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Author:
Hewitt-Stubbs, Mair

Title:
Exploring disabled young people's experiences of emerging adulthood using photovoice and other participatory, creative methods.

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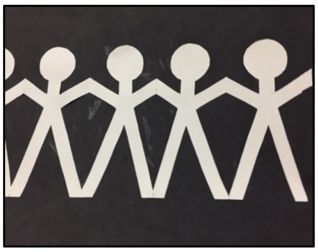
Exploring disabled young people's experiences of emerging adulthood using photovoice and other participatory, creative methods.

Mair Hewitt-Stubbs
September 2020



Doctoral dissertation submitted to the University of Bristol in accordance with the requirements for the award of the degree of Doctor of Educational Psychology (DEdPsy) in the Faculty of Social Sciences and Law (FSSL), School for Policy Studies, Norah Fry Research Centre, University of Bristol. *Word count: 44,962*

Abstract

Our lives are characterised by transitions and arguably the most “complex and far-reaching” (Heslop et al., 2002, p.2) of these is the transition to adulthood. This is especially true for disabled young people, who face additional challenges. Despite an abundance of research, legislation and guidance on how to negotiate successful transitions, support continues to fall short of expectation. Arguably, current approaches promote normative, linear developmental trajectories and outcomes for ‘successful’ adulthood. These fail to take account of potential differences relating to the experience of being disabled.

The aim of this study was to explore disabled young people’s conceptualisations and experiences of emerging adulthood and the opportunities and support needs they identified as important in preparation for transition. Given that little previous literature has attended to the gendered experiences of disabled young people, this study was also interested in the potential role of gender in shaping their experiences and future aspirations.

Six disabled young men and women aged 18-25, attending a specialist, residential college took part in this qualitative study which used photovoice and other participatory, creative methods to elicit their views. Thematic analysis of the data generated several themes and subthemes. Participants described emerging adulthood as a journey characterised by change and progression and highlighted the importance of this period for identity exploration and purpose-seeking. Although driven to become increasingly independent in many areas, participants valued ongoing support from others and the interdependent nature of these relationships. Participant’s accounts indicated an acceleration towards adulthood however, in contrast to the literature, they perceived this positively. Findings also revealed significant differences between the disabled young men and women, which were not being routinely acknowledged or discussed during transition planning. Finally, participants identified several key areas for support, including practical and social skill-building, fostering of resilience and person-centred planning.

There are implications for professionals, including Educational Psychologists, in relation to providing support to this group that is not based on normative assumptions of adulthood but recognises the heterogeneity of their experiences and aspirations. A framework, based on Bronfenbrenner’s (1979) ecological systems model, is put forward to guide collaborative conversations and co-construction of goals that are meaningful to each disabled young person.

Acknowledgements

It is only right that I begin by thanking the young people who took part in the research. Their commitment, energy and honesty was inspiring and I feel privileged to have had this opportunity to talk with them about their lives. Thanks also to the college staff who facilitated the research process and made sure everyone was in the right room at the right time (not always an easy feat!).

I am extremely thankful to my supervisor, Professor David Abbott, for his infinite knowledge and experience in this area of research and for achieving the balance of challenge and guidance I required. Thanks also to the Bristol DEdPsy tutor team for all your solution-focused support over the last three years and for helping me to develop an understanding of the sort of Educational Psychologist I hope to become.

A huge thank you to my wonderful TEP colleagues. Without your reassurance, humour and vast amounts of cake, I’m not sure I would have made it past the first term! I have learnt so much from you all and couldn’t have wished for a better group of women to embark on this journey with.

Finally, thank you to my friends and family for their endless encouragement, patience and providing some much-needed distraction when things got tough. Most of all, thank you to my fiancé Max…you have been there through the highs and lows and believed in me every step of the way and for that I am forever grateful.

Declaration

I declare that the work in this dissertation was carried out in accordance with the requirements of the University's Regulations and Cope of Practice for Research Degree Programmes and that it has not been submitted for any other academic award. Except where indicated by specific reference in the text, the work is the candidate's own work. Work done in collaboration with or with the assistance of others, is indicated as such. Any views expressed in the dissertation are those of the author.

Signed: [redacted]

Date: 24/08/2020

Table of Contents

List of Tables and Figures

List of Abbreviations and Acronyms

CYP	Children and young people
DfE	Department for Education
DMD	Duchenne muscular dystrophy
EA	Emerging Adulthood
EP	Educational Psychologist/s
EPS	Educational Psychology Service
ID	Intellectual Disability/ies
LA	Local authority/ies
LD	Learning Disability/ies
SEND	Special Educational Needs and Disabilities
TtA	Transition to adulthood
YP	Young people/ person

1. Introduction

1.1. Overview of thesis

This thesis contributes to existing literature around disabled young people's (YP) experiences of emerging adulthood (EA) and the support needs that they identify as important in preparation for transition. The research was undertaken as part of a three-year Doctorate in Educational Psychology at the University of Bristol. A qualitative approach was used - in line with my interpretivist epistemological stance - to better understand the conceptualisations and lived experiences of EA for six disabled YP aged between 18 and 25, who are attending a specialist, residential college.

Within this introductory chapter, I explain my personal motivation for carrying out research in this area of EA and provide further rationale, with reference to the issue of 'normative transitions' and both the fit and the 'mis-fit' with the experiences and aspirations of disabled YP. I introduce some key concepts relevant to the research, Arnett's (2000) theory of EA and the social-relational model of disability. Finally, I present the overall aims of the research and outline the following chapters.

1.2. My personal interest in the topic

Having completed my undergraduate degree in Psychology and with very little idea about which direction to go in next, I took a voluntary position in a Behaviour Support team at a specialist, residential college for disabled YP. Initially intended to be a few months experience for my CV, this turned into six years of employment and inspired my enrolment on the doctorate. During my time there, I gained a privileged insight into the lives of the students. Being in my early 20s, a similar age to many of the YP I was supporting, this enabled conversations about our experiences and aspirations as emerging adults, both shared and different. I reflected on my own experiences of 'growing up', the challenges, opportunities and relationships I was forming along the way and considered how these played a significant part in shaping the adult I would become.

‘Transition’ was high on the agenda, almost from the moment YP arrived at the college. Each student was assigned a transition officer, with whom they worked closely to explore their options for after college and create a plan. Although I understood the need for this proactive approach, given how little was often available to disabled YP, I worried that such hype around transition may overshadow other more important needs and priorities at this time. Putting pressure on YP to make decisions about their future seemed at odds with how I perceived this period of life, as relatively free from responsibility and an opportunity to try new things, make mistakes and learn from them.

Furthermore, I questioned the seemingly short-term nature of transition plans, the narrow focus on what could possibly have been considered as ableist outcomes and how these had been selected as being most meaningful to the disabled YP. Given their individuality, in terms of past experiences, strengths and interests and the nature of their impairments, it did not seem helpful to promote linear pathways based on normative assumptions of what a ‘good’ transition should look like. This issue resonated with me and I felt compelled to understand more about their lived experiences of EA and how these shaped their future goals and aspirations.

1.3. Broader rationale for research

Our lives are characterised by transitions, which often involve a process of movement from one environment or circumstance to another (Rous et al., 2007). Arguably one of the most “complex and far-reaching” (Heslop et al., 2002, p.2) of these is the transition to adulthood (TtA). For many YP, this can be an emotionally demanding time, with the combination of internal changes involved in puberty and external changes of leaving education, possibly starting work and moving out of the parental home. However, for disabled YP, the TtA can prove to be more complex as they face the additional challenge of moving from child to adult services. These services are often different in terms of culture and organisation, which can make it difficult to coordinate and leads to discontinuity, arising from “confusion and bargaining over inter-organisational relationships and responsibilities.” (Hudson, 2006, p.53)

The TtA for disabled YP in the UK has been a focus of attention for policymakers and practitioners for over 20 years. Despite an abundance of legislation and good practice guidance on how to negotiate a successful move from child to adult services (discussed in Chapter 2) support continues to fall short of expectation (Abbott & Carpenter, 2014). In addition to the poor communication between agencies and professionals, early research by Morris (2002) identified several other barriers to effective transition planning, including:

- Failure to involve disabled YP and their families in decision-making;
- Lack of easily accessible, comprehensive and up-to-date information about their options;
- Few opportunities to socialise and make friends;
- Varying availability of supported employment;
- Difficulties getting quality assessments of need and necessary support and equipment;
- Limited choice for disabled YP about where they live and often required to 'fit' existing provision.

The tone of transition research has changed little over the years and there is an ongoing narrative of concern regarding the lack of effective, person-centred support for disabled YP and their families at a time when they need it most. Furthermore, disabled YP are often treated as an "almost entirely homogeneous group" (Abbott & Carpenter, 2014, p.1202) and there has been minimal recognition of other important aspects of their identity (e.g. gender, race, sexuality) and how these intersect. Some researchers go as far as to raise the question of whether it is time to give up on the 'industry of transition' altogether, given the adverse effects that a poorly planned transition can have on both physical and mental health outcomes and the ways in which it limits opportunities for full participation in adult life. Although this may seem drastic, it is clear that a change of focus is required. There is growing support for a move away from 'the idealised transition' with its normative developmental trajectories and expectations, towards a model of support that takes account of the differences relating to the experience of being disabled (Abrams et al., 2020; Gibson et al., 2013; O'Dell et al., 2018) and addresses deficits in the environment rather than the individual (Yates & Roulstone, 2013). With this in mind, I argue that a richer understanding of how disabled YP conceptualise and experience this important life stage, is required.

1.4. Introduction of key concepts

1.4.1. Arnett's theory of emerging adulthood

> Emerging adulthood is a time in life when many different directions remain possible, when little about the future has been decided for certain, when the scope of independent exploration of life's possibilities is greater for most people than it will be at any other period of the life course (Arnett, 2000, p.469).

EA is a theory of development which argues that the period from the late teens to the mid-20s (approximately 18-25), is "neither adolescence nor young adulthood but is theoretically and empirically distinct from them both" (Arnett, 2000, p.469). Arnett acknowledges that EAs in Western societies are no longer dependent on others, as they were in childhood and adolescence, yet do not have the level of enduring responsibility characteristic of adulthood. This allows them the freedom to explore a variety of possible life directions in areas such as love, work and world views. Arnett (2004) noted the five core characteristics of EA as *identity explorations, instability, self-focus, feeling in-between adolescence and adulthood,* and *a sense of broad possibilities for the future*.

Arnett's theory of EA, whilst widely accepted, has been subject to criticism, particularly in its promotion of discontinuous development and 'life-stages' (Bynner,2005). This could be considered prescriptive and infer that failure to achieve each stage at the right age may be thought of as abnormal or problematic (Salt, 2019). Furthermore, as the theory of EA was developed in response to changing demographic trends in Western societies, with YP delaying traditional markers of adulthood such as employment, marriage and having children in favour of self-exploration and psychosocial development, it may not be generalisable to those in other cultures, of different ethnicity and lower socio-economic status (Cote & Bynner, 2008). Arnett himself recognised these limitations and proposed that further research be carried out to examine the form EA takes in different countries worldwide (Arnett, 2007). It is also important to note that his theory was based on a sample of typically developing University students and little research has subsequently explored experiences of EA for other minority groups, such as disabled YP, hence the motivation behind the present study.

1.4.2. Conceptual models of disability

The term ‘disabled young people’ is used throughout this thesis to describe those experiencing a physical impairment. This identity-first language is in keeping with current usage in disability studies and reflects a belief that disability is not ‘something within’, rather that people are disabled by the world around them as a result of social discrimination and exclusion (Morris, 2001). This view comes from the social model of disability which will be discussed further now, alongside two other prominent models.

Disability is arguably a contested concept that has social, psychological, biological, historical and political dimensions (Goodley, 2011). Beliefs differ as to what constitutes the ‘origin’ of disability, which in turn effects how the label is applied and to whom. Two predominant models have been theorised which seek to explain how disability is understood and experienced through alternative lenses. Those ascribing to the medical model of disability, view disabled people as inherently different, victims of a personal tragedy who are dependent on the expertise of professionals to help bring them closer in line with the norm (Oliver, 1996). Framing disability in this individualised way can be potentially harmful, as it portrays it as an innate ‘problem’ belonging to the disabled person and is likely to alter how others perceive and treat them as well as their own sense-of-self (Goering, 2010).

Alternatively, advocates of the social model view disability within the context of society and place the ‘problem’ not with the individual but as a result of disabling social arrangements and infrastructure (Finkelstein, 1980). As Oliver (1996) states, this includes;

> All of the things that impose a restriction on a disabled person; ranging from individual prejudice to institutional discrimination, from inaccessible public buildings to unusable transport systems, from segregated education to excluding work arrangements, and so on (p.21).

This social understanding of disability is considered to be empowering, as it positions impairment as an important part of human diversity that should be respected, valued and celebrated (Goodley, 2011). It has been transformative in addressing the oppression experienced by disabled people, developing a political dimension to disability movements and fighting for their improved economic, social and political rights however, it has been suggested that it is inadequate in explaining all the challenges that people with chronic impairments face (Hoskin, 2017). This has prompted a demand from feminist disabled writers and activists to 'bring back the body' (Crow, 1996).

A social-relational model has since been proposed, which acknowledges that disability is experienced through the body but is also socially constructed and culturally located (Thomas, 2004). This model recognises the 'impairment effects', that is, the restrictions imposed on disabled people that are directly attributable to the nature of their impairment (Thomas, 1999). There has been further consideration of the psycho-emotional dimension of disability, referred to as 'barriers to being' (Thomas, 1999) and how they can often be internalised, leading to a belief that their impairment is to blame for their marginalisation, a lack of confidence and reduced aspirations (Hoskin, 2017). It has been suggested that these barriers to being will have particular significance during childhood, when children are developing their identity and "laying the foundations of self-confidence and self-worth for years to come" (Connors & Stalker, 2007, p.31). As Arnett has recognised that identity exploration continues into EA, it is likely that barriers to being will continue to play a significant role in the lives of disabled YP.

By focusing on the lived experiences of disabled YP, the focus is shifted away from the medical model, which emphasises issues such as suffering or searching for a cure *and* the social model, which ignores important 'impairment effects', to a social-relational model that seeks a more holistic, interactional understanding.

1.5. Research aims

The aim of this research is to, first and foremost, listen to and represent the views of disabled YP and explore their conceptualisations and lived experiences of EA. Within these discussions, I want to pay attention to the role of gender and how the similarities and differences between disabled young men and women are considered during transition planning. Finally, I hope to develop a greater understanding of the opportunities and support needs identified as important by disabled YP and facilitate a sharing of key messages with relevant stakeholders and services, so that they can improve support.

1.6. Thesis outline

Chapter 1 has provided a personal and professional background to the study, highlighted its significance and introduced the relevant concepts of transition, EA and a social-relational model of disability.

Chapter 2 will present a critical review of the existing literature around TtA for disabled YP, including the historical and political context, transition experiences, meaning of adulthood, current support and the emerging role for Educational Psychologists (EPs). Gaps in the literature will be highlighted, providing a justification for the present study.

Chapter 3 will present the methodology, including the approach to theory and research, philosophical assumptions and commentary on my role within the research. The research context will be described, along with sampling strategy, an outline of the four-phase research design and description of methods. The reasons for selecting thematic analysis will be presented and ethical considerations discussed, including the measures taken to address them.

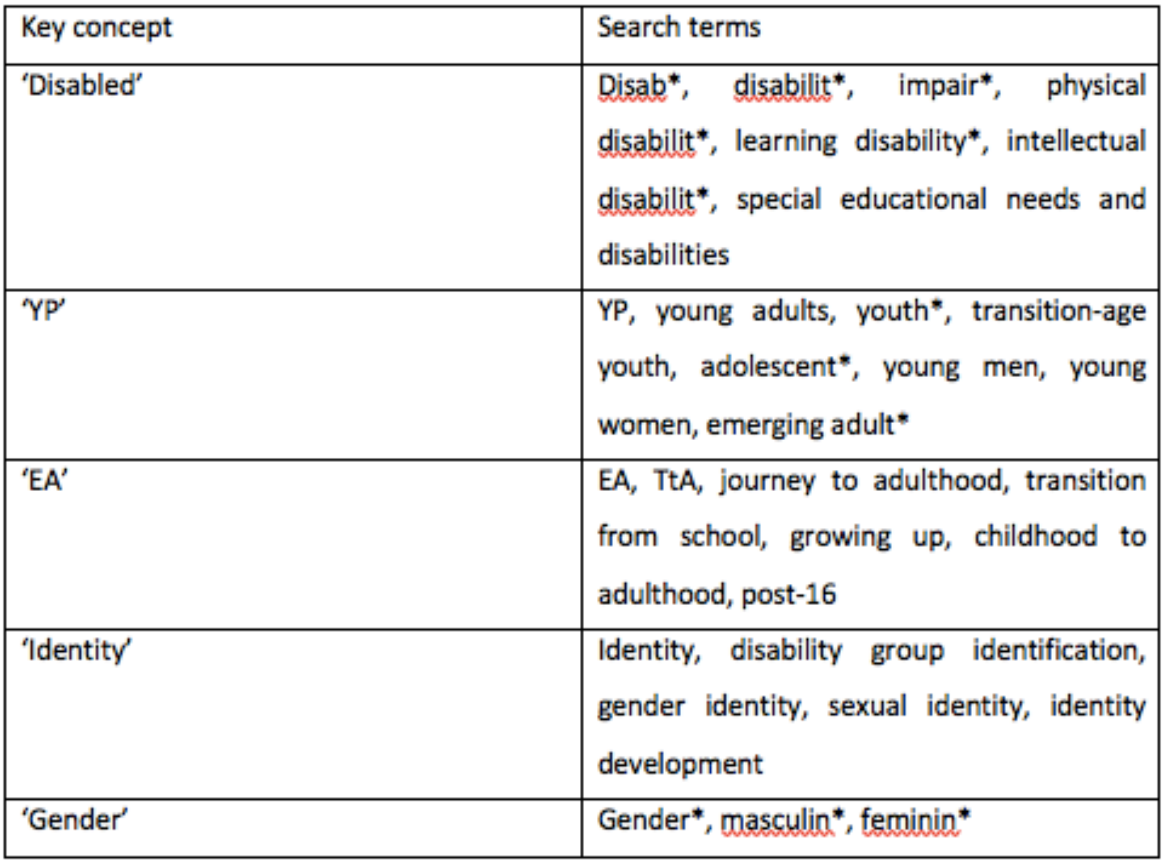
Chapter 4 will present the findings, with themes and subthemes organised into four thematic maps under each of the research questions. Participant's photographs and accompanying quotes will be included to support the reader's understanding of how themes and subthemes were generated.

Chapter 5 will begin with a summary of findings for each research question and then relate these to the existing literature. It will consider the implications for practice and propose a framework that aims to guide practitioners' conversations with disabled YP about EA. This chapter concludes with a critical evaluation of the research with reference to its strengths and limitations, suggestions for future directions and some key reflections from the research process.

2. Literature Review

2.1. Approach to the literature search

A systematic approach was adopted when searching and collating literature that was pertinent to the research questions. An initial scope of the literature was carried out in August 2018, to gain a broad understanding of the volume and genre(s) of relevant research and generate key search terms, which can be found in the table below:



Key concept	Search terms
'Disabled'	Disab*, disabilit*, impair*, physical disabilit*, learning disability*, intellectual disabilit*, special educational needs and disabilities
'YP'	YP, young adults, youth*, transition-age youth, adolescent*, young men, young women, emerging adult*
'EA'	EA, TtA, journey to adulthood, transition from school, growing up, childhood to adulthood, post-16
'Identity'	Identity, disability group identification, gender identity, sexual identity, identity development
'Gender'	Gender*, masculin*, feminin*

Table 1. Key search terms

In July 2019, using the University of Bristol Library website, six recommended databases were searched: British Education Index, Educational Resource Information Centre (ERIC), PsychINFO, PsychARTICLES, Web of Science and Child Development and Adolescent Studies. In addition, the British Library's Electronic Thesis Online Service (EThOS) was used to identify unpublished doctoral theses of relevance to the topic and other 'grey' literature was found using Google Scholar. As relevant literature was identified, hand searches through reference lists led to identification of further related research. Once the search was complete, duplicates, studies with limited relevance and those that did not meet inclusion and exclusion criteria were removed based on reading the titles and abstracts.

2.1.1. Inclusion and exclusion criteria

Titles had to contain at least three of the search terms listed above. All study methodologies (e.g. qualitative, quantitative, mixed methods) were included. Articles were selected on the basis of meeting the following criteria;

- *Language and location*- studies must be written in English and conducted in the UK or other Western countries that are comparable to the UK context (e.g. Spain, Australia, Canada, America).
- *Timeframe*- studies must be conducted between 2000-2020 as this is the period of time following the conception of 'EA' and the introduction of important legislation.
- *Relevance*- studies must be directly relevant to the topic/ population of interest. For example, research participants must be within, or close to, the 18-25 age range and there should be a focus on the holistic experience of EA for YP and their families. Participants nature and severity of disability vary.

2.1.2. Literature search strategy

Searches yielded the following results which, in the interests of transparency, have been presented in a flow diagram:

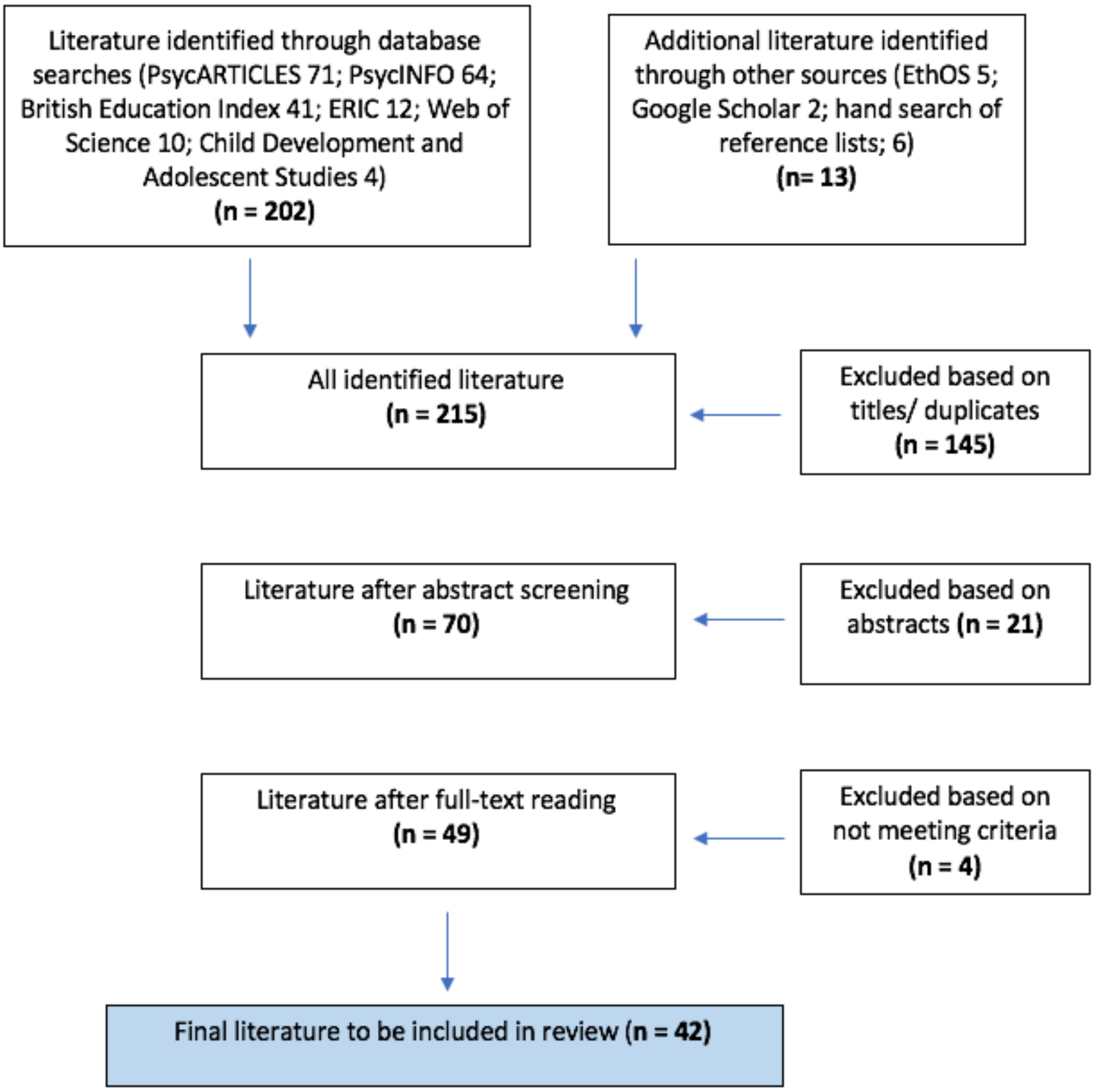


Figure 1. Literature search strategy

2.1.3. Structuring the literature review

The selected literature was organised into a table, based on the key themes presented by the authors. This helped to structure the literature review, by focusing on the most salient ideas which subsequently became useful headings and sub-headings. It is important to note that although the literature has been organised in this way, there is considerable overlap and many studies highlight multiple themes.

Quality criteria, adapted from the Critical Appraisal Skills Programme (CASP, 2013) was used as a guide to critically appraise research. The criteria included consideration of the appropriateness of aims, methodology, research design, recruitment procedures, data collection, any potential biases, ethical issues, data analysis and findings and overall contributions to the field (Appendix 1).

2.2. Policy and legislation

This section will outline relevant policy and legislation around educating and supporting disabled children and young people (CYP) and those with special educational needs and disabilities (SEND). It will then look more specifically at what is currently in place for those transitioning to adulthood.

2.2.1. Historical and political context

*The Warnock Report (*1978) was a key landmark in the history of SEND as it prompted a fundamental shift in discourse and the introduction of policies that shaped the way in which CYP are supported and educated today. Prior to this, many CYP with SEND were deemed ineducable or placed in segregated provisions such as hospitals or institutions (Elson, 2011). The report gave rise to the 1981 Education Act, which also coincided with the United Nations International Year of the Disabled and recommended major changes in how SEND was understood, identified, assessed and supported. It also enabled parents to appeal against decisions made about their CYP's SEND and support, a right which continues to be exercised within a landscape where tribunals are becoming an increasing occurrence.

Legislation continued through the 1990s and early 21th century. The 1993 Education Act introduced the first *SEND Code of Practice* (SEND CoP) (DfE, 1994), which detailed how LAs and school governing bodies were expected to carry out their duties. *Valuing People; A New Strategy for Learning Disability in the 21st Century* (2001) set out an action plan to improve support for people with learning disabilities (LD) from birth through to old age and reinforced four key principles;

1. That people with LD should have equal legal and civil rights.
2. That people with LD should be given the chance and the means to lead more independent lives.

3. That people with LD should have more choice and be able to express and achieve their preferences.
4. That people with LD should be included in mainstream society.

To support this and establish legal rights for CYP with SEND in compulsory and post-16 education, training and other student services, the SEND Act (DfE, 2001) was passed. The aim was to eradicate discrimination against disabled students across these settings, promote social inclusion and highlight “the importance of continuing education for all and acknowledgement that disabled learners should have the same opportunities as others” (Clark, 2003, p.186). In line with this, the Disability Discrimination Act (1995, 2005) and the Equality Act (2010) stated that various organisations were required to make reasonable adjustments for disabled CYP so that they did not experience significant disadvantages in comparison to their non-disabled peers. Furthermore, the *Every Disabled Child Matters* (EDCM) campaign was launched in 2006 by several leading organisations working with disabled children and their families. EDCM helped to secure £440m of extra funding for services for disabled children and was instrumental in lobbying and monitoring implementation of the Children’s and Families Act (2014), discussed further in the following section.

A government report, *Improving the Life Chances of Disabled People* (Prime Minister’s Strategy Unit, 2005) set out its vision that by 2025, “disabled people in Britain should have full opportunities and choices to improve their quality of life and will be respected and included as equal members of society” (p.7). It focused on the four key areas of helping disabled people to achieve independent living, improving support for families with disabled children, facilitating a smooth transition into adulthood and improving support and incentives for getting and staying in employment. Regarding the third area of transition planning, the report highlighted a need for overlap of child and adult services to avoid the ‘cliff edge’ of provision that many disabled YP face. It also emphasised the importance of individualised budgets, accessible information and person-centred processes.

Despite these numerous initiatives, policies and laws which have led to some positive developments over the last few decades, progress has been limited and there remains “huge inconsistencies in the quality and range of provision offered" (Elson, 2011, p.158). In accordance with the Education and Skills Act (DfES, 2008), the minimum age that YP can leave full time education has risen from 16 to 18, therefore, it is important that they have access to a range of high-quality provision and support, in order to successfully negotiate their journey to adulthood. The Act also contained measures that should be taken to support YP accessing post-16 education, particularly those who face barriers to participation and included reference to the Connexions Service amongst other sources of support. The following section will explore what further, specific guidance has been put in place in the UK, to ensure this is a reality for disabled YP.

2.2.2. Support for disabled young people in the UK preparing for adulthood

Arguably the most significant piece of statutory guidance to emerge in the last 10 years has been the revised SEND CoP (DfE, 2014). This coincided with the introduction of the Children and Families Act (2014) and Care Act (2015), which brought in a single system of integrated Education, Health and Care Plans (EHCPs) for all students from 0-25 years of age. Prior to these, guidance documents such as *Transition: getting it right for YP* (DoH & DfE, 2006) and *Transition: moving on well* (DfCSF & DoH, 2008) had highlighted the risks for YP with long term health and care needs, but not led to great improvements in transition support. The reforms, therefore, aimed to increase protection for these YP and to promote a greater focus on outcomes and preparing for adulthood.

Chapter 7 of the SEND CoP (2014) recognises the diversity of the post-16 education and training landscape and stipulates that all settings, including mainstream school sixth-forms, specialist further education colleges and post-16 training providers, have a duty to cooperate with the local authority (LA) on arrangements for YP with SEND and put appropriate support in place. Chapter 8 sets out how professionals across education, health and care should support YP with SEND to begin thinking about and preparing for adult life from Year 9 at the latest and that this support should "centre around the child or YP's aspirations, interests and needs" (p.122). Furthermore, the *Preparing for Adulthood* programme provided a planning tool that matched the four key outcome areas outlined in Chapter 8 (Employment, Independent Living, Community Inclusion and Health) and suggested activities and resources that could support progress towards these outcomes at different ages and stages of development.

The SEND CoP (2014) places a greater focus on the participation of CYP and their parents/carers in decision-making processes regarding their support and future. The importance of listening to CYP and adopting a person-centred approach has been consistently emphasised in previous UK policy, including *Every Child Matters* (2003) and the *Munro Review of Child Protection* (2012). Various LAs have also published 'best practice' guidance documents on person-centred planning, for example, the Tower Hamlets model (2015) which was adapted from Helen Sanderson's work and developed through a pilot project with several schools in the area. Given the focus within policy and legislation on CYP voice and increasing their participation, this literature review will begin by looking at the research around how disabled YP and their families experience the TtA.

2.3. Transition experiences

When searching for literature on the broader topic of EA, it was difficult not to acknowledge studies that focused specifically on transition experiences. As mentioned in Chapter 1, there is a narrative of concern around the quality of transition support in place for disabled YP and therefore it is an area that has been well researched over the last 20-30 years. Perhaps surprisingly- given the legislation described above- much of this research has been from the perspective of parents/carers, rather than the disabled YP themselves. This section will begin by looking in more detail at the potential reasons behind this lack of participation. It will then examine key findings from studies on transition experiences, highlight the pervasive theme of limited choice and control and finally, consider the psychological impact that transition can have on those it is designed to help.

2.3.1. Lack of young person participation in transition research and planning

Jacobs et al. (2018) carried out a recent systematic review of 14 studies that looked at experiences of transition to adult services for YP with profound intellectual disabilities (ID). Amongst key themes, they noted a significant lack of YP involvement in transition research, which was mirrored by the lack of participation in transition planning processes. YP were largely excluded due to communication difficulties and only four studies discussed possible ways of facilitating meaningful participation, through video, photography and observation. This lack of participation was not limited to research looking at YP with the most severe LD. Leonard et al.'s (2016) mixed-methods research into the transition experiences of YP with a range of ID- once again using parent-report questionnaires- found that less than two thirds of YP were involved in their own transition planning. They posed the valid question "…if YP are not viewed as able enough to participate in their own planning for their adulthood, how are they going to successfully live in adulthood?" (Leonard et al., 2016, p.1378).

Abbott and Carpenter (2014) looked specifically at the challenges faced by young men with Duchenne muscular dystrophy (DMD) and their families. As with the other studies, they concluded that there were few examples of YP being actively involved in transition reviews, despite it being a requirement of legislation. However, an interesting observation by the authors was around the emerging discourse of 'living for the day' and a resistance from the young men with DMD and their families to the future-orientated discussions that formed part of transition planning. It was, therefore, possible that their lack of participation was a personal choice, as they preferred to focus on the present day rather than thinking about an uncertain future.

In his dissertation exploring post-16 support for YP outside of mainstream education, Clarkson (2018) presented a similar finding regarding YP's reluctance to engage in transition planning. Although he concluded that participants understood and appreciated the importance of these decisions, they did not appear to be ready for the responsibility or burden of making them and preferred to rely on professionals' support. Similarly, Lawson (2018) noted that YP reported perceived passivity in decision-making during their transition from special school to further education, which seemed to be associated with a lack of choice and options. As both pieces of research were unpublished, doctoral dissertations and not peer-reviewed articles, their findings should be interpreted with caution. However, they add to the overall picture of a group who often have little support- and in some cases, motivation- to be involved in discussions about their own futures, which raises questions about whether these plans and outcomes truly meet their needs.

2.3.2. The gap between best-practice principles and real-world processes

Studies have demonstrated a disconnect between how TtA should be managed and what actually happens 'on the ground' (Beresford, 2004, Heslop et al., 2002, Morris, 2002). For example, research by Heslop et al. (2002) sought to establish the extent to which legislation and guidance was being followed by asking parents of YP with LD about their experiences. A strength of this study was that, alongside surveys, they interviewed YP using a workbook on 'growing up', designed specifically for this purpose. The researchers found that, despite the requirement for annual transition meetings to be held from Year 9, only two thirds of YP had a plan. For those that did, there was a significant discrepancy between the information that was deemed important by the family (e.g. leisure and social opportunities, housing options, benefits) and what they received. This theme of discrepancy was echoed in Jacobs et al.'s (2018) review which highlighted two further mismatches. Firstly, between government policies and societal values emphasising independence and the reality of lifelong high dependency for many YP, and secondly, between services view of transition as a "one-off" event and parents' understanding of it as a continuous, ongoing process. It must be noted that the studies included in the review focused on YP with profound ID and concluded that the needs and pathways for this population differ to those with mild or moderate disabilities. Therefore, parental experience may vary depending on their child's level of cognitive impairment.

Gauthier-Boudreault et al. (2017) identified another gap, this time between solutions proposed in the literature and the needs of YP. In response, they carried out interviews with parents and highlighted four types of unmet need (informational, material, cognitive and emotional) and solutions for each. The authors presented these in a clear, user-friendly table which was simple for transition services to 'pick up and go'. This research was novel in its solution-focused approach to questioning and it is likely that more research of this nature would be beneficial in aligning theory and practice and moving it forward.

2.3.3. Limited choice and control

When thinking about 'what works', several researchers emphasised the importance of having a range of services, facilities and opportunities for disabled YP to choose from (Beresford, 2004; Forbes et al., 2002). Heslop et al. (2002) put forward five C's of a good transition, which included the element of *choice* and access to information on potential options and post-school alternatives however, these principles do not appear to have translated into practice. For example, Gillan and Coughlan (2010) interviewed parents in Ireland, who identified a range of barriers and supports of the transition process. These included a lack of alternatives to the specialist vocational training provider, leading the authors to conclude that despite a shift in mainstreaming services for disabled YP, they continue to be matched to a narrow range of existing services. The current relevance of these findings should be taken into account, as the study is over ten years old and was carried out prior to the extension of the Disability Act (2005) in Ireland and the Care Act (2014) in England, which placed a duty on LAs to promote better choice and control over care and support for YP and families. Therefore, it may be that options for continued care, education, training and employment have improved since.

Remaining with the issue of choice and control, Redgrove and colleagues (2016) reviewed the literature on constructions of adulthood and how these effected transitions for YP with moderate ID. They noted that YP experienced an 'accelerated adulthood' (Lee, 2014), whereby early entry into the workplace meant that they missed out on the experiences that non-disabled YP took for granted. The authors recognised the very linear pathway that disabled YP were often expected to take and advocated for a change in policy that supported the stage of EA, with opportunities for travel and freedom without responsibility, should they want them. Hudson (2006) used the metaphor of a bridge to illustrate an effective transition, highlighting the importance of "what lies at the end" (p.56). He questioned the usefulness of continued investment of time, energy and resources into transition support and participation of disabled YP if there are no real choices to make regarding their future destination.

2.3.4. The psychological impact of transition

Transition is known to be a challenging time for all YP, but it is recognised to be more "precariously pitted with dilemmas" (Redgrove, 2018, p.8) for disabled YP and their families. Parents often describe the process as stressful, disempowering and characterised by fighting for their child's rights (Gillan & Coughlan, 2010). Parents in Gauthier-Boudreault et al.'s (2017) study reported feeling significant anxiety throughout the transition years and expressed that their emotional needs were often ignored, given the focus on keeping the YP at the centre of transition planning. They suggested a need for regular parent discussion groups, supervised by a professional, to share experiences and information.

Several quantitative studies have investigated the factors that may predict negative psychological symptoms such as anxiety and depression in YP with ID transitioning to adulthood. Austin et al. (2018) asked 137 YP (55 with an ID and 82 controls) to complete multiple questionnaires and scales, including one they created to rate expected and achieved adulthood. As they hypothesised, the prevalence rates of anxiety and depression were greater in YP with ID than in age-matched controls. Whilst these findings added to what was currently known, the language and methods used suggested a medical model perspective and there was a lack of rich data regarding the YP's experiences of these emotional states and what helped or hindered. Furthermore, participants in each group were recruited from different places (university and community disability services) making comparison more difficult and the adulthood questionnaire was created by the authors for the purpose of the study and therefore was not validated.

In contrast, Forte et al. (2011) recruited 52 YP with and without ID, who were closely matched and attended the same college in Scotland. They used a mixed-methods approach to explore in more detail the nature of worries experienced by the YP as they made the transitioning to adulthood. Participants were asked to complete an anxiety and self-efficacy scale as well as a semi-structured 'worry interview', using photographic images to aid discussion and be sorted in terms of salience. This was piloted beforehand which added to the strength of the study. Qualitative differences were found in the nature of worries between the two groups and the YP with ID ruminated more, experienced higher levels of distress and lower self-efficacy. Forte et al. (2011) suggested that their distinct concerns (e.g. regarding bullying and loss of significant others) may be related to different developmental histories and social circumstances and offered an alternative view that this should be seen as adaptive and helpful in preparing them for the real challenges they were likely to face.

As Vincent (2019, p.1581) highlighted, the psychological dimension of transition is as important as the practical one. The themes that emerged from his qualitive study of young autistic adults leaving higher education focused on anxiety, avoidance and loss, but also pride, excitement and a sense of achievement which, as he noted, offered a more holistic and affirming view of transition. Rather than making assumptions about how disabled YP may be affected by transition, it seems important to explore both the practical and psychological dimensions of this with them to gain an understanding of their experiences and support needs.

2.4. Meaning of adulthood

Having looked at transition experiences of disabled YP and their families, this next section reviews the literature around what it means to become an adult. It begins with a brief look at the perceptions of adulthood held by different parties and the potential issues that arise as a result, before focusing on the experiences, beliefs and expectations of those who really matter, the YP themselves. Finally, the concept of self-determination, often highlighted as a key component of adulthood, is critically explored and an alternative focus proposed.

2.4.1. Conflicting perceptions of adulthood

Definitions of adulthood and the associated rights, roles and responsibilities are socially constructed and continuously negotiated (La Fontaine, 1986). Legal adulthood, or the 'age of majority', is understood as the point at which parents relinquish their legal rights and responsibilities for their children. This differs from country to country and despite the assumption that 18-year olds are 'legally' adults, for many, their perceptions of adulthood are likely to be based on a combination of psychosocial, biological, legal, and experiential factors (Salt, 2018). It becomes increasingly complex for disabled YP, as the issues of capacity and 'rights of adulthood' are raised. Studies have shown that they may have their adulthood status denied or contested if they are unable to meet certain traditional markers of adulthood (Dorozenko et al., 2015; Liddiard & Slater, 2018).

During TtA, numerous important decisions have to be made by the disabled YP, their parents and professionals and the success of this may be dependent on a cohesive understanding of what it means to be an adult and where the YP is in relation to that. Murphy et al. (2011) carried out interviews and focus groups with 28 YP, their parent/carers and professionals to explore their conceptualisations of adulthood. Two conflicting discourses were identified, where YP were either positioned as self-determining adults or described as still child-like with ongoing dependency, vulnerability and a lack of understanding, all compromising their adult status. Interestingly, the YP themselves rarely referred to the concepts of childhood or adulthood explicitly, despite prompting from facilitators. The authors suggested two possible reasons for this, the first being that the abstract terms were not meaningful to them, given their ID and the second referring to a lack of exposure to a discourse that positioned them as adult. A third interpretation is that the verbal interview methods used by the researchers did not empower the YP to share their true understandings, experiences and aspirations for adulthood. In comparison, studies presented in the following section of this review appear to achieve this using more accessible, creative methods.

As Murphy et al. (2011) concluded, polarised views such as this can create an unhelpful context for good decision making around the future of disabled YP, however, there is an opportunity for integration of perspectives to create a more inclusive and tolerant framework. They propose that ongoing debates such as this are important, as they are what “keep our judgements in good order” (p.73). Redgrove et al. (2016), in their review of the literature, appear to disagree. They similarly found that parents, teachers and disability service providers did not seem to share an understanding of adulthood or the markers of a successful transition but emphasised the importance of everyone “speaking the same language” (p.187). There is value in both conclusions, but the key component, which is largely missing from each, is the perception of the emerging adults themselves.

2.4.2. What does adulthood mean to disabled young people?

Relatively few studies have explored disabled YP’s understanding and experiences of adulthood. As mentioned above, the challenge of this is enabling discussion of such abstract concepts with a group that are likely to have had little previous exposure to this type of language and questioning. Salt et al. (2019) interviewed eight YP with ID in Scotland, to explore how they conceptualised, related to and experienced the process of becoming an adult. The researchers thought carefully when developing their interview schedule, ensuring that the questions were open-ended to elicit nuanced responses and using prompts adapted from a pre-existing adulthood questionnaire to scaffold. Questions were also simplified following a pilot study with three YP. Analysis of the transcripts generated two core themes, one that focused on the YP's attitudes towards themselves and another that placed them within their socio-ecological context. Participants talked about responsibility and increased independence being key aspects of adulthood, as well as developing values of trust, honesty and respect for others. They also referred to the freedom and opportunities that came with getting older, such as drinking, voting and having sex, but interestingly, none demonstrated a desire to take advantage of these new liberties. With regards to the second theme, participants referred to other's expectations of them and the impact their disability had on these expectations, sharing decision-making with their parents and frustration/acceptance about their lack of control in certain situations. With some exceptions, participants' perspectives of adulthood were recognised as being similar to those held by typically developing YP (Salt et al., 2019). It is important to note that the participants in this study were described as having "borderline or mild ID" and all attended a mainstream education setting. A person's environment, as well as their biological make-up, plays a significant part in the development of perceptions and therefore, it is likely that those YP with more severe disabilities who attend specialist settings, may have different ideas and experiences of becoming an adult.

