Listening to their adult voices: two narratives of lived experience beyond the formal provision for Special Educational Needs and Disability (SEND) in England.

by

Bernadette Gregory

Canterbury Christ Church University

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Abstract

This thesis delves into the experiences and perceptions of two adults with a previous designation of mild to moderate SEND (Special Educational Needs and Disability – in this case autism and dyslexia) who have transitioned to independent adulthood, where formal support ends at the age of 25. While the research does not offer generalised outcomes, it uncovers individuals' perceptions of success and the challenges that occur beyond formal support.

An interpretative methodology emphasising the development of a researcher-researched relationship provided a safe and emancipatory research space. Reflexivity was embedded as the participants revealed their stories as experts in their own lived experience, challenging professional assumptions. The conceptual framework for analysis incorporated an ecological model of engagement combined with acknowledged success criteria in SEND further education provision.

This study affirms individuals' perceived achievements while acknowledging any challenges they identified. The engaging conversations shed light on how the participants navigated systems and developed support networks and personal relationships. Their narratives included perceptions of their experiences in relation to success, self-identity, and resilience, dealing with formal authority, and engaging with employment. The research highlights potential gaps in policy concerning the needs of adults with a mild to moderate designation of difference once they move away from the provision of formal support. The narratives challenge a deficit-based, needs-focused view of SEND, where individuals affirm their agency, proactivity and creativity in choosing how to live their lives.

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Chapter 1 – Introduction

1.1 Focus and context

This thesis is a study of the experiences and perceptions of two adults who have previously been designated with a mild to moderate learning difficulty (National Association of Disability Practitioners, 2015), while in formal education. The research focused on their personal narrative, from their school years through supported further education provision to where they currently exist as adults, living independent lives. During the time spent in formal education they would have received support with their learning, linked to their designation of Special Educational Needs and Disabilities (SEND) (Department for Education and Department of Health, 2015). Similarly, the time spent in further education would have provided a curriculum that included personal skills development designed to provide a successful transition to adulthood (ASDAN, 2023), alongside the acquisition of employability skills (DfE, DoH, 2015).

I chose to enroll in the educational doctorate program and pursue this research to discover more about the reality of life from an individual's perspective. I perceived instances where those who had left formal provision struggled to connect with their community. As a researcher, I wanted to understand what the reality was like for those adults once they moved into independence, as, from my perspective, my role was to support development and aid the transition by providing the required skills. I was also aware of the challenges as I identified the disparities between the educational provision and a successful transition due to the complexities of adulthood and the potential need for further support. I became aware of individuals being unable to sustain employment, individuals who appeared isolated as the formal provision ceased to exist, and peer groups dissipated.

The study investigated the participants' perceptions of what occurred when they moved away from formal education, as their SEND designation was no longer at the forefront, once they lost access to a specialised provision of support aged 25 (DfE, DoH, 2015). The support diminishes unless individual needs become more severe, such as an additional diagnosis of a mental health condition requiring medical intervention or a safeguarding issue that could link them back into the social care system, as described within The Care Act (2014). I became interested in what happened to those with mild to moderate learning needs on leaving formal provision, having worked with such individuals within the further education sector. From an educational perspective, I was interested in whether they felt prepared to live independently and connect with the community. I also wanted to explore what support they accessed from family, friends and supportive others, as well as from state-run or charitable organisations.

The research was designed to allow the telling of stories from their life experiences from school to college and transition into adulthood, including details of the key relationships that had supported them along the way. A conversational method allowed the stories to unfold as the individuals were actively listened to (Clandinin and Connelly, 2000). These individuals might have previously been silenced by circumstances related to their difficulty or they might have intentionally camouflaged problems, as a way of obscuring any differences (Hull *et al.* 2017), due to a fear of discrimination and an inability to access a support system (Bernardin *et al.,* 2021). Nevertheless, the storytelling was approached with a positive outlook to affirm individuals' achievements, highlighting key personal attributes, relationships and aspirations that were fundamental to their daily lives. This deliberately avoided a deficit model (Kara, 2018), while still allowing issues and problems to emerge where they had raised them themselves. Participants were fully engaged in the conversations, understanding that their stories might contribute new knowledge to support other adults in similar circumstances who were also transitioning into adulthood and independent lives. The research conversations included how the individuals availed themselves of the same systems and provisions as other adults in the community, once they no longer had access to formal support. This generic access included jobseeker support, access to benefit systems and healthcare, along with informal support structures such as family and friends. The research was conducted with recognition that due to a combination of age and their milder form of SEND, they no longer had access to formal provision. This potential policy gap is explored further in the next section.

