was at that particular moment in time. The discussion is a reflection of the present and the flows of affect acting within the research assemblage over the previous four years (Ribenfors, 2021). Inevitably, whilst some decisions I have made, and elements that have entered into the research assemblage have opened up the research, others have constrained or limited it, and it is necessary to pay attention to some key areas where this has happened. Therefore, in the next section I focus on the limitations of the research and how these could be used to develop the research further. I then reflect on my role as a becoming researcher and how I have developed due to the research.

Limitations of the research

Whilst desiring to draw on the three participant groups to provide a rich understanding of transition, one limitation of this research is that I only draw on the perspectives of mothers and do not include other family members (e.g., fathers or siblings) who are likely to be an important part of a young person's transition assemblage. Although I argue within Chapter Eleven and Twelve the importance of considering people's wider contexts, including them as participants would offer a different perspective on transition and could lead to the development of different themes. Furthermore, fathers and siblings are two groups of people who are often neglected in disability research (Davys et al., 2017; Francis et al., 2018; Boyd et al., 2019), and my research does little to address this. The omission was not a deliberate decision but a result of my recruitment strategies and a reflection that mothers tend to be the main caregivers and thus feature more heavily in research (McConkey et al., 2008; Boyd et al., 2019).

I intended to return to participants during the data analysis stage to discuss the development of the themes. I considered this important from both an ethical perspective and to enhance the validity of the findings; researchers are in a position of power, particularly when analysing and interpreting other people's words in isolation from participants data (Mullings, 1999; Doucet and Mauthner, 2007; Ackerly and True, 2008) and, therefore, taking steps to mitigate this should be welcomed. In addition, checking back in with participants ensures data is not included which misrepresents participants or makes them feel uncomfortable (Nind, 2008). However, we do not know what elements might enter the research assemblage affecting the development of our research, and the outbreak of coronavirus was one such element. The multiple lockdowns during 2020 coincided with the data analysis stage of my research and it was not appropriate to return to participants during this time. The time parameters imposed by the PhD meant it was not possible to delay the research. Thus, the themes and the subsequent discussion chapters were developed in isolation from participants.

Future research

Whilst it is helpful to acknowledge the limitations of the research, reflecting on them offers possibilities to develop the research further. There is much to be gained from widening the participant pool and incorporating the perspectives of fathers and siblings into transition research (Gauthier-Boudreault et al., 2017).

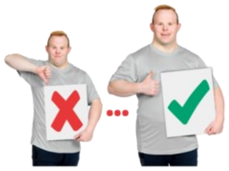
Furthermore, whilst this research took transition as the starting point, my developing understanding of critical disability studies has led me to consider problematic normative constructions. This was not helped by being unable to involve participants in developing the themes and the subsequent approach put forward. Thus, I propose that future research takes the ideas formed within Chapter Eleven and Chapter Twelve as the starting point exploring, with young people, their families, and professionals, how transition can be disrupted, how we can facilitate the enabling of becomings, and the mapping out of one's assemblage.

Becoming researcher

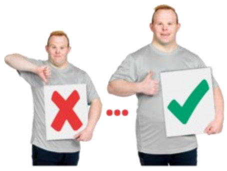
Dunne et al. (2005: 173) suggest that “if you do not feel transformed at the end of a substantial piece of research, you might want to question whether it was worth all the effort” and there is no doubt that I feel transformed. The research has been, and continues to be, part of my becoming. Parts of this were to be expected; I embarked on the PhD keen to develop my research skills and with a desire to develop my critical awareness, and this has certainly happened. I am currently working as a research assistant, which would not have been possible without the research undertaken, and I have learnt a lot from critical disability studies literature. I have become more aware of the normative discourses surrounding us and understand the need to go beyond a rhetoric of sameness or narrative of inclusion, both of which I now know fail to address the underlining othering of people with learning disabilities (Shildrick, 2012; Slater, 2015). I am also more sensitive of my role in perpetuating these discourses and more attuned to the power of language. However, whilst learning from different theoretical perspectives is to be expected within doctoral research, I was not expecting just how much I have learnt from engaging with Twitter, from following disabled people, parents, carers, allies, and activists, reading the information they share, their blogs and tweets. My growth in this area is reflected within my thesis and visible in my belief that literature should be treated as a ‘community of knowledge.’ The inclusion of Chapter Five and Chapter Six, meanwhile, chapters dedicated to ethics and the research participants respectively, demonstrate that ethical research is about so much more than just procedural ethics.