In their study, Cheak-Zamora et al, (2016) used photovoice to explore how autistic YP experienced EA. Participants were asked to "tell their stories" (p.434) of what it was like growing up with autism by taking photos and sharing them with the rest of the group. The success of this method was evidenced in the high level of commitment shown by the participants, with all of them attending every group session and interview. They also fed back how much they had enjoyed and benefited from the process, for example, through stepping out of their comfort zone, forming friendships, hearing other's experiences and gaining a better understanding of their own lives. One of the key themes to emerge from analysis of the photos and transcripts was 'the meaning of adulthood'. As in Salt et al.'s (2019) study, taking on increased responsibility was cited as a key component and the YP's comments suggested that, for them, adulthood was defined by behaviour rather than chronological age. Having more control and independence was also perceived as important, as it meant they would be able to do more of what they wanted, without having to rely on someone else. Finally, every participant mentioned getting a job and earning money, which indicated that they believed being employed and financially independent to be an integral part of being an adult. Although the authors mentioned that an exhibit of the photographs had taken place, they did not provide details of how this was received by stakeholders, which is an integral part of the photovoice method (Latz, 2017).

MacIntyre (2014) challenged this dominant idea that paid employment is central to citizenship within Western societies and argued for a broader and more inclusive understanding of the different ways in which disabled YP can contribute. Using a case study approach, she tracked 20 YP with moderate LD for a period of six to nine months as they negotiated the period of TtA. Despite the difficulties faced by participants in obtaining and sustaining paid employment, they continued to place great value on it and remain highly motivated to find work. They showed little awareness of the important *social* roles they took on, such as being a caring older cousin or son/ daughter. In order for disabled YP to demonstrate their contribution as active citizens and 'feel adult', citizenship should be viewed as a relational concept where what is most important is feeling involved and having a sense of belonging.

2.4.3. Questioning the focus on self-determination, autonomy and independence

Self-determination, which is defined as a "combination of skills, knowledge, and beliefs that enable a person to engage in goal-directed, self-regulated, autonomous behaviour" (Field et al., 1998, p.2), is considered an essential right of adulthood. Furthermore, Deci and Ryan's (1985) Self Determination Theory stipulates that autonomy is a basic human need that motivates other behaviours and is fundamental to achieve psychological growth. Self-determination and independence are frequently cited as important and desirable outcomes of the transition process, particularly for disabled YP (Salt, 2018) and this is supported by policy such as the *Valuing People* white paper (DoH, 2001), but more recently, this emphasis has been called into question. Parents in Murphy et al.'s (2011) study, for example, expressed differing views on self-determination. For many, it had to be consistently promoted and encouraged, often in the face of their child's resistance. They described situations where they had over-ruled the YP's preferences to stay at home or attend a local college and justified this with statements about their long-term best interests. As Murphy et al. (2011) summarised:

> …promoting all of those who reach the age of majority to unqualified self-determination, irrespective of their capacity to reflect critically and rationally may mean abandoning the most vulnerable in our society to the consequences of choices made with only limited understanding of their implications (p.72)

Similarly, Salt (2018) suggested that self-determination may not be the universal, dispositional phenomenon it is often characterised to be. She found that disabled YP felt burdened by the social expectation for independence and battled between wanting to meet the transition norms for their age and fearing their inability to cope without support. Whereas typically developing YP place greater emphasis on individualistic expressions of responsibility, self-sufficiency and causal agency, disabled YP seem to prioritise interconnectedness and interpersonal dimensions of responsibility such as looking after other people and fulfilling one's familial obligations - as being the most salient criteria for adulthood (Salt, 2018). It should be acknowledged that, despite the researcher's plans to meet with the participants to undertake conformability audits following analysis of transcripts, factors such as sickness and exams prevented her from doing so. This could be seen to increase the risk of her judgements influencing interpretation of the data, although this is an accepted part of qualitative research. Nevertheless, these are interesting findings that warrant further investigation so that normative assumptions of adulthood can be challenged, professionals can gain a better understanding of what is important to disabled YP and they can be supported to set and achieve goals that are personally salient.

2.4.4. An alternative focus on systems, interdependence and social inclusion

Redgrove (2018, p.175) referred her readers to the well-known saying "no man is an island", which recognises how everyone, no matter who they are, relies on the support of others at one point or another in their lives. The Disability Support Workers in her study did not see independence as a necessary component of being an adult and acknowledged that many relationships within the adult age range involve aspects of interdependence. Much of the literature highlights the ongoing importance of relationships for disabled YP, particularly within the family, but also with the wider social network, including friends, teachers and mentors.

In Bronfenbrenner's ecological systems theory (1979), these relationships form part of the disabled YP's *microsystem*. His model, which is shown below, illustrates the five systems of interaction around the CYP (*microsystem, mesosystem, exosystem, macrosystem* and *chronosystem)* and draws the emphasis away from the individual by providing a more holistic framework through which to understand the complexities of EA for disabled YP. Several papers have used it to organise and make sense of their findings (Leonard et al., 2006; Jacobs et al., 2018; Small & Raghaven, 2013).

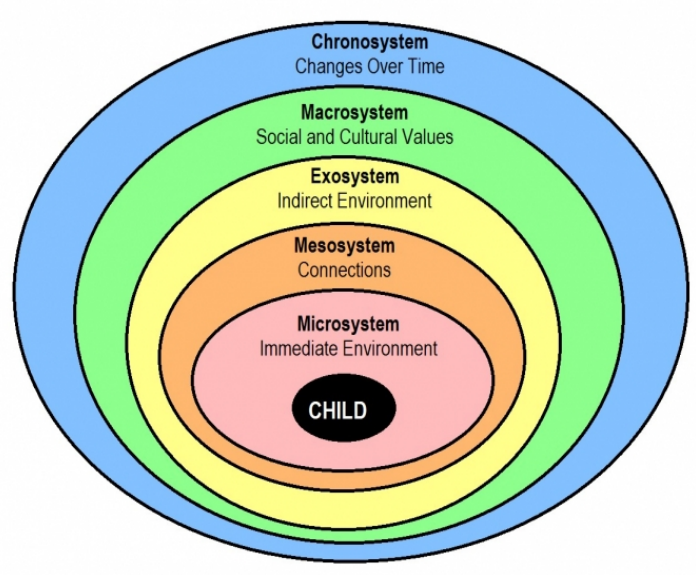


Figure 2. Bronfenbrenner's ecological systems model (1979)

In their review of the literature, Jacobs et al. (2018) adapted Bronfenbrenner's (1979) model, placing the family at the centre rather than the child or YP, to illustrate the importance of seeing them in the context of their whole family. They recognised that this stood in opposition to 'person-centredness' and individualised approaches, which are often considered best practice, however believed it to be more meaningful and appropriate when supporting disabled YP. Similarly, Small & Raghaven (2013) argued that person-centred planning promoted "an individualist ideal to a group of people whose needs might best be pursued via privileging interdependence" (p.286). They also used Bronfenbrenner's model in combination with a visual communication tool called Talking Mats, to seek the views of 43 YP with a range of disabilities. The importance of family was a feature on every participant's map, with mothers being cited as the main source of practical and emotional support. College was a central aspect of their social world, which was otherwise limited, and teachers and support assistants were often seen as friends. These insights led the researchers to conclude that transition planning requires a whole-systems approach, with greater emphasis on supporting social inclusion. The use of Talking Mats to enable the YP to articulate their views was a strength of the study, however, there was still considerable mediation from the interviewer and parents, which may have influenced the data.

Pallisera et al. (2016) carried out a qualitative study, using ‘photovoice methods’, to explore eight disabled, YP’s perceived barriers and support in the process of TtA. A key finding was that most of the participants had few friends; they worried about losing the friendships they had and rarely participated in social activities unless they were planned by their parents or support services. Pallisera et al. (2016) concluded that having a stable social network is “not only a target related to adulthood, but a strategy to support the actual process of independent living and social inclusion” (p.403). Although the authors claimed to use photovoice, their design did not meet the criteria of this participatory action research method (Eisen et al., 2018). and would therefore have been better described as photo-elicitation Similarly, Hurd and colleagues (2018) explored disabled YP’s experiences of friendship. The design of this study was a strength, as it involved three in-depth interviews with the final one taking place in a community setting of the participants choice, with a friend invited along too. Analysis of interview data revealed that participants viewed friendships as meaningful, a pathway to self-knowledge and a medium for negotiating independence and interdependence. To enable more opportunities for this, the authors stated that disabled YP needed more spaces to build friendships and suggested integrating skill-based programmes and leisure activities as a way of achieving this.

Finally, whilst much of the literature focused on the care and support disabled YP require from others, there were a few important examples of this working in the opposite direction. For example, Dorozenko et al.’s (2015) study highlighted the reciprocal and mutually caring relationships experienced by participants and noted that this was helpful in challenging dominant, but hidden, world views about disabled YP. Furthermore, Clarkson (2018) interviewed YP with SEND from two non-mainstream, post-16 provisions. In one, the YP formed part of a steering group that worked with commissioners of services to influence and adapt support offered to other YP with SEND. Several participants frequently mentioned their desire to help others and make a difference following their own experiences and cited their role in the steering group as providing them with a sense of purpose. The author concluded that their involvement in the group had led to personal growth, for example, increased confidence and communication skills as well as development of a "compassionate identity" (p.135). The next section of this review will look in more detail at EA as a time of identity formation.

2.5. Identity exploration in Emerging Adulthood

One of the five key features of EA, as proposed by Arnett (2000), is identity exploration. Although he criticises its likening to a 'quarter-life crisis', he acknowledges that identity issues are prominent during these years and navigating them can generate much stress and anxiety (Arnett, 2007). Whilst he was referring to typically developing emerging adults, this is also true of disabled YP who, whilst developing their identity and notions of self, also have to contend with the opinions of others and stigma surrounding them. It has been acknowledged that TtA presents a window of opportunity during which YP attempt to break free from the often-infantilising disability identity (Wilkinson et al., 2015) to pursue other, more desirable, identities. This section will begin by looking at disability identity in more detail, before focusing on gender and sexuality as two identities which are often over-looked in the TtA for disabled YP.

2.5.1. Acceptance/rejection of a disability identity

> Visible disability typically becomes a master status and a master identity. It is a master status because this position overrides and subsumes others; it is a master identity because it defines every other identity (Charmaz, 1994, p. 277).

Watson (2002) discussed theories around disability identity and put forward the idea of an *epistemological self* which is "created through knowledge about the self, built up from other's opinions of the individual, predominate in constructions of the self" (p. 513). In his study, only three out of fourteen participants incorporated disability within their identity and for the vast majority, impairment was not seen as important to their sense of identity or self. Instead, their identity was disembodied, the product of relationships, social roles and their skills and abilities. He noted that disabled YP did not deny their impairment but seemed to go through a process of challenging and reconstructing what is ‘normal’, choosing to assimilate with the majority rather than celebrate and call for recognition of their difference. He concluded that there appeared to be little support for identity politics built on the notion of shared experience and a common group identity of disabled people. It is possible that, given these interviews were conducted almost 20 years ago and much has changed in society since, disabled YP may express different views today. Interestingly, more recent studies support these findings, indicating that emerging adults who experience impairments continue to emphasise their multiple, alternative identities and choose not to conform to an ascribed, stigmatised identity of disability (Dorozenko et al., 2015; Midjo & Aune, 2016).

In contrast, there have been a number of quantitative studies that have examined the relationship between disability self-identification and wellbeing. Chalk (2016) asked 1,353 emerging adults to complete measures of self-esteem, markers of adulthood, mindfulness and disability status. They found that those experiencing an impairment who did not self-identity as disabled reported the lowest self-esteem. This suggests that disability identification may be a protective factor against low self-esteem as it encourages advocacy and other collective coping strategies (Chalk, 2016). Similarly, participants in Raver et al.’s (2018) study who reported a positive disability identity also reported a stronger sense of belonging. The findings have implications for support of disabled YP, including the importance of fostering feelings of positive disability identity and belonging, possibly through support groups with other YP with similar impairments. A critique of both studies is that they lacked diversity, in terms of educational background, ethnicity and gender as participants were predominantly white, female college students.

Disabled YP’s involvement in disability rights and advocacy groups has also been a growing area of interest and aims to extend the literature on psychological benefits of group identification, as presented above. Another quantitative study conducted by Nario-Redmond and Oleson (2016) found that emerging adults with disabilities demonstrated more political conviction, were more other-focused and were twice as likely to be involved in disability-rights groups compared to their non-disabled peers. Furthermore, participation in these groups was highest amongst those who identified strongly as members of the disabled community. This notion of disability pride and shifting of “personal shame to system blame” (p. 216) is in line with the social model of disability and can act as a buffer to the stigma and discrimination faced by disabled people. Given the lack of rich data that quantitative research offers, more qualitative studies are required to add to our understanding of the experiences of the YP involved.

2.5.2. The role of gender in emerging adulthood

As Gibson et al. (2014) recognised, there is a dearth of research that has attended to the gendered experiences of EA for disabled YP. Despite significant changes in how gender roles and expectations are understood and a recognition of gender identity as multiverse, fluid and self-determined, gender remains an important mediator of YP’s lives. Disabled YP are often treated as an “almost entirely homogeneous group” (Abbott & Carpenter, 2014, p.1202) and there is little recognition of how gender may play a part shaping their experiences, aspirations and support needs in EA.

Few studies have looked at the role of gender at this important life-stage and these have often focused on specific aspects of transition, such as employment outcomes (Hogansen et al., 2008; Lindsay et al., 2018; Lindstrom et al., 2012; Powers et al., 2008). Midjo and Aune (2016) explored the identity self-constructions of YP with LD and found that their daily life and future dreams were partly gendered. They noted a “striking difference” (p.44) between young men and women’s constructs of themselves in relation to independence and what was important to them. For example, young women spoke a lot about their creative and social competence, their interest in housekeeping and constructed themselves as autonomous actors in their lives. In contrast, the young men enjoyed outdoor activities like biking and working with cars, seemed to rely on parents or staff for household chores and experienced limited self-determination. Given the small size of this sample and the fact that secondary data analysis was carried out using data from a previous study evaluating a habitualisation programme, comparisons such as this should be interpreted with caution.

Gibson et al. (2014) looked specifically at the intersectionality of gender, disability and TtA in research with 15 young men with Duchenne muscular dystrophy (DMD), using a combination of photo-elicitation, interviews and diaries. They found that participants photographed and discussed typically masculine interests, such as sports, fast cars and violent video games. Participants also emphasised the importance of hard work, academic achievement and independence which are all considered forms of masculine capital. A narrative of non-difference- where the young men distanced themselves from a disabled identity- was also noted and although the researchers did not directly compare to a female sample, they suggested that this may be particularly aligned with disabled masculinities.

Although gender differences have been identified in the literature, Norona et al.'s (2015) chapter on 'How Gender Shapes EA' warns against overstating these differences as there is often more variability within gender categories than between them. In support of this, Basit (2012) highlights how, in an ever-increasingly diverse society, we should be focusing on similarities rather than differences. Although there was still some evidence of traditional notions of masculinity and femininity in the YP's narratives, he concluded that the vast majority of YP believed in social justice with similar roles, responsibilities and opportunities for men and women. It appears that more research is required to understand both the similarities and differences between disabled young men and women and whether these are being considered by those supporting them into adulthood.

2.5.3. Overshadowing of sexual identity development

Sexuality and sexual relationships are considered a basic human right and essential to overall physical, social and emotional health and well-being (Maslow, 1970 as cited in Dorozenko et al., 2015). Furthermore, EA has been identified as a time of continuous identity negotiations of which sexual experimentation is likely to play a part (Arnett, 2000). Despite this, societal attitudes towards disabled bodies as non-normative and the pervasive belief that disabled people are asexual, has limited their opportunities to access and enjoy sexual experiences and expression on the same level as their non-disabled peers (Shah, 2017). The negative messages this sends and the general avoidance of discussion relating to disabled people as sexual beings has an impact on their self-perceptions and may, in part, explain why sex is so rarely mentioned in the research.

In their interviews with 15 young men with DMD, Gibson et al. (2013) found that few referred to sexual relationships and all appeared uncomfortable when doing so. Similarly, Björquist et al. (2014) carried out a study in Sweden with 12 emerging adults with Cerebral Palsy (CP) to gain a deeper understanding of how they experienced their health, well-being and support needs. Although the participants talked about the importance of love and finding a partner, they talked very little about sexuality. It must be noted, however, that focus groups were used in this study which may have made it more difficult for the YP to discuss their sexual desires and experiences.

Wilkinson et al.'s (2015) study was one of the few to explore sexual identity development in YP with an ID and the role of the carer in this process. They found that the YP faced many obstacles to developing their sexual identity, within the context of the overshadowing disability identity and the stigma that surrounded this. Some YP had internalised the message that they needed protection, whereas others challenged the view that they were non-sexual. Further restrictions arose when stigma around disability was combined with stigma around homosexuality and one participant explained how he had changed his sexual identity to reflect a more acceptable norm. The authors discussed how the carer's risk-averse nature, beliefs about disability and sexuality, their embarrassment and lack of expertise had a significant impact on the YP's ability to achieve a sexual identity.

Another study that used photovoice with four disabled young women revealed similar experiences (Payne et al., 2016). Participants noted that in interactions with others, their disabled identity was often the focus and they were rarely seen as the young women they were. Through their photographs, they presented their alternative identities, including an identity of sexuality, sensuality and romance and challenged societal assumptions that disabled women could not be seen in this way. The use of photovoice not only provided a unique space and opportunity for the women to come together and share their stories, but also enabled production of an exhibition that was attended by 55 people and further dissemination through conferences, magazines and blogs. In light of these positive outcomes, it appears that photovoice may be a suitable research method to use when exploring more complex and sensitive topics such as disability, gender and sexuality and raising awareness of these issues in the communities in which disabled YP live.

2.6. Support needs of disabled young people in their transition to adulthood

So far in this chapter, I have reviewed the limited research around disabled YP's transition experiences, their understanding of adulthood and the importance of identity exploration during the EA years. This final section will consider the support needs identified in the literature and how these are currently met, as well as looking at the developing role of EPs in this area.

2.6.1. Where to target change and support

When considering how best to support disabled YP during TtA, it is important to think about where best to focus efforts and resources. Abbott and Carpenter (2014) recognised that the emphasis was still largely on addressing deficits in the individual, rather than creating change and opportunity in society to increase inclusion. Leonard et al. (2016) discussed the implications of their findings at the individual, family and system level and concluded that a general lack of available opportunities, difficulties navigating complex systems and poor communication with services were all barriers to effective transition. Gillan and Coughlan (2010) also highlight key factors in the wider social system such as competitive labour markets, negative employer attitudes and restrictions on disability benefits which all require review.

However, Hoskin (2014) highlighted the importance of acknowledging 'impairment effects' that no level of legislation or accessibility can remove. This theory is supported further by Abbott and Carpenter (2014), who drew attention to the physiological and psychological impact of living with a life-limiting, degenerative condition that featured strongly in the YP's narratives. They questioned whether these inherent challenges were understood well enough by transition professionals or really considered during the planning process, leading to unhelpful and unrealistic expectations of these YP following a normative life trajectory.

Stewart et al. (2014) appear to address this issue by suggesting a focus on person–environment interactions. Their qualitative study involved triangulating the views of disabled YP, parents, service providers and researchers to better understand transition experiences. The authors identified an over-arching theme of 'complexities' that occurred within 6 areas of early school experiences, societal attitudes, capacities, transition information, services and policy. They promoted a *holistic, life-course* view of TtA that recognised all aspects of a YP's life and did not attempt to address personal and environmental factors in isolation. To ensure the best person-environment fit they recommend "strengths-based services and supports that focus on building capacities of everyone involved, rather than focusing on a youth's limitations alone" (p.2003).

2.6.2. Information needs and transition programmes

Two primary support needs were identified in the literature. Firstly, disabled YP and their families require relevant, up to date *information* in order to make decisions about their future. This has consistently been cited as a priority (Gauthier-Boudreault et al., 2017; Leonard et al., 2016), however research has indicated a continued lack of easily accessible information. To understand the information needs of YP and their parents in more depth, Tarlton and Ward (2005) ran focus groups and used a piloted, visual activity to support participant's engagement and understanding. They produced a list of information needs, with work, money, sex and relationships ranked as some of the most important areas not currently being met. Similarly, Hanson-Baldauf's (2013) thesis explored the Everyday Life Information (ELI) needs, practices and challenges of four YP with ID. She found that participants displayed high motivation and great initiative for seeking information and employed a wide range of tools, resources, and strategies despite significant challenges. She also produced a model to inform future ELI initiatives, research and practice that adopted a more holistic and developmental view of YP and their need for information to support identity exploration, changing relationships, maturing roles and responsibilities, which she called "tasks of self and world exploration" (p. 357). Although the researcher's 'native' status in the field and personal experience of having a sister with ID was likely to have aided rapport and trust with participants, it increased the risk of bias and subjectivity. She acknowledged, however, that this was consistent with her qualitative research design and case study methodology, and also described a number of ways in which she had safeguarded against it.

The second type of support identified in the literature were evidence-based *transition programmes,* designed with the involvement of those who are going to benefit from them. Chen et al. (2019) highlighted the importance of having conversations with parents to identify their ideal hopes, realistic expectations and acknowledge fears and uncertainties. These can then be used to inform transition planning and construct a balanced vision for the YP's future. In their study, parents of autistic YP identified eight valued areas in transition planning which were recognised to be broader considerations and priorities than the measures typically used in conceptualising 'successful outcomes'. The authors concluded that transition programmes and interventions should offer real-life, practical experiences to not only develop important skills in the YP but also to help challenge and refine parent's expectations of their children in the future. As previously noted in the transition literature, the views of the autistic YP were not sought, which would have added a further dimension to research findings and reflected the importance of full participation of YP at all stages of their transition planning.

Evaluations of transition programmes are needed to determine how helpful they are in preparing disabled YP for adulthood. One such evaluation was carried out in specialist settings and looked at the processes they had in place to elicit the views of YP when planning for their TtA (Fayette & Bond, 2018). Their findings indicated that both schools were able to elicit the views of their pupils, regardless of their communication needs and identified factors that enabled this, including a person-centred ethos, commitment from all staff, visits to multiple college provisions and work settings, opportunities for YP to practice making informed decisions and the use of tools such as Talking Mats, PECS and switches to support communication. Another evaluative study by Hoskin (2014) explored the ways in which the Takin' Charge project had been helpful in supporting YP with DMD and their parents to prepare for the future. A key theme that emerged from interviews was the importance of disabled adult role models from the DMD community for the YPs sense of hope and what was possible. The researchers were mindful of the potential impact of asking YP with a life-limiting impairment questions about the future. They used solution-focused questioning and encouraged YP to think about what was working well in their lives, recognise progress and positive change (Hoskin, 2014). This was recognised as a methodological strength as it was sensitive to the needs of the participants and fulfilled "an empowering as well as investigative role" (p.180).

2.6.3. The developing role of the Educational Psychologist in supporting transition to adulthood

The notion of empowerment is one that EPs are familiar with. A key aspect of their role is to enable CYP to understand what they want from life and support them to achieve it, with the help of those around them. As EPs become increasingly involved in supporting the post-16 population of emerging adults, they are likely to take a more active role in transition planning at an individual, group and systemic level (Morris & Atkinson, 2018).

Several doctoral theses have explored the emerging role of the EP in supporting YP in their TtA. Bell (2015) carried out a timely piece of thesis research (soon after the new SEND Code of Practice extended the age range to 25) into the needs of YP with LD at college. Her mixed-methods approach identified a number of challenges faced by YP and the ways in which EPs could support them. Challenges fell into five categories of personal, social, college, transition and becoming an adult (Bell, 2015). The author concluded that EPs are well-placed to support in a number of ways, including applying their knowledge of adolescent development, resilience and self-concept to direct work with YP, facilitating peer support groups, training and supervision for college staff and acting as a link between colleges and outside agencies. She referred to it as an exciting time for EPs to think about how to address their own knowledge and experience gaps, to allow them to "fulfil the critical role of supporting YP developing into adulthood" (Bell, 2015, p.157).

More recently, Clarkson's (2018) research explored the experiences of YP in non-mainstream provision and the developing EP role in these contexts. He argued that EPs were in a position to take a holistic view of the YP's needs and environment in order to support decision-making about the future. The importance of mentors was highlighted by the YP as key to successful transition, therefore EPs understanding of Maslow's Hierarchy and the human need for security and unconditional positive regard would enable them to support the prioritisation of these unique relationships which would in turn support the development of identity, personal growth and self-belief. Finally, he recommended that the future of the EP role with this group should focus on "developing an understanding of the aspirations of a YP without expectation" (p.150).

2.7. Chapter summary

This chapter has presented a critical review of the literature around disabled YP's transitions to adulthood. As noted, much of the research has been from the perspective of parents/ carers and has focused narrowly on the limitations of current transition planning. There appears to be a significant discrepancy between 'best practice' guidance and the support that disabled YP and their families receive, including a lack of participation in decision-making and limited choice and control. Conflicting ideas around the meaning of adulthood as well as an unhelpful focus on normative life trajectories and outcomes are adding to this complex picture.

A small number of studies have sought a more holistic understanding of how disabled YP conceptualise adulthood and have shed light on the importance of interdependence and the systems around them however, this remains a significant gap in the literature. A focus on the disability identity and how this is experienced by YP has taken precedent over other, potentially more meaningful understandings of the self and these require further exploration. Whilst gender differences have been noted in transition outcomes for disabled young men and women, there is limited research on the role of gender throughout EA and how it may shape their priorities and aspirations. Finally, although some studies have utilised participatory action research methods such as photovoice (with varied success), there is greater scope for this method to be used in empowering disabled YP to share their experiences of EA.

2.7.1. Research questions

Given the gaps in the literature that are highlighted above, the aim of this research is to gain a rich, holistic understanding of disabled YP's conceptualisations and lived experiences of EA. The research questions are as follows:

1. How do disabled young people understand the concept of emerging adulthood?
2. What are disabled young peoples' lived experiences of emerging adulthood?
3. What part does gender play in emerging adulthood for disabled young people?
4. What opportunities and support needs do disabled young people identify as important in emerging adulthood?

The next chapter will outline the methodological approach to the present study, including a detailed explanation of the study design and procedures.

3. Methodology

3.1. Chapter introduction

This chapter will begin with an outline of the overall methodological approach, including a justification for my decisions to adopt an inductive, qualitive approach to exploring disabled YP's experiences of EA. Next, the philosophical assumptions are discussed, I acknowledge my role within the research and the importance of reflexivity. The chapter proceeds with a description of the research context, participants and sampling strategy before providing a detailed outline of the four-phase research design. The chosen method of analysis is explained, including a consideration of alternative approaches and why these were rejected. The chapter concludes with a section on ethical issues and how these were addressed.

3.2. Overall methodological approach

The language and terminology used to discuss research methodology, explore philosophical assumptions, debate the existence of "truth" and determine the best way of studying phenomena, is complex. To structure my thinking around my methodological approach, I found it helpful to present this visually, as can be seen in the flow-chart below. Each aspect will be expanded upon in the following sections.

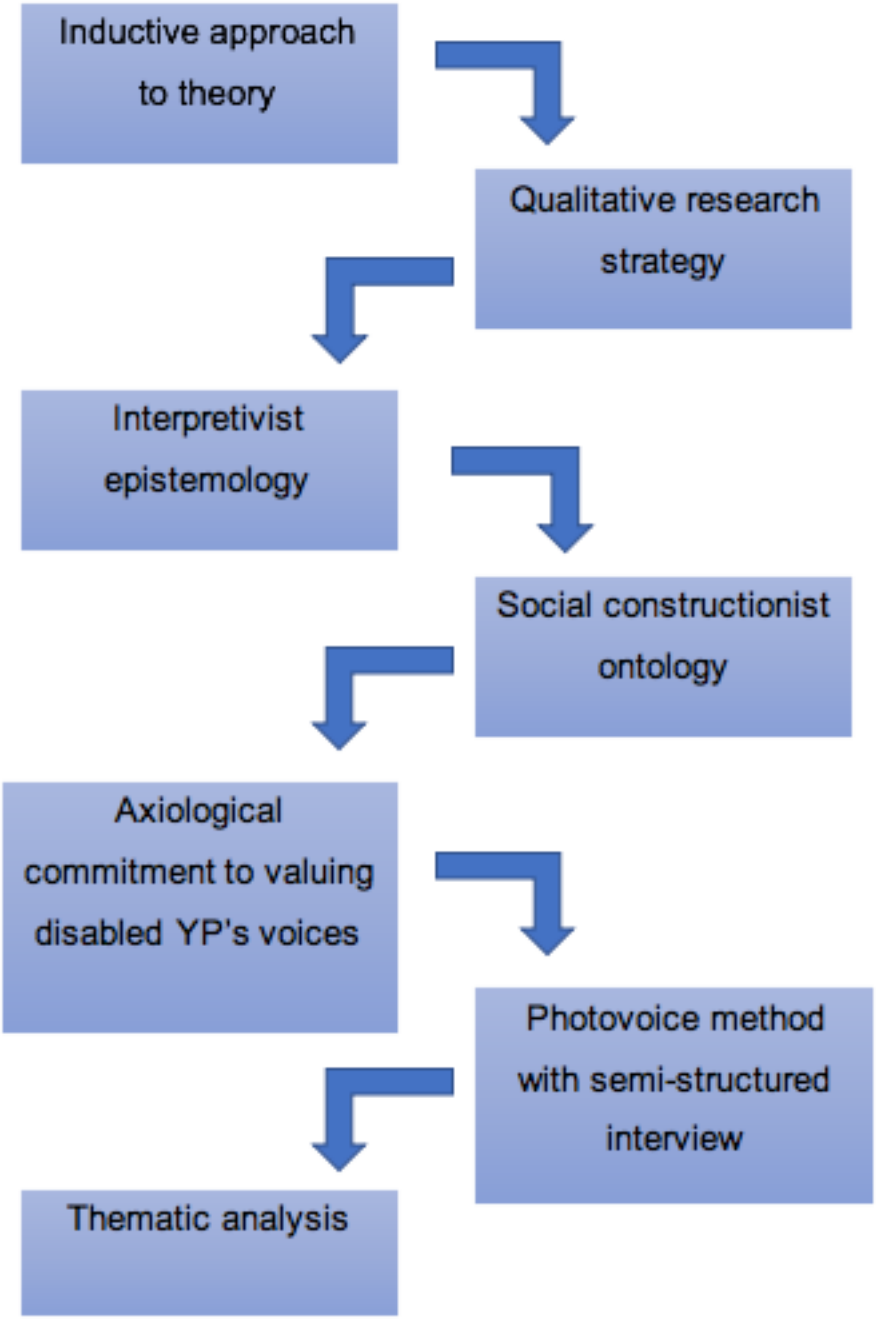


Figure 3. Methodological approach to study

3.2.1. Inductive approach

Bryman (2012) acknowledges that, prior to taking any action, it is important to consider the nature of the relationship between theory and research. Theory can either guide the collection and analysis of data or it can be derived from the data itself. The first is called a deductive approach and is concerned with formulating a hypothesis based on existing theory and designing a research strategy to test this (Wilson, 2010). An inductive approach, however, begins with data collection and uses the information gathered to develop theory, which becomes the outcome of the research (Bryman, 2012). This is the approach more often adopted by qualitative researchers and the one I chose to utilise, given that I was focusing on the views and experiences of the participants and making inferences based on their words and photographs.

Bryman (2012) suggests that these approaches be seen as “tendencies rather than as a hard-and-fast distinction” (p.28), as elements of one can often be found in the other. For example, although I did not arrive at my research with a testable hypothesis, the research aim and questions were informed by my previous experiences of supporting disabled YP during transition and also by the EA literature. To ensure I remained as true to an inductive approach as possible, I took measures to reduce potential bias, such as using a semi-structured topic guide for the interviews and focus groups, rather than a strict list of questions. These were adapted and refined throughout the data collection process, following reflection on previous responses. Furthermore, the participants were given broad photography prompts, which allowed them the freedom to capture a range of images of their choosing. Finally, inductive thematic analysis was used whereby participant responses were coded and organised into themes before returning to the research questions.

3.2.2. Qualitative research

Due to my interest in the individual and subjective views and experiences of a small group of disabled YP, it was appropriate to adopt a qualitative approach to the research. Attempts to define qualitative research have proven difficult as it spans across many fields and disciplines, involves different kinds of data collection and analysis techniques and can be associated with various theoretical and epistemological frameworks (Guest et al., 2013). However, it is evident that all qualitative researchers are concerned with richness, quality and texture of experience (Willig, 2013). They seek to understand the ‘how?’ and ‘why?’ of human behaviour and attempt to “make sense of or interpret phenomenon in terms of the meanings people bring to them” (Denzin & Lincoln, 2011, p.3).

The language used in my research aims and questions clearly reflects a qualitative approach and a focus on exploration and understanding over prediction and measuring. It also fits with an inductive approach and my philosophical standpoint which will be discussed next.

3.3. Philosophical assumptions

To ensure philosophical coherence, it is important that a researcher's ontological and epistemological stance informs the qualitative research process from start to finish. Ontology is concerned with the nature of reality and asks, "What is there to know?" whereas epistemology addresses the question "How can it be known?", as well as the reliability and validity of knowledge claims (Willig, 2013). These philosophical assumptions shape how qualitative researchers understand and represent the world and impact all decision-making regarding the use of data collection and analysis methods.

3.3.1. Interpretivist epistemology

Interpretivism is a contrasting epistemology to positivism and considered to be more suited to the study of the social world (Bryman, 2012). Positivism has its roots in the natural sciences and assumes that there is an objective reality that can and should be studied using "scientific", experimental methods (Fox et al., 2008). Interpretivism rejects these assumptions, arguing that "objective reality will never be captured. In depth understanding, the use of multiple validities, not a single validity, a commitment to dialogue is sought in any interpretive study" (Denzin, 2010, p. 271). This study took an interpretivist stance, by viewing knowledge and meaning as being created and negotiated between human beings as well as historically and socially contingent (Burr, 2006). It was expected that the accounts of the YP would be highly subjective and influenced by their personal experiences, beliefs and core values. This required interpretation on a number of levels, whereby I, as the researcher, provided an interpretation of participants' interpretations and these were further interpreted in terms of the related concepts, theories, and literature (Bryman, 2012). I did not seek to *explain* the behaviour of the YP or identify an absolute truth, as would be the motivation of a positivist researcher. Instead, my aim was to *understand* more about their truth as applied to their lived experience of EA.

3.3.2. Social constructionist ontology

A researcher's ontological position reflects their belief that either social phenomena exist as objective entities and have a reality outside that of the social actors, or that they cannot be separated and must be understood as a product of the perceptions and actions of the social actors who have a bearing on them (Bryman, 2012). These contrasting positions are referred to as objectivism and constructionism respectively and the latter was adopted for this study, in particular, social constructionism. This is the idea that there are multiple realities and that individuals jointly-construct meaning through their interactions with others and their environment (Burr, 2003). The role of language is important within social constructionism, as the same event can be experienced and described differently by each individual, leading to diverse understandings and perceptions that are constantly changing and evolving (Willig, 2013). Given that every YP experiences TtA in different ways, this was an appropriate ontological position to take for this research. The chosen method provided an opportunity for participants to make sense of their experiences in relation to others, through sharing of their images and group discussion. Social constructionism also acknowledges the relationship between researcher and participant, the co-construction of meaning that occurs between them and the inevitable impact of the researcher's own beliefs and experiences on this process (Snape & Spencer, 2003).

3.3.3. Axiological commitment to valuing disabled young people's voices

Axiology is concerned with the nature of value and what is thought to be intrinsically worthwhile. It is important to consider how values and assumptions of the researcher influence the scientific process and how they shaped my approach to this study. Through my past work with CYP with SEND, I have developed a strong belief that they are the experts in their own lives and should be positioned as such, both within their own support planning and the research process. Therefore, I do not perceive my role as "the author of the findings", but as "someone who uses their skills to unearth the evidence" (Willig, 2013, p.12). This notion is supported by government policy and legislation which has emphasised the importance of listening to and valuing the voice of CYP (see Chapter 2) The YP who participated in my study experienced a range of physical, learning and communication needs. The nature of their difficulties has meant that, historically, researchers have focused on the perspectives of their parents or professionals, rather than taking the additional time and skill required to gain to the views of these CYP (Eisen et al., 2018). As qualitative research has been recognised to give voice to those whose views may otherwise be disregarded (Willig, 2013), this fitted well with my core values and my desire to engage and empower disabled YP.

3.4. My role within the research

It appears that in seeking to privilege the voice of the YP, the voice or presence of the researcher may sometimes be rendered invisible or irrelevant (Abbott, 2012). Academic research was traditionally regarded as an impersonal activity, where researchers were expected to “adopt a stance of distance and non-involvement” (Etherington, 2004, p.25). More recently, however, *reflexivity* has become a significant theme in social research, with ongoing debate around its meaning and value. Some see it purely as a process of checking against potential subjective bias (Stiles, 1993), whereas for others, it takes on a greater significance and should permeate every aspect of the research process (Hertz, 1997).

My understanding of reflexivity is in line with Etherington (2004, p.31), who described it as “the capacity of researchers to acknowledge how their experiences and contexts (which might be fluid and changing) inform the process and outcomes of enquiry”. I am aware that my interest in disabled YP’s experiences of EA sparks from my years of working in a specialist, further education college. In my roles there, I had a privileged insight into the students’ experiences of ‘growing up disabled’ and observed the potential impact this could have on their opportunities to meet recognised markers of adulthood. As a result of hearing their stories and being part of a team of professionals that provided support to YP during this time of transition, I developed core values and beliefs that I inevitably brought to the research process. For example, I held the belief that some disabled YP may not have the experiences typical of those their age or being given the freedom to make “risky decisions” because the adults around them did not deem this safe or appropriate. I also considered that, as a non-disabled person, my journey to adulthood may have looked quite different to theirs. Brighton and Williams (2017) argued that prior to engaging in research with disabled individuals, researchers should reflect on why they are interested in disability, if they share any of the experiences they are investigating and how their own embodiment influences their relationships with others and perspectives on their work.

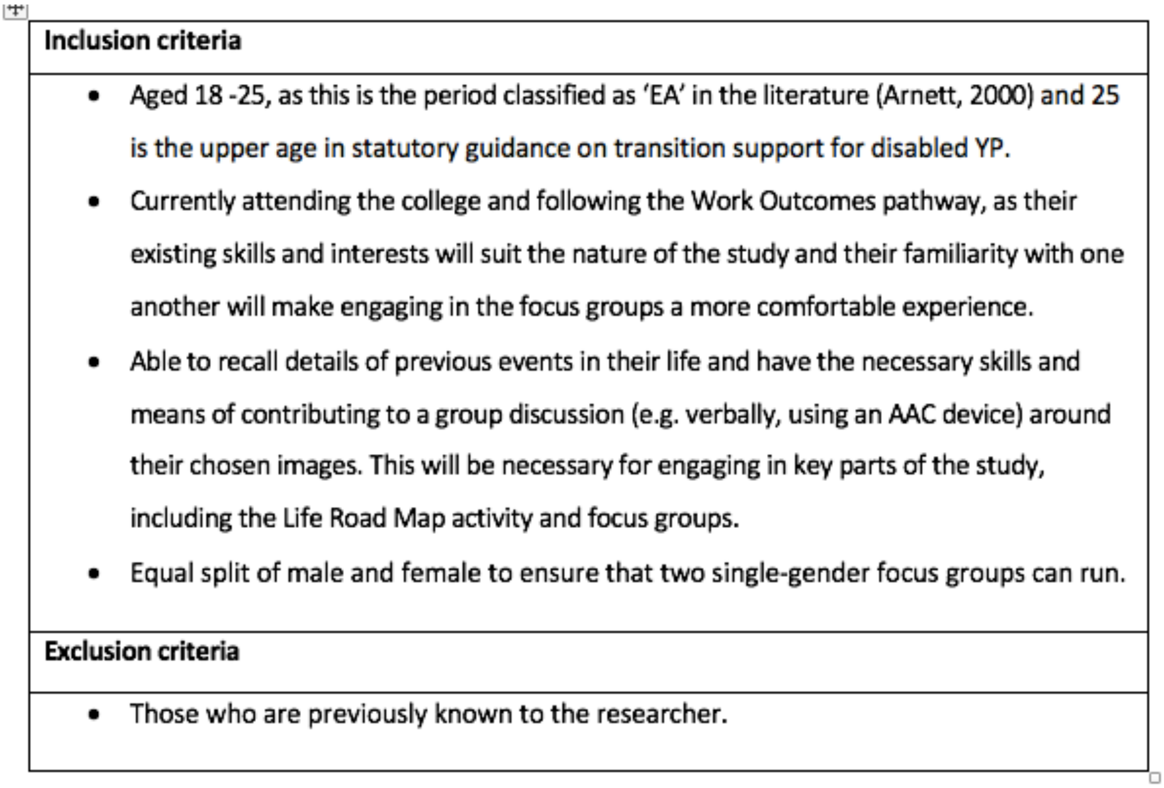
It was crucial that I accepted that I would become a part of the data and my thoughts, feelings and previous experiences would inform the questions I asked, the personal information I shared and my analysis of these conversations (Hofisi et al., 2014). My continuous, critical reflections on the dynamic nature of the research process helped me to achieve greater transparency, reflexivity and a better understanding of the experiences of disabled YP.

3.5. The research context

The research was carried out in a specialist, residential college for disabled YP, YP with LD and acquired brain injury. Students at the college ranged from 16-25 and all had an Education, Health and Care Plan (EHCP). Students followed one of three pathways (‘Engaging with the World’, ‘Making a Positive Contribution’ and ‘Work Outcomes’) and had a small team dedicated to supporting students with transition planning. The college was approached specifically due to its uniqueness, both as a setting and with regards to the needs and experiences of the YP who attended. Having previously been employed there, I was familiar with this group and had some prior understanding and awareness of the issues that were pertinent to them. The study was designed in collaboration with the college’s National Lead for Policy and Research and the manager of the Psychology and Behaviour Team, who both felt that a research project exploring disabled YP’s views and experiences of adulthood would be of interest and value to their organisation and beyond. The ethical considerations around this are discussed later in the chapter.