1.2. Policy gap

Within the SEND Code of Practice (DfE, DoH, 2015) it is noted that all individuals designated with SEND up to the age of 25 are eligible for support to achieve their goals, which would have been set for students with a SEND designation as part of their further education course. This would have comprised individual dimensions within a generic skills framework. The Code of Practice also reports that, “with high aspirations, and the right support, the vast majority of children and young people can go on to achieve successful long-term outcomes in adult life' (ibid, p.28). There is a discrepancy in available support post 25 years between the ongoing social care for those adults with moderate to severe challenges and the cessation of support for adults with a designation of a mild to moderate difference, carrying the assumption that the latter can successfully transition into adulthood without subsequent targeted support (DfE, DoH, 2015). Monitoring whether successful outcomes were achieved and maintained during the next stage of adulthood for those designated with mild or moderate difficulties is therefore imperative. However, the notion of ‘success’ is clearly problematic (Burt and Paysnick, 2012) and may vary according to individual and societal perceptions.

During formal education, the policy (ibid) recognises the importance of individual aspirations, stating that educational providers should work with other partners to help young people to ‘realise their ambitions’; this includes accessing higher education, where appropriate, and transitioning towards independent living and employment, while recognising the importance of individual aspirations. Overarching policy in England asserts that employability is a fundamental component of a successful transition to adulthood. This is set within the context of global recognition that supported education, access to skills development and work experience provides the opportunities to develop the tools required for a suitable quality of life (World

Health Organization, 2015). The World Health Organization (2015) describes this quality of life in the Global Disability Action Plan (WHO, 2014 - 2021) as the development of appropriate living standards, goal achievement, and the achievement of expectations (Rahman, *et al.* 2022). However, a potential gap appears as adults move beyond 25 years and out of formal education. Although they have been privy to skills development, work experience and supportive employment opportunities at college, they now exist in adulthood without these structures in place. This thesis explores life experiences from the adult's perspective related to their social experiences, relationships and connections with the community and considers whether there is evidence to support such a gap in provision.

1.3. Research process

I hoped to gain insights into whether this study’s participants felt confident and well supported, or whether there were occasions when they required additional support. I sought to discover whether their time spent in education had prepared them adequately for adult life. Finally, I was particularly interested in social integration and their connections with the community; I wanted to discover more about their personal aspirations from their own perspective, while acknowledging that personal preference and lifestyle choice should also be considered. In order to understand more about these adults and their life experiences, I undertook a narrative enquiry with two such adults, exploring their accounts of their education and their perceptions of their lives to date.

While individual life choices and preferences are an essential dimension of conducting a narrative enquiry, I also needed to be sensitive to the kinds of issues and needs that might arise. Adults with a difference, including learning difficulties such as dyslexia and Autistic Spectrum Condition (ASC), can experience aspects of mental illness at a higher rate; some studies note that this could be up to double that of the general population (Hughes-McCormack *et al.,* 2017). From discussions with some of my previous further education students, I have discovered how individuals can feel isolated (Malkani, 2021), particularly as they transition into adulthood. Connecting with others is essential as people can live in our communities without being integrated (Gilmore and Cuskelly, 2014), and financial hardship can further isolate individuals (Cross, 2013). The concept of social inclusion is vital to all our wellbeing (Abdul Kadir and Mohd, 2021), and this research investigated where the links with others existed and how adults with SEND engaged with their community (Malkani, 2021). I realised that if I built up trustful relationships for research, I would need to tread carefully and consider the longer-term implications as the research relationship came to an end.

I was interested in discovering more about social experiences and to what extent a support network might exist for adults with a mild or moderate SEND diagnosis outside of the formal support structures. I had previously found that provision of a 'local offer', which is designed to meet an individual's developmental needs, as mentioned within the SEND Code of Practice (DfE, DoH, 2015) might not always reflect what is readily available within the local community (Gregory, 2017; Matthews *et al.* 2023) for adults up to 25 years. Despite the inference of Government legislation that describes collaboration between services (DfE, DoH, 2015), a dichotomy appears to exist between the provision of formal courses in further education and ongoing access to community organisations and other local provisions beyond formal provision. This makes the reality of available support for those adults with a mild or moderate diagnosis of SEND complex and inconsistent (Malkani, 2021). Both policy (DfE, DoH, 2015) and research (Carroll, 2015; Abdul Kadir and Mohd, 2021) mention skills development and support as a method of facilitating a connection and contribution to society. However, if an adult has a diagnosis of a mild or moderate SEND, they might be unable to source additional support once they leave the formal provision, even if it is available within the general population.

1.4. Research questions

The following main question and sub-questions therefore guided the research:

> *What can we learn about the lives and experiences of independent adults who have previously been designated with mild/moderate*

Special Educational Needs and Disabilities (SEND) from their personal narratives?