I believe I am a more conscientious and considerate researcher and person as a result of what people have shared. I am more aware of the multiple tensions within health and social care systems, the differing perspectives and the damaging impact practices and dehumanising language can have on people, causing me to reflect on my own practice.

Chapter Thirteen summary

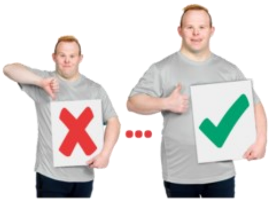
	This chapter is the last chapter.
	It tells you why the research is different to other research.
	It says how the research could be better.
	It explains how the research has changed Francesca.

Why the research is different

	This research is different to other transition research because it says we should think of transition as an **assemblage** and a time to **enable becomings**.
	Francesca thinks this will improve people's experiences of transition.
	Francesca thinks this will also help stop people thinking people with learning disabilities are different to other people.

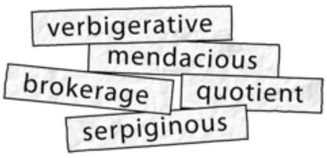
	Because this has not been said before it is called an **‘original contribution to knowlegde.’**

Making the research better

  	Francesca thinks 2 things would make the research better: 1. Including other family members of people with learning disabilities in the research. 2. Francesca meeting with the people who took part when she was writing the themes to check they were happy.

How Francesca has changed

	Francesca has learnt a lot from doing the research.
	Francesca has new skills as a researcher and now has a job as a research assistant.

	Francesca knows more about the things which make life difficult for people with learning disabilities and their families.
	Francesca thinks more about the words she uses and the things she does.

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Appendices

Appendix 1: Information sheet for parents

Participant Information Sheet

1. Study Title

Working title: Exploring transition to adulthood for young people with learning disabilities and their families.

2. Invitation

You are being invited to take part in a research project. Before you decide you need to understand why the research is being done and what it will involve for you. Please take time to read the following information carefully and discuss with others if you wish. Please ask me questions if there is anything that is not clear of if you would like more information. Take time to decide whether or not to take part. Thank-you in advance for taking the time to read this.

3. What is the purpose of the study?

The research is taking place as part of a PhD project at Manchester Metropolitan University. The aim of the research is to explore transitions to adulthood for young people with learning disabilities and their families in Greater Manchester. The transition period is often a difficult time for young people and their families. There are numerous challenges attached to transferring from children to adult services, very few people with learning disabilities enter into employment and transition can be viewed as a time which sets people with learning disabilities out as different from their non-disabled peers.

Therefore, I want to look at how transition can be improved and what can be learnt by exploring transition from the perspectives of those most affected by transition. To do this I want to talk to young people with learning disabilities, their parents and carers, and professionals to find out more about transition based on their individual experiences.

4. Why have I been invited?

You have been chosen as you fit the criteria for participants in the project. You live within Greater Manchester and, as a parent or carer of a child with learning disabilities who is in the ‘transition’ period or has been through it, you have first-hand experience of the process. Alongside yourself, I hope to meet with approximately 20 other people (including parents, professionals and young people with learning disabilities).

5. Do I have to take part?

It is up to you to decide whether or not to take part. If you do agree, once you have read the information sheet, you will be asked to sign a consent form. You will have a copy of the information sheet and consent form to keep for your personal records. If you do consent you can still withdraw at any time, without giving a reason.

6. What will happen to me if I take part?

If you agree to take part, you would meet with the researcher either in a focus group or as a 1:1 interview (lasting roughly an hour). She will visit you at a time and place of your choosing and talk with you about your experiences of the transition process. With your consent the meeting will be audio-recorded so that it can later be transcribed by the researcher.

7. What will I have to do?

Spend time with the researcher discussing your experiences of the transition process. Provide feedback to the researcher about the interviews at a later date to ensure your views are accurately recorded.

8. What are the possible disadvantages and risks of taking part?

You will have to give up your time to meet with the researcher. Due to the nature of the research topic there is a chance that you may touch on subjects that you find upsetting. If this happens the researcher will offer reassurances and offer to pause or stop the interview.