3.6. Sampling strategy and participants

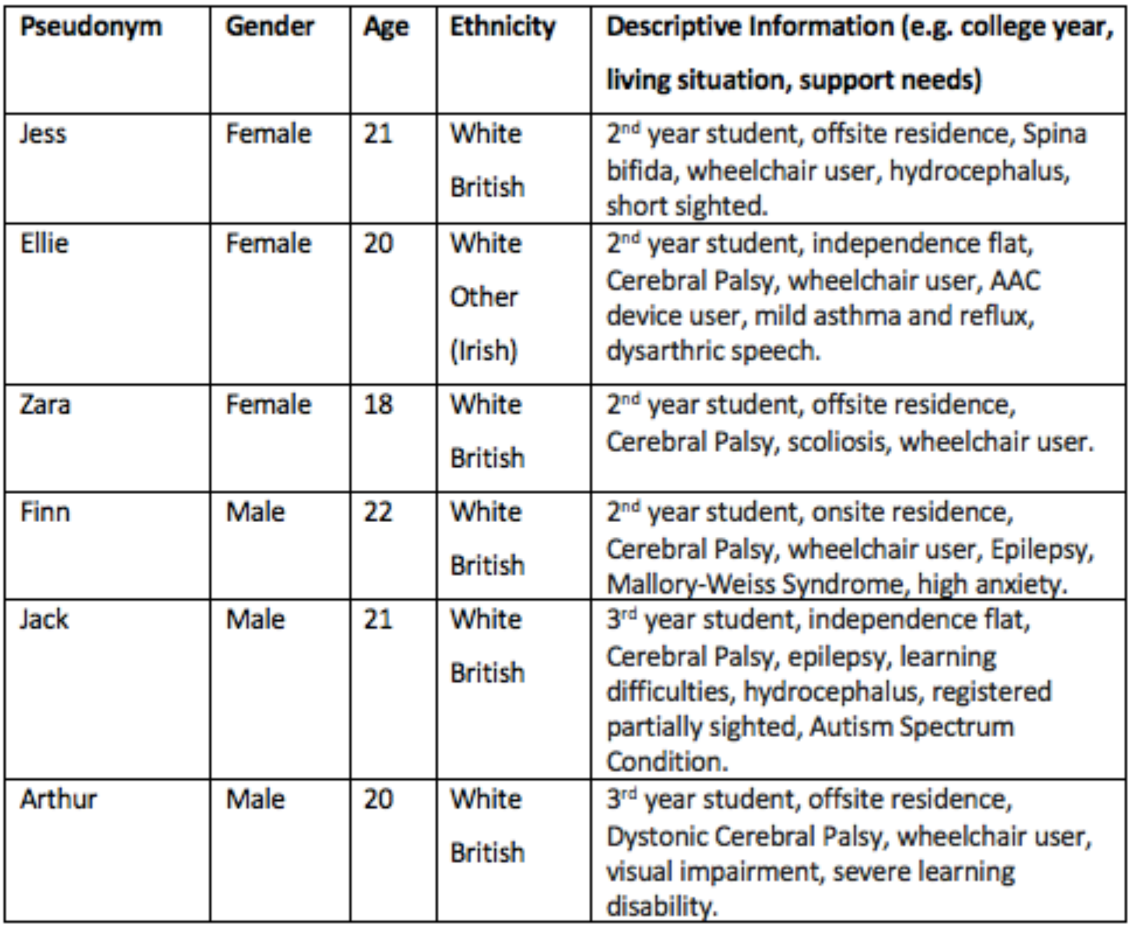
A purposive sampling strategy was used to recruit participants from the college. This was a convenient method for a qualitative research study in which the findings would not be generalised beyond the specific sample (Cohen et al., 2007). A Programme Manager within the college was provided with an information sheet (Appendix 2) and asked to identify a group of students that he believed would be willing to take part and who also met the following criteria:



Inclusion criteria
• Aged 18 -25, as this is the period classified as 'EA' in the literature (Arnett, 2000) and 25 is the upper age in statutory guidance on transition support for disabled YP. • Currently attending the college and following the Work Outcomes pathway, as their existing skills and interests will suit the nature of the study and their familiarity with one another will make engaging in the focus groups a more comfortable experience. • Able to recall details of previous events in their life and have the necessary skills and means of contributing to a group discussion (e.g. verbally, using an AAC device) around their chosen images. This will be necessary for engaging in key parts of the study, including the Life Road Map activity and focus groups. • Equal split of male and female to ensure that two single-gender focus groups can run.
Exclusion criteria
• Those who are previously known to the researcher.

Table 2. Sample inclusion and exclusion criteria

An initial group of students were given a brief overview of the study and invited to an introductory session where they could learn more about the research aims and what they would be required to do should they choose to participate. Out of the 12 students invited, six attended the introductory session and were provided with an 'easy read' information sheet (Appendix 3) and consent form (Appendix 4), which they were supported to read through. At the end of the session, all six students agreed to take part. The table below provides a summary of participant information. Pseudonyms have been given for the purpose of confidentiality.



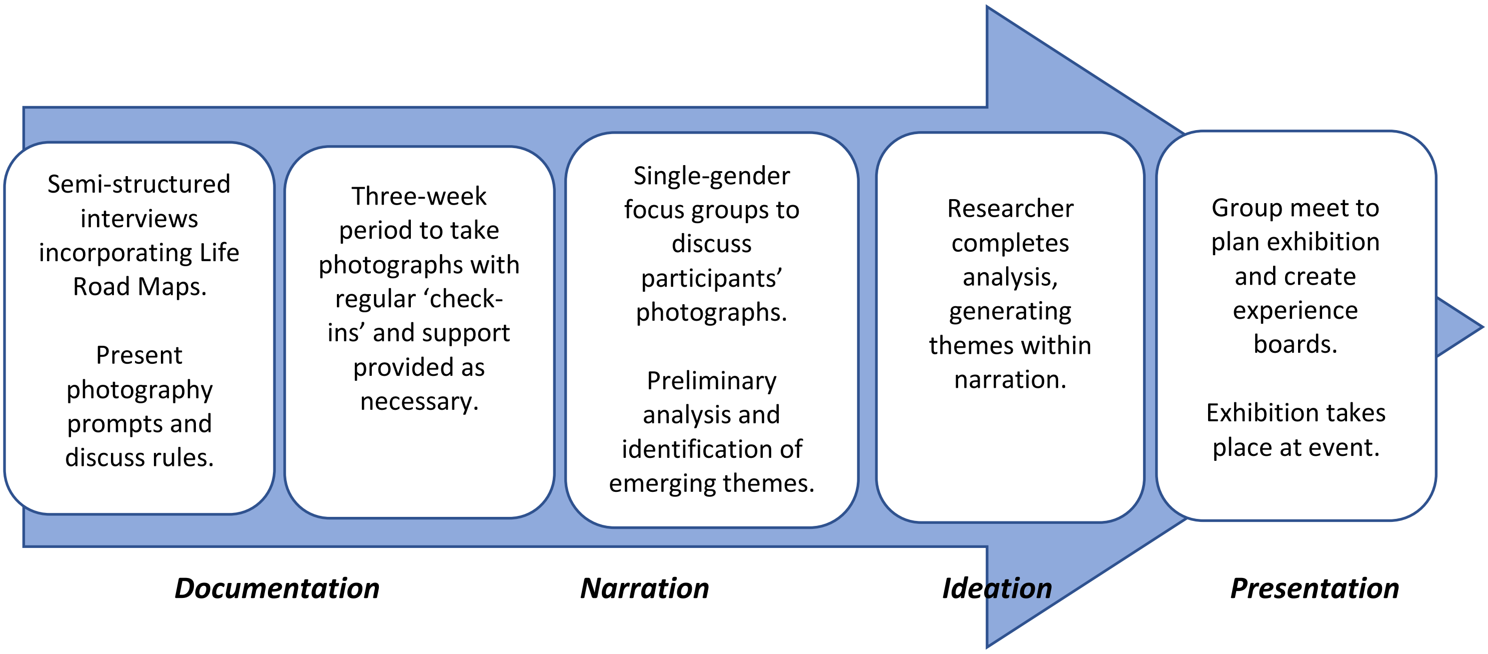
Pseudonym	Gender	Age	Ethnicity	Descriptive Information (e.g. college year, living situation, support needs)
Jess	Female	21	White British	2nd year student, offsite residence, Spina bifida, wheelchair user, hydrocephalus, short sighted.
Ellie	Female	20	White Other (Irish)	2nd year student, independence flat, Cerebral Palsy, wheelchair user, AAC device user, mild asthma and reflux, dysarthric speech.
Zara	Female	18	White British	2nd year student, offsite residence, Cerebral Palsy, scoliosis, wheelchair user.
Finn	Male	22	White British	2nd year student, onsite residence, Cerebral Palsy, wheelchair user, Epilepsy, Mallory-Weiss Syndrome, high anxiety.
Jack	Male	21	White British	3rd year student, independence flat, Cerebral Palsy, epilepsy, learning difficulties, hydrocephalus, registered partially sighted, Autism Spectrum Condition.
Arthur	Male	20	White British	3rd year student, offsite residence, Dystonic Cerebral Palsy, wheelchair user, visual impairment, severe learning disability.

Table 3. Participant demographic information

3.7. Design and data collection methods

3.7.1. Overview of research design

The design of this study was based on the eight steps of photovoice (*identification, invitation, education, documentation, narration, ideation, presentation and confirmation*) as have been put forward in the literature (Latz, 2017). The *identification* stage involved selecting a target audience, which in this case, were the policymakers, professionals and services involved in supporting disabled YP in their TtA. The *invitation* stage, as described above, involved recruiting a group of participants from the population of interest to explore their conceptualisations and experiences of EA. The photovoice method was introduced to the participants and there was discussion about consent, ethics and the intricacies of the process (*education* stage). The figure below summarises what happened at the *documentation, narration, ideation and presentation* stages and this is followed by a detailed look at each data-collection method used.



Semi-structured interviews incorporating Life Road Maps.

Present photography prompts and discuss rules.

Three-week period to take photographs with regular 'check-ins' and support provided as necessary.

Single-gender focus groups to discuss participants' photographs.

Preliminary analysis and identification of emerging themes.

Researcher completes analysis, generating themes within narration.

Group meet to plan exhibition and create experience boards.

Exhibition takes place at event.

Figure 4. Research timeline

3.7.2. Semi-structured interviews with Life Road Maps

One of the appealing features of photovoice is its flexibility and ability to be augmented by other methods (Latz, 2017). Wang and Burris (1997) recognised that the photovoice process can be adapted for a range of contexts, communities and goals and that not all steps will be carried out or done in the order suggested. I, therefore, made the decision to include semi-structured interviews as part of the *documentation* step and incorporated creative techniques to facilitate this dialogue.

The interviews were an opportunity to begin exploring participants' unique understanding and experiences of EA. I used a semi-structured interview approach, which is considered to be the most widely used method of data collection in qualitative research (Willig, 2013). It is sufficiently structured to address specific dimensions of the research question, but also leaves space for a narrative to unfold (Galletta, 2013). My interview schedule (Appendix 5) was informed by research and developed through extensive reading of those used in other similar studies. I also considered items in the Inventory of Dimensions of Emerging Adulthood (IDEA) (Reifman et al., 2007) and adapted these to be used in an interview format (Appendix 6).

To support accessibility and increase participants’ engagement in the interviews, I incorporated creative activities alongside traditional, discursive methods. It is recognised that CYP with receptive and expressive language difficulties may find it challenging to understand and respond to verbal questioning, therefore using creative interview methods can reduce these barriers and enable the researcher to capture their experiences more accurately and fully (Eisen et al., 2018). A visual Life Road Map (Appendix 7) was co-constructed between me and each participant, which facilitated reflection of their life experiences and focused particularly on the EA years. Life Road Maps are a therapeutic assessment technique used by various practitioners (e.g. psychologists, social workers) with their clients as a tool for self-discovery and expression. Their theoretical underpinnings lie in existentialism, humanist theory and narrative theory and they provide a means of reviewing and connecting up various aspects of the clients past, present and future (Strydom & Herbst, 2007). They are also solution-focused in that they encourage clients to focus not only on problems and challenges, but also their personal strengths, values and coping skills. This was a key feature for me when choosing to use them in my research, as I felt it would set a positive, optimistic tone to the interview and empower participants to look at their lives in a new way.

Another purpose of the introductory interview was to understand what participants viewed as important when ‘becoming an adult’ and prompt any initial thoughts and ideas about what they may choose to take photographs of. This also involved discussion around logistics, for example, rules around taking photographs and how they would share them with me in preparation for the group sessions (Appendix 8).

3.7.3. Photovoice

Photovoice was the primary method used to gather data for this research project and fitted well within the interpretivist approach adopted. Initially called photo novella, it was developed by two researchers who carried out a seminal study with Chinese women living in rural farming communities, exploring their lived experience in order to improve their health outcomes. Wang and Burris (1997) noted that “feminist theory and practice has shed light on the male bias that has influenced participatory research” (p.370) and they sought an alternative method that positioned women as active and engaged participants, rather than objects of study. Photovoice is therefore theoretically underpinned by *feminism* as well as Freire's notion of *critical consciousness*, which suggests that through group reflection, introspection and discussion of photographic images, participants develop a deeper understanding of their experience and consider how they can contribute to the change of social structures (Liebenberg, 2018). Finally, Wang and Burris were influenced by the work of researchers like Wendy Ewald and Jim Hubbard, who used *participatory documentary photography* to raise awareness and advocate for marginalised individuals and societies who otherwise would not have had their stories told (Latz, 2017).

Given the complex needs of the participants in this study, it was important that the method of data collection was accessible, empowering and placed them in an expert role. By providing them with cameras to document whatever they chose, the aim was to "shifts the essential nature of the research itself, making it more authentic to the experiences and perspectives of the participants" (Latz, 2017, p.21). Furthermore, as taking, sharing and talking about photographs is such an integral part of modern life, especially for YP, I felt that this would facilitate their interest and engagement in the research. The key principles of photovoice as a participatory action research method, are to a) enable participants to reflect on facets of their identity and experiences within their own terms, b) promote critical dialogue about important issues within a community and c) reach policy makers with project findings to catalyse positive change (Wang & Burris, 1997). The third component, regarding dissemination of findings, is considered important and must be done in a way that meaningfully addresses the highlighted issues and has an impact on policy and practice. This phase of the research will be discussed further later in this chapter, including a brief explanation of how the COVID-19 pandemic prevented it from being completed at this time.

3.7.4. Single-gender focus groups

The *narration* stage of the photovoice process involved participants "discussing the images they have produced, and by doing so, they give meaning to, or interpret, their images" (Wang, 1999). If the research topic is particularly sensitive or it is likely to be difficult to arrange for all participants to meet together, it may be best to do this through one-to-one interviews. However, as Latz (2017) highlights, the "synergies" (p.83) created through group dialogue can lead to generation of data and meaning-making that would not have been possible in a discreet interview situation. From a social constructionist perspective, I was interested to explore how participants' views and understandings were advanced, elaborated and negotiated in a social context (Wilkinson, 2003 as cited in Smith, 2007). Therefore, for the purpose of this study, I chose to run focus groups, where participants presented their photographs to be viewed and discussed as a group. As I was interested in the role of gender in disabled YP's experiences of EA, I ran two, single-gender focus groups. I hoped that this would encourage participants to be open and share stories that the other members of the group could more easily relate to, as well as allowing identification of similarities and differences when analysing the data.

Mnemonic devices such as SHOWeD (Wang, 1996, 1999) have been used to guide discussion in previous photovoice studies, with varying success (Latz, 2017). These provide prompt questions like 'What do you **S**ee here?' 'What is really **H**appening here?' 'How does this relate to **O**ur lives?' '**W**hy does this situation, concern, or strength exist?' and 'What can we **D**o about it?'. Given the learning and communication needs of some of the participants in my study, I chose to adapt these and use a topic guide (Appendix 9) that included questions aimed to draw in the other members of the group and maintain the flow of discussion. A strength of utilising a focus group method was that, as the participants already knew each other well, they could interact in a natural way. The limitations of using focus groups were acknowledged, for example, there was a risk that some participants would dominate the discussion to the detriment of others whose voices may be less likely to be heard. I attempted to address this imbalance by drawing out the views of quieter members using subtle and supportive probing questions. All interviews and focus groups were audio-recorded using a Dictaphone and transcribed verbatim as soon as possible after they had taken place.

3.7.5. Exhibition and the impact of the COVID-19 pandemic

As Latz (2017, p.42) identifies, "We must bring the work into the practical realm; we must act". An important part of the photovoice process is deciding how best to disseminate the findings to those that can affect change. The plan for the *presentation* stage of this study was to work with participants to select images, quotes and captions to create ‘experience boards’ for an exhibition. This would have formed part of a national event held at the college, which would be attended by members of the community and relevant policymakers, professionals and services. Unfortunately, due to the COVID-19 pandemic and subsequent restrictions put in place by the government to limit the spread of the virus, this event was postponed until the following year. The alternative possibility of an online exhibition was considered, and ethical approval was granted to arrange virtual meetings with participants so that we could continue with the creative process. However, many of the participants had returned home which made it difficult to contact them and given the general feeling of disruption, stress and uncertainty, it was agreed that this would also be postponed.

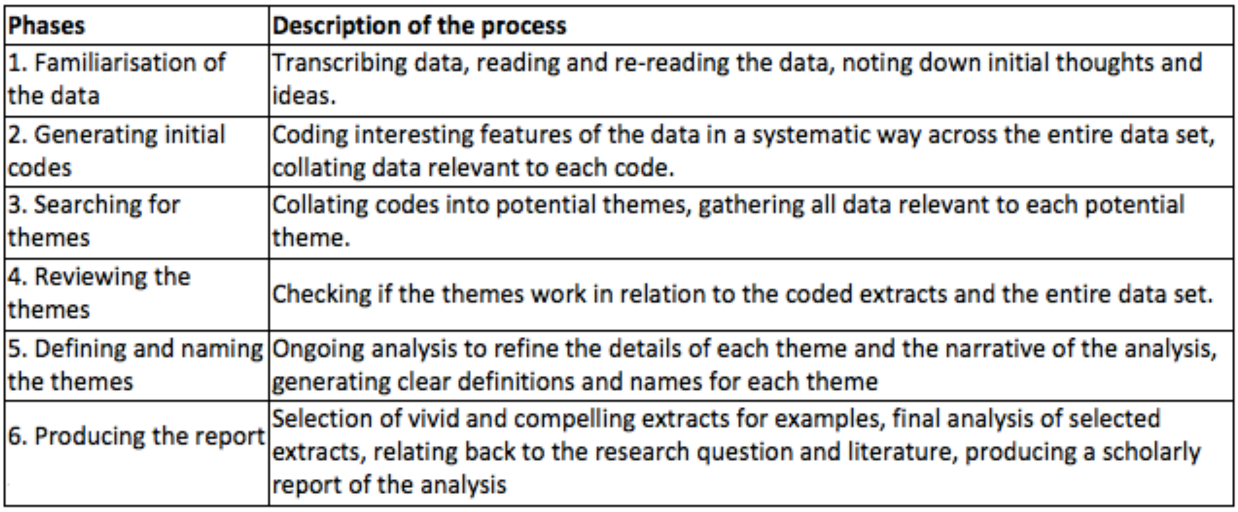
3.8. Data analysis

Photovoice does not come with prescribed analytical steps (Latz, 2017) and therefore it was important that I identified an appropriate method of data analysis that not only fitted with my interpretivist and social constructionist assumptions, but also with the concept of photovoice itself. This meant I was keen to involve participants in the process of analysis in some meaningful way. Wang and Burris (1997) proposed a participatory three-stage approach that involves *selecting, contextualising* and *codifying.* Within the focus groups, each participant was asked to select six photographs from those they had taken, that best represented their understanding and experiences of adulthood. Using these, we began the process of contextualisation through storytelling and discussion. Throughout discussion, I prompted participants to identify any emerging themes they noticed within the images and made a note of these as they were mentioned so that I could refer to them later in the analysis process.

3.8.1. Thematic Analysis

Thematic analysis, as described by Braun and Clarke (2006), was used to analyse the data from both the interviews and focus groups. It was chosen on account of its simplicity and flexibility, especially given the range of data collection methods used within this study (i.e. semi-structured interviews, photovoice and focus groups) and production of both visual and descriptive data. Although considered flexible, there are certain types of research questions for which thematic analysis is particularly well suited, including those that focus on “people’s ways of thinking about social phenomena” (Willig, 2013, p.59). Given that I was exploring young, disabled people’s conceptualisations and experiences of EA and working from ‘the bottom up’ (i.e. the themes emerged directly from the data rather than being theoretically informed), an inductive, thematic analysis approach was appropriate.

Thematic analysis involves a systematic search for “themes that emerge as being important to the description of the phenomenon under investigation” (Fereday & Muir-Cochrane, 2006, p.82). With the research questions in mind, I identified patterned responses and recurrence of themes. As Willig (2013) argues, it is important to have a clear understanding of the research questions, as this has implications for the researcher’s approach to thematic analysis. The table below details the six-phase, recursive approach put forward by Braun and Clarke (2006) that was followed. As Braun and Clarke (2019) recognised in their recent reflective commentary, quality thematic analysis is not about following procedures correctly but about the researcher’s “reflective and thoughtful engagement with the analytic process” (p.594).



Phases	**Description of the process**
1. Familiarisation of the data	Transcribing data, reading and re-reading the data, noting down initial thoughts and ideas.
2. Generating initial codes	Coding interesting features of the data in a systematic way 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 the themes	Checking if the themes work in relation to the coded extracts and the entire data set.
5. Defining and naming the themes	Ongoing analysis to refine the details of each theme and the narrative of the analysis, generating clear definitions and names for each theme
6. Producing the report	Selection of vivid and compelling extracts for examples, final analysis of selected extracts, relating back to the research question and literature, producing a scholarly report of the analysis

Table 4. Summary of Braun and Clarke’s (2006) phases of thematic analysis

By transcribing each of the interviews and focus groups myself, I became immersed in the data, developed a comprehensive understanding of what had been said and began to make initial interpretations. During phase 2, I read transcripts multiple times and adopted a “bottom-up” approach to coding, driven by the data rather than a pre-existing coding frame. Having coded two transcripts, I sent them to my supervisor for inter-coder validation. This was helpful for the refinement of my analytical skills (e.g. moving from a semantic to a latent interpretive level) rather than an attempt to achieve consensus. Braun and Clarke (2013) use the following metaphor to explain the inevitable variation in the coding process:

> Two sculptors with different tools, techniques and experiences would produce (somewhat) different sculptures from the same piece of marble. Likewise, two researchers would code the same dataset somewhat differently (p.207).

Phase 3 involved collation of the coded text iand consideration of how they combined to form overarching themes and subthemes (Appendix 10). Each initial code was either grouped into a subtheme with other codes, amalgamated into another code or discarded (e.g. due to lack of strength or relevance to the research questions). Physical representation of codes on coloured post-it notes (Appendix 11) organised alongside the participants’ photographs, proved to be beneficial during phase 4 of the process, with several cycles of review required before themes and subthemes were finalised. Following another read through of the entire data set to recode any data that was relevant and had been missed, phase 5 involved finalising names for each theme and subtheme, making sure to capture their essence clearly within these titles (Appendix 12). Finally, phase 6 involved planning how best to present findings in a way that was both coherent and compelling for the reader. As the participants had dedicated significant time and effort to producing their photographs and they were a rich source of information, I felt it was important to include them throughout my findings chapter. When combined with key extracts from the data, the images provided further evidence to demonstrate the prevalence of themes and strengthened my overall argument in relation to my research questions.

3.8.2. Alternative approaches

As previously mentioned, there were a number of justifications for my use of thematic analysis within this study. These included its ability to cope with data from various sources, its application to a range of research questions and its suitability given the time constraints of this research. It is important, however, to note the criticisms of thematic analysis and consider other possible approaches. Although it is presented as a relatively straightforward method to use, this can lead researchers to conduct a thematic analysis that, rather than producing insights which make sense of social phenomena, present “a selection of extracts with analytical comment which simply or primarily paraphrases their content” (Braun & Clarke, 2006, p.94). Furthermore, as it does not provide the researcher with a clear theoretical basis, a lot of conceptual work must be done beforehand to ensure it is theoretically and epistemologically located (Willig, 2013).

Prior to making this decision, I considered and subsequently rejected other approaches to analysis. Grounded theory involves the construction of theory through the analysis of data, without the constraints of predetermined research objectives and aims (Martin & Turner, 1986). This was appealing to me, as I was keen to move away from the current “process-focused” TtA literature and unearth new, holistic understandings of this life stage, from the perspectives of the disabled YP themselves. Latz (2017) justified her use of a grounded theory analytical framework by suggesting that its combination with the photovoice method can “provide a powerful means to reach those decision makers whose choices will directly affect the educational lives of the participants involved” (p.94). However, it has been argued that grounded theory has its roots in a positivist epistemology and does not address questions of reflexivity (Willig, 2013). Furthermore, its focus on uncovering social processes and generation of theory means that is it less applicable to studies which seek to capture the meaning that a particular experience holds for an individual, which was the aim of my research. Finally, a grounded theory approach was further deemed impractical due to the limited timescale for data collection.

Interpretive Phenomenological Analysis (IPA) was also considered, as it has the ability to gain an in-depth insight and ‘give voice’ to an individual’s lived experience whilst the interpretive element allows the researcher to contextualise and make sense of these experiences (Smith et al., 2009) I was drawn to it as an approach due to its ability to represent the lived experiences of participants as well as its detailed method of understanding and interpreting participants’ experience of reality. However, IPA is bound to a phenomenological epistemology and is often valued for its commitment to examining a small quantity of cases (Smith et al. 2009) Given that data for IPA solely gathered through individual interviews, this also did not suit my research design and use of focus groups as part of the photovoice method, therefore thematic analysis was considered the most appropriate approach.

3.9. Ethical considerations

As a trainee EP, I hold an up to date Disclosure and Barring Service certificate and have regular Child Protection and Safeguarding training. I also adhere to the British Psychological Society (BPS) Code of Ethics and Conduct (2009), BPS Code of Human Research Ethics (2014) and the Health and Care Professions Council Standards of Proficiency (HCPC, 2015). Although these provide a helpful guide to practice, there was a need to go beyond regulatory compliance and ensure that ethics were an integral part of my research design from the outset and were interrogated at every stage. A research proposal, including detailed ethical considerations, was submitted to the University of Bristol Ethics Committee in March 2018. The committee raised a number of queries in response to the initial proposal and having provided further information, ethical approval was granted (Appendix 13).

3.9.1. Acknowledging a conflict of interest

The first ethical consideration I faced was that of a potential conflict of interest. Having previously worked at the setting where I carried out the research, I had existing knowledge of the system and relationships with members of staff there. This was positive for a number of reasons, as it enabled quicker access to participants and facilitated the planning process. However, it also meant there was a risk that I would face pressure not to report any information or views that may be perceived to reflect negatively on the setting. This concern was raised by the gatekeeper early on and addressed through clarification of the aims of the research and the focus on students' experiences of EA, rather than the quality of support they received from the college. King (2010) suggests that negotiation of how sensitive data (e.g. quotes that may cause hurt or effect an organisation's reputation) will be managed should happen in advance to avoid later issues. The ethical requirement to act with honesty and integrity throughout the research process was pertinent here and I was careful to avoid "any fabrication or dishonest manipulation of data or presentation of findings" (King, 2010, p.104).

3.9.2. Gaining informed consent

Informed consent was another important ethical consideration in this study. Typically, this involves the participants being briefed as to what the research entails as well as other key details (e.g. their right to withdraw, limits to confidentiality, risks and benefits of participating) before they agree to take part. With the additional learning needs of some of the participants in mind, I designed an 'easy read' information and consent form using the 'Guidelines for Accessible Information' document (available at the Norah Fry Research Centre website). Careful consideration was taken when choosing appropriate images to support the simplified text and I followed recommendations from the Ethics Committee to adjust these as necessary. Participants were supported to read both forms, given time to process the information and regular opportunities to clarify anything they did not understand. All participants were over the age of 18, therefore they were given the option to inform their parents/carers if they wanted to, but specific parental consent was not sought.

Problems with gaining informed consent can arise in qualitative research, which is flexible, participant-led and often evolves over the course of project (King, 2010). This makes it difficult for the researcher to articulate exactly what participants will be asked or the direction an interview or focus group may take. In order to address this issue, I adopted a *processual consent* approach (Rosenblatt, 1995 as cited in Willig, 2013), whereby consent was revisited at various points throughout the research and participants were reminded that they could opt out at any time. This was particularly important, given the duration of research activity and the relatively high level of commitment required of participants when utilising a photovoice method.

3.9.3. Limits of confidentiality and anonymity

Confidentiality and anonymity are often the most difficult ethical issues for qualitative researchers (King, 2010) and, as in the present study, this complexity was further compounded by the use of photography. Although measures were taken to reduce the likelihood of participants being identified, for example, by giving them pseudonyms and setting ground rules for the focus groups, the fact that the research was carried out in a single setting made it almost impossible to guarantee 'complete' confidentiality and anonymity, particularly within the college community. It was, therefore, important that I provide a clear explanation of these terms, how I planned to protect their identities and the limitations of these measures (King, 2010). I also made explicit reference to the need to break confidentiality should they choose to share anything that prompted concern for their safety.

With regards to photo-taking, participants were instructed not to take photographs of themselves or other people and were supported to consider alternative ways of representing what was important to them. However, some participants still chose to share images that could have been identifiable to others (e.g. wheelchairs) and when reminded of this, were happy for them to remain part of the data set. Some images were not included in the final write up and changes were made to quotes to protect participants' and their families' identities as much as possible.

3.9.4. Challenges of using the photovoice method

The use of participatory action research methods, like photovoice, "do not dissolve all power relations between researcher and researched, nor are they free from ethical dilemmas" (Kesby, 2000, p.432). There are many ethics-based justifications *for* using such methods, such as giving participants more agency and control over the research process and providing an alternative or additional means of expression to verbal language (Rose, 2007). However, Latz (2017) highlights specific ethical considerations that must be carefully navigated by the photovoice researcher.

Firstly, the issue of ownership; there can often be tensions around copyright and consent regarding images produced by participants, so it was important that I was explicit from the beginning about how any visual materials would be used. As the Life Road Maps were simply used as a tool to elicit the participants past experiences and facilitate initial thinking about the topic of EA, I did not need to keep them to analyse directly or include in the data. Therefore, these were considered to be the property of the participants and they were able to take them away following the initial interview. However, I required the participant generated photographs for further analysis and inclusion in the data set. This was stated clearly on the information sheets and consent form and participants were asked if they agreed to share their photographic images as part of the group and with a wider audience, through the exhibition and final report.

Another consideration was “the burden of representation” (Latz, 2017, p.106). She recognised that social change was not straightforward and that, although they can have some influence, photovoice participants have minimal power when it comes to decisions about the policy and practice that affects them. Whilst explaining my aim of reaching out to relevant professionals and services, I made sure to have an open and honest conversation with participants regarding the challenges of this and also how they felt about the idea that their narratives and images may be seen to represent their community. We discussed how their images would not only be created, but also consumed, within a social context (Banks, 1995). It was agreed that, to minimise the chances of misinterpretation, we would use quotes and captions alongside visual their images, to make the intended meaning as explicit as possible (Prosser, 2000).

3.9.5. Protecting participants from psychological harm

The in-depth nature of qualitative research means there is a greater chance that participants will find themselves talking about experiences that are potentially distressing (King, 2010). Given that EA was the topic of interest in this study, it was likely that participants would share personal information about ‘growing up’ and this may prompt feelings of shame, anger or embarrassment. The photovoice method, particularly when it involves discussing images as part of a group, has been recognised as quite exposing (Latz, 2017) and when not managed effectively, participants in previous studies have expressed concern about their images being criticised by others (Cheak-Zamora et al., 2016).

Measures were taken to preserve the participant’s wellbeing and dignity throughout the research process. Firstly, rapport was developed over a period of time and the design of the study allowed for an introductory interview, prior to the group sessions. This was recommended in a number of research studies involving photovoice with YP with ID (Jurkowski, 2008; Cheak-Zamora et al., 2016) as it would help them to feel more at ease and know what to expect from the rest of the process. Participants were given the option to have a familiar member of college staff join them in the interview or wait outside, in order to provide emotional support if required. This was important for one YP in particular, who warned me that he may get “panicky” and would benefit from either myself or his keyworker running through his relaxation exercises. The opportunity for a break was built into the allocated time for each meeting and a visual ‘Stop’ card was provided which allowed the participant to stop the meeting or change the subject without having to articulate why (Appendix 14).

I was able to draw on professional interpersonal skills developed through my EP training, such as sensitive questioning, active listening, warmth and empathy, to support participants to continue where possible. Willig (2013) cautions against the danger of role confusion and the possibility of a “quasi-therapeutic relationship” (p.26) forming, which can lead to the participant developing expectations that the researcher is unable to fulfil. I, therefore, made the boundaries of my role clear and signposted them to the college’s psychology and wellbeing team should they require further support of this nature. Given the length of the project and the substantial amount of time I had spent with the participants, I also had to consider how best to end the research relationship. I chose to write an ‘easy read’ letter thanking each YP for taking part and noting their contribution to the research.

In order to remain cognisant of these ethical dilemmas, it is essential to engage in continual reflective processes when working with CYP in research. I kept a reflective diary that I added to following each meeting with participants and at various ‘milestones’ during the research journey.

4. Findings

4.1. Chapter introduction

This chapter will present the findings from the individual interviews and photovoice focus groups carried out with the six participants which explored their understanding and experiences of EA. Thematic analysis of the data generated several themes and subthemes and will be discussed in relation to each of the four research questions. A thematic map will be presented at the start of each of the four sections of this chapter and the participants' photographs, their direct quotes and my interpretation of what they told me- in line with my interpretivist stance- will be included in the descriptions of themes and subthemes.

4.2. Research Question 1; How do disabled YP understand the concept of EA?

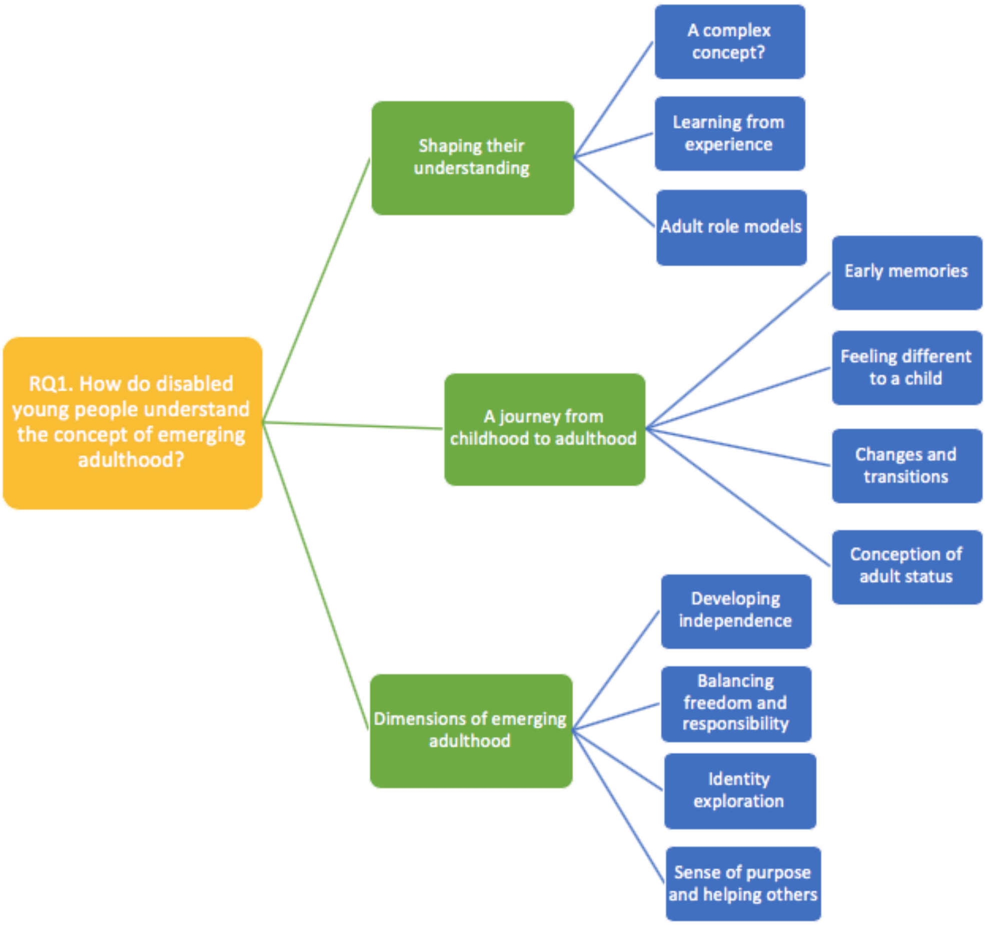
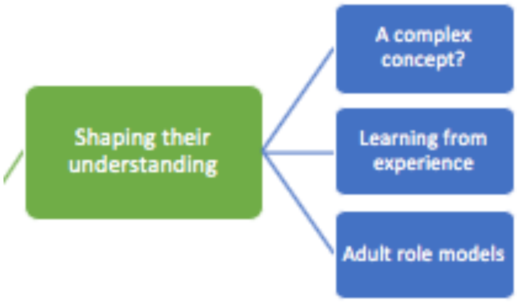


Figure 5. Thematic map for Research Question 1

Using data from both the individual interviews and the focus groups, three themes were generated in relation to the first research question; 'Shaping their understanding', 'A journey from childhood to adulthood' and 'Dimensions of EA'. Each of these will now be discussed, starting with the first, which captured the factors that have contributed to the shaping of participants' understandings of adulthood and EA.

4.2.1. Shaping their understanding

Participants' understanding of EA appeared to have developed in different ways and been influenced by a range of factors. Therefore, it was important that I had some insight into how these thoughts and ideas had formed, before exploring them in greater detail.



4.2.1.1. A complex concept?

Some of the participants spoke about not yet having a clear understanding of what it meant to 'become adult', indicating that it was perhaps not a straightforward concept:

> *Zara: Um…to be honest, I haven't quite worked it out yet.*

Similarly, another participant shared his initial uncertainty about adulthood, but explained that, as he grew older, he felt he was beginning to understand it better:

> *Arthur: (pause)… I didn't know what an adult would be like at first. But now I kind of get the idea.*

Other participants took a much more literal interpretation, often citing the legal age of majority when discussing the process and when this begins:

> *Int: When would you say you started feeling like an adult?*
>
> *Jack: I'd say about 18. At 18 you are classed as an adult…it's definitely been the last couple of years.*

None of the participants provided one, clear definition of adulthood or were completely unanimous in their beliefs and understanding about becoming an adult. This seems to support the theory that it is a socially constructed concept which can be understood in different and personal ways. But what contributes to this understanding?

4.2.1.2. Learning from experience

Many of the participants spoke about the value of experience in developing an understanding of adulthood and moving towards their own adult status. This was illustrated in Finn's first description of an adult:

> *Finn: Someone who has lived for a while and they may not know everything about the world, but they have a fair idea!*

He appeared to be referring to the wisdom gained from years of life experiences and how this sets an adult apart from a child. There was a clear discourse around achieving deep knowledge and understanding throughout Finn's account and it became apparent that this was an important part of his developing adult identity. Zara also highlighted the importance of experience, specifically regarding her own ability to make decisions:

> *Zara: I think I can make my own decisions…I can do that…just not to the level of an adult. Unless you have had all the experience you need, I don't think you can.*

It is possible, given that Zara was just 18 and the youngest participant in the group, she believed she needed to be exposed to more diverse experiences, before she could feel like a confident and competent 'adult' decision-maker. Certain experiences seemed to hold particular relevance and meaning for participants. In a discussion about whether drinking alcohol was an important aspect of growing up, Jack shared his own experience and emphasised the value in trying new things:

> *Jack: I guess you have to do it to see how you are going to feel and know not to do it next time, otherwise you'll never know!*

Emotional experiences also seemed to be powerful in shaping understandings of adulthood. Jess talked about the impact that an early relationship had on her and the lessons she learnt from this:

> *Jess: When you're 13, you think you know better and I was like "Shut up Mum you don't know what you are saying".*
>
> *Int: It's all part of growing up though isn't it? I think we have all thought we know better at one point or another…*
>
> *Jess: Yeah and when I look back, it's actually made me stronger. Because it made me mature quicker than I would have done. Because of how it made me feel.*

Although this was clearly a painful experience, Jess gained strength from it and would perhaps now feel more equipped to manage a similar situation. She also highlighted the importance of listening to more experienced others, like her mother, and taking on board their advice. The final subtheme relates to this and explores the effect of role models that are present in the participants' lives.

4.2.1.3. Adult role models

All the participants had someone in their lives who they viewed as a role model for adulthood and many cited positive behavioural traits and personal qualities when describing their reasons why. For some, these role models were members of their family;

> *Ellie: She always helped me when things got hard.*

It was evident that Ellie had a close relationship with this family member and admired many things about her. Similarly, Jess talked about a school nurse whom she had known since she was young and who continued to be an important person in her life:

> *Jess: I always look up to my old school nurse to be honest. She has a laugh and joke with me. When we are together, it's like we are 10. But what it was, was how she used to care for me. It's like… "I feel safe around you".*

In both the young women's descriptions, there is a clear theme of providing care, support and protection which they appear to consider as a highly valued quality in an adult. In contrast, the young men in the study referred to celebrities as their role models and focused on quite different aspects:

> *Arthur: Danny from McFly maybe? He is my inspiration…he is a good guitarist. I like his way of playing. He's talented and works hard.*

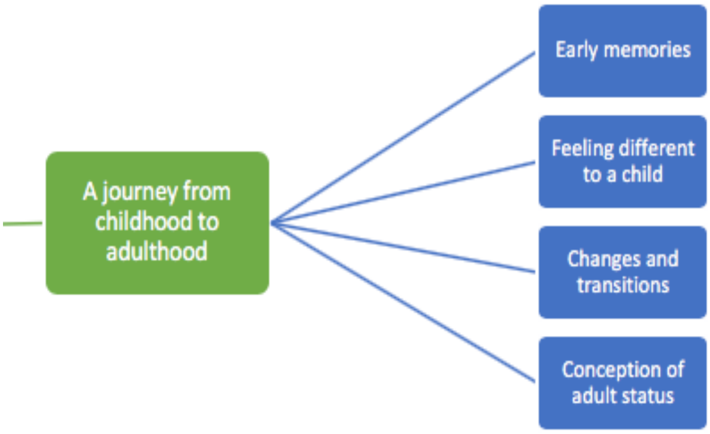
Here, Arthur is highlighting the individuals' skills, talents and work ethic as key criteria for an "inspirational" adult. Arthur's interest in music and performance is likely to play a part in his selection, however these may also be qualities he looks for generally and hopes to develop himself throughout EA. Finn also named a musician as his role model and referred to his ability to endure suffering and hardship:

> *Finn: Well…Dave Grohl, because when he was in Nirvana and Kurt Cobain killed himself, he went through depression but now he has got a wife and kids and friends in the band and is the happiest he has ever been.*

During the Life Map activity, Finn described various difficult experiences, including his own battles with mental health, which perhaps explained why he looked up to others who had overcome similar challenges and drew strength from them. When considering how participants' understandings of EA are shaped and identifying what they consider to be important for successful adulthood, it seems helpful to explore who their role models are and why in order to be able to support them to achieve this. The second theme generated from the data was 'A journey from childhood to adulthood' and will be discussed next.

4.2.2. A journey from childhood to adulthood

Much of the language used by participants when discussing their understanding of EA implied a journey. They were all enthusiastic about using the visual Life Map activity to structure these conversations and many chose to keep hold of their Life Maps after the interviews, which further supports the significance of this theme.



4.2.2.1. Early memories

When given the option to start at any point they felt like for their Life Map, all participants chose to talk about at least one or two early childhood memories, often focusing on their school experiences. Some of the YP described their time at school positively, such as Zara, who was one of the few participants to have attended mainstream settings prior to the specialist college:

> *Zara: I went to a mainstream primary and secondary school, by where I live. And I have some really fond memories of growing up. I've got loads of good friends from there, we went on loads of trips…*

This positive educational experience had clearly had an impact on Zara's aspirations for the future as she expressed a wish to go on to higher education and study Fashion Design at a local college or University. In comparison, Finn appeared to have a rather traumatic school experience, which involved lots of stress and upheaval and had a lasting impact on his mental health:

> *Finn: It was the start of many years of anxiety which I very much still have. It was mainly because the teacher wasn't very nice and didn't understand me. She did things like make me read out loud to the rest of the class and have a go at me if I didn't type as many sentences as she wanted and stuff like that.*

Here, Finn highlights the lack of understanding and support he received from teaching staff in a mainstream setting, an experience shared by many disabled children. He described subsequent negative experiences of attending a local special school where he did not feel he was being *"challenged enough"* and only reported feeling settled and happy when he got a place at a specialist residential school, at the age of 14. Although these experiences lie outside of the life phase in question (18-25), they remain significant and seemed to play a key role in participants' thoughts, feelings and behaviour as emerging adults.

4.2.2.2. Feeling different to a child

The second subtheme refers to the first of many transitions that some participants seemed to experience when moving from childhood to EA. They described it in terms of changing thought processes and priorities:

> *Zara: You do different things, like, you're not playing with toys! You're also more focused on getting to the next stage.*
>
> *Ellie: Adults think differently. I think more about family now.*

Zara's comment suggests that she no longer feels as carefree as she was in childhood, as she is now thinking about how to develop herself and progress to the *"next stage",* which does not appear to be something concrete, but more of a mental and emotional state. Ellie meanwhile, seems to refer to a growing selflessness and need to consider other people, rather than just her own needs. Another participant spoke about how a medical emergency brought on this change of mindset very suddenly:

> *Jess: I think when I had my cardiac arrests, that actually made me, like, grow up even more. I was like "This is a big change… this is serious now". Because, yeah, we all have a laugh about people when they say they've been ill. When you are young, you think it's funny, because you don't see the dangers, then when it happens to you…now it's happened, I see the serious side.*

As with Zara's account, Jess seems to recognise the disappearance of childhood naivety and the need to take things more seriously after this life-changing experience.