9. What are the possible benefits of taking part?

Whilst there are no immediate benefits for those people participating in the project, it is hoped that this work will allow people to better understand how the transition process is currently experienced. It is also hoped that the analysis of the data will contribute to shaping transition services for young people with learning disabilities in the future.

10. What happens if the research study stops earlier than expected?

If this is the case the reason(s) will be explained to you.

11. Will I be recorded, and how will the recorded media be used?

The interviews will be audio-recorded so that the researcher can transcribe the interviews for analysis. Handwritten notes may also be taken during the interview. Extracts from the transcripts may be used for illustration in conference presentations and in any subsequent write-up of the research, for example journal publications and the researcher's PhD thesis. However, any identifying features will be removed. No other use will be made of the recordings without your written permission, and no one outside the project will be allowed access to the original recordings.

12. What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do their best to answer your questions.
If you remain unhappy please discuss your complaint with:

Professor Carol Haigh
Brooks Building
Birley Fields Campus
Manchester
M15 6GX

Tel: 0161 247 5914
Email: c.haigh@mmu.ac.uk

13. Will my taking part in the study be kept confidential?

All the information that is collected about you during the course of the research will be kept strictly confidential. You will not be able to be identified in any reports or publication. Interview transcripts and original recordings will be password protected on the researcher's computer so that others do not have access.

14. What will happen if I don't carry on with the study?

You may withdraw from the study at any time. If you do choose to withdraw, the researcher will ask for your permission to use any data collected up to the point of withdrawal.

15. What will happen to the results of the research study?

Analysis from the project and excerpts from interviews may be published in journal articles, conference presentations and in the researcher's thesis for their PhD. As well as sharing findings with participants, they will also be shared with key stakeholders within Greater Manchester and further afield.

16. Who is organising or sponsoring the research?

The research is being funded by a Vice Chancellors Bursary at Manchester Metropolitan University and forms part of a PhD project.

17. Who has ethically reviewed the project?

The project has been reviewed by the Faculty of Health, Psychology and Social Care Ethics Committee at Manchester Metropolitan University.

18. Contact for further information:

For further information, please contact the researcher:

Francesca Ribenfors
Faculty of Health, Psychology and Social Care
Manchester Metropolitan University

Email: Francesca.Ribenfors@stu.mmu.ac.uk
Telephone: 07792919978

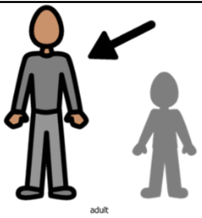
Thank you for taking the time to read this information

Appendix 2: Information sheet for young people

	My name is Francesca. I am a PhD student at Manchester Metropolitan University
	From September 2016 – September 2019 I am working on a research project.
	I am looking at **‘transition to adulthood’**
	I want to know what different people think about this.
	I would like to ask you some questions about what is important to you growing up.
	We will meet once and the meeting will last about an hour.
	You can choose where and when we meet. I could come to your house or we could go somewhere else.

	It is up to you whether you take part in the research. You can say no
	I would like to record our meetings so I can write about it later and tell other people what you say
	When I write about it and tell other people I will not use your name.
 	You can say yes you want to take part and you can still change your mind and say no.
	If you are unhappy with the research you can talk to: Professor Carol Haigh Brooks Building Birley Fields Campus Manchester M15 6GX Tel: 0161 247 5914 Email: c.haigh@mmu.ac.uk
	If you have any questions or would like more information you can contact me on 07792919978 or by email: Francesca.Ribenfors@stu.mmu.ac.uk

Appendix 3: Information sheet for participants using photography

	My name is Francesca. I am a PhD student at Manchester Metropolitan University
	From September 2016 – September 2019 I am working on a research project.
	I want to find out what happens when young people with learning disabilities grow up and leave school.
	I want to know what makes this easy, what makes this hard, and what is important to you growing up.
	I want to write about this and tell other people about it.
 	I would like you to take photos of what is important to you growing up.
	You can take photos of whatever you like. You could take photos of work, your home, going out, friends and family.

	You could take photos of what you would like to happen in the future. For example, where you would like to live or work.
	Don’t forget the camera has a flash. You can use this if there is not much light.
 	When you have finished let me know. I will collect the camera from you and get the photos printed.
	We can then meet to look at the photos together and talk about them.
	It is up to you whether you take part in the research. You can say no
	You can say yes you want to take part and you can still change your mind and say no
	I will not use your name in the research so people will not know you have taken part.

	If you have any questions or would like more information you can contact me on 07792919978 or by email: Francesca.Ribenfors@stu.mmu.ac.uk

Appendix 4: Information sheet for professionals

Participant Information Sheet

1. Study Title

Working title: Exploring transition to adulthood for young people with learning disabilities and their families

2. Invitation

You are being invited to take part in a research project. Before you decide you need to understand why the research is being done and what it will involve for you. Please take time to read the following information carefully and discuss with others if you wish. Please ask me questions if there is anything that is not clear of if you would like more information. Take time to decide whether or not to take part. Thank-you in advance for taking the time to read this.

3. What is the purpose of the study?

The research is taking place as part of a PhD project at Manchester Metropolitan University. The aim of the research is to explore transitions to adulthood for young people with learning disabilities and their families in Greater Manchester. The transition period is often a difficult time for young people and their families. There are numerous challenges attached to transferring from children to adult services, very few people with learning disabilities enter into employment and transition can be viewed as a time which sets people with learning disabilities out as different from their non-disabled peers.

Therefore, I want to look at how transition can be improved and what can be learnt by exploring transition from the perspectives of those most affected by transition. To do this I want to talk to young people with learning disabilities, their parents and carers, and professionals to find out more about transition based on their individual experiences.

4. Why have I been invited?

You have been chosen as you fit the criteria for participants in the project. You live (or work if you are a professional) within Greater Manchester and have first-hand experience of the transition process or devolution. Alongside yourself, I hope to meet with approximately 17 other people.

5. Do I have to take part?

It is up to you to decide whether or not to take part. If you do agree, once you have read the information sheet, you will be asked to sign a consent form. You will have a copy of the information sheet and consent form to keep for your personal records. If you do consent you can still withdraw at any time, without giving a reason.

6. What will happen to me if I take part?

You can choose how you wish to take part in the project. You can meet with the researcher for roughly an hour to discuss your views on the transition process. Alternatively, this discussion can take place over the telephone or the researcher can send you an email with some questions for you to answer in your own time. The meeting (or telephone call) will take place at a time (and place) of your choosing. The meeting or telephone call will be recorded so that it can later be transcribed by the researcher.

7. What will I have to do?

Spend time with the researcher discussing your views and experiences of the transition process either in a face to face meeting or via a telephone call or answer questions via an email.

8. What are the possible disadvantages and risks of taking part?

You will have to give up your time to meet with the researcher. Due to the nature of the research topic there is a chance that you may touch on subjects that you find upsetting. If this happens the researcher will offer reassurances and offer to pause or stop the interview.

9. What are the possible benefits of taking part?

Whilst there are no immediate benefits for those people participating in the project, it is hoped that this work will allow people to better understand how the transition process is currently experienced. It is also hoped that the analysis of the data will contribute to shaping transition services for young people with learning disabilities in the future.

10. What happens if the research study stops earlier than expected?

If this is the case the reason(s) will be explained to you.

11. Will I be recorded, and how will the recorded media be used?

The interviews will be audio-recorded so that the researcher can transcribe the interviews for analysis. Handwritten notes may also be taken during the interview. Extracts from the transcripts may be used for illustration in conference presentations and in any subsequent write-up of the research, for example journal publications and the researcher's PhD thesis. However, any identifying features will be removed. No other use will be made of the recordings without your written permission, and no one outside the project will be allowed access to the original recordings.

12. What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do their best to answer your questions.

If you remain unhappy please discuss your complaint with:

Professor Carol Haigh
Brooks Building
Birley Fields Campus
Manchester
M15 6GX

Tel: 0161 247 5914
Email: c.haigh@mmu.ac.uk

13. **Will my taking part in the study be kept confidential?**

All the information that is collected about you during the course of the research will be kept strictly confidential. You will not be able to be identified in any reports or publication. Interview transcripts and original recordings will be password protected on the researcher's computer so that others do not have access.

14. **What will happen if I don't carry on with the study?**

You may withdraw from the study at any time. If you do choose to withdraw, the researcher will ask for your permission to use any data collected up to the point of withdrawal.

15. **What will happen to the results of the research study?**

Analysis from the project and excerpts from interviews will be published in journal articles, conference presentations and in the researcher's thesis for their PhD. As well as sharing findings with participants, they will also be shared with key stakeholders within Greater Manchester and further afield.