4.2.2.3. Changes and transitions

> *Zara: Those few years were just a bit of a blur, to be honest, now I think about it. So much went on, it's like mish-mashed in to like…but the transition to college was really good.*

The participants' journeys towards adulthood all seemed to be characterised by change and transition. Many spoke about time passing quickly and multiple things happening at once, which some found difficult to manage at times. Finn experienced several educational placement breakdowns and moved between different settings throughout this period. He also referred to other changes going on in his life at the time:

> *Finn: Because alongside all this, my parents announced that they were splitting up.*
>
> *Int: Oh, how did that make you feel?*
>
> *Finn: I was alright with it because they were still going to stay in my life and also, I had (residential specialist school) to distract me at that time.*

Here, he noted that his school community and the physical distance were protective factors during his parents' separation. Many of the participants discussed their transition from home to college and the range of emotions they experienced during this:

> *Int: Oh yes, so you had to move away from him and your family and friends. How was that?*
>
> *Ellie: Hard. But I was happy.*

Ellie recalled experiencing both sadness and excitement when she had to leave important people behind in Ireland to attend college in England. As Arthur and Jack were in their final year at college, they were looking ahead to another significant transition, once again with mixed feelings:

> *Jack: Yes, this year is going to be quite hard I reckon.*
>
> *Arthur: But I am looking forward to seeing what the future holds!*

Arthur appears optimistic and able to embrace the unpredictability of life after college. It is possible that he is looking back at past transitions and how they resulted in positive outcomes, which has helped him to feel more relaxed about upcoming change. The following comment from Zara summarises well this notion of being 'comfortable with the uncertainty':

> *Zara: …in a way I do get nervous because I don't know what is going to happen in the future but then I have to remember that no one technically does so…(laughs)…you just have to follow the path that you want to follow and find out!*

4.2.2.4. Conceptions of adult status

The final subtheme focuses on the participants' subjective view of their adult status and how this related to traditional markers of adulthood. Jess considered how her adult status was fluid and changing, depending on the context she was in and the people she was around:

> *Jess: No, I do [see self as an adult]. Just…we all have that inner child. We all have a little child hiding. I mean, mine comes out quite often. When I have got my little cousins with me I can't help but play with them. But other than that, when I'm around college, I try to be more mature and adult.*

Similarly, Jack appeared to have conflicting ideas about his adult status. He initially stated that he was an adult however, questioned whether his family would agree with this:

> *Jack: Yes, I would say that anyway! I'm not too sure what my Mum and sister would say. I'm hoping they would, but I'm not sure if they would. But I feel like I am!*

Jack regularly referred to his close relationship with his mother and sister and appeared to have an ongoing dependence on their support, which may have contributed to this indecision. Interestingly, conceptions of adult status had little to do with whether participants had met traditional markers of adulthood. For example, many considered themselves to be adult, despite not yet being in full-time employment, married or having children. This is not to say they did not see these in their future:

> *Arthur: That one (pointing at the picture card) 'Settling down'. Because eventually I want to get a place of my own, with my girlfriend. That's*

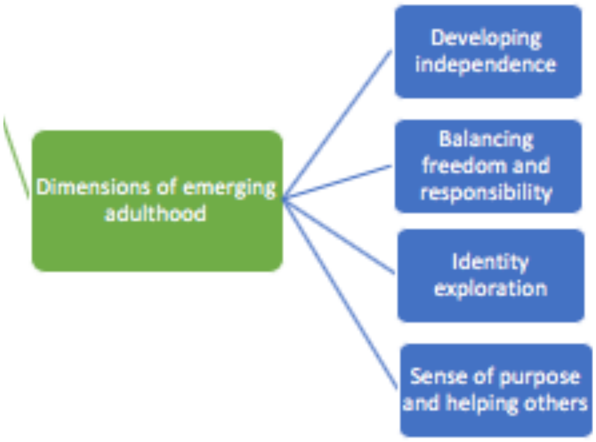
> *what I picture… I want a family too. I've always wanted children. I started thinking about it when I was really young.*

Despite being an important part of his vision for later life, Arthur did not appear to base his perceived adult status on having achieved these goals. Instead, participants emphasised their development in other areas, such as independence and responsibility:

> *Jess: I have become more of an adult since leaving home, starting college because I knew I had to be more responsible for my own care. Knowing what needs doing, when it needs doing.*

The important qualities highlighted here by Jess, as well as a number of others, will be explored further now in the final theme of 'Dimensions of EA'.

4.2.3. Dimensions of emerging adulthood



Participants described EA and what was most important to them at this time in very different ways, however, there were four key dimensions that were repeatedly referred to in all accounts and were also present in the wider literature.

4.2.3.1. Developing independence

All the participants talked about the need to become more independent and for many, this coincided with the move away from home to college. The notion of being independent held different meaning for each disabled YP. Jack spoke about his independence in relation to being more in control of the support he received and having a better understanding of his own strengths and needs:

> *Jack: An adult is someone that is independent…doesn't need much support and if they need it, they would be asked how they like their support because sometimes I like it in a different way to other times.*

He spoke about recently moving into an independence flat in the college and how this had helped him to develop self-awareness and skills. Similarly, Jess acknowledged the importance of developing independence with managing her medication, so that she could be less reliant on others in the future:

> *Jess: Because there won't always be someone there. So knowing what medication you take at what time is really useful. We aren't going to have a 24-hour carers stuck to us.*

For others, developing independence in decision-making was a key aspect of EA and one that they were particularly enthusiastic about, as it gave them increased autonomy in their daily lives:

> *Arthur: Yeah, because then I don't have to rely on my Mum to do things for me. I guess also having the freedom from my parents. Because when I was at home, my Mum used to make decisions for me. Whereas now, I get to make the choice, say, of what clothes I would like to wear.*

Although this may be a seemingly small decision to a non-disabled emerging adult, it is clearly significant to Arthur and perhaps represents the opportunity to have greater independence in all areas of his life.

4.2.3.2. Balancing freedom and responsibility

In addition to seeing EA as a time of developing independence, participants also spoke about having the freedom to explore, experiment and meet new people:

> *Zara: Venturing out on your own and having your own experiences, rather than relying on, like, family.*

Although Zara's comment here suggests that she relishes the idea of having more freedom, she later contradicts herself:

> *Zara: You can do a lot more when you are an adult, like, in terms of the law and stuff. But I've never really been interested in that… (laughs).*

Interestingly, this lack of interest in taking advantage of certain liberties, particularly with regards to drinking alcohol, was shared by the majority of participants. It is possible that they had to restrict their intake due to medical needs or that a 'drinking culture' had been discouraged by parents and college staff over the years, although this was not made explicit:

> *Jack: On my 18th, I wasn't sure if I wanted to have a pint, because obviously at 18 you are allowed to have a pint. So, I did have a pint and*

> *thought "Actually, that's really nice!". So usually on special occasions, we would go out for a drink. I don't go too mad!*

On the whole, participants placed little emphasis on taking risks or pushing boundaries. One participant, Finn, reflected that he had never been *"that rebellious"* and suggested that this was because he was preoccupied with being *"stressed about different things".* Potentially, disabled YP have so much else going on at this phase of their lives and such a focus on 'preparation for adulthood' that they do not perceive this to be an important part of growing up, as other non-disabled people their age may do.

Participants in this study seemed to be more mindful of balancing their new-found freedom with their increasing responsibilities as emerging adults. For a few, this was about taking more responsibility for themselves, in terms of their care, personal belongings and college activities:

> *Jess: Like, for me, it's about being responsible for my own stuff. Say I'm going to be late for a lesson, or can't get there, making sure that I have rung them for myself.*

Here, Jess is demonstrating accountability and the responsibility she has to let her tutors or workplace supervisors know if she is running late or unwell. For Ellie, there was more of a focus on taking responsibility for looking after others and ensuring that she set a good example as a responsible adult:

> *Ellie: An adult is someone who has to be a role model for younger years… I have little brothers and a sister.*
>
> *Int: Ah so you see them as your responsibility? And you feel you need to be a role model to them?*
>
> *Ellie: Yeah. I also have a godson.*

Ellie's family and her faith featured strongly throughout her account and therefore it is understandable that this was associated with her sense of responsibility. Other participants also spoke of their religious beliefs, values and developing sense of self, which were grouped into the following subtheme of 'Identity exploration'.

4.2.3.3. Identity exploration

Most of the participants made reference to EA as a time for learning about themselves, deciding on core beliefs and values and developing their sense of identity. In her account, Jess explained why she so frequently changed her hair colour:

> *Jess: I think it's because I wasn't sure of the person I wanted to be. I think that's what it was about… that's why I don't need to do it anymore. I just needed to grow up a bit and decide "This is who I am, this is who I want to be". And once I had got to that stage, I was fine.*

For others, their environment and sense of belonging within a community played a key role in the development of their identity:

> *Finn: I really found myself there. In the years before that, I was quite an anxious person with low confidence and I didn't really like myself. So, the teenager that came to (residential specialist college) was very different to the young man that came out!*

Here, Finn reflected on his low self-worth as a teenager and the transformative experience he went through to become the person he is today. This had evidently had a profound effect on him, and throughout the data gathering process, he came across as a young man with a strong sense of who he was. When asked about how disability played a part in their identity, several participants appeared to challenge the notion that they were different or other:

> *Arthur: I mean…I am just a normal human being. I don't see myself in a wheelchair, although I know I am, I don't let that stop me.*

Although Arthur acknowledged his support needs, he did not see them as important to his sense of identity or self. As with many of the participants, Arthur emphasised his alternative identities as a loving boyfriend, a dedicated McFly fan and a sociable, confident young man with aspirations to work in the theatre. Finn's comment below suggests he is comfortable with his disabled identity but considers other aspects of himself to be of greater salience:

> *Finn: I've never wished I wasn't disabled so that's positive! It doesn't define me…my interests and the people I care about define me.*

It is clear that caring for others is significant to how he perceives himself, which was the case for many of the YP and will be explored further now.

4.2.3.4. Sense of purpose and helping others

The fourth and final dimension of EA was possibly the most prominent and mentioned by every participant at some point:

> *Finn: I think when you are disabled, the notion of doing nothing, is a different perspective to non-disabled people. Because when you are non-disabled, you can just go off and do things. Disabled people have more to think about, like arranging transport. It's easier for us to become isolated. So we have to make sure that the end of college isn't the end of our lives, so to speak.*

This was a powerful statement from Finn regarding his fear of *"doing nothing"* and what this meant for him as a disabled person. He reiterated it throughout our discussions, using phrases like *"do something with my life"* and needing *"a purpose"* when he spoke about his reasons for having an online presence (discussed further in the following section of this chapter).

For the majority of participants, this sense of purpose seemed to be lived out through a desire to help others. Arthur emphasised his helping role as Student Union President and frequently referred to the multiple ways in which he offered support to other students with more complex needs:

> *Arthur: Although I can speak, it's good that I understand sign language, so like, if someone asks for a biscuit (signs Makaton for biscuit) I can get them one.*

In their focus group, Zara, Ellie and Jess had a discussion about the importance of 'giving back' and the personal fulfilment they got from this:

> *Ellie: My Mum set up a charity to help people with disabilities. We bought the first accessible surfboard to Northern Ireland and it is really important to me to help people to take part and have fun together.*

> *Jess: And the fact that Ellie has been involved in that is amazing. Even though she's got her own disability, she's still helping other people with disabilities. That's something I want to do too.*
>
> *Zara: Yeah everyone has their own issues, and I think we just want to give back the support that we have had in some way.*

Collectively, they seemed to be highlighting the importance of interdependence and the ways in which they can offer care and support to others who are also vulnerable (e.g. through charity work, counselling). It could also be interpreted that, as disabled YP, they do not want to be viewed as passive recipients of care but as active, valued members of their community.

4.3. Research Question 2; What are disabled young people’s lived experiences of emerging adulthood?

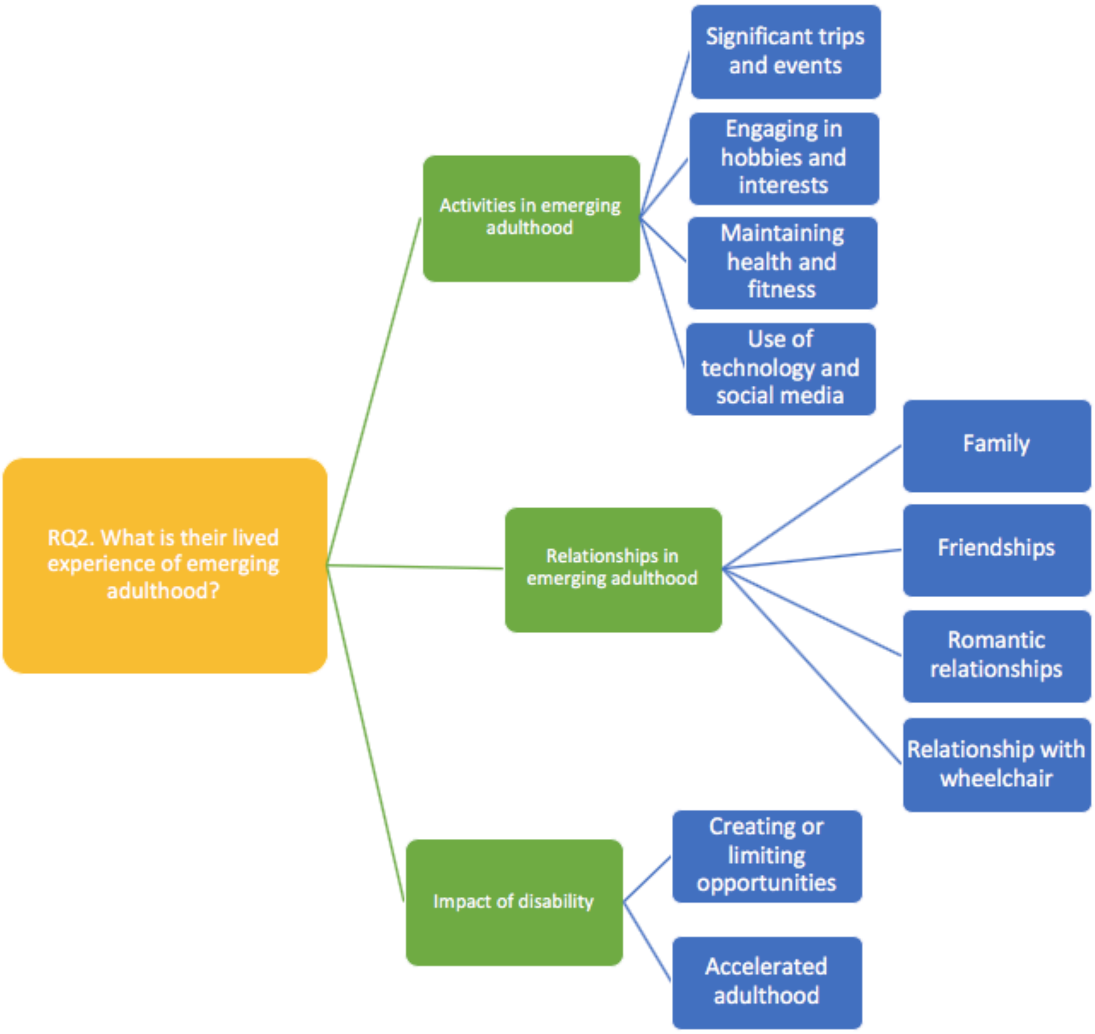
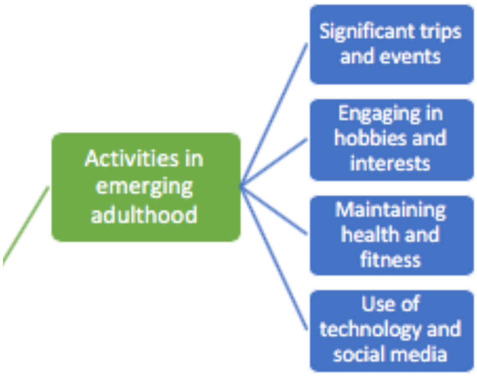


Figure 6. Thematic map for Research Question 2

Using data primarily from the focus groups including the photographs and images gathered by participants and discussion around these, three themes were generated in relation to the second research question; ‘Activities in EA, ‘Relationships in EA’ and ‘Impact of disability’. Participants took an active role in noting patterns and themes emerging during the focus groups and therefore contributed to the analysis of this data. Each theme will now be discussed, starting with the first, which captures the range of activities participants viewed as significant in their TtA.

4.3.1. Activities in emerging adulthood



Participants shared images and spoke about several experiences that they felt either represented what was important to them, had taught them a valuable lesson or skill or simply resonated with them as a meaningful experience in their EA years. The first of these were organised into the subtheme 'Significant trips and events' which will be discussed now.

4.3.1.1. Significant trips and events

Many of the participants talked about their experiences of going away with friends or family. Jess had the following to say about her photograph of the Blackpool ferris wheel:

> *Jess: It represents how much I enjoy being with my family…we do it every year. It is quite a traditional holiday, always in the summer. And I just love being with my family. I want it to be something we do forever.*

Despite her aspirations to live independently in the future and be as self-sufficient as possible, Jess wanted to maintain close relationships with her family and planned to continue these important traditions. For others, it was about getting away from the watchful eye of their parents and experiencing that *"first girl's holiday".* Ellie's image of a holiday resort not only prompted a conversation about the issue of wheelchair accessibility (discussed in a later section of this chapter), but also another significant event:

> *Ellie: I met my boyfriend there!*
>
> *Int: Ah a holiday romance! How exciting! Did you stay together after the holiday?*
>
> *Ellie: We are still together (smiles).*

What was initially a fun trip away with friends, something experienced by many non-disabled emerging adults as a matter of course, turned out to be the start of a long-term romantic relationship for Ellie. Many of the participants talked about similar trips with peers, often organised through charities, school or college and how these had an impact on them. For Zara, a visit to Calvert Kielder was particularly memorable as it was the first time she had stayed away from home following a big operation:

> *Zara: Because it was a good opportunity and it might help me in the future. To do more things like it…work on it so I don't get so anxious. Because I have had to learn to do things a bit differently, it has given me that experience for the future.*

She reflected on the importance of stepping out of her comfort zone and challenging herself, in order to overcome the anxiety she felt about using unfamiliar equipment and being supported by different carers.

4.3.1.2. Engaging in hobbies and interests

This was a particularly strong subtheme and one that had clear links with the previous subtheme 'Identity exploration'. Participants engaged in a wide range of hobbies and interests and often took these seriously:

> *Finn: I'm very much a YouTube kind of guy. When I find something I'm interested in, I want to learn everything about it.*

Describing himself as a *"YouTube kind of guy"* suggests that Finn has taken this interest on as part of his identity and is proud of the depth of knowledge he has about popular culture. He seemed to do the same with music and emphasised how it had given him an alternative identity to being disabled:

> *Finn: Yes it was the first sort of thing that people really associated with me other than my chair. They were like yeah that's Finn… "the rocker" as you put it. A metal-head.*

Music was a shared passion amongst many of the participants, but had a different function for each individual, ranging from comfort, escapism, belonging and a social opportunity. For Zara, her love of Harry Potter also formed part of her career aspirations. She shared a photo of her well-loved Harry Potter jumper and explained how it had become such an important part of her journey to adulthood:

> *Zara: …Sometimes they have helped me to deal with things I am going through. And it is also linked to what I want to do in the future… as in fashion for film. Also, my Dad used to read the Harry Potter books to me as a kid so I kind of grew up with the series. I don't know how it can be a part of you, but once you are a fan, it's always there.*

This subtheme also highlighted the individuality of each participant and how they often had different views and opinions, which they felt able to express during the focus groups:

> *Jack: I am a bit sporty. I play darts most nights. I'm hoping to enter a competition soon, to win! I'm very competitive, I don't like losing.*
>
> *Arthur: I'm not competitive at all… I'm quite the opposite actually. It's about the taking part.*
>
> *Finn: I don't do sports or go to the gym. I'm kind of pop culture nerd (laughs)!*

Debates like these were important and enabled the YP to see that there were both similarities and differences between them and celebrate this diversity. This is explored later in the chapter, when looking at person-centred transition planning.

4.3.1.3. Maintaining health and fitness

Maintaining their health and fitness seemed to be a priority for many of the participants, particularly the young men. Given that all the participants used wheelchairs or had mobility difficulties, regular exercise and physiotherapy appeared to be important:

> *Jack: I wear a splint when I go horse riding, particularly when the instructor asks us to trot, as it helps me grip the reigns. It's very hard work, but I do enjoy it.*

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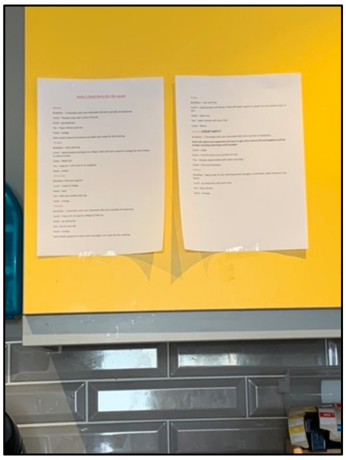
The need to rest was highlighted by Finn, who reported that he often struggled with fatigue and had learnt to listen to his body and give it the relaxation time it required to function effectively:

> *Finn: This is a photo of my Acheeva. For when I need downtime. My energy levels fluctuate quite wildly and if there's one thing I've learnt, it's that I need to not overextend myself. It's very important otherwise I will burnout!*

This growing self-awareness seemed to have only come about in recent years and could therefore be considered a key skill to develop in EA. Some participants referred to other health and well-being routines they had put in place since starting at college, including weight management meal plans:

> *Jess: Yeah, it's something I want to continue. Staff have helped me to develop it and stick to it. It's helping with my health and self-esteem. If I have a weekly food plan, then I know what I will be cooking each night.*



Here, Jess noted the help she received from her care team to develop and maintain this plan. Throughout their descriptions of health and fitness activities, the participants referred to the importance of support from a wide range of professionals, including physiotherapists, keyworkers, nurses and carers. This is explored further in the final section of this chapter, in relation to disabled YP's support needs.

4.3.1.4. Use of technology and social media

The final subtheme was predominantly generated from discussion with the young men in the study, however, having spent time with all the participants I was aware that they all engaged in social media use to some degree. For example, Ellie mentioned that she did some part-time social media work for a Performing Art Company back home in Northern Ireland and therefore evidently had skills in this area. Jack, Arthur and Finn spoke at length about their use of various social media platforms, including Facebook, Twitter and YouTube:

> *Jack: It's funny you should mention YouTube, because there are two of us in here that have our own channels!*
>
> *Finn: I tried to be a YouTuber myself but there were some complications. I've been trying to do a video since March, but nothing has ever really come of it.*

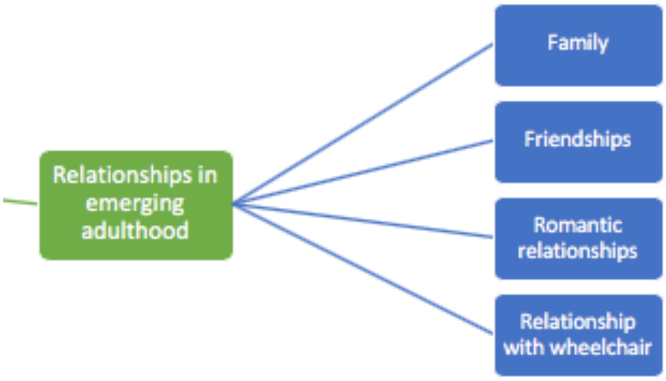
Having identified that Finn was having difficulty with his channel, the other two young men offered to help him. This was another positive example of how the focus group facilitated opportunities to share problems that might otherwise not have been revealed and collaborate to find solutions. Once again, participants expressed a multitude of reasons for their social media use, but ultimately it was about connection with others:

> *Finn: To share knowledge. And to talk about things you are interested in.*
>
> *Arthur: To share all types of different music.*
>
> *Jack: And like in the holidays, when we're back home, we can message each other.*

It is likely that, given these YP were disabled and faced more barriers to socialising than their non-disabled peers would, the value of technology and social media in enabling this to at least happen in a virtual capacity, was even greater.

4.3.2. Relationships in emerging adulthood

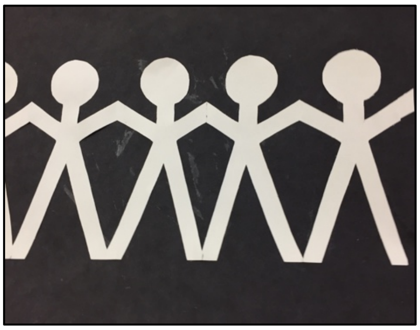
Relationships played a key role in all the participants' experiences of EA. Participants talked about their family members, friends, partners and wheelchairs, which were often referred to as an extension of themselves and felt significant to include in this theme.



4.3.2.1. Family

All of the participants talked about the close bonds they had with family members, which often seemed to have been strengthened by the challenging experiences they faced together, as a result of their disability:

> *Zara: This one is about my family because they have always been there, and I couldn't have been the way I am without them and all of their support.*



Both Zara and Jess spoke about the importance of family support throughout their accounts, particularly during medical emergencies, operations and mental health difficulties. In Jess' case, this had a lasting impact on her relationship with her father:

> *Jess: And now, he's really protective over me…the staff know. And when I tell them why, they understand.*

For both these young women, their parents continued to play a key role in their lives, despite the fact they had moved away to college and were enjoying elements of freedom and independence. For others, finding this balance had been more difficult and there was a sense that they struggled with not being able to see their parents as regularly as before. For example, Jack's comment below suggests that he is still not quite comfortable with the decision that was made for him to remain at college throughout the year:

> *Jack: … she just wanted me to actually move out properly and become a 52-weeker. In my first year, I used to go home for holidays and then it went up. I wasn't sure at first, because I was thinking "How often am I going to see you?" because if I didn't see her for 2 terms, that would be quite a lot.*

It is possible that Jack's mother felt this little "push" was necessary to support his independence in the long term. Similarly, other participants acknowledged a change in their family relationships as they grew older. Finn spoke about reminding his mother of his adult status and by doing so, demonstrated a consideration of her needs:

> *Finn: Well, sometimes I say to her, you don't have to fight all my battles for me anymore. I have other people to help me with that, so you can look after yourself a bit more.*

4.3.2.2. Friendships

Many of the participants were friends with one another and shared inside jokes and stories, engaged in "banter" and provided support to one another when talking about difficult situations. This added a certain quality to the focus groups, but also to my understanding of how they experienced their friendships. As is common, friendships had been built around shared interests such as playing darts, watching gameshows and engaging in creative arts. For others, it was about maintaining connection through difficult times and having a support network that they could rely on to get them through:

> *Zara: Yeah, my friends would visit and we would chat and catch up. I couldn't have done any of it without my support system, I would have been like a shell.*

Some friendships were less conventional, such as those between participants and staff. Jess talked about the dynamic between her and her old school nurse, who despite being in a caring role, she seemed to value as a friend. Similarly, Finn talked about his *"life-long best friend",* a non-disabled boy he had met at school and who was now a staff member at the college. Interestingly, Finn did not perceive this to have affected their friendship in any way and they still met weekly to go to the cinema. Unlike the other participants, he did not seem to place emphasis on having lots of friends and talked instead about the importance of reciprocal care and support:

> *Finn: I don't think it's about how many friends you have, it's about whether they are there for you or not and if they comfort you in crisis and you comfort them. It's quality, not quantity.*

Many participants talked about the importance of living with *"an appropriate peer group"* at college and how this had facilitated the forming of friendships and their social confidence in general. For example, Jess had requested a change of residence as she felt it was important that she had other YP around her who could communicate verbally. Zara reflected on a similar experience, but also acknowledged that in coming to a specialist college and meeting a wide range of YP with different communication strengths and difficulties, she had developed a more nuanced understanding of friendship:

> *Zara: The people I have met here have helped me in so many ways. Like my one friend, she's not verbal, as in talking, but communicates through sounds and high fives you left, right and centre. I'd never met someone like that before and it's helped me realise that friendship is bigger than that.*

4.3.2.3. Romantic relationships

Participants expressed a range of views and experiences of romantic relationships. As mentioned, Ellie met her boyfriend on holiday and since she had started at college, their relationship had been long-distance. Despite this, she seemed committed and was thinking about their lives together after college:

> *Ellie: My plan is to go travelling with my boyfriend.*

She also hoped that he would be able to move in to her purpose-built flat with her at some point in the future. Arthur had similar plans for him and his girlfriend and appeared to have a traditional idea of partnership, whereby a man and a woman meet, move in together, get married and have children. This may be the 'normal' life trajectory that he perceived all other YP to be following and therefore wanted this for himself as well. Other participants expressed different views and seemed to be less certain about when or how a boyfriend or girlfriend may feature in their lives:

> *Zara: No, it's never really happened. I like the idea of having a boyfriend one day, but it's never really come about… it's not my strongest subject.*

This suggests a lack of confidence and opportunity. Finn also cited difficulties he faced when attempting to meet a potential partner, which were associated with having a disability:

> *Finn: The biggest barrier to being in a relationship for me is figuring out when we're both free, deciding where to go and what to do, then organising transport! So that's quite a big obstacle.*

Finn expressed many 'typical' worries experienced by YP who are hoping to meet someone however, here he highlights the additional barrier of accessibility. This leads into the final subtheme, which was generated from the photographs some participants chose to take of their wheelchairs.

4.3.2.4. Relationship with wheelchair

Two of the young men in the study talked about the importance of their wheelchairs and how they enabled them to do things that other non-disabled YP were doing:

> *Arthur: This is a picture of my legs. Well it's my wheelchair which is practically my legs. Because I have cerebral palsy. It helps me get around in the community as well as indoors… Like this weekend I went down to the pub!*

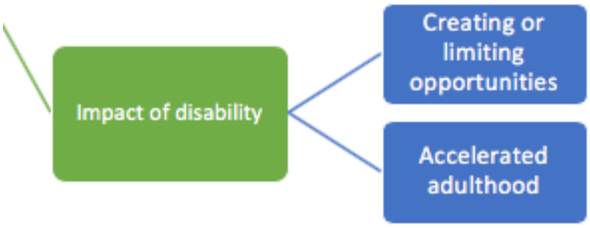
By describing his wheelchair as *"practically my legs",* Arthur is demonstrating how he perceives his chair as an extension of his body and crucial to his freedom and independence. This was further illustrated in a conversation about having to use a manual chair at times and the impact this had on Finn's sense of being an autonomous adult:

> *Finn: And now whenever I have a mishap and have to be in a manual for a few days, I hate it! Because I have to ask people to do things for me and I can't just go to places that I want to go to. I have to rely on other people…*

Alongside this appreciation of his power chair, Finn expressed his concern about not having the same level of access to a maintenance service once he had left college. This did not seem to be an issue the other participants had considered and when asked, most were unsure where they would seek support for this when they were living in the community. It is possible that, given the implicit nature of the relationships with their wheelchairs and how it had become part of them over the years, it was difficult for participants to view it as a piece of equipment that required fixing. Furthermore, if this had always been the responsibility of someone else, they may not have had the opportunity to develop this knowledge.

4.3.3. Impact of disability

Although there were no photographs or images directly related to this theme, all participants made reference to the ways in which their disability had impacted on their experiences of EA. This included both positive and negative impacts and these were organised into two distinct subthemes of 'Creating or limiting opportunities' and 'Accelerated adulthood'.



4.3.3.1. Creating or limiting opportunities

Several participants talked about the unique opportunities they had had over the years and seemed to acknowledge that these may not have occurred had they been non-disabled. One participant reflected on her visit to Universal Studios:

> *Zara: We went into the wand shop and he chose me to pick it and did the whole scene. Because when you go to places like that, they always give you a specific spot to sit in don't they? Because of being in a chair and stuff.*

For Zara, who admitted to lacking social confidence, opportunities such as this appeared to be about more than just having fun as they also facilitated the development of important skills. Similarly, Arthur had been on multiple trips abroad organised through a charitable organisation and college:

> *Arthur: Well the skiing trip to Andorra I went on. And I hope to be going back next year. But I have to raise a lot of money for it. And also, if I didn't have a disability, I probably wouldn't have been able to meet as many famous people!*

These trips appeared to have exposed him to different people, cultures and, as with Zara, had a positive impact on his self-confidence. However, not all participants described their experiences so positively and in comparison, highlighted how being disabled limited their opportunities in some ways. For example, Jess expressed a desire to travel the world like Ellie, but recognised the challenges involved in this:

> *Jess: It wouldn't stop me; I would just need to think about it more. If I go somewhere further than 4 hours away, it could make me ill, so that limits me. And I would need to arrange for people to come with me. So, I couldn't just go tomorrow! I would have to plan it in advance.*

Unlike other non-disabled YP, who could plan a gap year to any destination with relative ease, Jess would be restricted in where she could travel and had to consider her various support needs.

4.3.3.2. Accelerated adulthood

As Jess' comment above alludes to, many of the participants had ongoing medical needs and talked a lot about their time spent in hospitals, talking to health professionals and having complex operations:

> *Zara: …I missed a lot of Year 10 and 11 because I had my hip replacement… They had to rotate the hip to make sure it was in right, and this made my scoliosis worse. So I had 8 months off school that time and then in 2017, I had 2 rods put it my back.*

Zara went on to note the impact this had on her schoolwork, social life and overall mental health. Several other participants' accounts gave the impression of highly medicalised lives and this appeared to have affected them in different ways, but ultimately had required them to 'grow up' quicker than their non-disabled peers. Both Zara and Jess spoke about forming close, trusting relationships with the professionals involved in their care and the open dialogue that had enabled them to develop a good understanding of their needs:

> *Jess: Yeah, like, obviously, being in hospital quite a lot and staff and nurses that have looked after me have explained what things are, what happens and why I need it.*

When talking about her own body and an intimate procedure involving a catheter, Jess showed little embarrassment. Similarly, when I asked Zara how it felt to share such personal information, her response was surprisingly positive, but once again indicated that she had learnt to handle these types of conversations with more maturity than her years:

> *Zara: It's helped a lot growing up to, because all the awkward things, I didn't find them that awkward because I would just ask!*

Participants also talked about how other experiences had led to an acceleration of adulthood. These included moving out of the family home earlier than many other YP might and having to adapt to different living environments:

> *Finn: Well, a lot of people say I am wiser than other people my age. I would agree and I think that has come from being on my own a bit more and that started when I was at (residential specialist school) and lived in a care home.*

In the same way as Jess and Zara, Finn did not perceive this negatively and, on the contrary, seemed content with this description of himself. There was a general acceptance amongst the participants that their experience of EA had been accelerated and rather than resenting this or feeling that they had missed out, it was believed to have been beneficial in many ways.

4.4. Research question 3; What part does gender play in emerging adulthood for disabled young people?

In order to facilitate discussions about how participants understood their gender to have played a part in their experience of ‘growing up’, two single-gender focus groups were run. It was hoped that by designing the study in this way, the disabled young men and women would be more comfortable talking openly amongst peers with whom they had likely shared more similar experiences. It also allowed for a general comparison of content, to identify potential similarities and differences between the groups. Two contrasting themes were generated from the data and will be discussed now.

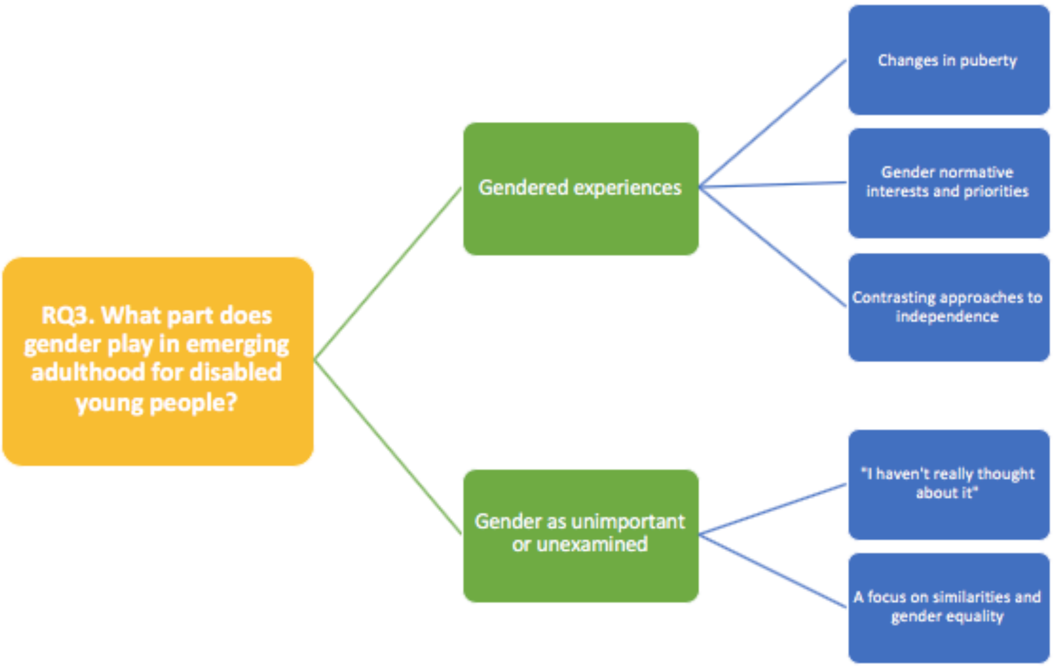
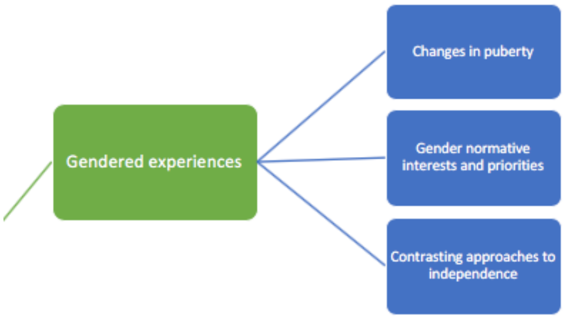


Figure 7. Thematic map for Research Question 3

4.4.1. Gendered experiences

There were notable differences in the photographs that the male and female participants took/ gathered and what they chose to talk about. This suggests that, in some ways at least, gender had played a part in their understanding and experiences of EA as well as what they considered important now and for their future.



4.4.1.1. Changes in puberty

Two of the young women in the study referred to their experience of menstruation and the effect this had on them, both mentally and physically:

> *Jess: Yeah, puberty and your body's changing and you're a bit up and down. You get emotional. That's the worst thing about being a woman!*

Jess spoke honestly about her first period and we discussed how this had been a different experience for her, given her disability and need for support during personal care. Similarly, when Zara was asked how, if at all, her gender had played a part in her EA years, she highlighted the need to adapt to and cope with changes in puberty:

> *Zara: Umm…well…it might get a little bit tricky because you have to do different things to what you used to do…It's just getting passed all the physical stuff…and the emotions that go with it.*

The way in which both women described this experience indicates that it is an aspect of their gendered experience that they least enjoy. The young men did not express the same level of angst and frustration regarding physical changes in puberty, however, one comment from Finn illustrates that it was not an easy time for him either:

> *Finn: I was more stressed about different things. I would say that I went from my lowest point to my highest all in the same year!*

Their experiences of puberty were not the only identified difference between the young men and women in the study. The next subtheme focuses on the activities, interests and priorities each group discussed and considers the importance of recognising these distinctions when providing support for disabled YP into adulthood.

4.4.1.2. Gender normative interests and priorities

From a quick comparison of a selection of each group's photographs, it appeared that what the young men and women felt was important, could be interpreted as being in line with gender norms. Overall, the young men seemed to have more of a focus on *things*, whereas the young women talked about *people and relationships*.

The young men talked about their use of technology, including computers, mobile phones and DJ equipment:

> *Arthur: This is my phone. I use it a lot to ring people and message people.*
>
> *Jack: YouTube, Facebook, FaceTime, playing games…*

Enjoyment of technology is often considered a more masculine interest and the young men certainly engaged in an enthusiastic discussion about the process of uploading a video to YouTube. Technology was not mentioned at all by the young women. Sport and exercise was also a strong theme in the male focus group, with two of the young men keen to share how much time they spent being physically active:

> *Arthur: I do a lot of swimming. And I work out in the fitness room in college. I try and go there four times a week.*

Once again, regular engagement in sports and this competitive streak is commonly thought to be a more masculine trait and was not something that the young women shared an interest in at the same level. Ellie briefly mentioned winning a Sports Award for Boccia when she was younger but seemed to have developed other interests as she entered her EA years. Other typically masculine topics of conversation included being attracted to women, driving fast cars and taking on important leadership roles in the college community (e.g. Student Union President).

> *Finn: Whilst I was there, I was voted as president of the 6th form! I promoted the school a lot, I took visitors around, I did a quiz to raise money and people recognised how much I cared about the school.*

In contrast, the young women spoke of their charity involvement, which was significant, and expressed an interest in taking on future volunteering opportunities, where they could care for and support others:

> *Ellie: My Mum set up a charity to help people with disabilities. We bought the first accessible surfboard to Northern Ireland and it is really important to me to help people to take part and have fun together.*

As Ellie mentions here, family was also important to the young women and they frequently referred to the close relationships they had with parents and how much they appreciated these. When Jess was asked how her priorities compared to that of her male friends, she replied:

> *Jess: I don't know. I guess different things are important. As a girl, I think your family are more important. And a lad wouldn't necessarily put his family first. But that's only from experience…what I've seen.*

Amongst the young women, there was also more discussion about managing social situations and specifically, their tendency to be overly sensitive to the feelings of others at the detriment of their own needs and wishes:

> *Zara: Sometimes I find it hard saying what I want to do, because I want to please people. And I don't want to force another person to do what I want to do, so I tend to go along with things.*

Both Zara and Jess spoke about how, since coming to college, they had developed their assertiveness and communication skills. Jess, who had previously lacked the confidence to direct her personal care and feared *"offending"* staff, described a recent time when she had been unhappy with how two members of agency staff had carried out her care and had felt able to report this to her residential manager:

> *Jess: Obviously, I felt guilty that I had said something, but I also felt good about it. Because I knew I was sticking up, not just for me, but for my peer group as well.*

Another notable difference between the two groups was their motivation to take a more active role in domestic tasks. Jess shared a photograph of her oven and laundry bag, which prompted a conversation amongst the disabled young women about developing life skills and the importance of this for future independence. Although some of the disabled young men briefly mentioned that they were learning how to prepare simple meals, they did not seem to get the same sense of achievement from these tasks and generally, it was less of a priority for them. The final subtheme focuses on this in more detail.

4.4.1.2. Contrasting approaches to independence

Overall, the young men and women seemed to have contrasting approaches to developing their independence skills. As presented above, the young women gave multiple examples of how they were making the most of their time at college, as well as the resources and staff support, to learn various life skills in preparation for adulthood:

> *Jess: It's about building my confidence. I am much more confident now than I was when I first started. I wasn't sure I would ever be the sort of person to do things like that for myself. Then one day I thought 'what am I messing about for, I can do this'.*

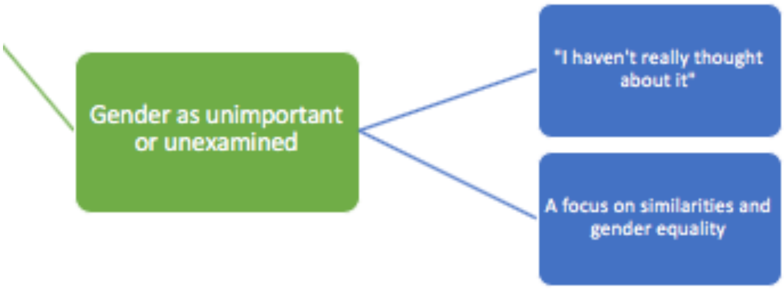
On the other hand, the young men seemed to view college and their EA years as a time to have fun, spend time with friends and develop personal interests. Finn, who was the only participant to live in supported accommodation outside of the college, made it clear that his current focus was on his emotional well-being and expanding his social opportunities:

> *Finn: No, I can see why other people would think they (domestic skills) were important, but it's not at the top of my list right now.*

Similarly, although Jack had moved into an independence flat and seemed proud of it, he had not yet used the oven or hob, which indicated some possible reluctance to begin cooking more independently. He mentioned other barriers that seemed to be contributing to this, such as a previous experience of spilling a hot cup of tea and a resulting preoccupation with Health and Safety. The young men were, however, preparing for adulthood in other ways, with their priority seeming to be work experience and securing future employment:

> *Arthur: Yes, through college. I have worked at the theatre in (town), on the stage door. So, I am hoping that will become my job.*

4.4.2. Gender as unimportant or unexamined



Despite the above observations, when asked directly, many of the participants had not considered how gender played a part in their experiences of EA. They seemed more comfortable when talking about the impact of being disabled, which suggested that this may be the social identity that is fore fronted and discussed more often in their day to day lives. The following two subthemes were generated from the data, with one named using a participant's quote, as it seemed the best descriptor.

4.4.2.1. "I haven't really thought about it"

The majority of participants responded with confusion and hesitation when asked about the influence of their gender. For example, having expressed her belief that women prioritised their families more than men, Jess was unable to identify any other ways in which her gender played a part:

> *Int: That's interesting. Is there anything else you think is more or less important to you as a woman?*
>
> *Jess: I can't think of anything else really. It's a difficult question!*

Similarly, Zara could only cite the biological differences (e.g. women's experiences of menstruation) and otherwise, struggled to discuss the topic in any more detail:

> *Zara: Not really, I just see all of them (male students) as like friends. I haven't really thought about it until now.*

4.4.2.2. A focus on similarities and gender equality

Several participants seemed to prefer to focus on the similarities between men and women, rather than the differences:

> *Arthur: No, they all want slightly different things. But we are all on the same wavelength.*

Here, Arthur appears to be highlighting the presence of individual differences over gender differences and feels that these are more important to consider when discussing support for their TtA. Another participant, Jack, appeared to understand gender as fluid and therefore questioned the purpose of considering 'differences' in this binary way:

> *Jack: I actually don't think it matters. Well, when I was young, I couldn't really make up my mind…I didn't know what I was going to be…a boy or a girl, so… it didn't really matter.*

Finally, some of the participants highlighted the importance of gender equality and the need to ensure that everyone should have the same opportunities in life, regardless of their gender:

> *Finn: Again, I have always felt that men and women should be treated equally so I don't care if you are male or female or trans or whatever. As long as you are a decent person, that is good enough for me!*

Even when prompted to think about the potential for different support needs, Finn continues with the equality agenda, reflecting that he belongs to a generation of YP who are increasingly aware of these rights issues and motivated to advocate them.

4.5. Research question 4; What opportunities and support needs do disabled YP identify as important in EA?

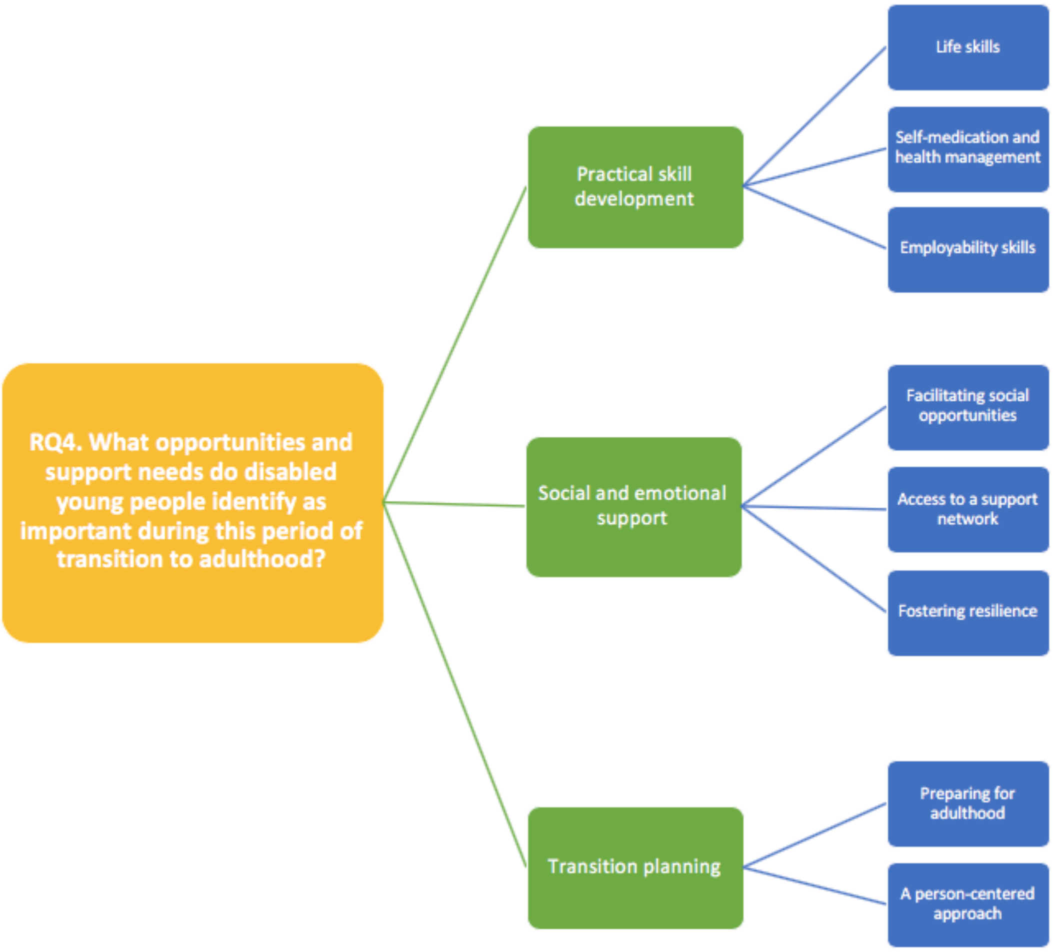
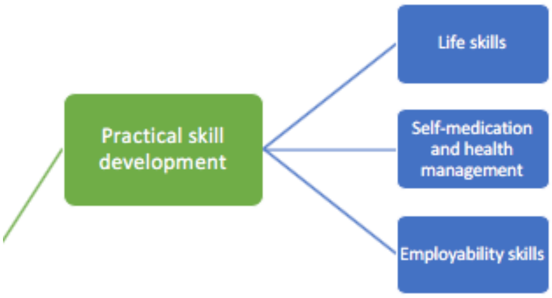


Figure 8. Thematic map for Research Question 4

Through analysis of the focus group data and remaining photographs, the participants and I were able to identify a number of key areas for support and why these were important in facilitating their TtA. Overall, the participants expressed positive views of the support they had received and the opportunities college, in particular, had provided them. Throughout their accounts, there was a strong sense of the nurturing and holistic support they had experienced during their time there. Support needs were organised into three themes, including ‘Practical skill development’, ‘Social and emotional support’ and ‘Transition planning’.

4.5.1. Practical skill development

All the participants referred to the practical skills they were being supported to develop in preparation for adult life after college. These included taking a more active and independent role in daily living tasks, learning to manage their own health and medical needs and gaining work experience, further qualifications and employability skills.



4.5.1.1. Life skills

As mentioned previously, involvement in life skills development was predominantly discussed by the young women in the study, but it seemed to be an area that was promoted for all. Several participants spoke about working towards life skills targets and having designated time each week to focus on these:

> *Arthur: This is my toasted sandwich maker! I love food!*
>
> *Int: Me too! So, is preparing meals something you are learning to do more independently?*
>
> *Arthur: Yes, in my life skills sessions every Thursday.*

As Arthur mentions here, meal preparation was something many of the participants were learning how to do and this involved carrying out every step, from managing a food budget to loading the dishwasher:

> *Jess: Then I started here, and it was like, "You've got a £25 allowance" and I just sat there, and I was like "What?". To do a week's shop. At first, I was like, "Nah", I just couldn't get my head around that was I shopping and cooking for myself.*

As Jess acknowledges, this was initially daunting for many of the YP who had never had to do it before, but with opportunities to practice and the right level of support, she was keen to do as much as she could for herself. Several participants talked about the importance of being allowed to make mistakes and learn from them, which indicated that they appreciated not being over-supported in these situations. Others highlighted the need for support from a range of professionals, to overcome barriers that they experienced in relation to developing these skills. For Zara, driving her wheelchair in the community was particularly anxiety-provoking, but she was able to access support from a Psychologist and an Occupational Therapist whilst at college:

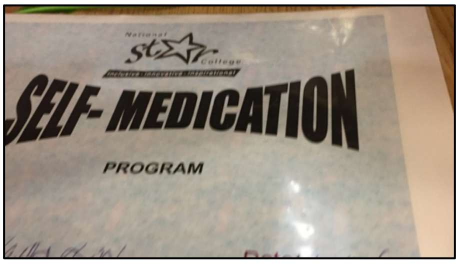
> *Zara: I wasn't really confident with driving my chair before. Everybody would say my ability was much better than my confidence. Which is the hard part to change!*

This support had enabled her to enjoy opportunities she had previously been unable to, such as going out to eat at restaurants with her friends which subsequently, had led to the development of other important social skills.

4.5.1.2. Self-medication and health management

Maintaining their physical health was a priority for many of the participants and this often involved taking daily medication to manage symptoms associated with their disability. Several participants talked about the self-medication program that was run by the college nurses and how they had been encouraged to complete this, given the existing knowledge and understanding they had:

> *Zara: So all through last year, the staff were like you can do your own medication. And I was like yeah, I can do it with my eyes shut, except the ordering of everything which I wasn't sure about. So, I started doing it this year with the nurses.*



SELF-MEDICATION

PROGRAM

Both Zara and Jess recognised that these skills would be vital for their future independence, as it would mean they didn't have *"24-hour carers stuck to us"*. Similarly, Finn spoke about developing a better awareness of his body's needs and the importance of scheduling regular rest into his weekly timetable, to avoid *"burnout"*.

4.5.1.3. Employability skills

The third subtheme was generated from discussion around the wide range of work experience placements participants had engaged in and the skills they had developed during these. Most of the participants had allocated job mentors and their strengths and interests appeared to have been considered when matching them to their different work settings:

> *Jack: This is a photo of Heart radio station. I haven't worked there, but I had some work experience at another local radio station.*

Jack's frequent mentions of music, singing and performing suggests that this had been planned in consultation with Jack himself. Similarly, Arthur had worked in a theatre box office, Jess in children's nursery and Finn had an upcoming placement in a cinema. Rather than being expected to fit to a limited number of work placement opportunities, participants spoke of having options, which had had enabled them to make informed decisions about their future careers:

> *Zara: I want to work in costume and theatre, because I like films and fashion. I did my textiles GCSE and my main course here is Art and Design. I've learnt new skills and I've been told I can tailor my end project towards textiles, so I did that.*

Zara and Ellie aspired to go to University after college, rather than entering the world of work straight away and it was evident that their college experiences were being tailored towards these goals. Like many of the participants, both young women expected to eventually get paid employment:

> *Zara: Yeah, I want to work, but I don't want another one of these part-time voluntary things, I want it to be a permanent, paid thing…*

The challenges of this were acknowledged by both groups, but it didn't seem to prevent them from believing it would be possible. For Ellie, this was already a reality:

> *Ellie: I was part of a Performing Arts company when I was younger and now I work there.*

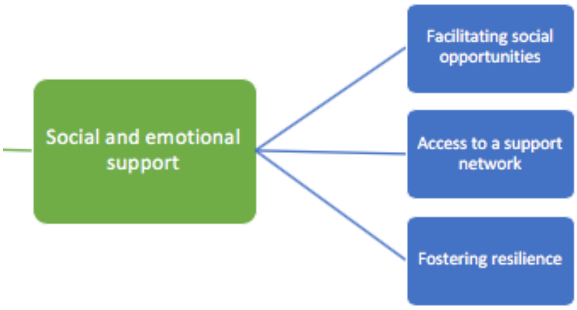
Alongside the financial benefits, participants acknowledged the social opportunities that work provided them with. Jack reflected on his past job in a supermarket and the relationships he had formed there:

> *Jack: On my final day, I actually thought "I don't want to go!" because the staff were really good, really good to talk to, I had loads of good friends there.*

The next theme takes this aspect further and explores the support and opportunities participants valued in terms of their social and emotional development during the TtA.

4.5.2. Social and emotional support

This was a strong theme throughout all the participant's accounts and was highlighted as a key part of their EA years. Many of the YP talked about the challenges they had faced, when it came to socialising, maintaining their emotional wellbeing and coping with their disability, but also gave numerous examples of how they had been supported to overcome these.



4.5.2.1. Facilitating social opportunities

For several participants, starting at a residential college and becoming part of a large, diverse community of disabled YP had enabled many enjoyable and beneficial social opportunities. Although Jack couldn't share a photograph of it, he described in detail a Drag Show that was organised annually, which appeared to be a highlight of his college experience:

> *Jack: At college we also have loads of events like that. There's been discos with some drag queens. They are so funny, they are fantastic… every year, I take the opportunity to go up and dance with them.*

This had exposed Jack to form of entertainment and potentially a social group that he may not otherwise have interacted with. Other participants shared similar examples of how they had been supported to meet like-minded peers:

> *Finn: Yeah, when I started here, they were worried that I wasn't socialising very well, but I took the initiative and set up a club so that I could find other people who liked films and stuff. So now I run this thing called Geek Club every Wednesday where people can watch YouTube clips and discuss them.*

For Finn, this was about more than just making new friends, as he had identified that developing his social skills and confidence was a personal goal. Ellie, who used an Alternative and Augmentative Communication (AAC) device, acknowledged that this was an ongoing challenge for her as well:

> *Ellie: I'm not confident using my device.*
>
> *Int: Oh, I see, so that lack of confidence sometimes gets in the way when you meet new people?*
>
> *Ellie: Yeah. It's got a bit easier. But it needs more work.*

AAC users like Ellie require the right support and opportunities to use their devices in social situations and therefore it was important to her that she was in an environment where this was understood and facilitated. She talked about how she was supported to attend a church service every Sunday, which, alongside meeting her spiritual and belonging needs, also provided an alternative social environment to practice her communication:

Ellie: My faith is the most important thing to me.

4.5.2.2. Access to a support network

Alongside the ongoing support from their friends and families, several participants talked about the importance of having access to a wider network of people and professionals. Keyworkers were mentioned by several participants, including Jack, who seemed to value the responsive daily support:

> *Jack: Yes, we all have a keyworker. I have a really good one, she does loads for me.*

For other participants, it was about having their emotional and psychological needs met. Some of the YP were supported members of the college's wellbeing team and expressed how important this support was for their mental health:

> *Zara: Well, I go to the Talk2Team with my big worries that I have had for a while…they just help to break it down, like with my driving. It's good to just talk to them and if they know what you mean then it is better.*

Having this space to talk seemed to be having a positive impact on Zara and was helping her to develop coping strategies that would be essential for adult life. Similarly, Finn experienced high levels of anxiety and spoke of a previous eating disorder which he had to be hospitalised for. As a result, the college appeared to have put additional support in place to ensure there was always a familiar member of staff available if he needed them:

> *Finn: I have a core team of about five or six people. That way there is always someone about who knows me well and I feel relaxed and comfortable with.*

4.5.2.3. Fostering resilience

> *Ellie: My disability doesn't stop me doing the things I want to do in my life. Sometimes it might take me a bit longer to do them, but it never stops me.*

As illustrated in Ellie's statement above, the YP maintained extraordinary positivity, determination and resilience, despite the challenges they faced. Arguably, this seemed to be facilitated by the support of those around them, strong relationships and the nurturing college culture. Ellie spoke of a family member, who had been the inspiration behind her family's charity:

> *Ellie: She was a big part of my life. She saw my ability, not my disability.*

Similarly, Finn spoke about how both his parents and his best friend had instilled in him the belief that *"just because you are disabled, it doesn't mean you are less than anyone else".* Other participants also spoke about how the attitudes of others had either helped or hindered in their journeys towards adulthood:

> *Jess: Yeah I think it is like how people talk to me. I think when they talk to me like an adult, that boosts my confidence. But if you are talking to me like I am not all there in the head, I don't like it.*

Although participants acknowledged that there were still those in society who lacked awareness and understanding around disability, their experiences within the college were overwhelmingly positive and empowering. They gave numerous examples of being encouraged, challenged and supported to develop in all areas of their lives. For Jess, the support she had received in college had not only promoted her independence, but also changed the way she viewed herself:

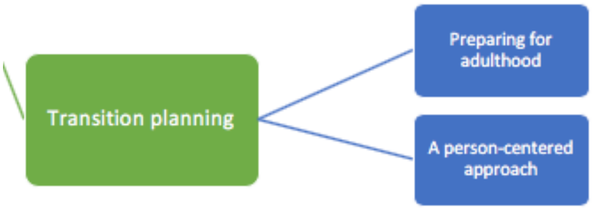
> *Jess: The college has really helped me come to terms with the way I am. Because I used to get really down about it and ask, "why am I like this?". The college helped me to feel more accepting and celebrate who I am.*

Although their environment played a key role in the participant's ability to be resilient, Finn also noted the importance of having inner strength, vitality and motivation if he was going achieve what he wanted to in adulthood:

> *Finn: Yes, you probably need that drive even more when you're disabled, because you face more challenges than the average person. Enthusiasm is everything… to achieve something you have to really want it.*

4.5.3. Transition planning

Although participants were in different years at college and therefore at varying stages of transition planning, it was something they were all aware of. The YP seemed to be experiencing feelings of apprehension, excitement and hope, depending on how prepared they were to leave college and start their adult lives.



4.5.3.1. Preparing for adulthood

> *Zara: I'm hoping that all the skills that we have learnt here will help…we will look back on the experiences and opportunities we had, and they will motivate us to keep moving forward and educate others.*

As Zara recognises here, college had acted as a catalyst, but the learning and development would continue long after and even be shared with others along the way. An important part of the planning process seemed to be a decision around the most appropriate living environment. Many of the participants had experienced living in different types of college accommodation, which was helping to inform their final decision:

Ellie: My mum built my house a few years ago because she wants me to live independently after college…this flat has really helped me to be independent…

For Ellie, this decision was made and provision in place to ensure it worked out, however hers seemed to be an exceptional situation. Other participants still seemed to be figuring this out and considering what would be right for them. For example, Jess had trialled an independence flat, but decided to move back into a shared living environment, for medical reasons:

> *Jess: No moving into the bungalows actually made me feel more confident. I needed reassurance that if anything happened with my catheter, I could just press the bell and staff would come to help.*

Some participants were already facing obstacles and realizing that some of the decision-making was out of their control:

> *Arthur: She's [social worker] going to start looking for a place for me to live. I want to move closer to home, but I have had conversations with my Mum, and it may not be possible.*

Although availability was not guaranteed, it was positive that Arthur was actively involved in this process and that professionals were asking for and being mindful of his preferences. This is in line with person-centred support, which is considered to be 'best practice' and is the focus of my final subtheme.

4.5.3.2. A person-centred approach

It was striking that, despite being alike in age, ethnicity, from similar backgrounds and on the same college pathway, all the participants had different ideas and aspirations. This was apparent in almost every theme that was generated from the data, including participant's varied understandings of adulthood, views on gender, hobbies and interests, significant relationships and career choices. The conversation below highlights the importance of a person-centred approach and holistic questioning, in order to truly understand a YP's priorities in adulthood and identify what support they may need to achieve these:

> *Arthur: I want a family too. I've always wanted children. I started thinking about it when I was really young.*
>
> *Int: What about you Jack?*
>
> *Jack: No no no, definitely not rugrats running around! (laughs) Too much like hard work!*
>
> *Finn: We all have our own personal preferences and ideas for our future.*

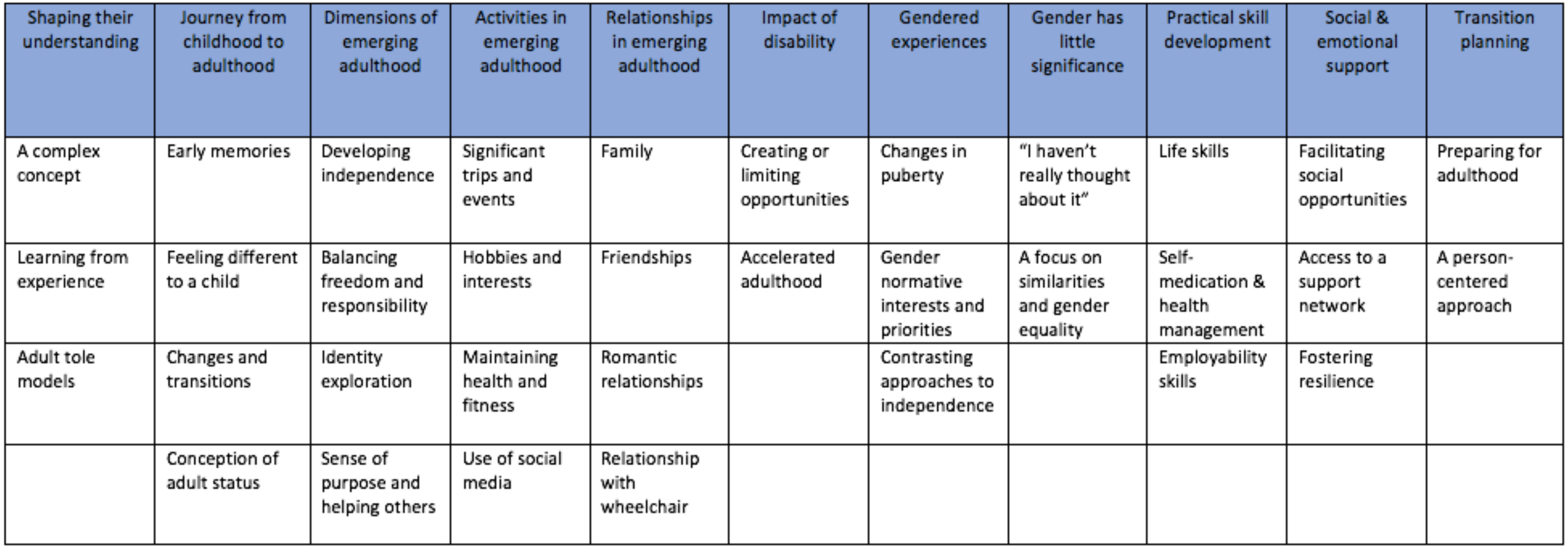
For disabled YP to be able to express views such as these with confidence and clarity, they require regular opportunities to practice throughout their EA years. Several participants talked about their involvement in annual EHCP reviews and other internal meetings regarding making changes to their timetables or care arrangements. Finn had taken this one step further and initiated a meeting with members of his core team, which was a first-time experience for him:

> *Finn: I called a meeting off my own back to tell everyone what I wanted to do whilst at college and they were all really impressed…I wanted to discuss my emotional state because it is a bit fragile at the moment for various reasons but I also wanted to talk about what I wanted to achieve in the 2 years I have left….We are going to have another one to discuss bigger picture stuff as well. I'm looking forward to it.*

This is a strong example of person-centered planning in which the YP is participating fully and being empowered to take control of their future and this model should be promoted for all disabled YP at this important stage which could determine the rest of their adult lives.

4.2. Chapter summary

This chapter has outlined the themes and subthemes that were generated from the disabled young people's accounts of emerging adulthood. These are presented in the table below for ease of reference and more detailed summaries regarding how they relate to the research questions are provided in the following chapter.



Shaping their understanding	Journey from childhood to adulthood	Dimensions of emerging adulthood	Activities in emerging adulthood	Relationships in emerging adulthood	Impact of disability	Gendered experiences	Gender has little significance	Practical skill development	Social & emotional support	Transition planning
A complex concept	Early memories	Developing independence	Significant trips and events	Family	Creating or limiting opportunities	Changes in puberty	“I haven’t really thought about it”	Life skills	Facilitating social opportunities	Preparing for adulthood
Learning from experience	Feeling different to a child	Balancing freedom and responsibility	Hobbies and interests	Friendships	Accelerated adulthood	Gender normative interests and priorities	A focus on similarities and gender equality	Self-medication & health management	Access to a support network	A person-centered approach
Adult tole models	Changes and transitions	Identity exploration	Maintaining health and fitness	Romantic relationships		Contrasting approaches to independence		Employability skills	Fostering resilience	
	Conception of adult status	Sense of purpose and helping others	Use of social media	Relationship with wheelchair						

Table 5. Themes and subthemes

5. Discussion

5.1. Chapter introduction

This chapter begins with a short summary of key findings for each of the four research questions, before exploring how these findings relate to the current literature around disabled YP's experiences of EA. Given the richness of the data, and the significant number of themes and subthemes generated, it would not have been feasible to examine each of these discursively within the limitations of this thesis. Therefore, themes have been organised in order to focus on the most salient points from the research, in terms of their theoretical and practical implications. Several subheadings use direct quotes from transcripts, to foreground the voices of participants:

Research Question 1 and 2:

- Expressing an understanding of emerging adulthood
- Constructing alternative identities to the disabled identity
- Recognising positive experiences in emerging adulthood
- "I guess for me it is a purpose, I wanna do something with my life"
- Accelerated adulthood: a problem for disabled YP or not?
- Sex and relationships: "…it's not my strongest subject"

Research Question 3:

- Acknowledging gendered experiences
- The role of gender in transition planning: "I haven't really thought about it until now"

Research Question 4:

- "I couldn't have done any of it without my support system…"
- Promoting attributes of resilience

I later consider the implications for professional practice and propose a framework that aims to guide practitioners' conversations with disabled YP and support them during this period of TtA. This chapter concludes with a critical evaluation of the research with reference to its strengths and limitations, suggestions for future directions and some key reflections from the research process.

5.2. Summaries of findings

The short summaries below aim to provide a helpful recap of the findings presented in the previous chapter and introduce the key concepts that will be discussed in relation to existing literature.

5.2.1. Summary for RQ1: How do disabled young people understand the concept of emerging adulthood?

Three themes were generated in relation to the first research question: 'Shaping their understanding', 'A journey from childhood to adulthood' and 'Dimensions of EA'. The Life Map activity facilitated discussions around how key events, people and transitions had played a part in shaping participant's conceptualisations of EA. Although no single, clear-cut definition of EA was put forward, many of the YP described it in terms of a journey characterised by change and progression. Each YP had a unique vision of how their life as an adult would look, with some considering themselves to have already reached adult status and others not. Despite these differences, there were specific dimensions of EA that were identified as important by all, including independence, freedom, responsibility, identity exploration and a sense of purpose. The need to "do something useful", help others and feel like a valued member of their community was prominent throughout all accounts and is therefore considered a key finding of this study.

5.2.3. Summary for RQ2: What are disabled young people's lived experiences of emerging adulthood?

Participant's photographs and dialogue regarding their experiences of EA and what they valued most at this time in their lives fell under two themes of 'Activities' and 'Relationships'. Many of the YP recalled significant trips that had led to new experiences, helped them to overcome barriers and acquire useful skills for adult life. Participants spoke about hobbies and interests, which were not only fundamental in maintaining their emotional wellbeing and social engagement but also facilitated the development of alternative identities (to their disabled identity) such as being a YouTuber, Harry Potter enthusiast or competitive darts player. Some participants emphasised the importance of maintaining their health and fitness, which seemed to be linked to their increasing sense of responsibility and a need for continued access to services and support that could facilitate this. Furthermore, participants' daily use of technology and social media and the role this played in empowering and connecting them was discussed.

Participants' relationships and how these had changed and developed throughout EA featured strongly in the data. There was an ongoing appreciation for family support alongside an understanding that opportunities to meet like-minded peers and develop friendships were vital. Participants spoke little of their experiences of romantic/ sexual relationships and those that did cited barriers to these, including a lack of confidence and the logistical considerations of being in a wheelchair. The final theme was generated from discussion about how being disabled had either created or limited their opportunities and, in many ways, had led to an acceleration towards adulthood. They did not express frustration or resentment about this, but instead perceived their increased maturity as positive and beneficial for their future.

5.2.4. Summary for RQ3; What part does gender play in emerging adulthood for disabled young people?

The two contrasting themes relating to this research question were 'Gendered experiences' and 'Gender as unimportant or unexamined'. There were many similarities, but also notable differences between how the young men and young women in the study experienced EA and what they considered important in their lives, which seemed to be in line with gender norms. For example, the young men talked about technology, exercising and taking on leadership roles whereas the young women focused on relationships with family, involvement in domestic tasks and taking on helping roles. There was also a difference in their attitudes towards developing independence and preparation for adulthood. For example, the young women were career-focused and provided multiple examples of how they were developing their life skills whereas the young men appeared to have a more relaxed approach about their future and viewed their EA years as a time to have fun with friends and develop personal interests.

When asked directly about the impact of gender, most of the participants had not considered this as an important factor and responded with uncertainty. This suggests that it may not be a factor they had previously been prompted to think about and did not feature as important in discussions regarding their TtA. Many participants preferred to focus on the similarities between men and women and highlighted the importance of gender equality.

5.2.5. Summary for RQ4; What opportunities and support needs do disabled young people identify as important in emerging adulthood?

The YP identified several key areas for support, which were organised into three themes of 'Practical skill development’, ‘Social and emotional support’ and ‘Transition planning’. Participants drew on their experiences at the residential college, which overall, appeared to have been very positive and nurturing. They highlighted the support they had received from a range of professionals to develop life skills, work skills and manage their own health and medication. For many, the motivation behind this was to be as independent as possible in the future and be able to enjoy the same opportunities as their non-disabled peers, such as living with friends, going to university or having paid employment. Alongside practical support, participants emphasised the importance of social opportunities, access to emotional and psychological care and an environment that fostered resilience. For some, this had contributed to the development of a more positive disabled identity and helped them to understand how they could utilise their personal strengths and qualities in order to achieve in their future. Finally, there was a focus on preparing for adulthood and beginning the transition planning process as early as possible. The different views and aspirations expressed by the YP in the study further highlighted the need for a collaborative, person-centred approach as well as regular opportunities to develop and practice the skills required to be fully involved in this process.

5.3. Discussion of key themes in relation to RQ1 and RQ2

Having provided a summary of findings for each research question, I am now going to look more closely at some of the key themes that were generated in relation to the first two research questions and determine whether they reinforce or challenge current thinking. I will start by examining how participants in the present study developed and expressed their conceptualisations of EA and how this compares to previous studies on the topic.

5.3.1. Expressing an understanding of emerging adulthood

The present study was one of the first to carry out an in-depth exploration of how disabled YP understand and experience EA and therefore there is limited existing literature with which to compare my findings. As a relatively new theory, first coined by Arnett in 2000, the concept of EA as a distinct life stage has generated much research, critique and consideration of how best to measure it. Reifman et al. (2007) developed the IDEA which directly assessed the five dimensions that were thought to characterise EA. The IDEA was first validated in a sample of predominantly white, female undergraduates at a University in Texas, however it has since been adapted and used increasingly with diverse populations and cultures, such as adopted YP (Musante, 2010) and Latino older adolescents considered to be ‘at risk’ (Lisha et al., 2012). To my knowledge, few researchers have used the IDEA or any similar tool in studies with disabled YP and rather than seeking to understand their perceptions in relation to EA, there has been too narrow a focus on their experiences of transition to adult services.

A potential reason for this was put forward by Murphy et al. (2011) who considered that such concepts as ‘childhood’ and ‘adulthood’ may be too abstract for many disabled YP who had little prior exposure to conversations of this nature. In *contrast* to this view, I found that participants in the present study were able to clearly articulate what EA meant to them and engage in discussion about where these views and beliefs had come from (e.g. their experiences in childhood, adult role models). They described how their thought processes and priorities had gradually changed as they moved from adolescence to EA and gave specific examples, such as putting other’s needs above their own and taking their health more seriously. In line with Salt et al.’s (2019) study, which was one of the few other studies that sought the views of YP about growing up and adulthood, participants varied in their self-perceived adult status and considered this to fluctuate depending on the situation or context. When comparing perceptions of disabled and non-disabled YP, DeVoe-Hall (2018) found that a significantly higher number of disabled YP felt they had reached adulthood, despite rating all items on the IDEA consistently lower. Similarly, several of the participants in the present study considered themselves as adults and based this not on meeting traditional markers of adulthood (e.g. marriage, having children) but on their increased independence and sense of responsibility since moving out of the family home and into residential college. This finding challenges the traditional, normative view of adulthood and implies a need to adopt a different understanding of what it means to be an adult, when supporting disabled YP.

It is possible that the methods used in the present study facilitated participants' ability to communicate their understanding of EA. For example, the visual prompts adapted from the IDEA appeared to 'open up' discussion about dimensions the disabled YP may not otherwise have considered and the use of photo-elicitation supported their recall and enabled them to provide rich accounts of their experiences. Several other studies using similar creative and visual methods of data gathering (Cheak-Zamora et al., 2016; Gibson et al., 2013; Pallisera et al., 2016) have acknowledged how these helped to engage disabled YP in a more participatory research process, capture experiences from their perspective and provide space for personal and group reflection. It is important to consider that the participants may well have been able to express themselves without the use of these methods. It is possible that during their time at the college, if not before, they would have engaged in similar conversations with professionals and family members and through these, developed the skills and confidence to communicate their views on these more complex concepts. Whilst McLaughlin and Coleman-Fountain (2018) recognised the benefits of using visual methods in research with disabled CYP, they argued that they were no more 'age-appropriate' or 'authentic' than other approaches. Instead, their value lay in "the particular insight they bring on how social relations and positions influence how they articulate and present their identity" (p.2). This seems pertinent when considering how and why disabled YP chose to emphasise their alternative identities and involvement in particular EA activities through their photographs and verbal descriptions. This will be explored further in the next section.

5.3.2. Constructing alternative identities to the disability identity

In line with Arnett's early writings on EA, identity exploration and formation were understood by participants to be key dimensions of this life stage. They shared stories about experimenting with physical appearance, discovering personal strengths and finding the places where they truly felt they could be themselves and belong. Participants also talked about their developing hobbies and interests and how these had come to form an important part of their identity, whether it be as a "metal-head" or a Harry Potter super-fan. Finally, they emphasised the importance of relationships with family, friends, partners and college staff and the roles they played within these.

When asked directly about the impact being disabled had on them growing up, participants acknowledged several ways in which this had affected their lives, both positively and negatively. However, in general, the disabled YP appeared to prefer to present themselves as leading 'ordinary' lives engaging in the same everyday activities as their non-disabled peers. A similar theme emerged in Gibson et al.'s (2014) study; rather than focus on the atypical aspects of living their lives with DMD, the participants chose to highlight their academic achievements, employment goals and plans for greater independence. By doing so, they made claims to themselves as 'normal' and distanced themselves from a disability self-identity. The authors labelled these as "narratives of nondifference" (p. 99) and noted how participants were using them as a strategy to function effectively within the dominant social order in which they were immersed. It is possible that, in emphasising their alternative identities and minimising their disability identity, the participants in the present study were using a similar strategy. Despite being at a specialist college with multiple other disabled YP, where diversity is accepted and celebrated, it is interesting that participants may still have felt pressure, albeit subconsciously, to conform to norms and present themselves 'just like everyone else'.

Several other studies have looked at identity issues in EA and similarly discovered that disabled YP value multiple, alternative identities over a disability identity (Dorozenko et al., 2015; Midjo & Aune, 2016; Watson, 2000). For example, findings from Dorozenko et al.'s

(2015) research suggested that disability was not an identity that was salient to participants and instead, their identities were derived from the broader social context, including the relationships and interactions they engaged in and the multiple roles they occupied in society. The authors argue that the stigmatised identity of disability and the view that they are different is often imposed on these individuals, beginning at birth, and forms part of a process of dehumanisation (Dorozenko et al., 2015). In support of this theory, participants in the present study described how medical professionals had expressed to their parents a tragic view of the future, with a focus on their limitations and the inevitable difficulties they would experience. In contrast to this perception, the YP's accounts of their lives so far contained numerous examples of their capabilities, achievements, beliefs, adventures and relationships. As Dorozenko et al. (2015) notes, these experiences are common to all people, disabled and non-disabled, yet the similarities are rarely acknowledged and the differences often problematised.

Although the present study focused solely on the views of disabled YP, Midjo and Aune (2016) compared them to professionals' views and identified a conflict. Despite intentions to listen to and involve disabled YP, there was an expectation that they would accept or adapt to the label of disability to "fit" the services on offer, thereby restricting the influence they had over their identities. In order to improve transition support for these YP, services must strive to meet specific support needs e.g. appropriate care, equipment, skill-building opportunities, but avoid standardising these needs or allowing the disabled identity to overshadow other equally meaningful identities. Furthermore, rather than promoting typical life trajectories and a linear pathway into adulthood, it would perhaps be more beneficial to encourage careful consideration of what good quality of life and outcomes looks like to them.

Research such as the present study, which explores the richness and diversity of lived experience whilst drawing attention to the likeness in goals and aspirations of disabled and non-disabled YP, is key to challenging unhelpful perceptions of disabled people, developing a more nuanced and positive view of what their lives are or could be like.

5.3.3. Recognising positive experiences in emerging adulthood

In contrast to much of the transition literature, which has tended to paint a gloomy picture of the *process* for disabled YP and their families, overall, participants in the present study reflected on their experiences of growing up positively. They described happy, early memories of school, supportive families, strong friendships in adolescence, unique opportunities to meet their idols and exciting new challenges in EA. Despite acknowledging it as a time of great instability and uncertainty, many reflected on these experiences as learning opportunities that had led to personal development, growth and a greater ability to cope. This is in line with the views put forward by participants in Stewart et al.'s (2014) study, which highlighted the importance of exposure to typical experiences and being allowed to try, fail or succeed in order to develop resilience and build capacities.

It was important that I took a life-course approach in order to capture the complexities of their lives and develop a holistic understanding of their experiences throughout all developmental stages. Previous research supported this concept and recognised how daily life experiences, starting from childhood, can influence a disabled YP's developmental journey and whether it takes a positive or negative trajectory (Stewart et al., 2014). One recent study adopted also this life-course approach when exploring the transition experiences of a group of young autistic people who were followed from childhood to EA (Cribb et al., 2019). Instead of focusing on what they considered to be traditionally defined outcomes (e.g. employment rates), they interviewed participants about their school experiences, goals and self-perceptions, which revealed far greater optimism about their current and future lives than previous studies suggest. For example, like participants in the present study, the young autistic people reflected positively on the progress they had made since childhood and expressed that they felt more in control of their lives, which the authors associated with their developing sense of identity, autonomy and strong social connections.

Having frequent opportunities to engage in activities with friends throughout all developmental stages or being able to connect with like-minded others through social media and technology was also important to the participants in the present study. They spoke of friends supporting them through difficult times and how much they had learnt and grown as a result of meeting different people. This finding was in contrast to the literature and it appeared that the residential college environment had facilitated these social opportunities and prevented them from experiencing the exclusion and isolation that so many disabled YP are at risk of (Heslop et al., 2002). Previous studies have emphasised the difficulties this population face when building and maintaining a social network in comparison to their non-disabled peers (Morris, 2002) and note how the TtA is a crucial point at which any existing friendships can be lost (Pallisera et al., 2016; Small & Raghaven, 2013). Given that research has highlighted the importance of friends for identity formation and mental health (Hurd et al., 2018) there is a key message here for all professionals working with disabled YP. For those who identify it as important, enabling regular access to social spaces (both physical and online), encouraging involvement in leisure activities and fostering friendships throughout their childhood and EA is likely to be key in creating powerful and sustainable social support networks in adulthood.

This section has shed light on a new and more optimistic narrative around EA experiences for disabled YP and has demonstrated how taking a holistic, life-course approach, both in terms of research and transition planning, can be beneficial. The next section explores the importance of finding a purpose, which featured as a strong theme in participants' accounts but demands a more critical examination.

5.3.4. "I guess for me it is a purpose, I wanna do something with my life"

Erikson's seminal work on identity development included discussion around the importance of purpose, which he described as ''…the courage to envisage and pursue valued goals uninhibited by the defeat of infantile fantasies, by guilt and by the foiling fear of punishment'' (1964, p. 122). Having examined Erikson's writings, Hill and Burrow (2012) highlighted three key propositions about purpose and carried out questionnaire research with non-disabled emerging adults to explore these further;

1. Having a purpose is beneficial during the identity development process as it leads to greater wellbeing.

2. Purpose can facilitate the resolution of identity crises, therefore purpose commitments should correspond with identity commitments.
3. Having a sense of purpose is related, but not synonymous, with having a sense of identity and each will uniquely predict important outcomes (e.g. maturity).

Their findings largely supported the above claims and provided further understanding about the constructs of purpose and identity and how they develop in EA. Correspondingly, participants in the present study placed great value on finding a purpose in their lives, having meaningful occupation and helping others. This seemed to have become increasingly important to them in recent years, with many talking enthusiastically about their altruistic goals, involvement in charity projects, student representative roles and the small, every-day ways in which they helped others. Participants emphasised the sense of fulfilment this gave them and several shared aspirations to work in caring professions, such as counselling, in the future. Participants in Clarkson's (2018) doctoral research shared similar views, describing how their need for purpose had been met through their participation in setting up an alternative provision and advocating for other YP with SEND. Furthermore, one of the subthemes in Dorozenko et al.'s (2015) study was 'The carer (not the cared for)', in which participants described multiple scenarios where they were actively supporting elderly parents with dementia or friends with health needs. A participant in the present study also referred to looking after her younger siblings and godchildren, which was a responsibility she took seriously. Emphasising the interdependent nature of these relationships is important as it challenges the dominant representation of disabled people as dependent and passive recipients of care (Dorozenko et al., 2015).

Another way in which disabled YP appeared to seek purpose and meaning was through their engagement in disability-rights activism. As Nario-Redmond and Oleson (2016) discovered, they were twice as likely as their non-disabled peers to be involved in disability-rights groups. Although participants in the present study did not express strong political views, several spoke about their involvement in raising awareness in the community to change attitudes, improve accessibility and facilities in the local area. EA could, therefore, be understood as a time where disabled YP are not only developing their sense of identity, but also making decisions about their beliefs and values, their purpose in life and how they can become active, contributing members of society. A quote by McAdams (2001) supports this theory:

> In late adolescence and young adulthood, people living in modern societies begin putting their lives together into integrative narratives of the self, reconstructing the past and imaginatively anticipating the future in such a way as to provide their lives with some sense of unity and purpose (p.117).

Although this may seem fitting for the disabled YP in the present study, given their focus on seeking purpose at this time in their lives, the quote could be perceived as having quite normative, future-oriented assumptions. The above implies that this *must* happen at this stage and that lot of time and energy *should* be spent on such activities, however this may not be viable for all disabled YP. For example, Abrams et al. (2020) discussed the issue of crip time, widely defined as “formulations of time that challenge ableism” and the lack of understanding and support there is for those disabled YP who are likely to have shorter lifespans. The authors recognise how transition planning, amongst many other processes that disabled YP are expected to engage in, may not take this into consideration or acknowledge how living a shorter life might impact on their priorities and goals. This reminds us of the problematic nature of seeing life trajectories through a singular, normative timeframe and the importance of challenging the ‘one size fits all’ approach to supporting disabled YP in EA (Abrams et al., 2020). To cite Kafer (2013, p.27), “…rather than bend disabled bodies and minds to meet the clock, crip time bends the clock to meet disabled bodies and minds." This helps to reframe ableist constructions around what is important in the lives of disabled people, when it should happen and how long it should take. Whereas for some disabled YP, engaging in purpose-seeking discussions and activities may be meaningful and worthwhile, for others this will be the last thing on their mind and it is important that all are supported to make these judgements and use their time as they feel is best for them.