16. **Who is organising or sponsoring the research?**

The research is being funded by a Vice Chancellors Bursary at Manchester Metropolitan University and forms part of a PhD project.

17. **Who has ethically reviewed the project?**

The project has been reviewed by the Faculty of Health, Psychology and Social Care Ethics Committee at Manchester Metropolitan University.

18. **Contact for further information:**

For further information, please contact the researcher:

Francesca Ribenfors
Faculty of Health, Psychology and Social Care
Manchester Metropolitan University

Email: Francesca.Ribenfors@stu.mmu.ac.uk

Telephone: 07792919978

Thank you for taking the time to read this information

Appendix 5: Consent form for young people

Note to ethics committee: The participants in this research may have a range of communication needs. Therefore, whilst this consent form shows the information that will be provided, the exact layout and wording may vary depending on the individual participant. Please also note that both 'yes' and 'no' options are given to participants to ensure that they are aware they have a choice. If just 'yes' was given, participants may feel obliged to tick this box.

Consent form

Consent is being asked if you agree to something

This means saying yes or no

I have read the information I was given and I have asked if there was anything I was unsure about.

yes ✓ ☐ no ✗ ☐

I am happy to talk to the researcher and for her to visit me.

yes ✓ ☐ no ✗ ☐

I am happy to talk about what is important to me growing up

yes ✓ ☐ no ✗ ☐

I am happy for other people to read about my life (my name will not be used)

yes ✓ ☐ no ✗ ☐

I know that if I do take part in the research I can stop at any time.

yes ✓ ☐ no ✗ ☐

I agree to take part

yes ✓ ☐ no ✗ ☐

Name: ____________________

Date:_____________

Signature____________________________________

Signature of parent/carer if under 18______________

Signature of researcher__________________________

Appendix 6: Consent form for professionals and parents

Participant Identification Number for this project:

CONSENT FORM

Title of Project: **Towards Adulthood: exploring transitions to adulthood for young people with learning disabilities and their families.**

Name of Researcher: **Francesca Ribenfors**

Please initial all boxes

1. I confirm that I have read and understand the information sheet/letter/email (delete as appropriate) for the above study dated_____________. I have had the opportunity to consider the information and ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. ☐
3. I agree that the interviews will be audio-recorded and that verbatim quotes may be used in subsequent publications relating to the research project. ☐
4. I understand that my responses will be anonymised before analysis. I give permission for the researcher's supervisors to have access to my anonymised responses. ☐
5. I agree to take part in the above research project. ☐

____________________	____________________	____________________
Name of Participant	Date	Signature
____________________	____________________	____________________
Name of researcher	Date	Signature

To be signed and dated in presence of the participant

Appendix 7: Interview guide

Parents

- Introduce myself and explain about the research/PhD.
- Check information sheet/consent form and whether they have any questions.

Prompt questions:

- Can you tell me about your son/daughter?
- What is your son/daughter currently doing? (I.e., across education, social participation, relationships, living situation)
- Can you tell me about your experiences of transition?
- What is working well?
- What is not working well?
- How could transition be done differently?
- Can you tell me about what your hopes and expectations for the future and your child's hopes and expectations for the future?

Young people

- Introduce myself and explain about the research/PhD
- Check information sheets/consent forms and whether they have any questions
- Reiterate there are no right or wrong answers, they can leave if they want to/stop whenever they want and don't have to talk about anything they don't want to.
- If using photos explain I have not looked at the photos and give them to participants to look at first (explain they can take out any they are not happy with). Explain it would then be good to go through them together and they can tell me what each photo is about.

Prompt questions/topic areas

- Can you tell me what you are currently doing? (i.e., college/work/activities/living situation)
- What does transition to adulthood mean?
- What is important to you now and in the future?
- What barriers are in place and what support is required?
- What are your hopes and expectations for the future?
- What would a good day look like?
- What would a bad day look like?

(if necessary, prompt in regards to housing, relationships, education/activities/work, social participation)

Professionals

- Introduce myself and explain about the research/PhD.
- Check information sheet/consent form and whether they have any questions.

Prompt questions

- Can you tell me about your role?

- What is transition? Can you tell me about your experiences of transition? What is the current situation like?
- What works well / what doesn't work well in relation to transition?
- What could be done differently?