Continuing with the issue of time, the next section explores the concept of ‘accelerated adulthood’ (Lee, 2014) and how this was perceived by the participants.

5.3.5. Accelerated adulthood: a problem for disabled young people or not?

The term ‘accelerated adulthood’ has previously been used in the literature when considering the race to transition from child to adult services and how disabled YP are often introduced to pre-structured adult lives without having the time or opportunities to explore who they want to be (Lee, 2014; Midjo & Aune, 2016; Redgrove et al, 2016). EA is characterised as an extended transition period where the individual is free from both the constraints of childhood and the commitments of adulthood (Arnett, 2000) and those who do not get the chance to experience it and are forced into adult roles earlier, are often considered to be at a disadvantage (Lee, 2014).

Several participants in the present study lived highly medicalised lives, experiencing multiple hospital visits and procedures and being exposed to ‘adult’ conversations from an early age. Their accounts suggested that these experiences had required them to grow up faster and take life more seriously than their non-disabled peers, who did not routinely have the same health concerns and worries and were therefore potentially more able to enjoy the freedom of the EA years. Furthermore, several participants had moved out of their parent’s homes at 16, which is significantly earlier than the average YP these days, and had experience of living in shared accommodation, sometimes with much older adults. They reflected that these experiences had made them “wiser” and “more mature” and showed no indications that they were resentful of missing out. Interestingly, in other ways, participants’ experience of being at residential college meant that, conversely, this accelerated process could be slowed down. One participant had already attended another residential college prior to this one and seemed particularly appreciative of this “extra time” and determined to make the most of the opportunity’s college afforded him, as he felt sure they would not be available to him forever. Other participants did not seem to feel under any pressure to rush into adult life and talked about her plans to travel and go on to a University course following her 3 years at college. So, despite some of the participant’s experiences in childhood and adolescence resulting in them moving towards adulthood more quickly than their non-disabled peers, many believed that they could still enjoy the benefits of a non-settled existence.

Midjo and Aune (2016) suggested that as a result of growing up in a historical period that paid significant attention to equality and rights, this generation of disabled YP have greater expectations of what is possible and achievable (e.g. travelling, university). For the participants in this study, it was also likely that the specialist college ethos around challenging stereotypes and raising aspirations had positively influenced their outlook on life. Furthermore, several had the support of their families, who had nurtured a belief that they could do everything anyone else could and taken steps to support them in this, such as setting up charities. It is important to note here the somewhat atypical nature of this sample and this is discussed further as part of a reflective account at the end the chapter.

Although the participants in the present study did not appear to feel disadvantaged by what could be seen as their acceleration towards adulthood, it is an area to be mindful of. As Redgrove et al. (2016) highlight, professionals should avoid viewing EA as synonymous with the transition to adult services and efforts should be made to ensure young disabled people have the freedom and choice to experience this extended life stage. The next section looks at another aspect of EA that is considered to have been historically neglected for this population.

5.3.6. Sex and relationships: "…it's not my strongest subject"

EA is understood to be characterised by identity negotiation and exploration, with sexual experimentation forming an important part of this process for many (Arnett, 2000). However, as highlighted in several studies including this one, this is rarely the case for disabled YP, whose sexual identity is often overshadowed by their disabled identity and whose opportunities for sexual expression are sometimes controlled and limited by others (Payne et al, 2016; Wilkinson et al, 2015). As in Gibson et al.'s (2014) study, where it was noted that the young men with DMD struggled to talk openly about their sexual relationships, participants in the present study were quick to admit a lack of experience and confidence and appeared eager to move on from the subject. It is important to reflect on the part I played, as the interviewer, in these conversations and how my own preconceptions and anxieties surrounding disability and sexuality may have influenced what the disabled YP chose to or *not* to share. This is discussed further as part of a reflective account at the end the chapter.

Despite the assumption that sex is a fundamental part of ‘normal’ modern life, with sexual engagement and participation believed to be a requirement for fitting in, disabled people continue to be viewed by some as innocent, naïve and asexual, which presents significant barriers to their sexual citizenship (Shah, 2017). Only one participant in the present study spoke about accessing sex and relationships education (SRE) at secondary school and although she did not refer to her own sexual experiences, she was by far the most open and knowledgeable when talking about her body, intimate care and other topics of this nature. Previous research has shown that disabled YP are often withdrawn from sex education, with only 50% of participants in one study reporting having received it (MCabe et al. 2000 cited in Payne et al., 2016). Similarly, Wilkinson et al. (2015) found that access to education and support was not influenced by the YP’s needs, but by their carer’s embarrassment, expertise, and beliefs about how their sexuality should develop. It is possible that participants in the present study had also been restricted by those around them, due to a belief that ‘the less they knew about it, the better’.

Liddiard and Slater (2018) examined the concept of *containment* using data from two doctoral studies looking at disabled YP’s lived experiences of youth, gender, disability and sex. The authors provided several definitions and examples of how disabled people have been contained- or controlled- throughout history and in the present day, both at the individual and macro level. They questioned the ableist belief that to become adult is to become contained, whereby all children must be shaped by their parents, schools and youth services into complete, rational and productive adults. If complete containment is not possible, for example, if a disabled young man cannot put on his own condom or a disabled young woman struggles with incontinence, then they are denied adult status and sexual selfhood. In the present study, one participant talked about her experiences of using a catheter and seemed determined to manage this process as independently as possible, despite stating that she “couldn’t feel anything down there” and had relied on her old school nurse to tell her when she had started her period. Liddiard and Slater (2018) proposed that containment was an expectation of normative adulthood which led to oppression and infantilisation. A significant shift in mindset regarding this is needed if the sexual rights of disabled YP are to be respected, protected and fulfilled (World Health Organisation, 2006).

5.4. Discussion of key themes in relation to RQ3

The previous sections explored key themes in relation to participant's conceptualisations and experiences of EA. The next sections look at the role of gender within these experiences and the need to consider the intersection of disability and gender more explicitly in discussions regarding disabled YP's TtA.

5.4.1. Acknowledging gendered experiences: "I haven't really thought about it until now"

As discussed in Chapter 2, little previous literature has attended to the gendered experiences of EA for disabled YP. A narrow focus on disabled identity, with almost no consideration for how gender and other important characteristics may influence their TtA, is unhelpful and risks painting a one-dimensional picture (Abbott et al., 2019).

Research has highlighted that gender-related barriers continue to exist for disabled young women, and they remain at a disadvantage in terms of health, social and employment outcomes (Hogansen et al., 2008). A recent systemic review found that disabled young women had lower career expectations, were paid less and experienced parental over-protectiveness which limited their opportunities in comparison to disabled young men (Lindsay et al, 2018). Powers et al. (2008) argued that the lack of understanding on the matter was likely due to research having historically disproportionately represented males. It appears that this is an ongoing bias, as the few studies I found that examined gender and transition primarily included disabled young men and focused on their perceptions of masculinity (Abbott et al., 2019; Giacomin, 2013; Gibson et al., 2014). This highlights the importance of firstly, including more disabled young women in research and secondly, exploring the role of gender in transition experiences and hopes and goals for adulthood.

The present study went some way in addressing this gap in the literature by comparing qualitative data from single gender focus groups, albeit using a small sample size. Findings revealed a number of similarities and differences between the disabled young men and women, not only in terms of what was important to them now and in the future but also how they engaged in the research process itself. For example, the disabled young women seemed more enthusiastic and autonomous in their gathering of images, whereas the young men required prompting and support to complete this phase. Interestingly, the differences often seemed to fall in line with traditional gender stereotypes, which closely supports the findings of previous studies, such as Midjo and Aune (2016), who found that disabled women focused on their creative and social competence and viewed housework as an important part of their adult lives. Similarly, in Lindsay et al.'s study (2017) gender differences were noted in relation to career choices, with disabled young women gravitating towards social sciences and helping professions and disabled young men going into technology related disciplines.

These patterns were reflected in the present study, but in relation to the participants interests and possible voluntary work rather than employment aspirations. In further support of this, the disabled young men in Gibson et al.'s (2013) study discussed typically masculine interests and goals and the authors considered whether they felt some societal pressure to present themselves as "a normal guy" (p.108) and follow an expected life trajectory. Shuttleworth et al. (2012) termed this *the dilemma of disabled masculinity*, describing how masculinity and disability are often seen as being in conflict with each other because the former is associated with power and autonomy, whereas the latter is denoted by helplessness and dependence. Although some of the young men in the present study identified with hegemonic ideals of masculinity, such as engaging in competitive sports and taking on leadership roles in the Students Union, there were notable exceptions. For example, Finn rejected the 'sporty' label in favour of being a 'pop culture nerd' and Jack spoke about how much he enjoyed attending Drag Shows. Furthermore, the disabled young men had plans to settle down, get married and have children whereas this did not seem to be a priority for the disabled young women, as may have been expected when considering stereotypical gender roles. Instead, they appeared to be more career-minded and had looked into getting further qualifications and experience after college. This is an important finding, as it highlights the growing diversity in what disabled YP want and visualise for their future and how this may challenge what is understood or expected of them, according to their gender.

5.4.2. The role of gender in transition planning and support

Given the gender inequities in transition outcomes for disabled young men and women highlighted in the research discussed above and the notably different interests and priorities presented by participants in the present study, it seems pertinent to consider their unique support needs in the TtA.

There are a limited number of studies that have examined gender-specific transition support and those that have, seemed to have focused on employment outcomes (e.g. Lindsay et al., 2017). As Hogansen et al. (2008) acknowledged, there is a need to move beyond this and carry out “careful investigations of the factors that explain the ways in which gender influences the transition planning process” (p. 217). They found that the young disabled women in their study had unique experiences related to the type of transition goals, the factors that shaped these and sources of support/barriers. One key factor, which was also identified by the disabled young women in the present study, was the influence of role models and mentors on their transition goals. As with Jess and Ellie, who spoke about being encouraged and inspired by their school nurse and grandmother (respectively), the disabled young women in Hogansen et al.’s (2008) study felt that role models, such as the school psychologist, were critical to exposing them to possible career paths and supporting them to believe in themselves. A second similar study by Lindstrom et al. (2012) corroborated this finding, highlighting that a unique need for disabled young women was to develop a stronger sense of self-worth, confidence and assertiveness in preparation for adult life. These were key areas highlighted by the disabled young women in the present study who, having had support and opportunities for practice at college, felt more able to direct their care and report and deal with issues as they arose.

Although the present study did not include the views of professionals with regard to how they considered gender in their practice, a study has looked at this and highlighted that although they recognised gender differences, they did not tailor their approach to be gender sensitive (Lindsay et al., 2018). Interestingly, the researchers noted that professionals seemed uncomfortable with being asked to reflect on the role of gender, which was not dissimilar to the reactions of participants in the present study (discussed further in the reflective section at the end of this chapter). It is possible that by providing training and support to professionals involved in transition planning, to develop their skills in recognising, discussing and adjusting their practice in accordance to gender differences, this will in turn encourage disabled young men and women to feel more comfortable when having these conversations.

5.5. Discussion of key themes in relation to RQ4

Having proposed a need for more gender specific and sensitive transition support, the next sections will look at other key areas highlighted as important by disabled YP, namely ongoing social support and a focus on developing resilience.

5.5.1. "I couldn't have done any of it without my support system…"

As discussed in the literature review, self-determination and independence are frequently cited as important and desirable outcomes of the transition process, particularly for disabled YP (Salt, 2018). Findings from the present study partly support this, as many of the participants spoke about their desire to be as independent as possible in the future and to develop the necessary life skills in order to achieve this. However, they appeared to place far more emphasis on relationships and the crucial role these played in supporting their identity exploration, emotional wellbeing and general development throughout EA. As Burt and Paysnick (2012) recognise;

> Close relationships, whether continuing relationships with parents or supportive romantic partners, close friends, and mentors, are prominent factors influencing resilient adaptation in the TtA (p.502).

Several participants talked about the ongoing importance of the parent-child relationship and how this had been redefined and reshaped over the EA years, resulting in a more positive and equal dynamic. Thornton et al. (1995) noted the increased mutual respect, confidence and understanding between parents and their non-disabled children as they grew older and moved out of the family home. This change appears to be further intensified in situations where there is a disabled child, as almost all participants in the present study indicated that their relationship with their parents had improved noticeably and they now willingly sought their parent's advice and support, particularly in difficult times or when making important decisions. As noted by Abbott and Carpenter (2014), YP who lead highly medicalised lives routinely make decisions in close conjunction with their parents. Giacomin (2013) similarly found that young men with acquired impairments benefited from strong relationships with their parents, both in terms of the tangible and emotional support they provided and concluded that professional and services should encourage them to draw on these whenever necessary and possible.

Friendships and relationships with other key individuals were a further source of support during the EA years. Participants seemed to value the opportunity to meet a diverse group of YP, from whom they could learn more about the world and themselves. This aligns with the existing literature, which highlights friendships as a pathway to self-knowledge and a medium for negotiating independence and interdependence (Hurd et al., 2018; Pallisera et al, 2016). A potentially more novel finding of the present study was the importance the participants placed on having access to what they called "an appropriate peer group". This tended to include other disabled YP with similar cognitive functioning, communication skills and abilities to their own. On a practical level, this enabled them to interact on a similar level, engage in shared activities and support each other to develop new skills. Furthermore, it facilitated the strengthening of bonds and a sense of belonging, which was important for their overall emotional wellbeing. There were exceptions to this, for example, Jess' relationship with her old school nurse and Finn's best friend, who was a non-disabled young man employed at the college. These relationships were just as highly valued, despite the difference in age and personal circumstance. Hartup and Stevens' (1997) model of friendship, although based on typically developing individuals, proposed that reciprocity was the fundamental principle underlying friendships. This was supported by participant's comments which inferred the importance of a mutual, two-way relationship, with both parties contributing and receiving.

5.5.2. Promoting attributes of resilience

Having strong social *connections*, as described above, is considered to be one of the Seven C's model of resilience (Ginsburg, 2006). This model was initially put forward to help parents build resilience in their children through recognising their abilities and inner resources, however, it seems pertinent for those supporting disabled YP to prepare for TtA. The Seven C's are:

1. Competence
2. Confidence
3. Connection
4. Character
5. Contribution
6. Coping
7. Control *(Ginsburg, 2006)*

Participants in the present study made numerous references to the ways in which they had developed these characteristics, particularly during their EA years. As already discussed in relation to research question one, the participants' need to have meaningful purpose and make a *contribution* was mentioned frequently. Once a child or YP has experienced the feel-good factor of helping others, it becomes easier for them to ask for help when they need it, which is another important part of being resilient. Lindsay et al. (2018) identified the ability to ask for help, support and accommodations in the workplace was a key skill for disabled YP to develop. Participants in the present study also demonstrated growing *confidence* in their own strengths and abilities and noted how these had been harnessed at college and used to plan future goals. Furthermore, the development of practical life, work and communication skills had increased their sense of *competence* and *control* so that they felt able to go out into the world and achieve these goals.

Participants also talked about their various *coping* strategies, which included art, music, humour, talking therapy and going to church. Giacomin (2013) identified similar strategies used by the disabled young men in his study to address their own needs and labelled them "innovations" (p.66). He recommended further research and development of programmes to support innovative thinking and the sharing of these ideas so that more disabled YP can learn to address the barriers in their lives. A final important attribute, highlighted in both Giacomin (2013) and the present study, was participants' positive outlook, which seems to relate to the *character* element of Ginsburg's model. Despite their challenging past experiences, ongoing exposure to the negative or ignorant attitudes of others and some expressed feelings of anxiety about the future, participants remained optimistic and determined to overcome any barriers they faced. For example, Zara recognised the importance of being comfortable with the uncertainty of the future and shared the message "…follow the path that you want to follow and find out". Similarly, Finn acknowledged that being disabled meant that he had to be more driven than his non-disabled peers, stating that "Enthusiasm is everything…to achieve something you have to really want it". Finally, Jess explained that she had only recently learnt to "feel more accepting and celebrating who I am". This supports the findings of Mannino's (2015) study, which highlighted equanimity- the ability to take the good with the bad and maintain calm in times of difficulty- as a key attribute for facilitating positive mental health and successful TtA.

As Luthar et al. (2014) state, resilience theory and positive psychology are closely related as both focus on strengths over limitations and are concerned with how protective factors - such as those outline above- work to facilitate wellbeing. These are, therefore, important frameworks for professionals and service-providers to draw from when supporting disabled YP in EA. Few studies have directly examined resilience in this group, but one that has, concluded that the use of individual and environmental attributes of resilience mitigated adversity and facilitated transition (Mannino, 2015). With this in mind, she recommended fostering resilient growth by determining current attributes, building on these and developing new ones so that disabled YP are better equipped to manage the challenges of transition and beyond.

5.6. Implications for professional practice

Despite an abundance of literature on transition processes for disabled YP and their families and the efficacy of support, there has remained an unhelpful promotion of a linear life trajectory based on normative understandings of adulthood. The findings of this study challenge these assumptions and argue for a more holistic and nuanced view of EA which takes into consideration the specific experiences of disabled YP and the support needs they identify as most important.

The next sections look at how the information gained from this study can be used to inform knowledge and practice. Frameworks are often helpful when making sense of complex situations and deciding a best course of action with a YP, therefore one has been developed using the key themes in the data, Bronfenbrenner's ecological systems theory (introduced in

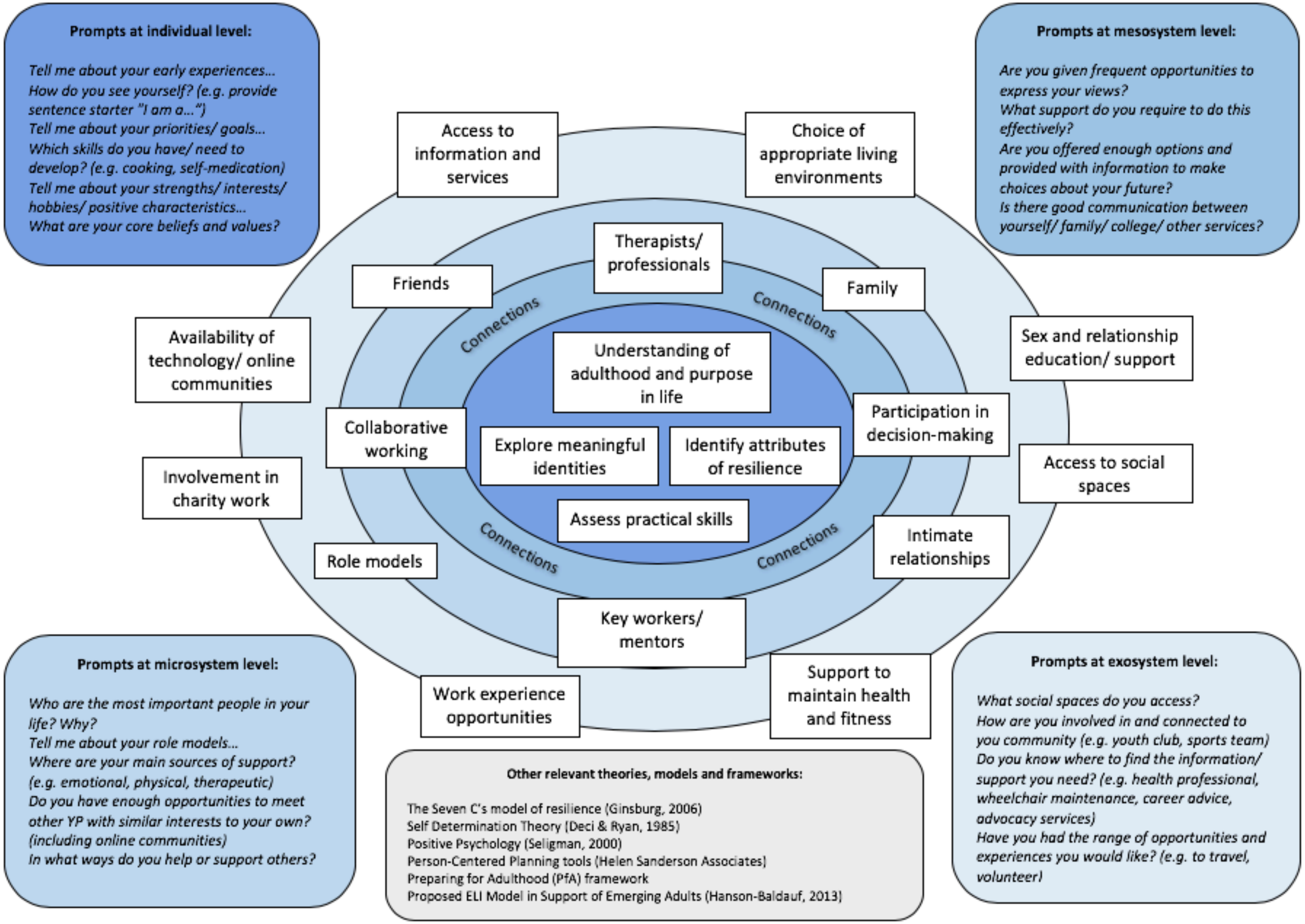
Chapter 2) and other relevant approaches (e.g. Person-Centred Planning). Following that, there is a section that examines the specific implications for EPs, given their growing involvement with the post-16 population.

5.6.1. A framework for supporting conversations with disabled young people in emerging adulthood

Participants in the present study expressed a preference for a person-centred approach to transition planning that took account of their individual needs, strengths and aspirations and gave examples of how this had benefited them during their time at the college. Person Centred Planning (PCP) is underpinned by humanism and positive psychology and is described as an empowering philosophy that shifts control from professionals to service-users and assists them in leading independent and inclusive lives (Robertson et al., 2005). In PCP, the YP and their family are placed at the centre of a process which is strengths-based and solution-orientated and uses creative methods to explore their identity, beliefs and values in order to plan for a better future (Sanderson, 2000). However, several researchers in the field of transition caution against a narrow focus on the individual and argue for a whole-systems approach (Small & Raghaven, 2013) or one which acknowledges person-environment interactions (Stewart et al., 2014).

To achieve this balance, Bronfenbrenner's ecological systems model (1979,1986) was adapted to meet the specific needs of the population in question. The model is underpinned by Bronfenbrenner's theory that a child's development is influenced by five systemic layers present within their environment and that this influence is bidirectional. Small & Raghaven (2013), amongst other authors, advocate for the value of this model when supporting disabled YPs' TtA as it allows for identification of strengths and weaknesses in their various systems, provides a picture of how these can change over time (e.g. before and after transition) and helps to target intervention. Perhaps most importantly, the emphasis on how the child or YP can influence the systems around them provides a sense of active agency. It is also a reminder that, although it is the responsibility of the systems to modify and accommodate the child or YPs' needs, they also have the power to shape how this is done, if engaged in the right way.

Figure 9. Framework for supporting conversations with disabled young people in emerging adulthood



Prompts at individual level:

Tell me about your early experiences…
How do you see yourself? (e.g. provide sentence starter "I am a…")
Tell me about your priorities/ goals…
Which skills do you have/ need to develop? (e.g. cooking, self-medication)
Tell me about your strengths/ interests/ hobbies/ positive characteristics…
What are your core beliefs and values?

Prompts at mesosystem level:

Are you given frequent opportunities to express your views?
What support do you require to do this effectively?
Are you offered enough options and provided with information to make choices about your future?
Is there good communication between yourself/ family/ college/ other services?

Prompts at microsystem level:

Who are the most important people in your life? Why?
Tell me about your role models…
Where are your main sources of support? (e.g. emotional, physical, therapeutic)
Do you have enough opportunities to meet other YP with similar interests to your own? (including online communities)
In what ways do you help or support others?

Other relevant theories, models and frameworks:

The Seven C's model of resilience (Ginsburg, 2006)
Self Determination Theory (Deci & Ryan, 1985)
Positive Psychology (Seligman, 2000)
Person-Centered Planning tools (Helen Sanderson Associates)
Preparing for Adulthood (PfA) framework
Proposed ELI Model in Support of Emerging Adults (Hanson-Baldauf, 2013)

Prompts at exosystem level:

What social spaces do you access?
How are you involved in and connected to you community (e.g. youth club, sports team)
Do you know where to find the information/ support you need? (e.g. health professional, wheelchair maintenance, career advice, advocacy services)
Have you had the range of opportunities and experiences you would like? (e.g. to travel, volunteer)

The framework above incorporates the key themes from the present study which seemed to fit best at the individual level, microsystem, mesosystem and exosystem. Understandably, the three 'closest' systems were the most salient to participants and featured more commonly in their accounts of EA. These systems are also, arguably, the most amenable to change and therefore it makes sense for them to be the focus of conversation and intervention. It is important to note that, as in Bronfenbrenner's original model, the various aspects are not fixed and can be part of multiple systems. Each level of the framework will now be discussed in turn.

5.6.1.1. Suggestions for discussion/support at the individual level of the framework

Providing a safe space for disabled YP to talk about their early experiences and exploring how these have shaped the person they are in EA, is an important first step. Life Road Maps, as used in the present study, could be a useful visual tool to facilitate this process and are accessible to YP experiencing communication or memory difficulties. Next, gaining an understanding of what adulthood means to the individual and what they consider to be important milestones will facilitate goal setting and visualisation of their preferred future. This research has demonstrated that disabled YP are capable of discussing abstract concepts such as adulthood and identity and therefore should be given more opportunities to do so. The present study adapted the IDEA (Reifman et al., 2007) and used this to help identify which dimensions were most salient to each individual, therefore other tools that support such conversations could be developed. As identity exploration was a key dimension of EA for all the participants, the framework provides prompt questions around this, including a suggestion of using sentence starters (e.g. "I am a…") to determine which identity labels are most meaningful to the disabled YP. Other tools for identity work include sorting value cards (from Acceptance and Commitment Therapy), strength cards and completing the Aspects of Identity Questionnaire (Cheek & Briggs, 2013). Here, open discussions about sexuality should be pursued, so that disabled YP can begin to feel more comfortable expressing this important aspect of their identity. Aforementioned studies suggest that lack of opportunity for sexual identity development is reinforced by the attitudes and practices of those around them (Payne et al., 2016; Wilkinson et al., 2015). Therefore, alongside improving the quality and scope of sex education for disabled YP, training should be provided to practitioners, parents and carers in how to effectively support sexual exploration, break down barriers and addressing their own biases. Finally, mindful of the unique needs of disabled men and women which were identified in this study, practitioners must develop the skills to have helpful, gender-aware conversations so that they can tailor support accordingly.

5.6.1.2. Suggestions for discussion/support at the mesosystem level of the framework

Given the number of professionals and services involved in supporting disabled YP, it is vital that they are all working collaboratively, with the YP and their family at the centre of decision-making processes. This is emphasised in the SEND CoP (DfE, 2014) and supported by transition literature (Gauthier-Boudreault et al., 2017; Jacobs et al., 2018; Leonard et al., 2016). Participants in the present study valued their increasing autonomy and opportunities to make their own choices, however, many appreciated the ongoing support from their parents or other key people when making more significant decisions. It is recommended that practitioners use the prompts in the framework to explore the dynamics between those in the YP's microsystem, understand what level of participation they would prefer (for themselves and others) and how best to facilitate this. It is likely to look different from one individual to the next, as illustrated in the views shared by participants, some of who wanted to be fully involved with minimal input from family and others who felt much less confident in their own capacity to make these decisions independently. A suggested PCP approach, that has been used across education, health and social care and brings everyone together to plan a positive way forward, is a PATH (Promoting Alternative Tomorrows with Hope). A PATH is an accessible, visual meeting involving graphic facilitation which provides clarity, fosters alliances and encourages ownership and action amongst pathfinders (O'Brien et al., 2010). Recent studies evaluating the effectiveness of PATHs have found that they can increase confidence, participation and a sense of direction in the YP (Wood et al., 2019) and lead to improvements in parent-school and parent-child relationships (Bristow, 2013). With a growing evidence base, it could be argued that arranging a PATH meeting early on in the EA period and subsequent person-centered reviews until the point of transition, would be beneficial for all those involved.

5.6.1.3. Suggestions for discussion/support at the microsystem level of the framework

The interdependent nature of EA was made clear through the participants' descriptions of their various relationships, which appeared to have become increasingly important to them despite their growing independence. Previous research has shown that the social networks of disabled YP are often limited and that transition can lead to further isolation as existing connections are broken (Hurd et al., 2018), therefore this is an important area to target support.

Relationship maps or circles can be a helpful way to identify key people in the disabled YP's life and any gaps they feel may need addressing, for example, a lack of friendships or keyworker support. A further tool developed by the NDTi (2002) is the Inclusion Web, which can be used to explore the disabled YP's current opportunities for social engagement and the roles and relationships they have in their wider community. Participants in the present study had formed close friendships with one another through having shared interests and valued the ways in which the college had provided them with access to more social spaces, including shared living environments, work placements and recreational activities. It is important that regular opportunities such as this are embedded throughout EA so there is more chance of them being maintained following transition. With physical accessibility and transport being an ongoing challenge, use of social media and involvement in online communities will help to provide disabled YP with a sense of belonging. With this in mind, they require access to technology and support to develop the ICT skills required to make the most of available forums and platforms.

Having positive role models was another key aspect of the disabled YP's microsystem, although these were sometimes not people with whom they had regular and direct contact with (e.g. celebrities, musicians). Surprisingly, none of the participants' role models were disabled, although one had been through significant hardship and experienced mental health difficulties, which he related to. Hoskin (2014) concluded that service providers should "give mind to the novel power of adult role models" (p.180) and provide opportunities for them to hear from people living with their disability and thriving.

5.6.1.4. Suggestions for discussion/support at the exosystem level of the framework

This final level of the framework refers to aspects of the organisational context that featured as most important to the participants, in terms of finding employment, university courses that matched their interests, appropriate living environments and support to remain fit and healthy. As they were all on a Work Outcomes pathway at the college, they had been assigned job mentors who had a thorough knowledge of the local area and relationships with various businesses. Similarly, there was a small team dedicated to transition support, who organised and accompanied the YP on visits to potential placements providers and linking them with other relevant services. Having policies and processes in place to ensure all disabled YP have access to this type of support is crucial, but empowering disabled YP to go out and seek it for themselves is equally as important. As recognised by Hanson-Baldauf (2013), disabled YP demonstrate high motivation and great initiative for seeking information and employ a wide range of tools, resources, and strategies despite significant challenges. As all LAs now have a legal obligation to publish their Local Offer, which includes a list of activities, opportunities and support services available. Furthermore, disabled YP should be made aware of local advocacy services, so that if they do not feel able to voice their concerns or challenge decisions that have been made independently, they know how to contact those who can help.

5.6.2. What does this mean for Educational Psychologists?

The findings of the study hold significance for EPs as they continue to develop their knowledge and skills in working with the 16-25 population. A discussed in Chapter 1 and 2, the EP role was extended to working with YP up to the age of 25, following the introduction of the Children and Families Act (DfE, 2014) and the revised SEND CoP (DoH, 2014). Working with this older age group has presented new challenges, but also an opportunity for EPs to reposition themselves on the basis of the moral principles underpinning their work, including social justice and promotion of autonomy (Giles & Rowley, 2019), which were both at the heart of this study.

EPs are well placed within LAs to support disabled YP in the EA years- including at points of transition- and at each level of the proposed framework. At the individual level, EPs can use the findings of this study and their existing knowledge of psychological theory regarding identity, motivation and personal growth to inform direct work with disabled YP. Many are already adept at using a range of creative, person-centred techniques to elicit views and may find it useful to add the Life Road Map and photo-elicitation methods to their toolkit, which have proven to be a valuable way of gaining insight into disabled YP's experiences. Furthermore, some participants talked about having periods of low mood, difficulty accepting their disability and feelings of anxiety about change and uncertainty. EPs, with their training in coaching, counselling and solution-focused therapy skills, are in a prime position to offer support to disabled YP and help them to develop the strategies they need to cope effectively.

At the mesosystem level, with the emphasis participants placed on relationships, EPs can use their consultation and mediation skills to ensure that all those around the YP have a shared understanding of the situation and are working collaboratively to ensure a positive TtA. With a more nuanced understanding of EA provided by the present study, EPs will be able to focus attention on the areas of importance and facilitate meaningful goal setting. A large proportion of the work carried out by EPs is writing statutory advice for EHCPs. A recent project, carried out by a research team of disabled YP (aged 17-25) called RIP:STARS (Research Into Plans: Skilled Team with Ambition, Rights and Strength) has created a quality and rights based framework for developing EHCPs and a survival guide that will help disabled YP advocate for their rights and "for support which will meet their needs now and as they grow into adulthood" (RIP:STARS et al., 2018, p.7). This, alongside findings from the present study, will support EPs to write better quality advice and outcomes.

As community psychologists, EPs have access to all the microsystems around a disabled YP and can effect change within these. Given the importance participants placed on socialising and engaging in their hobbies and interests, this should be a primary area to target intervention and EPs can facilitate problem-solving to address barriers such as social confidence and accessibility. Findings also highlighted the need to develop disabled YP's attributes of resilience, therefore EPs could use their knowledge of organisation change to support families and colleges to create optimum environments where these can be fostered. Finally, at the exosystem level, bespoke training packages (e.g. how to promote positive sexual identity for disabled YP) and ongoing involvement in research that informs education, healthcare and policy systems about the needs of disabled YP in EA will be an essential part of the EPs developing role with the 16-25 population.

5.7. Critical evaluation of the research

In this section, I will provide a critical evaluation of the research with reference to its strengths and limitations, suggestions for future directions and a reflective account of researcher positionality and the uniqueness of the setting. When establishing the quality of qualitative research, it is important the criteria being used is compatible with its epistemological framework (Willig, 2013) and therefore I have referred to several authors who have put forward guidance regarding this.

5.7.1. Strengths and unique contribution

A significant strength of the study was its qualitative design and use of photovoice methodology. Few studies have explored disabled YP's understanding and experiences of EA, with one reason being the challenges involved in enabling meaningful discussion of such abstract concepts with this group. The qualitative, exploratory nature of the study 'gave voice' to a group that are often disregarded in favour of gaining the views of their parents and the professionals who work with them. A significant amount of time went into creating visual aids and learning new techniques (e.g. the Life Road Map) so that the initial interviews could be as accessible as possible. To meet Ellie's specific needs as an AAC user, adapted interview schedules were emailed to her in advance and additional time planned in for her interview. This demonstrates commitment and rigour, a quality criterion identified by Yardley (2000). The various phases provided multiple opportunities for them to really tell their stories and the photo-elicitation element allowed them a sense of control over the research process, as they could choose to share as little or as much as they wanted. It was apparent, both during the focus groups and in the debrief after, that the disabled YP enjoyed talking about why they had chosen their photos and listening to their peers do the same. There were debates, laughs, the giving and receiving of compliments and several moments where participants expressed that they were learning more about them themselves and others through the discussion. This was not only a privilege to observe and be a part of, but also added to the richness of the data.

A second strength was the transparency and coherence (Yardley, 2000) demonstrated at each stage of the research process. My history at the college and the pre-existing relationships I had with staff there were noted early in Chapter 3 and I was continually mindful of how it may affect my interactions with participants and interpretation of the data, thus demonstrating reflexivity. In closely following Braun and Clarke's (2006) six-phase model for thematic analysis and detailing my approach at each phase clearly and systematically- including photographic evidence of the early phases in the appendices and a final thematic map for each research question- my findings can be considered as credible and trustworthy. This was further supported by the use of inter-coder validation through comparing and discussing samples of coded data with my supervisor. The aim of this was not to arrive at a unanimous, 'correct' interpretation, but ensure consistency in my coding and prompt me to notice patterns I may not have previously. Participants were also actively involved in identifying initial themes during the focus groups and arranging photographs on the table accordingly. Incorporating the photos and images gathered by participants in the presentation of findings with their quotes alongside, met Elliot et al.'s (1999) criteria of 'grounding in examples' and added to the reader experience.

A final strength of the study was the way in which the themes and subthemes translated into a framework for professional practice, based on Bronfenbrenner's existing ecological model which is valued highly by EPs. This framework is in its earliest stage of formulation and is likely to require ongoing revision, however, it is hoped that those supporting disabled YP in their TtA will find it useful. As the framework is holistic, systemic and includes aspects of EA that may not currently be considered by those adopting a normative approach, it can be seen as a unique contribution to the field and a challenge to the status quo.

5.7.2. Limitations and challenges

As with all research, the study had its limitations and challenges were faced along the way that reduced the level of impact I had hoped to achieve. Firstly, despite having an existing link with the college, recruitment of participants was difficult and ate into the already restricted time I had to carry out the proposed 4-stage research design. The college had previously supported an MSc student with her research and had encountered some ethical issues along the way, which made them hesitant to engage in the process again and required a great deal of reassurance. Furthermore, once access was granted, participants were selected from a small pool of students who already had a number of other commitments within college. This caused delays during the photo-gathering stage and, at one point, a participant was asked to be part of another, similar project which required quick intervention and explanation that this would not be practical or ethical. Fortunately, due to a strong rapport that was built from the start, through a group introduction meeting, individual interviews and regular email contact, all six participants remained engaged throughout the process.

Despite the benefits of using photovoice, there were a number of challenges involved, some of which have been cited in previous literature on the use of participatory photography techniques (Eisen et al, 2018; Gibson et al, 2013). Due to issues of consent and confidentiality, participants were asked not to include any identifiable images of themselves or other people, which they noted as restrictive and likely had an impact on the data and subsequent themes that were generated. Some chose to use images from the internet or photographs that had been taken prior to the study (e.g. memorable birthdays and holidays), which is not typical of "pure" photovoice projects but was felt to be important to promote autonomy. Gibson et al. (2013) also allowed participants to augment methods in this way, suggesting that it helped them to "get a more diverse and longitudinal picture of the participants' lives and identities" (p.394). Although it was hoped that the initial interviews would prompt early thinking and allow for discussion of what they might photograph, the disabled young men in particular required a lot of assistance from college staff when making these final decisions. This, in itself, was interesting to reflect on and added to the data around gender differences and independence, however, as Eisen at et al. (2018) recognised, staff involvement would likely have influenced photographic content. It is important to be mindful that visual accounts are no more authentic than verbal ones and are subject to multiple social influences, which affect how participants choose to represent themselves and the lives they lead. McLaughlin and Coleman-Fountain (2018) highlighted the potential role that public images of disability- that either stigmatise or celebrate- play in disabled YP's engagement with visual methods in research. This would have been useful to explore further with participants in the present study and could be the focus of future research.

The main limitation was a lack of adherence to the research design, due to the lockdown restrictions of the COVID-19 pandemic. As a form of participatory action research, an integral part of photovoice methodology is the exhibition of findings to policymakers and other stakeholders in the field (Latz, 2017). Planning for the exhibition was due to be carried out in May and June, however I was unable to arrange the face-to-face creative sessions with the participants as the college had closed and many had returned home to be in isolation (due to being in a vulnerable group). I considered the possibility of an online exhibition instead and requested an amendment to my ethics application that allowed me to contact participants over remote video-calling platforms. After further thought and discussion with the college, it was decided that this would not have the same reach or impact and therefore it was felt that postponing till the event was rearranged the following year would beneficial. This was disappointing as it left the project feeling 'unfinished', however there were several positive outcomes including having more time to refine the exhibition with full participation from the disabled YP themselves.

5.7.3. Reflective account

As noted in Chapter 1, where I considered my role within the research, it is important to continuously reflect upon the various ways in which I, both as a researcher and a person, shape the process and its outcomes. To ensure this, I kept a reflective diary, extracts of which can be found in the appendices (Appendix 15). It felt appropriate to include two key reflections within the critical evaluation, as issues relating to these came up routinely throughout my discussion of the findings.

5.7.3.1. Considering positionality

When embarking on this research, I was aware that I would be carrying my own preconceptions and beliefs about disability, adulthood, sex and gender which would inevitably impact on my dialogue with participants. Despite this, I believed that as a younger woman with similar interests to them who had worked alongside and socialised with disabled YP for many years, this familiarity would help me to appear less ‘threatening’ to participants and aid rapport building. In hindsight, this may not have been as helpful as I had hoped, as Gibson et al. (2013) warn against presuming affinities based on identity categories such as age, race and gender, given that each are so internally diverse.

Through discussions with my supervisor following analysis, it became clear that I was, at times, rehearsing some of the ableist assumptions and notions of normalcy that I was attempting to critique. This was evident in the surprise I felt when hearing about participants’ positive experiences of growing up as disabled and their focus on these rather than barriers and limitations. My subconscious reactions implied an expectation that their lives would have been characterised by negativity and that they would be motivated to change the situation to be more in line with the norm (i.e. non-disabled lives). This reflected an implicit judgement which participants could have sensed, leading to a risk of ‘othering’ and a widening of the divide between us. For non-disabled researchers such as myself, reflexive practice is key to avoiding situations such as this and developing “multiple disability-centric subjectivities that can lead to unexpected phenomena being uncovered” (Brighton & Williams, 2017, p.10).

Related to this, being somewhat of an inexperienced researcher in this field, I found it difficult to negotiate conversations about disability, sex and gender sensitively and efficiently. Jepson et al. (2015) used Conversation Analysis to identify patterns of talk around sex in interviews with disabled men and discussed how these shaped the types of responses elicited. For example, interviewers would often highlight the personal nature of the question before asking it and provided chances for participants to opt-out of answering, both of which seemed to interrupt the flow of an interview but also acted as strategies to help both parties orientate these emotionally loaded conversations. When I looked back at my own transcripts, there were similar occasions where I projected my own anxieties by fumbling over the wording of a personal question and in response to the participants’ hesitation, quickly moved the conversation on to something I perceived as more comfortable for us both. It is likely that a pilot interview might have helped me to reformulate these questions so they were clearer and that sending interview schedules in advance, as Jepson et al. (2015) did, may have given participants additional time to reflect on the more arguably complex questions, thus positioning them to be more in control of their answers.

5.7.3.2. Uniqueness of the research setting

It felt necessary to reflect on the uniqueness of the research setting and how this may have influenced findings. Research has shown that securing funded places at specialist, residential colleges such as this one is notoriously difficult (Abbott et al., 2001) and can involve lengthy legal battles between parents and LAs. The decision to apply for out-of-area placements is often based on a perceived lack of local provision that meets the disabled YP’s educational, social and/ or medical needs (Abbott & Heslop, 2009). Furthermore, independent settings like the one in the present study often have superior facilities, accessibility, onsite therapy services and are able to offer a wider range of opportunities for YP with the most complex needs. This inevitably comes at a high cost to the LA and although the experiences of YP in these settings are often positive- given the focus on wellbeing and therapeutic support- there is a concern that educational outcomes are not as good as they should be and there is a “lack of ambition for what they can achieve” (DfE, 2017, p.38). Another reason why LAs, and often professionals, are reluctant to support these out-of-area placements, is that they remove YP from their local community which can present even greater barriers at the point of transition. For example, Abbott and Heslop (2009) found that the distance impeded good transition planning as it was more difficult for professionals to attend meetings, carry out assessments and monitor progress. Furthermore, there is an attitude of ‘out of sight, out of mind’ as YP in these placements dropped low on the LAs list of priorities and were often only thought of again once their transition reached crisis point.

Despite these controversies, it is difficult not to recognise the positive impact that being at the college was having on the disabled YP I spoke to, across all aspects of their lives. For some, it was their first experience of being in the majority, having been one of the only disabled people at their previous mainstream schools and this appeared to have facilitated a greater sense of belonging, increased confidence and self-esteem. The residential element had also enabled functional skill development and the enjoyment of social opportunities which participants considered important for their future and acknowledged that they would not have had access to otherwise. I reflected upon how different their accounts of EA and ambitions for the future might have been had they remained at home and attended local mainstream colleges. There was no evidence of the lack of ambition described in the government review, as participants described their aspirations to travel, attend University, have careers and families and felt they were being supported by the college in working towards making these a reality. Although it may seem controversial given the ongoing drive for inclusion, I argue that the more disabled YP who can benefit from these types of experiences and support at this important time in their lives the better and that a lot could be achieved from sharing good practice between settings of all kinds.

5.7.4. Suggestions for future research

The present study has added to the otherwise limited literature base on the experiences of EA for disabled YP and has shed light on the support they value in preparation for adult life. In conducting the research, several areas for potential future research emerged. Firstly, although the study was one of the few that has explored the role of gender and identified important differences between the experiences and priorities of disabled young men and women, the sample size was small. It would, therefore, be beneficial to use a larger sample size in order to make more meaningful comparisons. Given the interesting findings regarding gender, it would also be interesting to explore the experiences of disabled YP from different ethnic backgrounds and how these social identities intersect in EA. This was not possible in the present study as all participants were white British or Irish, therefore future research in this area should include a more diverse sample.

There were also several interesting findings that warrant further investigation. Participants highlighted the importance of social networks and cited online platforms, including Facebook, Twitter and YouTube as one of the ways they maintained connection with others. It would be helpful to examine their use of each of these in more depth and identify how it could be promoted to combat the isolation many disabled YP experience. Another key finding, both in the literature and the present study, was the lack of quality conversations, education and support regarding sex, sexuality and sexual expression available to disabled YP. More studies are needed to identify the barriers they face in developing positive sexual identities and raise awareness of this as an important human rights issue.

Finally, a piece of research evaluating the impact of the exhibition (once it has taken place in Summer 2021) and practitioner's use of the proposed framework when supporting disabled YP in EA would be beneficial.

5.8. Concluding comments

The overall purpose of this qualitative study was to explore disabled YP's experiences of EA and identify which opportunities and support needs they considered important in preparation for transition. This was achieved using a combination of photovoice and other creative methods which, despite the limitations discussed above, met the key principles of enabling participants to reflect on facets of their identity and experiences within their own terms and promoting critical dialogue about important issues within their community (Wang & Burris, 1997).

Through the images selected and their narratives around these, the disabled YP in the study - Ellie, Jess, Zara, Arthur, Finn and Jack - shared a rich variety of views and experiences with several themes running through them. They described EA as a journey characterised by change and progression and highlighted the importance of this period for identity exploration and purpose-seeking. Although participants enjoyed their increasing independence, they valued ongoing support from others and the interdependent nature of these relationships. There was evidence of an acceleration towards adulthood as a result of living highly medicalised lives and early departure from the parental home to residential settings, however, in contrast to the literature which tended to problematise this, these experiences were perceived as beneficial by participants. Gender was found to play a role in how the disabled young men and women experienced EA and what they considered important in the future. This highlights the importance of gender-specific transition support to address potential inequities in opportunities and outcomes for adulthood. Finally, participants identified several key areas for support, including practical, social and emotional skill-building, with an emphasis on fostering attributes of resilience.

This data lent itself to the development of a framework that could be used to guide thinking, conversations and planning at all system levels, whilst keeping the disabled YP at the centre. It takes account of identified similarities and differences relating to their experiences of emerging adulthood, when compared with those of non-disabled YP, thereby challenging normative assumptions and expectations of “successful” transition. It is hoped that this will be useful to practitioners (including EPs) in order for them to adopt a holistic, life-course perspective, ensure a truly collaborative approach and prioritise aspects of adulthood that are most meaningful to each disabled YP.

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7. Appendices

7.1. Literature summary table

Themes	Reference	Location	Aim/ question	Sample/ method/ analysis	Key findings	Critical appraisal
Understanding of adulthood- behaviour, responsibility, independence, control, self-care **Attitudes towards independence- obstacles, assistance, skills required,** **Importance of employment/ earning money**	**1. Cheak-Zamora, Teti, Maura-Batjer & Halloran (2016)** Snapshots of Growing Up: Youth with Autism Explore Adulthood Through Photovoice	Missouri	Exploratory research to gain youth with ASD's perspectives on becoming an adult and the implications of these experiences on needed interventions and services.	11 youths with ASD, 16-22 Photovoice Intro session, 2 group photo sharing, individual interview, exhibition TA	3 themes were the most prominent: the meaning of adulthood; desire to live independently; and employment experiences and goals.	- Good attendance to all sessions - Youth benefited from seeing participants with various perspectives, strengths, and challenges. - Excluded youth with no verbal comm skills - Difficult for all to contribute at the same level - Design-Pps fed back that they were nervous- recommend initial interview first. - Presented images in findings. - No exhibition stage
Understanding of adulthood- maturity getting older, adhering to legal age limits **Independence- want to meet norms, fear of coping, social expectation** **Responsibility- social role, familial**	**2. Salt, Melville & Jahoda (2019)** Transitioning to adulthood with a mild intellectual disability— Young people's experiences, expectations and aspirations	Scotland	To explore how young adults with mild intellectual disabilities conceptualize, relate to, and experience the process of becoming an adult.	8 young adults, 15-17 Semi-structured interviews, in school IPA	Theme A- On a developmental trajectory Theme B- Negotiations in the environment Similar perspectives/ aspirations to young adults without disabilities, increasing positive disability identity	- Pps on younger side of EA, may influence views - Conducted pilot, added more open questions, simplified, additional probes. - Questions transition focus on self-determination - Small sample size, could not achieve thematic saturation, but this wasn't the aim, interpretive depth was principle goal - Pps described as having "borderline or mild ID" and all

Impact of disability **Parent involvement in decision making**						attended a mainstream education setting.
Resistance to label of intellectual disability **Expectation of living an ordinary life** **Gendered experiences** **Possible selves/ possible futures- dreams, hopes, goals** **How they are viewed/ treated by others- seen as service receivers** **Participation in transition planning**	**3. Midjo & Aune (2016)** Identity constructions and transition to adulthood for young people with mild intellectual disabilities	Norway	Explores the self-constructions of young adults with mild intellectual disabilities in talk about their everyday living and how parents and professionals construct young adults with disabilities in talk about their involvement in transition processes.	4 young adults (18-24) flats and at home, all in jobs, 5 parents, 5 professionals Interviews from a previous study evaluating a habitualisation course	Inspired by the meaning interpretation tradition (Brink- mann and Kvale, 2015) Notes gender differences in self-constructions (around restriction and autonomy, dependence and independence)- suggests further research. Interesting- alternative identities over-ruled by professionals, standardisation of need to fit what is on offer.	• Secondary data and analysis, focus on housework as from an evaluation of a habitualisation course (greater attention to housework themes?) • Triangulation of data from various sources • Consider different culture/ environment
Interaction between person and environment, disability, inclusive attitudes **Impact of previous/ early experiences- school** **Process- information, services, policy**	**4. Stewart, Law, Young, Forhan, Healey, Burke-Gaffney & Freeman (2014)** Complexities during transitions to adulthood for youth with disabilities: person–	Canada	The purpose of this qualitative study was to explore the experiences of youth with different disabilities from across Canada during their transitions from	Purposeful sampling. 37 informants, 22 experts, 8 youth, 11 parents, 20 service providers and 2 researchers	6 sub-themes Early experiences in childhood and adolescence, Inclusion and attitudes, Building capacities, Providing information about transitions, Services and supports for youth, Policy and youth with disabilities.	• Large sample size, rigorous qualitative evidence • Minimal diversity in sample • Use of technology rather than face-to-face interviews

Importance of a holistic, collaborative, strengths-based approach	environment interactions		adolescence to adulthood.	Qualitative methods using a phenomenological tradition Semi-structured phone interviews Video conference focus groups with experts	Overarching theme of complexities.	
Loss of friendships- importance of a social network and social inclusion **Expectation of adult life** **Participation in transition planning**	**5. Pallisera, Fullana, Puyalto & Vila (2016)** Changes and challenges in the transition to adulthood: views and experiences of young people with learning disabilities and their families	Spain	To collect the experiences and perceptions of young Spanish people with disabilities and their families regarding perceived problems and support in their transition to adulthood.	8 YP with intellectual disabilities, 17-23, had all participated in a transition training course Qualitative case study Interviews and focus groups. Photovoice- things that help/ do not help the transition process.	Experienced difficulties obtaining their secondary education certificate and continuing their education Lack of YP participation, negative view of the guidance received Pps spent their free time doing activities organised by their families or the support services	- Process-based- educational pathways, social support networks, construction of plan for the future - Data triangulation- use of different methods and from different perspectives in order to capture the full complexity of the case - Detailed description of analysis - Findings determined by organisation and structure of education systems in Spain- not generalisable - No exhibition stage
Lack of participation in transition planning **Maladaptive coping strategies- avoidance**	**6. Abbott & Carpenter (2014)** Wasting precious time': young men with Duchenne muscular dystrophy	UK	This article focuses on the particular challenges faced by young people with DMD and their	3 regions of England, 37 young men and 58 family members	Very few examples of structured transition planning, no examples of young people being actively involved in transition	- DMD specific - Two young men with DMD who acted as project advisors and a project advisory group comprising professionals, academics, parents and clinicians.

Inclusive attitudes/ social change **Within-person considerations- gender, impairment experience** **Medicalised lives** **Disabled YP treated as homogenous group**	negotiate the transition to adulthood		families at transition in its broadest senses, including managing the complex dynamics of reaching a stage of adulthood that was not anticipated.	Semi-structured interviews- approx. 2 hours TA	reviews and many did not attend. Many young men – and their parents – resisted future- oriented discussion because the future was both so uncertain and so certain. Many families felt that the processes of transition were really 'tick box' exercises that acquitted professionals of their duties but were meaningless to young men and their families.	• Large sample size • Acknowledged challenges/ limitations of interview arrangements (e.g. parent involvement)
Psychological impact of transition- anxiety, depression, loss **Increased insight and decreased maladaptive coping to support well-being** **Delaying adulthood milestones** **Importance of meeting developmental milestones- employment/ earning money**	**7. Austin, Hunter, Gallagher & Campbell (2018)** Depression and anxiety symptoms during the transition to early adulthood for people with intellectual disabilities	Australia	This exploratory study aimed to investigate factors that may predict anxiety and depression for YA with and without ID. It also explored whether certain predictive factors may be related to the higher prevalence of these disorders in YA with ID.	Quantitative 137 young adults (18-30), 55 with ID, recruited from disability support providers Anxiety and depression measures, adulthood questionnaires, self-reflection and insight scale	The prevalence rates of anxiety and depression were greater in YA with ID than in age-matched controls albeit not statistically significant for depression The cultural shift towards delaying milestones like full-time employment may contribute to reduced well-being.	• Only quants, no rich data, although relationships exist, causal pathways can't be assumed, due to the design of the study, the direction and origins for these cannot be determined. • Language and methods used suggested a medical model perspective • Pps in each group were recruite from different places (university and community disability services) making comparison more difficult • Adulthood questionnaire was created by the authors for the purpose of the study and therefore was not validated.

Implications for support **Fostering family relationships**				2-hour session to complete them.		
Psychological impact of transition- anxiety, depression, loss, fear of unknown **Positive view of transition- fun exciting, improved self-concept, identity development** **Importance of preparation** **Preference for clear, predictable plan**	**8. Vincent (2019)** It's the fear of the unknown: Transition from higher education for young autistic adults	UK	Explore first-hand experiences of young autistic adults making the transition from higher education What are the perceived barriers and what enables a successful transition?	Qualitative 21 young adults with ASC (21-26) Semi-structured interviews, Skype or face to face	4 themes of transition as of (1) a source of anxiety and avoidance, (2) a positive departure, (3) loss and (4) identity development.	• Autism specific • Sole researcher, additional collaborators may have enhanced inter-rater reliability. • Sample- Sig more males than females over-represent male experiences of transition, all in arts/ humanities/ social sciences so doesn't include a range of subjects • Highlighted more positive emotions of pride and excitement. Offers a more holisti and potentially affirming perspective.
Psychological impact of transition- worry, rumination, lower self-efficacy **Impact of previous/ early experiences- being bullied, failure** **Dependence on family and limited social network** **Implications for intervention and support- emotional**	**9. Forte, Jahoda & Dagnan (2011)** An anxious time? Exploring the nature of worries experienced by young people with a mild to moderate intellectual disability as they make the transition to adulthood.	Scotland	Examines the content and salience of worries experienced by young people with mild ID during transition to adulthood	26 pps with ID and 26 typically developing YP (17-20) Recruited from FE colleges Semi-structured worry interview (sorting images), self-efficacy scale, anxiety scale	Qualitative difference in nature of worries between 2 groups, only overlap was in regard to failure ID- bullied, followed by worry about close friends and family members dying, failing in life, and worries about making and keeping friends. Non-ID- failing to get a job, followed by not having enough disposable income, fear of failing, and concern	• Mixed methods • Used photos of typical adolescent worries to aid discussion- piloted with 6 YP wit ID • Negative focus on worries

resilience and self-determination					about the number of decisions they would have to make in the near future.	
Transition support **Parental expectations** **The role of hope at times of uncertainty** **Importance of real-life experiences**	**10. Chen, Cohn & Orsmond, (2019)** Parents' future visions for their autistic transition-age youth: Hopes and expectations	Boston	Explore how parents express their future visions (i.e. hopes and expectations) for their autistic transition-age youth.	Qualitative 18 parents of Autistic YP Focus groups and individual interviews for those who couldn't make them Grounded theory	8 primary domains- community mobility, community participation, living situation, peer relationships, personal safety, post-secondary education, self-care, and work. Applies expectancy-value theory to findings- eight domains of parents' future visions can be understood as parents' valued areas in transition preparation.	• Recent study • Autism specific • 16 mothers, 2 fathers- under represented, sample lacked diversity • Doesn't involve YP Thorough description of analysis • Promotes a broader understanding of transition over linear focus on normative outcomes • Mentions psychological theory
Transition support **Importance of easy read information** **Issue of choice at transition- empowerment, rights** **Expectations of adult life**	**11. Tarlton & Ward (2005)** Changes and choices: finding out what information young people with learning disabilities, their parents and supporters need at transition	UK	What are the information needs of young people, their families and supporters at transition?	27 YP with LD, 19 parents/ carers Focus groups	Analysed by project team, simple TA 14 categories (order of importance)- work; college; where to live; money; friends; sex and relationships; safety; being in charge of your life; living independently (i.e. information on practical things like being able to tell the time or find out what was on the TV); healthy living; having fun; music; sport; helping others. Parents lacked understanding of process and their role.	• UK-based, but must consider age of study, information needs may be different now, accessibility better? • Good diversity in sample, effort made to include black and ethnic minority families • Growing recognition of the value and importance, of involving disabled people, and people with learning disabilities, in the research process.

Evaluation of transition planning **Person-centered ethos** **Participation** **Specialist setting**	**12. Fayette & Bond (2018)** A qualitative study of specialist schools' processes of eliciting the views of young people with autism spectrum disorders in planning their transition to adulthood	UK	How do special schools elicit the views of young people with ASD in preparation for transition to adulthood? To what extent are these processes perceived to be effective?	Case study of 2 special schools Semi-structured interviews with staff, observation of a transition meeting Thematic analysis	Both schools appeared to comply with UNCRC Article 12.1 (UN, 1989) as they were able to elicit the views of their pupils, regardless of their communication needs. Effective processes of eliciting and including the views of young people with ASD require a person-centred ethos, and a commitment from all staff to elicit the pupils' views and develop processes that enable pupils to make informed decisions throughout their time in school.	• In-depth case study approach • Special setting (like current research) • Didn't observe in both settings • Didn't involve young people • Staff members identified by head- possible bias/ limitations o gatekeeper approach
Role for transition programmes **Importance of role models for aspiration** **Within-person** **considerations- gender, impairment experience** **Social model** **Barriers to being** **Resilience- of families**	**13. Hoskin (2017)** Taking charge and letting go: exploring the ways a Transition to Adulthood project for teenagers with Duchenne muscular dystrophy has supported parents to prepare for the future.	UK	To explore the ways in which the Takin' Charge project has been helpful, if at all, in supporting young people with DMD and their parents to prepare for the future.	Qualitative 16 mothers, 4 fathers Interviews Thematic analysis	4 themes; hearing from adult role models within the DMD community; being able to share with and learn from families and young people with DMD; the need for resilience in 'letting go' as a parent; and finally, aspirations for a 'normal' life in the face of a life-limiting impairment. There is a role for Transition to Adulthood projects using solution focused approaches to elicit what works, acknowledge family	• Consideration of the role of the researcher in sensitive topic- good use of solution focused questioning (empowering, focus on what works well in their lives) • Transparency about position of researchers- both involved with project and one with a son with DMD- enabled trusting relationships • Recognition that project ran at a time of aspirational legislation being introduced • YP not involved

					expertise and identify best hopes.	
Lack of YP participation **Transition as an ongoing process** **Discrepancy between policy/ service provision and parent experience** **Experience of ‘difference’**	**14. Jacobs, MacMahon & Quayle (2018)** Transition from school to adult services for young people with severe or profound intellectual disability: A systematic review utilizing framework synthesis	Scotland	Critically review what is known about the transition to adult services for young people with severe or profound intellectual disabilities.	Systematic review of qual studies- focus on moving from school to adult services Spanned 3 decades and Western countries	Framework analysis The family appears to be the main support system for young people, highlighting the need for more substantial support for families in advocating and caring for their children. Identified a lack of understanding of organisational and political decision-making by families (exo and macrosystem). Need for more longitudinal studies.	• Focus on PMLD • Used CASP criteria • Synthesised findings using Bronfenbrenner- decision to put family at the centre of the framework- might be argued that this is problematic and stands in contrast to “person-centeredness” and individualise approaches. • Views of parents involved may not be representative • Comparisons to other cultures needed
Lack of YP participation **Role for transition programmes** **Psychological impact- parents** **Need for systemic change**	**15. Leonard, Foley, Pikora, Bourke, Wong, McPherson, Lennox, Downs (2016)** Transition to adulthood for young people with intellectual disability: the experiences of their families	Australia		Mixed-methods, parent report questionnaires with open-ended questions 340 respondents	Less than 2/3 YP involved in planning. Themes at indiv, family & system level; Indiv- capacity to adapt and change to life in adulthood, building connectedness. Family- strain on family wellbeing and finances and worry about the future in the longer term. System- difficulty navigating services and programs.	• Mixed methods- clear presentation of qual and quant findings (used Bronfenbrenner) • Large sample size across 2 states • No involvement of YP- exactly what they critiqued! • Parents required to recall experiences from over 10 years ago

Transition planning **Importance of social networks** **Impact of ethnicity and culture**	**16. Small, Raghaven & Pawson (2013)** An ecological approach to seeking and utilising the views of young people with intellectual disabilities in transition planning	UK	We will examine the insights that young peoples' accounts of their lives give us about the importance of considering transition using a whole system approach.	Qual, interviews using Talking Mats 20 pps aged 14-16, 12 aged 17-19 and 11 aged 19-22	Content analysis Findings presented as a play by Mind the Gap theatre company Key themes- family, school, friendships and leisure, aspirations and feelings about the future, transition and social networks	- Large sample size including YP with a range of needs/ ages - Effective use of Talking Mats (although considerable mediation from parents required) - Considered cultural impact unlike many other studies - Promoted use of Bronfenbrenner
Transition policy and practice **Lack of YP involvement** **Lack of choice**	**17. Heslop, Mallett, Simons, Ward (2002)** Bridging the Divide at Transition: What Happens for Young People with Learning Difficulties and Their Families?	UK	To establish the extent to which legislation and guidance was being followed.	Interviews with 27 YP and parents, questionnaires completed by 283 families	A fifth of YP had left school without a transition plan Lack of planning led to uncertainty and stress for some families. The topics covered in transition planning were often quite different from those families considered to be important.	- Mixed methods - Consider age of study (although findings still appear relevant today?) - Interviewed YP using a workbook on 'growing up', designed specifically for this purpose (considered accessibility) - Suggested 5 Cs of good transition
Transition policy and practice **Lack of YP involvement** **Lack of choice**	**18. Morris (2002)** **Moving into Adulthood: Young disabled people moving into adulthood.**	UK	Reviewing research, policy and practise regarding the transition to adulthood for disabled YP.	Review	Identified barriers to effective transition planning; few opportunities to socialise, lack of information, limited employment and housing providers.	- Consider age of review (although findings still appear relevant today?) - No criticality of studies demonstrated.
Parents support needs **Process of transition not systematic**	**19. Gauthier-Boudreault, Couture & Gallagher (2017)**	Canada	To propose realistic solutions based on the perspective of families with a	Qualitative 14 parents of young adults aged between	Highlighted 4 types of unmet need- material, information, cognitive and emotional support required.	- Solution-focused interview methods - Parents had 2 opportunities to share their views - Thorough explanation of analysis

Psychological impact- parents	How to facilitate transition to adulthood? Innovative solutions from parents of young adults with profound intellectual disability.		young adult with profound intellectual disability.	18 and 26 with profound intellectual disability 2 semi-structured interviews (2nd to validate and deepen understanding)	Planning should start 3 years prior to transition, review plan annually Current guidelines don't apply to PMLD	- Suggested limitation of not including field notes to understand what was "really done"- positivist? - Solutions presented in clear format to be used by professionals and services- useful
Limited choice and control **Psychological impact- parents** **Parental expectations- low** **Need for systemic change**	**20. Gillan & Coughlan (2010)** Transition from Special Education into Postschool Services for Young Adults With Intellectual Disability: Irish Parents' Experience.	Ireland	This study sought to explore the nature, factors, and psycho-logical impact of their child's transition to post-school services.	Qual, semi-structured interviews 4 couples, 4 single mothers, with children aged 19-24 Grounded theory (Strauss & Corbin, 1998)	Transition from special school was experienced as stressful, uncertain, frustrating, and disempowering, similar to key themes emphasized repeatedly in the literature However, also experienced two rewarding aspects of caregiving (supportive individuals and child's positive adjustment to new roles and settings)	- Meant to be inductive, but themes matched research questions therefore findings appear to be led by preconceive ideas rather than data- not truly inductive? - Some focus on positive aspects! - No involvement of YP
Lack of choice **Discontinuous experience** **The invisible transition** **No-one's responsibility** **Move towards a whole system understanding**	**21. Hudson (2006)** Making and missing connections: learning disability services and the transition from adolescence to adulthood	UK	To identify recurring factors that affect continuity or discontinuity of care in respect of this crucial stage of life – a focus on why it is happening rather than	Commentary piece Includes comments from fieldwork interviews with YP, parents, managers professionals in child/ adult services (e.g. Connexions)	LD and transition is low financial priority compared to care of older people and those with mental health needs, leads to decommissioning of expensive 'out of area' placements. Lack of long-term perspective, Reactive rather than proactive planning	- No data, focus on policy - Not recent, but provide good historical overview, much still appears relevant today

and person-centered mapping			“pointers for good practice”			
Meaning of adulthood **Self-determination** **Feeling in between** **Mental Capacity Act**	**22. Murphy, Clegg & Almack (2011)** Constructing Adulthood in Discussions About the Futures of Young People with Moderate-Profound Intellectual Disabilities	UK	This paper examines how those closely involved in young people’s transitions invoked and deployed contrasting discourses as they sought to resolve some of the dilemmas arising from the potential tension between the rights of adults and the capacity of people with intellectual disabilities.	Longitudinal study 28 YP Interviews and group discussions with YP, transition coordinators, connexions workers	2 conflicting discourses identified- YP positioned as adults with self-determination critical AND still child-like with ongoing dependency, vulnerability, lack of understanding all compromising adulthood Only 2 YP mentioned their adult status CWs saw YP as lacking capacity for independent decision making	• UK based, large sample size • Triangulation of data from different sources • Verbal interview methods used with YP- not accessible enough
Accelerated adulthood **Differing understandings of adulthood** **Lack of choice** **Focus on interdependency**	**23. Redgrove, Jewell & Ellison (2016)** Mind the gap between school and adulthood for people with intellectual disabilities	Australia	Explore understanding of adulthood and how these relate to the differing perspectives of families and service providers as they support young people through the	Commentary piece Review of lit	Differing values and measures of successful transition to adulthood The experience of young people with intellectual disabilities is impoverished when compared to the otherwise fulfilling “open door” pathway through the stage of “emerging adulthood” experienced by	• No data, review of literature, followed by doctoral dissertation. • Introduction to concept of accelerated adulthood- interested to follow up

			transition to adulthood.		their counterparts without intellectual disabilities. Contemplation of what is meant by the term "adulthood" could serve to ease tensions between service providers and family members.	
Focus on alternative and multiple identities **Reciprocal relationships and support** **Parental control and contesting adulthood** **Dehumanisation- inherently different vs mundane and ordinary**	**24. Dorozenko, Roberts & Bishop (2015)** The identities and social roles of people with an intellectual disability: challenging dominant cultural worldviews, values and mythologies.	Australia	To explore the social construction of intellectual disability, with an emphasis on the identities and social roles of people with an intellectual disability.	Qualitative Photovoice and interviews 18 pps from an advocacy group (11 male, 7 female, age 20-45) Causal Layered Analysis (CLA)	ID is central and damaging to those with the label Pps presented identities that were derived from their broader social context, social relations and social roles.	• Sample includes older adults as well as those in EA. • Not heard of method of analysis previously- little to compare to. But enabled in-depth deconstruction of complex issues. • No mention of exhibition stage.
Sexual identity **Containment** **Problem of normative adulthood** **Gendered experiences**	**25. Liddiard & Slater (2018)** 'Like, pissing yourself is not a particularly attractive quality, let's be honest': Learning to contain through youth, adulthood, disability and sexuality.	UK & Reykjavik	To reconceptualize containment in the context of youth, gender, disability, crip sex/uality and pleasure.	The first study was a 12-month auto/ethnography with 27 young disabled people. The second explored the complex ways in which 25 disabled men and women managed and negotiated their	Containment is a requirement of the able adult body If complete containment is not possible, disabled YP are denied adult status and sexual selfhood. Endemic cultural shame of leakiness leads to a psycho-emotional disablism which can mitigate experiences of and rights to pleasure.	• Secondary data from 2 doctoral dissertations • No explanation of analysis • Addresses a complex issue that is often ignored/ avoided • The research was collectively managed by a Research Advisory Group made up of loca disabled people who guided the research throughout. • Recognised the role of the researcher

				sexual and intimate lives.		
Disability self-identification **Self-esteem** **Markers of adulthood** **Implications for intervention and support- Mindfulness, CBT, ACT**	**26. Chalk (2016)** Disability Self-Categorization in Emerging Adults: Relationship with Self-Esteem, Perceived Esteem, Mindfulness, and Markers of Adulthood	USA	This study examines whether self-esteem, perceived esteem, and attainment of markers of adulthood differ based on disability self-identification and mindfulness in emerging adults with disability.	Quant 1353 emerging adults Measures of self-esteem, satisfaction with life, perceived esteem, mindful attention awareness and markers of adulthood.	ANOVA These findings suggest that identifying with one's disability status may be protective against the stressful effects of this marginalized identity on self-esteem, which follows logically from social identity theory.	• No rich data • Groups not evenly matched, lack of ethnic diversity limits generalisability • Predominantly white female college students • Could have used more detailed assessments of disability self-identification (just yes/no). • Discussion of psych theory
Understanding of citizenship **Interdependence** **Lack of social inclusion** **Dilemma of difference**	**27. MacIntyre (2014)** **PhD (article)** The potential for inclusion: young people with learning disabilities experiences of social inclusion as they make the transition from childhood to adulthood	Scotland	Focus on young people's experiences of further education, training and employment and highlights the ways in which they negotiate (or not) a range of barriers and challenging situations.	20 YP with MLD, left school within 2 years, mix of specialist and mainstream Tracked for 6-9 months, interviewed twice, nominated significant others to be interviewed,	Key themes identified- YP were often advised to go on from school to college by parents, teachers and careers advisers perhaps reflecting the concern that young people were not ready to participate as active citizens/ for life in the real world (needed sheltering) Barriers to participation in employment despite clear motivation- lack of support,	• Research advisor with LD used to sense check interview questions. • In-depth case study approach • Good sample size, from different settings, triangulation of data.

				also 15 key informants	unmet expectations, benefit system.	
Disability self-identification **Focus on relationships and social roles** **Challenging idea of normality**	**28. Watson (2002)** Well, I Know this is Going to Sound Very Strange to You, but I Don't See Myself as a Disabled Person: Identity and disability	Scotland	Explore disabled people's constructions of self and identity	Qual 14 disabled men, 14 disabled women Interviewed twice over 6 months	Only three of the participants incorporated disability within their identity. For the vast majority of the participants in the study, impairment was not seen as important to their sense of identity or self.	• Little detail re demographics, methods etc. • Possibly older than emerging adulthood age range
ID identity as child-like and non-sexual **Transition to adulthood as 'window of opportunity'** **Barriers to developing a sexual identity**	**29. Wilkinson, Theodore & Raczka (2015)** 'As Normal as Possible': Sexual Identity Development in People with Intellectual Disabilities Transitioning to Adulthood	UK	To investigate the development of sexual identity during transition into adulthood for young people with ID from the perspectives of young people with ID and their carers, to provide an enriched, triangulated understanding of this process and shed light on the nature of the care relationship and its role in sexual	Qual Interviews with 4 YP, 4 carers (selected by YP) YP-carer dyads enabled exploration of important relationship and the role it played. IPA	The master themes that emerged from the data were 'the struggle for an 'as normal as possible' adult identity'; and 'the struggle for sexual identity as a 'normal' adult identity' ID identity overshadowed gender and sexual identity, the struggle to receive (or in the case of carers, provide) accessible sex education and support; mutual embarrassment about discussing sexuality; and carers inhibiting sexual exploration in order to manage risk.	• Small sample size • Considered relationship/ support of those in their microsystem • Longer term involvement may have elicited more information • Discuss complexity of using open questioning but supporting pps to answer by providing concrete examples and fixed choice questions (leading?)

			identity development during transition to adulthood.			
Sexual identity overshadowed by disability identity **Disabling societal attitudes- asexual** **Social model- shifting attention to context** **Dilemma of difference/ other** **Challenging norms and social constructions of sexuality**	**30. Payne, Hickey, Nelson, Rees, Bollinger & Hartley (2016)** Physically disabled women and sexual identity: a PhotoVoice study	New Zealand	This study explored four young physically disabled women's experiences and perspectives regarding sexuality and disability.	Qual Photovoice 4 women aged 18-32 with a congenital disability (wheelchair users)	Two main themes were identified: being seen only as disabled, and the need to see beyond the disability.	• Disabled female researcher- referred to own experiences, acted as a support. • Included photos in write up • Used SHOWED acronym and involved pps in analysis • 2-month exhibition, attended by 55 people, disability advocates • Further dissemination through blogs, newsletters and magazines, PowerPoint version for conferences • One pps researching sex education and disability (impact of research)
Friendship **Hartup & Stevens theory-symmetrical reciprocity, surface structure changes throughout lifespan but deep structure remains the same** **Impact of context and developmental trajectory on friendship experiences**	**31. Hurd, Evans & Renwick (2018)** "Having friends is like having marshmallows": Perspectives of transition-aged youths with intellectual and developmental disabilities on friendship	Canada	Explored perspectives of transition aged youths regarding their own experiences of friendship	Qual 7pps (20-24), video-recordings of 3 interviews Secondary analysis of subset of data collected for a larger grounded theory study TA informed by constructivist grounded theory	Revealed three major cross-cutting themes Meanings of friends and friendship- qualities of a friend, disclosure, sense of belonging Deepening self-knowledge- opportunities for role development, negotiating social identity (religion, disability) Negotiating in(ter)dependence – living	• In depth interviews, including friend in community setting (respectful to pps) • Used psych theory to make sense of findings • Future research- to explore and model how the contexts (e.g. specialist FE college like NSC!) and developmental trajectories unique to individuals with IDD shape their friendship experiences • Combined methods of analysis?

					situation, barriers to independence.	
Disability identification **Political involvement** **Disability rights advocacy** **Social identity theory** **Positive identity development**	**32. Nario-Redmond & Oleson (2016)** Disability Group Identification and Disability-Rights Advocacy: Contingencies Among Emerging and Other Adults	USA	Three studies that investigate the relationship between disability as a group identity and participation in disability-rights advocacy, considering visible as well as less apparent impairments	Quant 204 EAs at Uni, surveys MOA, IDEA, 10-item measure of Political Attitude Conviction, questions re belonging to disability community and involvement in rights groups.	Study 1 findings- EAs with disabilities demonstrated more political conviction, were more other focused, and were twice as likely to be involved in disability-rights groups compared to same-age peers without disabilities.	• Lack of rich data- what motivated them to be more politically involved? • Used IDEA (consider for present study) • Sample of uni students, not generalisable
Positive disability identity **Belonging- need to belong, sense of belonging** **Social support** **Implications for support- group sessions for YP with similar disabilities**	**33. Raver, Murchake & Chalk (2018)** Positive Disability Identity Predicts Sense of Belonging in Emerging Adults with a Disability	USA	Examined the link between sense of belonging, need to belong, social sup- port, and positive disability identity in a sample of emerging adults with disabilities.	Quant YP with a disability (*N* = 502, 70% women) completed online, self-report measures of need to belong, sense of belonging, social support, and positive disability identity.	Emerging adults with greater perceived support from family, friends, or a special person experienced a stronger sense of belonging Positive disability identity significantly predicted sense of belonging in emerging adults with a disability,	• Limitation- Only used a single item to assess sense of belonging (no use of validated scale) • Sample lacked diversity • Good consideration of implications/ support needs

Sense of purpose- desire to support other YP with SEND **Role of the EP** **Compassionate identity/ time of personal growth- confidence, internal values, caring for others, want to make a difference** **Importance of family support** **He & Crews 'window of opportunity'** **Holistic view of transition support needed**	**34. Clarkson (2018)** DEdPsy Thesis Exploring Support for Post 16 Young People Outside Mainstream Education	UK	The aim of phase one was to explore what support there is for young people outside mainstream. The aim of phase two was to explore how this experience influences their identity.	Qual, influenced by ethnography 10 YP (5 from provision led and 5 from YP led settings), 5 EPs and 6 staff Semi structured interviews, observations, Drawing the Ideal Self Thematic analysis	EP themes- new area for EPs, process over knowledge, importance of fostering mentoring relationships, engage them in weighing up pros and cons, share their voice. Staff themes- influence of Children & Families Act 2014, working in a different way to mainstream, knowing the YP (person-centered), supporting them to learn about themselves (identity), nurturing approach (PACE) YP themes- felt problem was within themselves (beh, ADHD, Autism, anxiety), staff approach (treated like adults), calm environ, gaining the skills to help others	• Dissertation, not peer reviewed article • Personal Construct psychology method used • Triangulation of data- themes presented at each level • Interesting POV that YP don't want the burden of decision making about post 16 setting- EPs may need more knowledge to support an informed decision?
Self-determination theory-importance of connectedness to others and autonomy **Relationships with teachers as central to understanding and navigating their transition** **Role of EP**	**35. Lawson (2018)** DEdPsy Thesis How do young people with Education, Health and Care Plans make sense of relationships during transition to further education and how might this help to	UK	To explore the lived experiences of YP who have transitioned from and to specialist settings. How do they make sense of relationships	Qual 4 YP at a specialist 6th form IPA	Change in relationships at school and college, School relationships- provide security and safety, College relationships- related to independence, feeling trusted, valued, respected and given opportunities to demonstrate responsibility and autonomy Relationships with teachers appeared to support YP in	• Dissertation, not peer reviewed article • Focus on YP • Visual tool used that fit the concept of transition- adapted Clark, Laing, Tiplady and Woolner's (2013) 'Fortune Lines' • Small sample size, but in-depth analysis

	prepare them for adulthood?		during transition? How do these constructs prepare them for adulthood?		preparing for adulthood by providing a safe space to learn independence skills. Researcher noted a perceived passivity in decision making during transition- lack of choice and control?	
Everyday life information needs similar across YP **More holistic, developmental focus required**	**36. Hanson-Baldauf (2013)** PhD Exploring the Everyday Life Information Needs, Practices, and Challenges of Emerging Adults with Intellectual Disabilities	North Carolina	This case study research explored the ELI needs, practices, and challenges of four emerging adults with I/DD.	Thick description and case narrative- "generated in depth life storytelling and deeper reflection" 4 YP with ID (16-25) Semi-structured interviews, participant/non-participant observations, artwork, Photovoice, and document review of IEP and PCP reports.	Pps displayed high motivation and great initiative in their ELI practice as information seekers, consumers, producers, managers, and providers. Barriers are divided into five categories*: cognitive, psychological, physical, economic, societal,* and *institutional* Five conceptual frameworks serve as foundational building blocks of the proposed model: Emerging adulthood, Person-centeredness, Self-determination, the Theoretical Model of Urban Teen Development, and the Quality of Life Model.	• Researcher and prolonged engagement in the research fiel and "native" status which aided rapport • Range of data collection methods and flexible strategies used to gain rich, in-depth information of life experiences that could be triangulated • Case narratives sent to pps for member checking • No theoretical basis for analysis discussed (other than had read about grounded theory and coding handbook) • Challenges of photovoice Photovoice- pps not following/ understanding instructions, but very revealing and helped with recall.
Difference and similarity in conceptualisation of adulthood	**37. Salt (2018)** **PhD**	Scotland	Aimed to address this gap in the research by investigating young Scots'	Mixed methods- 2 phases (qual and quasi-experimental)	Autonomy- YP with ID restricted by parents, fewer opportunities to take risks	• Use of TA appropriate • Highlights the need for different transition outcomes.

Self-determination- more complex **Equalising of power balance between parent and YP** **Notion of freedom without responsibility**	Experiences of, and attitudes, towards growing up and adulthood: A comparative study of young people with and without mild intellectual disabilities		and their parents' experiences of, and attitudes towards growing up and adulthood.	Phase 1- 16 YP (8 with ID, 8 without ID) and 5 parents Phase 2- 105 YP (55 with ID, 49 without) Semi-structured interviews, interactive flashcard activities, a vignette, and a questionnaire.	YP with intellectual disabilities may prioritise interpersonal dimensions of 'responsibility' - such as looking after other people and fulfilling one's familial obligations - as being the most salient criteria for adulthood. Similar attitudes to independence and self-determination, both groups happy with current level of freedom and responsibility, accepted parental authority and restrictions, had different fears	• Illness prevented researcher from feeding back and checking her analysis/ interpretations. • Recognised social desirability impact on findings. • Despite creative methods, still struggled to engage full with questions about definition of adulthood- complex phenomenon.
Conceptions of adulthood **Emerging adulthood**	**38. Redgrove (2018)** **PhD** Are We There Yet? A study of concepts and conflicts surrounding intellectual disability and adulthood	Tasmania, Australia	To understand different conceptualisations of adulthood.	13 YP, aged 18-21, parents and support workers Focus groups and semi-structured interviews Concept analysis	5 themes of variance in perceptions of YP with ID as adults; independence and rationality, acceptance in the community, having meaning, adulthood as actual or virtual observation Stark difference between parents and professionals' perceptions.	• Dissertation, not peer reviewed article • Must consider unique context (island) • Paucity of demographic info gathered (gender differences?) • 2 pps with communication devices • Provides a clear conceptual framework • Evolved to include views of YP with ID • Use of case study to highlight dilemma
Importance of family support	**39. Giacomin (2013)**	Canada	To explore the experiences of emerging adulthood for men with an	Qualitative semi-structured	Three themes emerged: internal perceptions, dynamics of social	• Dissertation, not peer reviewed study • Small sample size for TA? IPA/ case study more appropriate? • Focus on men (again!)

Positive attitude **Coping mechanisms**	**Master's dissertation** The Experience of Emerging Adulthood in Men with Acquired Impairment.		acquired impairment.	interview with 4 men Thematic analysis	relationships, and barriers and opportunities Timing of meeting markers of adulthood may be delayed.	- Different impairments, not a homogenous sample - Retrospective data that required recall of EA years from 2 pps.
Gender differences **Impact of culture/ tradition/ religion** **Expectations and opportunities** **Protection and restriction of girls**	**40. Basit (2012)** '...But that's just the stereotype': gender and ethnicity in transition to adulthood	UK	Examines the role of gender and ethnicity in young minority ethnic British citizens' transition to adulthood	Mixed methods Survey and interviews 20 pps aged 14-24	The present research shows that gender and ethnicity have a significant impact on young people's transition to adulthood, with social class as an additional concern. Found both similarities and differences of perceptions between young men and women of different ethnic groups, which cautions against stereotyping gender-related beliefs and experiences of such groups.	- Mixed methods, large sample size - Some pps outside EA age range - Researchers matched to pps depending on age, work experience
Gendered experience of disability and transition to adulthood **Minimisation of difference- a point of intersection of gender, disability and generational identities** **Challenging "good" transition outcomes**	**41. Gibson, Mistry, Smith, Yoshida, Abbott, Lindsay, Hamdani (2013)** Becoming men: Gender, disability, and transitioning to adulthood	Canada	Investigate the intersectionality of gender, disability, and emerging adulthood	Qualitative 15 young men (16-27) Combination of interviews, photo-elicitation, and solicited narrative diaries.	Narratives of nondifference- trying to live a "normal" life in the face of multiple challenges Normative life trajectory, maintaining a positive attitude, independent living, identity (rejecting disability, adulthood, dilemma of masculinity.	- Use of a range of data collection methods that were more accessible/ less intimidating that face to face interviews - Despite this, pps seemed uncomfortable discussing intimate relationships, only one mentioned sex - Focus on men only

Multiple alternative identities to disability **Gender/ masculinity** **Sexuality and relationships**	**42. Abbott, D., Carpenter, J., Gibson, B. E., Hastie, J., Jepson, M., & Smith, B. (2019)** Disabled men with muscular dystrophy negotiate gender.	UK	Addressed question of whether the planning, organisation and delivery of support worked in ways which took account of and considered male gender, or not.	Qualitative 20 men with DMD Recruited through Facebook	Key themes- sense of self as a man, similarities and differences to other men, importance of sex and relationships	• Good diversity in sample (race, sexuality) • Disabled and non-disabled researchers • Conversation analysis to reflect on how sensitive questions were handled

7.2. Gatekeeper letter

School for Policy Studies

University of BRISTOL
8 Priory Road
Bristol BS8 1TZ
Tel: +44 (0)117 954 6755
bristol.ac.uk/sps

Dear Sir/ Madam,

My name is Mair Hewitt-Stubbs and I am currently in my second year of training on the Educational Psychology Doctorate at the University of Bristol. As part of this, I am conducting a piece of qualitative research with the title *'An exploration of young, disabled men and women's experiences of emerging adulthood'.*

I would like to ask some of the students at your college to take part and would appreciate if you could take the time to read the information below regarding the study and your potential involvement.

Research aim and importance

I am interested in gaining the voices of young, disabled people using creative methods and photo-elicitation. I hope to gain a better understanding of what they consider to be important markers of adulthood, their personal experiences of these and how they feel it has contributed to the ongoing development of their adult identity. I will be paying particular attention to the part that gender might play in their views and experiences. Transition planning for this population does not always take a holistic view of the young person and their priorities, concerns and aspirations. The findings from this study will potentially inform the support offered to young, disabled people by Further Education settings such as yourselves, as well as other professionals and service-providers during this time of transition.

What will be required of you if you agree to take part?

As the National Lead for Policy and Research in the college, I would ask that you liaise with key members of staff who work in the Creative and Performing Arts Programme, to identify a small group of young people who meet the following inclusion criteria;

- Participants must be between the age of 18 and 25.
- They must be currently attending the college and following a Creative Arts programme.
- They must be able to recall details of previous events in their life and have the necessary skills and means of engaging in group discussion in some way (e.g. verbally, AAC device, Talking Mats with staff support).

There should be no pressure put on young people to take part and they should be reassured that their care and support at college will not be affected if they decide not to. Once participants have been identified and have consented to taking part, I would ask that you arrange a suitable space in which the individual interviews and focus groups could take place on agreed dates in the summer term. I would also appreciate that a key member of staff, as identified by each participant, is made available during these times to provide support.

What will the participants be expected to do?

Participants will be asked to meet with me individually to complete a Life Road Map and discuss their initial ideas about becoming an adult and what is involved. At this point they will be given camera equipment and instructions to take photographs or collect pre-existing images of anything represents what becoming an adult means to them. They will be asked not to include any photographs of themselves or other people. Participants will then have three weeks to collect these images and select five to bring to an all-female or all-male focus group. Here they will be asked to share their images and engage in discussion about them with myself and other members of the group. Clear ground rules will be set out (e.g. regarding confidentiality and respect) and agreed to by all before the focus group begins. Finally, participants will be given the option to be involved in the creative process of planning for a community exhibition of their images and captions.

How will the information collected be kept safe and confidential?

Participants will be given pseudonyms and these will be used during transcribing to ensure anonymity. The name of the college will also be anonymised. The interviews and focus groups will be recorded using an encrypted device, saved to a secure server and transcribed by the researcher. All recordings will then be deleted. All data collected will also be treated with confidentiality, however information disclosed that puts people at risk of harm may need to be shared. Data will be archived anonymously for 20 years and may be accessed by other researchers.

Can participants withdraw from the study?

Participation in this study is completely voluntary and the young people taking part will have the right to withdraw themselves and their data at any time without having to give a reason. Thank you for taking the time to read this information. I hope it is something you would be interested in being a part of. Please do not hesitate to contact me on the details below should you want to discuss this further.

NB: Approval has been granted by the School for Policy Studies Research Ethics Committee

Kind regards,

Mair Hewitt-Stubbs *mh17887@bristol.ac.uk*

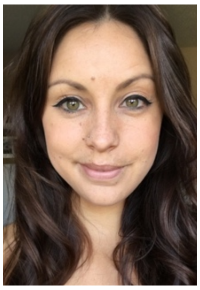
If you have any concerns or complaints which cannot immediately be resolved, please contact my research supervisor, Professor David Abbott *d.abbott@bristol.ac.uk*

7.3. ‘Easy read’ information sheet

School for Policy Studies

University of BRISTOL
8 Priory Road
Bristol BS8 1TZ
Tel: +44 (0)117 954 6755
bristol.ac.uk/sps

Hello,

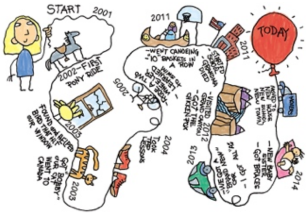


My name is Mair and I am a student at the University of Bristol.

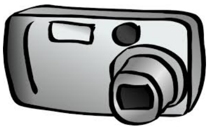
I would like to invite you to take part in a research project that explores your views and experiences of getting older and becoming an adult.

What will happen if you say yes?

First, we will meet to talk about what being an adult means to you. Together we will create something called a Life Road Map. This will include things that have happened in your life in the past few years as you have moved from being a teenager to a young adult.



Then you will have 3 weeks to take pictures and/ or collect images of anything that makes you think about becoming an adult. We will think of some ideas of what these could be in our first meeting.



Next, you will be asked to choose 5 of these images and bring them to a group discussion with the other young women (if you are female) and other young men (if you are male). We will look at everyone’s images and talk about what they mean and why they were chosen.

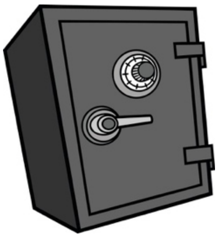
With your agreement, the images will be displayed at a community exhibition. This will help others to understand what is important to you and improve their services for disabled young adults.

It will be your choice if you want to be part of the exhibition. This will involve meeting as a group to arrange the images and choose words to go alongside them. The exhibition will be held at the college in June next year.

Now some important things you need to know!

All our conversations will be audio- recorded. I will use the recordings to write up the research paper and then they will be deleted.

I will use a fake name when I write about what you have told me so that people do not know it is you.



I will keep all the information you share with me private and safe, unless I think you or others are at risk of harm, then I will have to tell another adult.

You do not have to take part if you don’t want to. If you say no, nothing will happen. Even if you say yes now, you can still change your mind later. You can also ask for your images and the things you say to be taken out of the study at any time.

I will store your information safely for 20 years and other researchers will be able to read it and use it in their own work. It will remain anonymous, which means that they will not know who you are or be able to identify you or anyone else you talk about.

So what next?

If you are interested in this project, please let your Course Tutor or Personalised Learning Coordinator (PLC) know. I will then arrange to visit the college so I can meet you and tell you more about it. You will then be asked to sign a consent form agreeing to take part.

My email address is *mh17887@bristol.ac.uk* if you have any questions. I would love to answer them!

Thank you,

Mair Hewitt-Stubbs

7.4. ‘Easy read’ consent form

School for Policy Studies

8 Priory Road
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Tel: +44 (0)117 954 6755
bristol.ac.uk/sps

Consent form

Research project title; *An exploration of young, disabled men and women’s experiences of emerging adulthood*.

Please tick if you agree ✓

General;

I have read the Information Sheet with a trusted adult. ☐

I understand what it says on the Information Sheet. ☐

I was asked if I had any questions about the project and my questions were answered in a way I could understand. ☐

I understand that I will meet with Mair and we will talk about what it means to get older and become an adult. ☐

Use of photographs and images;

I understand that I will be asked to take photographs or collect images of anything that makes me think about becoming an adult. ☐

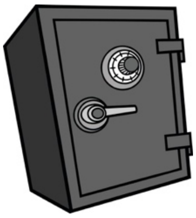
I understand that I must not include photographs of myself or other people. ☐

I agree to share my images and to talk about them in a focus group with other participants. ☐

I understand that my images may be displayed at an exhibition at the end of the project. ☐

Use of my information;

I understand that all conversations will be audio recorded. ☐



I understand that the things I say will be kept safe and that when Mair writes about them, she will use a fake name so no one will know it is me. ☐

I understand that Mair will have to tell someone if she thinks I, or others, are at risk of harm. ☐

I understand that I do not have to carry on with the study if I do not want to, even after I have said I will do it, and that I do not have to say why. ☐

I understand that I can ask for my images and the things I said to be taken out of the study at any time. ☐

I understand that all information will be stored safely for 20 years and may be shared with other researchers anonymously. This means that if someone looks at the information, they will not know who I am or be able to identify me or anyone else I talk about. ☐

I would like to take part in this study. ☐

Name: …………………………………………………………………………….

Signed: …………………………………………………………………………..

Date: ……………………………………………………………………………….

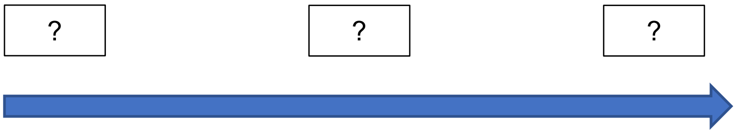
7.5. Semi-structured interview schedule

All questions and prompts are a rough guide and will not necessarily be used during the interview. Questions will be asked in a conversational tone at the level of the young person to ensure understanding. The researcher will ensure that the participant has all communication aids, AAC devices and adequate staff support in place before starting the interview.

Introduction;

- Greet participant, reminder of who I am and what the research is about.
- Read through the consent form together again and confirm they are happy to continue.
- Explain what we will be doing today, that it won't last longer than 45 minutes and we can stop for a break if needed.
- Show an example of the Life Road Map and allow time for them to think and ask any questions.

Questions	Prompts
Life Road Map activity *Large blank piece of paper and felt tips* *Show my example* *Participant can choose to draw or let the researcher draw as they talk* *Draw your life as if it was a road…* *Include all the important people, places and events that have happened…* *Ask if it is OK for the researcher to take a copy of this and they can choose to keep or destroy the original*	What thoughts and emotions did you have at that time? Did you feel more/less like an adult there? I wonder if any of these have affected whether you feel like an adult/ man / woman now… What are your future hopes/ aspirations/ goals?
What is an adult? *How can you tell someone is an adult?* *What does an adult do/ not do?* *Can you think of someone who you see as an adult? Describe that person.*	Young people in previous research projects have talked about…physical changes with age/ behaviour/ relationships/ employment/ earning money/ contributing to the community/ living away from home/ social

Has anyone spoken to you about what adulthood means (friends/ family/ college staff) *What has shaped your ideas about adulthood?* *What comes before an adult? How is that different?* *When does adulthood begin?* *What would it look like on a scale? What are the important markers?*  Do you feel like an adult? *Where would you place yourself on the scale? Why?* *Tell me about a time where you have felt like an adult/ not felt like an adult.*	opportunities/ risk-taking/ making decisions/ increased control over their lives/ material possessions/ increased responsibility/ self-care/ caring for others Are you always there or does it change depending one the situation? Visual IDEA prompts- which of these stand out to you as relevant to your experiences/ expectations of adulthood?
How does your disability have an impact on your experiences of becoming an adult? *Have there been any unique opportunities that you have experienced when compared to your friends who do not have a disability?* *Have there been any unique challenges that you have experienced when compared to your friends who do not have a disability?* *How have you overcome these?* *Has it made things easier/ harder?* *Has it made you think/ do things differently to others?* *Have other people around you had an impact on this? If so, how?* How does your gender have an impact on your experiences of becoming an adult?	Can you tell me what you mean by that? Can you give me an example? Can you tell me more about that? Can you describe that for me? Through their expectations… The way they talked to you… How they treated you… The support/ lack of support you have had…

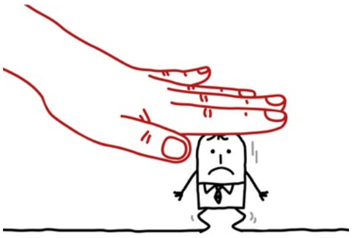
What does "being a man" or "being a woman" mean to you? *Are there things that are more/ less important to you as a disabled young woman/ man?* *Do you think you need different support as a disabled young man/ woman?*	

Closing;

- Explain that is the end of the interview, thank participant for their time
- Reminder that the next part of the project is to take photographs and/ or collect images of anything that makes the participant think of becoming an adult. Share photography prompts.
- Give them the camera and equipment or agree that they will use their own device (e.g. IPad, smart phone).
- Ask them to choose 6 of the images to bring to a group discussion in 3 weeks (give them the date and venue, reassure that staff will remind them).
- Chance to ask any questions, debrief, check they are OK, ask what they are doing next (offer a break before returning to their lecture).
- Thank again, say goodbye.

7.6. Dimensions of adulthood visual prompts

Possibility 	Commitment to others 
Freedom 	Stress 
Exploration 	Restriction 
Confusion 	Instability 

Optimism 	High pressure 
Finding out who you are 	Unpredictability 
Settling down  	Independence 
Worry 	Planning for the future 
Separating from parents 	Trying new things 

Making choices	Deciding beliefs and values
	

7.7. Example of a Life Road Map

7.8. Photography prompts

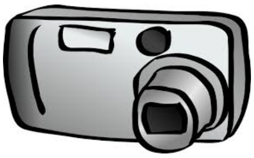
Photography prompts; Take up to 10 photos of anything that…

1. **Is important to you at this time of your life.**
2. **Would help others to understand your experience of growing up and becoming an adult.**

<u>Tips for Photographers</u>

- Enjoy it and be as creative as you like!
- Ask someone for help to take the photos if you need it, but don't let them influence what you choose to take photos of.
- Try not to talk to the other participants about the photos you are taking.
- Do not take photos of other people or 'selfies'.
- Keep the sunlight behind you when taking photos outdoors.
- Use the flash when taking photos indoors.
- Check the clarity of your photo once you have taken it. You can always take another if needed.
- Be sensible! Do not put yourself in dangerous situations when taking photos.
- Save all your photos and someone will support you to email them to me.

I look forward to seeing your photos ☺



7.9. Focus group topic guide

Introduction;

- Agree ground-rules for the group (e.g. respecting each other's views, confidentiality, listening whilst others speak) and write these up for everyone to see and refer to throughout.
- Ask the group how they would like the focus group to run and negotiate this together so that it is the most comfortable process possible (e.g. present their 5 images one at a time or put all images on the table in the middle and ask someone to volunteer to begin talking about one of theirs)

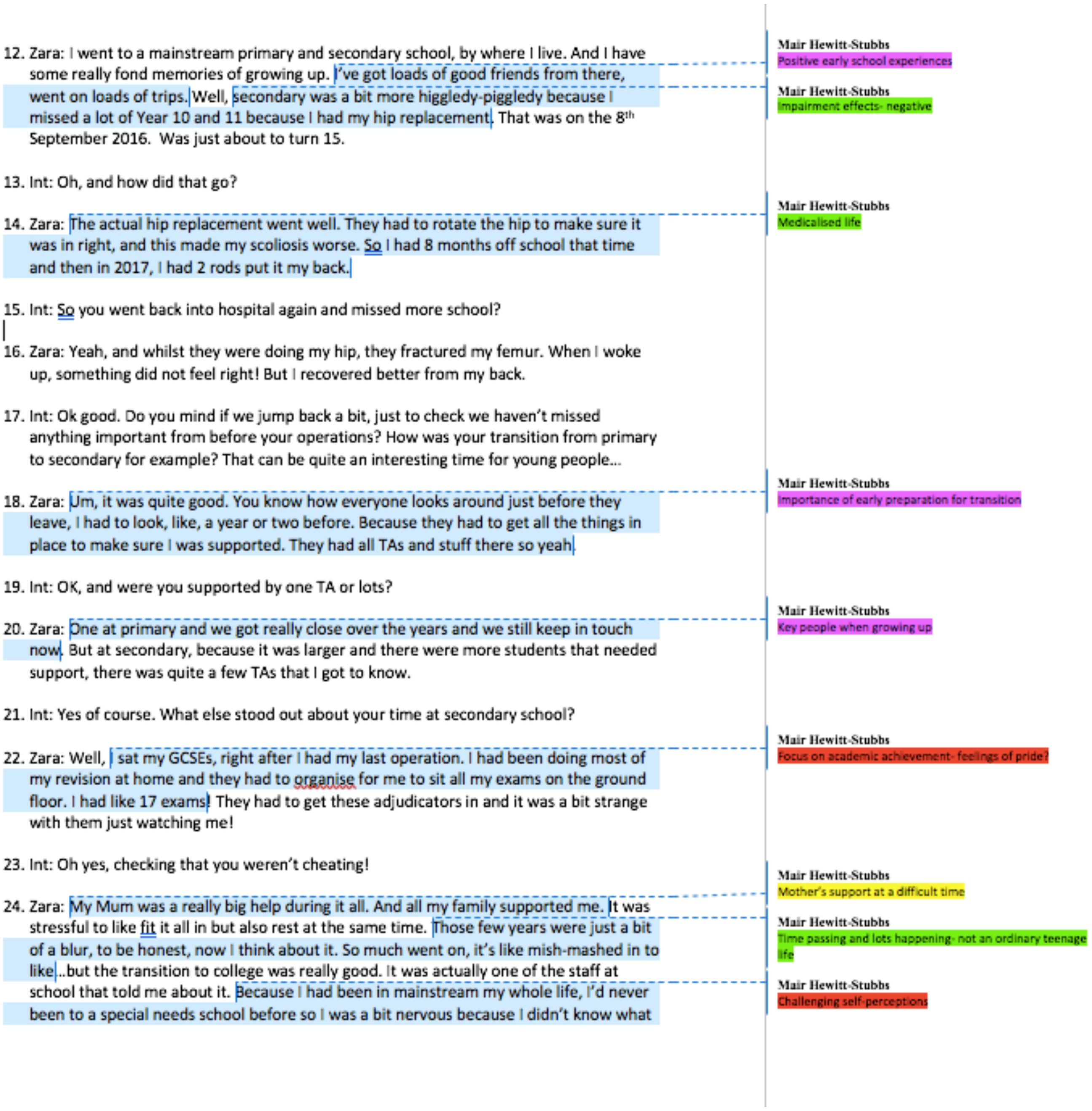
Questions and prompts
Process questions; *What was it like taking the photos?* *Did you make a plan or just take them when you spotted something?* *Are there any other photos you wish you could have taken?* **SHOWeD (Wang, 1996, 1999)** *What do you **S**ee here?* *What is really **H**appening here?* *How does this relate to **O**ur lives?* ***W**hy does this situation, concern, or strength exist?* *What can we **D**o about it?* **Further prompts for group;** *What do others notice about the picture?* *What does it say about your/ their life as an adult/ man/ woman?* *Does that image mean the same to you? Or something different?* *What strengths or challenges does it convey?* *What goals and aspirations does it convey?* *How does it make you all feel?*
Comparative questions; *Can you spot any similarities/ differences in the images you have all chosen?* *Are there any patterns emerging?* *Does it look as if some of these experiences are shared by a few of you?* *Are there any that are completely unique to one person?* *What are these images telling us about what is important to you as adults/ men/ women?* *What are the key messages in the images that would be useful to share with others?*
What does this mean for the support you receive in preparation for adulthood? *What is working/helping that you would like more of?* *What is not working so well?*

What do you want to change?
Who needs to know?
What suggestions do you have for them?

Closing;

- Explain that is the end of the focus group, thank participants for their time.
- Reminder that the next part of the project is a planning session for the exhibition. Let them know the date and venue if they would like to take part.
- Collect camera equipment and copy/ save images before returning the originals to participants (destroy if they don't want them).
- Chance to ask any questions, debrief, check they are OK, ask what they are doing next (offer a break before returning to the classroom).
- Thank everyone again, say goodbye.

7.10. Transcript and initial coding example



12. Zara: I went to a mainstream primary and secondary school, by where I live. And I have some really fond memories of growing up. I've got loads of good friends from there, went on loads of trips. Well, secondary was a bit more higgledy-piggledy because I missed a lot of Year 10 and 11 because I had my hip replacement. That was on the 8th September 2016. Was just about to turn 15.

13. Int: Oh, and how did that go?

14. Zara: The actual hip replacement went well. They had to rotate the hip to make sure it was in right, and this made my scoliosis worse. So I had 8 months off school that time and then in 2017, I had 2 rods put it my back.

15. Int: So you went back into hospital again and missed more school?

16. Zara: Yeah, and whilst they were doing my hip, they fractured my femur. When I woke up, something did not feel right! But I recovered better from my back.

17. Int: Ok good. Do you mind if we jump back a bit, just to check we haven't missed anything important from before your operations? How was your transition from primary to secondary for example? That can be quite an interesting time for young people...

18. Zara: Um, it was quite good. You know how everyone looks around just before they leave, I had to look, like, a year or two before. Because they had to get all the things in place to make sure I was supported. They had all TAs and stuff there so yeah.

19. Int: OK, and were you supported by one TA or lots?

20. Zara: One at primary and we got really close over the years and we still keep in touch now. But at secondary, because it was larger and there were more students that needed support, there was quite a few TAs that I got to know.

21. Int: Yes of course. What else stood out about your time at secondary school?

22. Zara: Well, I sat my GCSEs, right after I had my last operation. I had been doing most of my revision at home and they had to organise for me to sit all my exams on the ground floor. I had like 17 exams! They had to get these adjudicators in and it was a bit strange with them just watching me!

23. Int: Oh yes, checking that you weren't cheating!

24. Zara: My Mum was a really big help during it all. And all my family supported me. It was stressful to like fit it all in but also rest at the same time. Those few years were just a bit of a blur, to be honest, now I think about it. So much went on, it's like mish-mashed in to like...but the transition to college was really good. It was actually one of the staff at school that told me about it. Because I had been in mainstream my whole life, I'd never been to a special needs school before so I was a bit nervous because I didn't know what

Mair Hewitt-Stubbs
Positive early school experiences

Mair Hewitt-Stubbs
Impairment effects- negative

Mair Hewitt-Stubbs
Medicalised life

Mair Hewitt-Stubbs
Importance of early preparation for transition

Mair Hewitt-Stubbs
Key people when growing up

Mair Hewitt-Stubbs
Focus on academic achievement- feelings of pride?

Mair Hewitt-Stubbs
Mother's support at a difficult time

Mair Hewitt-Stubbs
Time passing and lots happening- not an ordinary teenage life

Mair Hewitt-Stubbs
Challenging self-perceptions

it would be like. We visited a few times actually, I showed my friends the map thing and I was like "yeah, it's good". It was a big change and I was a bit nervous about working with all the care staff.

Mair Hewitt-Stubbs
Time of change and new challenges

25. Int: Oh, how come?

26. Zara: Because when the pain got really bad, I stopped having care staff coming in so it had just been Mum and Dad doing it for ages. So then to come here and have loads of different people doing my care, it was a bit scary...(nervous giggle).

Mair Hewitt-Stubbs
Medicalised life

27. Int: Of course, so that took some getting used to?

28. Zara: Yeah, I still have some anxieties about different things, but that's got really good now and I am practicing directing my care. Confidence-wise, doing things without family. I've still got quite a long way to go, but coming to college has helped a lot.

Mair Hewitt-Stubbs
Developing new skills and confidence, growing independence from family

Mair Hewitt-Stubbs
College as an opportunity to develop independence and confidence with directing care

Mair Hewitt-Stubbs
Adulthood as a journey

29. Int: Great maybe we can talk more about that later. And how about relationships? Have you had a boyfriend or girlfriend?

30. Zara: No, it's never really happened. I liked the idea of having a boyfriend one day, but it's never really come about. Because when my hip was bad, I didn't really leave the house much. I always liked watching the romance films, but it is not really something I am fussed about. Maybe one day, but you have to go actually looking for them! (laughs) And I'm like, well, if I really want one, it will happen. Mum's like, most of the time, people become friends with someone first. But it's not my strongest subject...

Mair Hewitt-Stubbs
Romantic relationships not a current priority, something for the future

Mair Hewitt-Stubbs
Strong parental influence on her understanding of relationships

Mair Hewitt-Stubbs
Lack of confidence in this area, seemed uncomfortable talking about it

31. Int: That's ok. Doesn't sound like it is much of a priority right now. You mentioned that you were stuck inside a lot...did friends visit you?

Mair Hewitt-Stubbs
Role of researcher- moved on too quickly

32. Zara: Yeah, my friends would visit and we would chat and catch up. I couldn't have done any of it without my support system, I would have been in like a shell. I've been able to be more independent since. I'm hoping to do work when I finish here.

Mair Hewitt-Stubbs
Reliance in others at a difficult time, importance of a social network

33. Int: Ah OK, so that leads us nicely into your time at college and your future aspirations and goals. You've talked about your growing confidence, but is there anything else that has happened that is important?

34. Zara: Well I moved from an onsite residence to and offsite one which was another big transition.

Mair Hewitt-Stubbs
Time of change

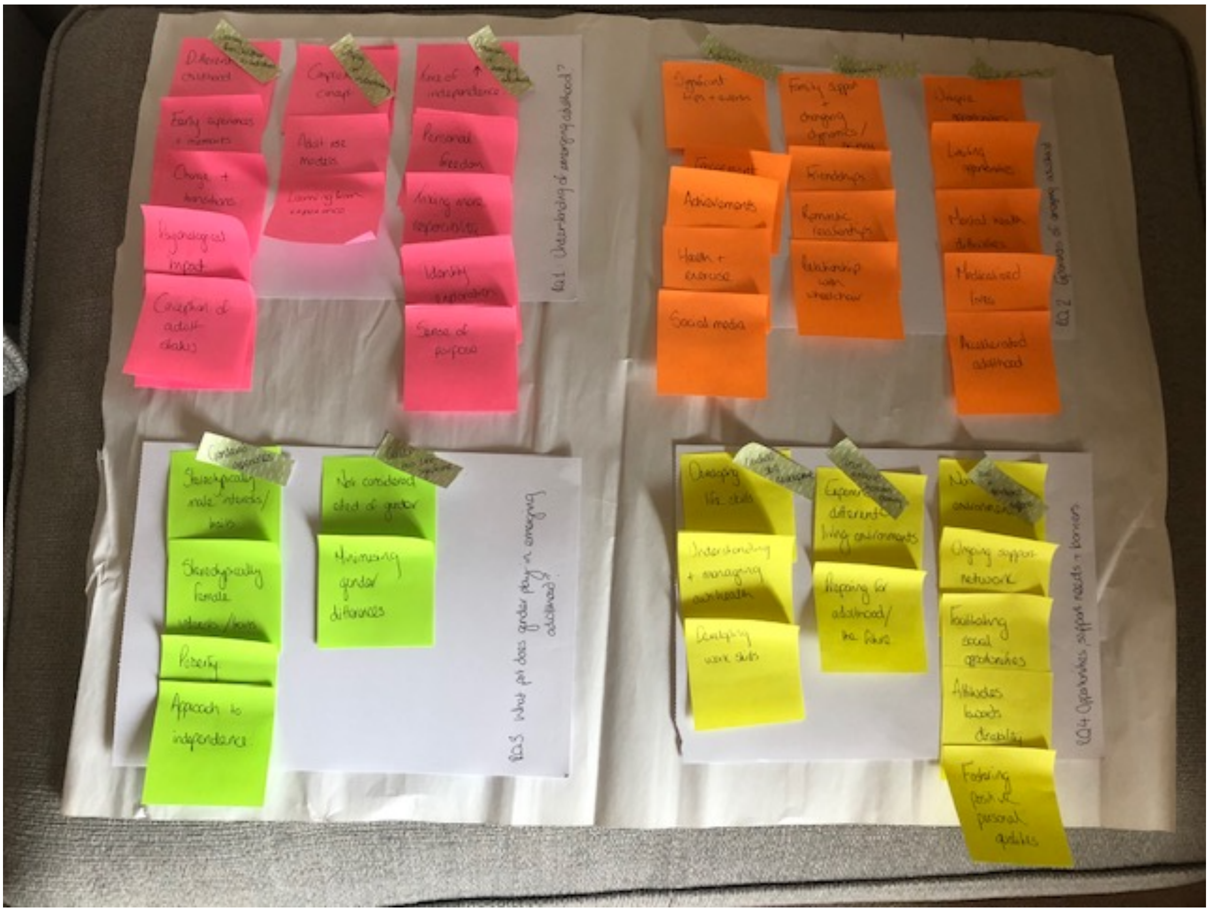
35. Int: How did you find that?

36. Zara: It was a bit complicated because they thought I wanted to stay with a student from my previous residence, but I wasn't really bothered to be honest. I wanted to stay friends with her but I was more focused on doing what I wanted to do. Sometimes I find it hard saying what I want to do, because I want to please people. And I don't want to force another person to do what I want to do, so I tend to go along with things.

Mair Hewitt-Stubbs
Female trait- accommodating

Mair Hewitt-Stubbs
Developing assertiveness

7.11. Physical representation of working themes, subthemes and codes

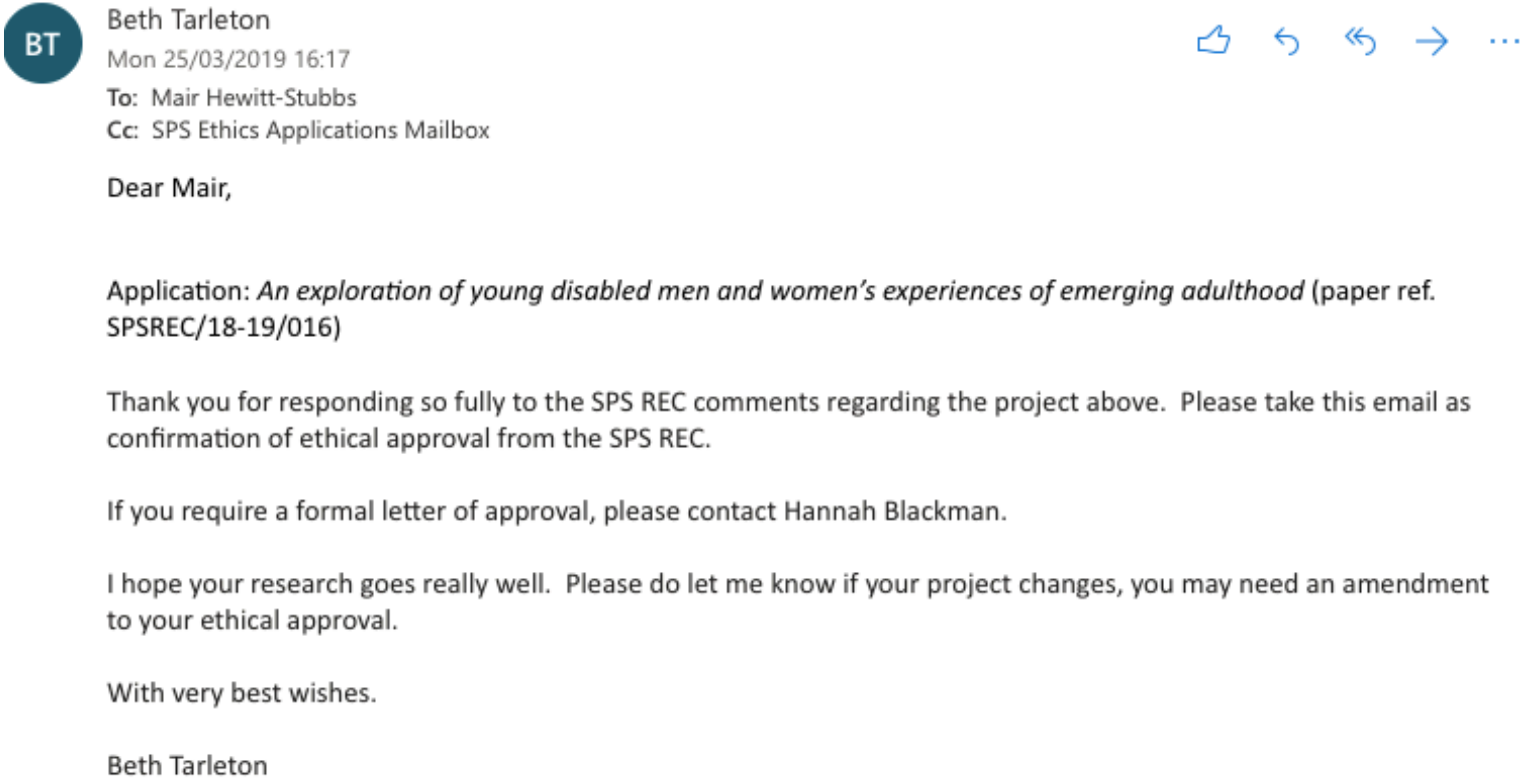


7.12. Extract of a final table of themes, subthemes and codes

RQ1. How do disabled young people understand the concept of emerging adulthood?			
Themes	**Sub-themes**	**Codes**	**Extracts from transcripts**
1. Shaping their understanding	*A complex concept*	*Still working it out* *Adult at 18*	(62) Zara: Um…to be honest, I haven't quite worked it out yet. (100)Arthur: (pause) I didn't know what an adult would be like at first. But now I kind of get the idea. (82) Jack: I'd say about 18. At 18 you are classed as an adult. (97)Int: So when do you feel like you became an adult? (98)Art: As soon as I hit 18. 74) Zara: Other than that, it didn't feel very different. I just think of it as a number and carry on…
	Adult role models	*Being open* *Being supportive* *Feelings of safety* *Good work ethic* *Helping others* *Resilience*	(78) Zara: Er…probably my parents, because they always said they wanted me to have lots of experiences and they've always been open. (115)Ellie: My Granny (116)Int: So she was important to you growing up? (117)Ellie: She always helped me when things got hard. (76) Jess: I always look up to my old school nurse to be honest. She has a laugh and joke with me. When we are together, it's like we are 10. But what it was, was how she used to care for me. It's like… "I feel safe around you".

		Experiencing pain to become stronger *Experimenting with alcohol*	me? When you're 13, you think you know better and I was like "Shut up Mum you don't know what you are saying". (18) Jess: Yeah and when I look back, it's actually made me stronger. Because it made me mature quicker than I would have done. Because of how it made me feel. (60) Jack: I guess you have to do it to see how you are going to feel and know not to do it next time, otherwise you'll never know (on drinking alcohol)!
2. Journey from childhood to adulthood	*Different to childhood*	*Different priorities* *Getting to the next stage* *Taking things more seriously*	(72) Zara: You do different things, like, you're not playing with toys! You're also more focused on getting to the next stage. (62) Zara: …you might like something different to what you did as a kid. (FG272) Zara: I would rather keep moving forward than take steps back. (94) Ellie: Adults think differently. I think more about family now. (88) Jess: I think when I had my cardiac arrests, that actually made me, like, grow up even more. I was like "This is a big change… this is serious now". Because, yeah, we all have a laugh about people when they say they've been ill. When you are young, you think it's funny, because you don't see the dangers, then when it happens to you…now it's happened, I see the serious side.
	Early experiences	*Enjoying school* *Finding school difficult*	(12) Jess: I loved it…I'd cry at home because I wanted to go back to school! It was a good school, I was there till I was 19, through primary, secondary and 6th form.

7.13. Ethical approval



Beth Tarleton
Mon 25/03/2019 16:17
To: Mair Hewitt-Stubbs
Cc: SPS Ethics Applications Mailbox

Dear Mair,

Application: *An exploration of young disabled men and women's experiences of emerging adulthood* (paper ref. SPSREC/18-19/016)

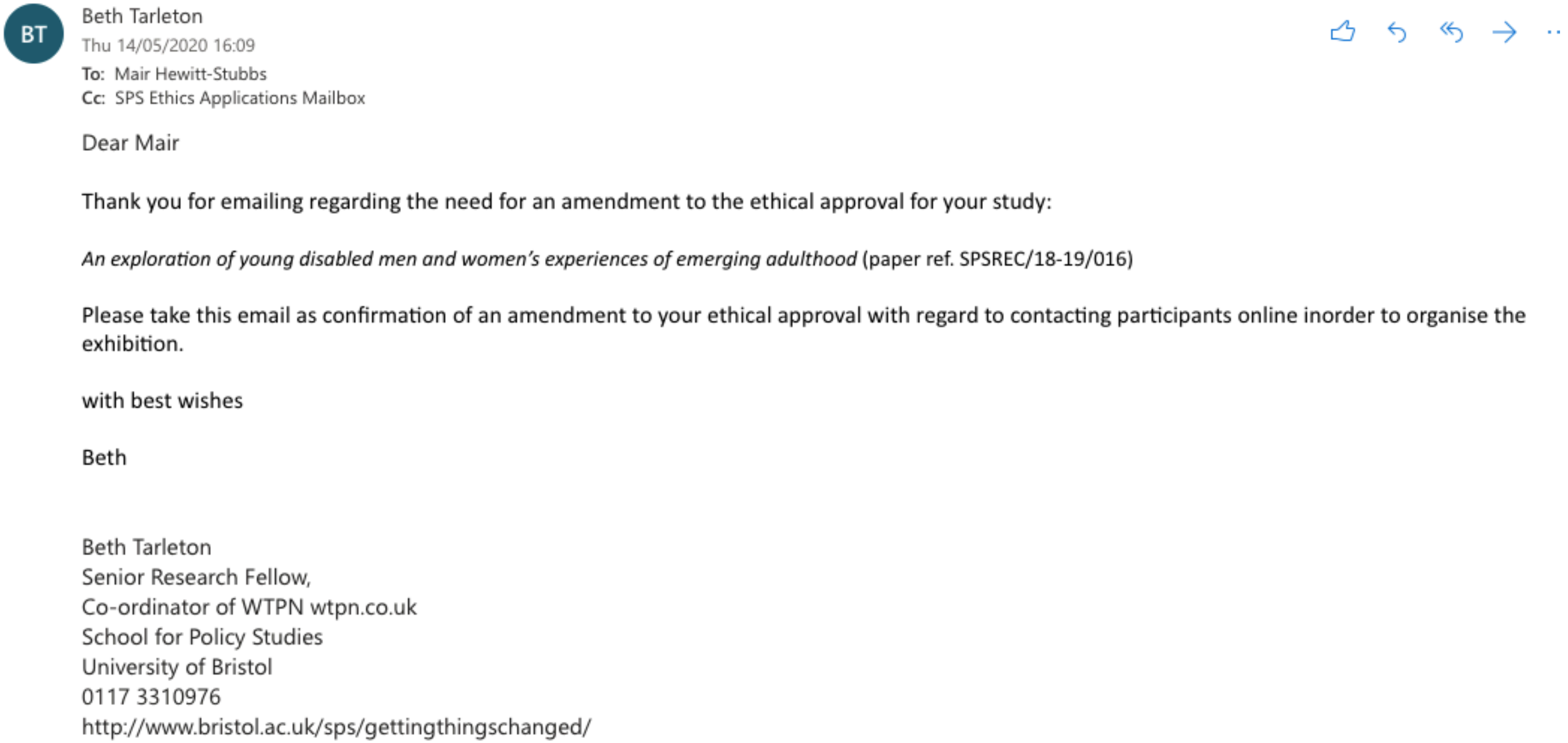
Thank you for responding so fully to the SPS REC comments regarding the project above. Please take this email as confirmation of ethical approval from the SPS REC.

If you require a formal letter of approval, please contact Hannah Blackman.

I hope your research goes really well. Please do let me know if your project changes, you may need an amendment to your ethical approval.

With very best wishes.

Beth Tarleton



Beth Tarleton
Thu 14/05/2020 16:09
To: Mair Hewitt-Stubbs
Cc: SPS Ethics Applications Mailbox

Dear Mair

Thank you for emailing regarding the need for an amendment to the ethical approval for your study:

An exploration of young disabled men and women's experiences of emerging adulthood (paper ref. SPSREC/18-19/016)

Please take this email as confirmation of an amendment to your ethical approval with regard to contacting participants online inorder to organise the exhibition.

with best wishes

Beth

Beth Tarleton
Senior Research Fellow,
Co-ordinator of WTPN wtpn.co.uk
School for Policy Studies
University of Bristol
0117 3310976
http://www.bristol.ac.uk/sps/gettingthingschanged/

7.14. ‘Stop’, ‘Break’, ‘Next’ and ‘Question’ cards

7.15. Extracts from research diary

16/06/19- Introduction session with potential participants

Within this reflection I will focus on my thoughts and feelings during the initial meeting with the young people. The aim of this meeting was to introduce myself, share the rationale and aims of the research and explain the photovoice process. I was mindful of achieving a balance of "just enough" information so that the young people were not overloaded but felt able to make an informed decision about whether they wanted to be involved. I felt it was important to make a good first impression and viewed it as a valuable early opportunity to begin developing rapport with the young people, which would hopefully facilitate the rest of the research process.

I arrived feeling fairly apprehensive. Until then, all my conversations with the gatekeeper had been via telephone and email and it was the first time I had returned to the college in my new role as 'trainee EP-researcher'. In peer supervision, we had discussed the challenges of this dual role, the importance of managing the expectations of everyone involved and being clear about boundaries from the outset. I was mindful of the additional factor of being a previous employee of the research setting and how this would influence not only my interpretations of the data, but also my decisions about how to communicate this (e.g. in a way that would not damage relationships/ reputations). I had discussed these concerns with my supervisor throughout the ethics application process and felt prepared to address them if and when they arose.

I was overwhelmed by the initial positive response from the young people. The majority seemed excited by the topic of emerging adulthood and were already sharing ideas about what they might want to take photographs of. Two young women were particularly interested in the Life Road Map and asked if they would be able to keep the drawings afterwards. I was conscious that members of staff were present and that the young people may feel pressure to agree to participate, therefore suggested that they take some time to think about it carefully before signing consent forms. One young man expressed some anxiety about the interview process and asked to speak to me privately with his key worker for support. I was pleased that he felt able to share his concerns with me at this early stage and felt this was evidence that a space of mutual respect and trust had been established. Together we discussed what measures would be taken to reduce his anxiety during the interview and focus group, which he seemed reassured by.

I left the setting feeling energised and quite impatient to get started! Unfortunately, the timing meant that I would have to wait until the young people returned to college after the summer holiday and hoped that they wouldn't forget or lose interest in the project in the meantime.

7/11/19- Second interview

Within this reflection, I will focus on my developing interview skills and the tools used. I had carried out my first interview the day before and following this, had made some changes to the schedule and my approach. For example, I felt I had been quite ‘fumbly’ when drawing the Life Road Map and had struggled to make quick decisions about what graphics to use for certain life events, therefore I created a bank of these for quick reference. There were also some questions that he had not fully understood or interpreted in the way I had expected (e.g. important life “events”) therefore I made a note to be clearer in the language I used. Finally, the previous interview had run over and there were several points where the young person had talked at length about something of interest to him which was not entirely relevant to the project. I reflected on how, this time, I could achieve a balance of listening to the participants story and giving it the space and time it deserved, whilst also getting rich data that would answer my research questions.

I noted that there was immediately a better flow to the second interview. This may have been due to my increasing confidence with setting the tone and phrasing the questions, but possibly also because we were both young women and could more easily relate about certain elements of ‘growing up’. There were several moments when she would leave things unsaid and look at me in a way that implied “I think you know what I mean…” so I would have to gently encourage her to expand and explain further (for the sake of the recording). She was extremely insightful and appeared to have thought about her experiences and how these had shaped her on quite a deep level. I found myself in awe of how positive and grateful she was, despite the time she had spent in hospital and the ongoing challenges she faced. She described herself as “lucky” several times, often when referring to her family and friends and this made me reflect on the importance of this support in terms of resilience. I noted my surprised reaction to her positivity and questioned what this meant- had I expected her to tell a tragic story and be angry/ sad/ resentful about the opportunities she had missed? What did this say about my ableist assumptions?

When transcribing this interview, I identified several comments that I could have explored further but didn’t, for one reason or another. Often, these were times where we were discussing something of a more sensitive nature (e.g. relationships, sexuality, periods) and either or both of us possibly felt uncomfortable. I reflected that, in an EP context, I frequently managed delicate conversations, however there was something about being in this new and different role as researcher that meant I found this more difficult. Perhaps it was because I was mindful of my ethical duty to protect the participant that I quickly moved on when I noticed she was embarrassed…regardless, I made a note to discuss this in my next supervision and think about how I could handle them more skilfully.

16/12/19 Photovoice focus group (young men)

Within this reflection, I will focus on the advantages and challenges of the photovoice process, as well exploring the dynamics of this group of young men when discussing their images. The other focus group had happened several weeks earlier, but due to a delay with the young men gathering their images, I had chosen to delay this one, to allow them as much time as possible. In the end, all three had required a high level of support from college staff to get their images to me and I was curious about this lack of ownership. I was mindful that I had asked a lot of participants and didn't want them to feel pressurised to complete this part of the process if they didn't want to. When we met, I began by gently enquiring about what had got in the way of them taking their photos and the general response was that they'd had other commitments and had forgotten about it. I thought about how the young women had seemed to enjoy the process, encouraged one another and shared ideas, which has not been the case with the young men. This was an interesting reflection given that I was looking at the role of gender and I wondered whether the photovoice process may work better for women than men.

I noted that there was a great rapport between the members of the group, which helped with the flow of discussion. Two lived in the same residence and shared lots of jokes and 'banter' which appeared to help the third feel more comfortable and share his views. I was mindful that he did not feel "left out" as the others had a tendency to dominate the conversation at times, however with some gently encouragement and direct questioning about his images, his voice was very strong throughout. At times, the young men had different opinions on certain topics (e.g. sport and competitiveness) and engaged in debates, which revealed more interesting views. I reflected that this was a benefit of the focus group method, as it enabled layers of meaning and opportunities to hear and take on board other perspectives.

As photovoice promotes participant's involvement in identifying themes, I asked the young men to look for patterns in the images and let me know if they noticed themes emerging. Technology was a key one which featured in the lives of all three in some way or another. One young man had a social media presence and YouTube account, which seemed to form an important part of his identity. The group got into a lengthy discussion about the difficulties of setting up an account which, although lovely to see them enjoying a shared interest, meant I had to interrupt and guide the conversation back to emerging adulthood. Having the images laid out on the table was helpful for this and seemed to provide a good visual reminder for the participants. The young men had gathered a large number of photographs between them which mean the focus group went on longer than I had anticipated, around 90 minutes. Although no one asked for a break, I recognised that one young man was getting very fatigued and losing track of the conversation regularly, so I made the decision to round it up. I was a little worried about the impact this would have on him for the rest of the day, so asked his keyworker (who had been present throughout the focus group) to ensure he was monitored and got additional bed rest if needed.