1.4.1 Sub-questions

1. *How do the individuals perceive their social experiences, relationships and connections with the community?*
2. *How well do they feel they were prepared for independent adult life beyond the formal provision, which ends at age 25 and what are the implications for both education and social care?*

My interest in these questions arose from my own personal and professional background, including previous research, which is explained in the next section.

1.5 The researcher's professional experience

I began my career working with young people who had been excluded from school and college for Kent County Council in the 1990s. At that time, the emphasis was on personal development and engaging with the skills related to emotional well-being, self-esteem and goal-setting to reengage with formal educational settings. I then moved into a further education college, where I delivered supported education to students with SEND who had left school and were focused on the transition to adulthood. The supported course was known as 'Into Work' and in my role, I focused on personal skills development, with the goal of either a transition into a mainstream course, or gainful employment. I worked at the further education college for many years; I became a course leader and then a cross-curriculum manager for literacy and numeracy, maintaining a link with young adults with SEND transitioning to mainstream activities and independent living.

In my professional capacity working alongside young adults with SEND, I observed instances when the course ended, and they were expected to transition onto another course or employment. Individuals seemed to become lost as their support system faded away. This led to my interest in finding out how effective the curriculum was in preparing students for an independent future - particularly related to personal skills development and employment or volunteering opportunities - and what, if any, support strategies they might require in the future. I have spoken to a few ex-students over the years; some have told me that they lost their jobs after leaving college; while others have spoken of isolation once they moved away from the support of the college and the associated friendship with their peers.

After leaving the college in 2003, I worked as a manager for a charity that provided training and courses in “Family Learning” within the London Local Education Authorities. The school curriculum was mapped to the adult literacy and numeracy curriculum so that parents engaging in the Family Learning courses could enhance their skills, to transition back into adult education or employment options (Wainwright and Marandet, 2017). The cohorts of parents of current students frequently included individuals who had originally been supported through their school years but were no longer within that system of support and felt isolated. The underlying purpose of family learning was to enhance the parents' literacy and numeracy skills, supporting them to re-engage with learning and maybe consider their progression into other aspects of Adult Education and Training.

After a fulfilling period with the family learning charity, I emigrated to Australia and ran a community literacy and numeracy project with adults in a similar situation. These adults were having mild to moderate difficulties and had left school or college appearing to be somewhat lost and requiring additional support to be able to manage in their daily lives. They attended our education centre for coaching and mentoring for employment, financial advice, literacy and numeracy support and assistance with workplace training and other paperwork. On my return to the United Kingdom, 10 years later, I commenced a role as a Family Learning Lecturer for the local authority, working in areas of social deprivation. The same circumstances were revealed once again, where adults who had left formal education still required support to manage their adult lives. Currently, I am working with students in higher education who have a designated difference that fits with the criteria of the Disabled Students’ Allowance of a ‘mental health problem, long-term illness or any other disability’ (Student Finance England, 2023). I frequently meet students who have been ‘masking’ their disability (Bernardin *et al.,* 2021; Cook *et al.,* 2024) in work and at college or university, and I have become interested in the balance between needing and seeking support, while risking becoming marginalised, by calling attention to their ‘difference’. This issue has thus caught my attention throughout my 20-plus years in various roles in this sector. For this study, I was particularly interested in how this would be experienced as an adult with disabilities that could lie hidden due to the mild to moderate nature of their diagnosed difference.

1.6 Previous research

I had previously carried out a case study on a local community organisation that caters for adults with moderate to severe disabilities for my Master’s dissertation (Gregory, 2017). The community organisation in the case study has both independent clients and those living in supported accommodation coming into the centre for courses. The case study found that people with moderate to severe difficulties required support to engage socially and within the community. However, these clients relied heavily on organisational connections and relationships. I wondered what would happen to people who were not eligible for such provision because of the mildness of their difficulties, and whether they could still make such connections and relationships beyond the support provided by their families.

In order to explore my questions and concerns, I needed to select adults who had attended a supported further education course, who were now living independently and would be willing to share their stories, perceptions and experiences. The community organisation in the aforementioned case study (Gregory, 2017) suggested two adults for this doctoral study who were willing to be involved in the research and met the research criteria. It is a challenge to access vulnerable participants, so when the opportunity arose to work with participants who were part of an organisation that provided an infrastructure and a safeguarding aspect required as part of the ethical considerations, that opportunity was taken. If insufficient data had emerged, ethical approval provided the scope to extend the number of participants. However, this was unnecessary as ample data led to a rich analysis from which valuable insights could be gained.

The smaller number of narratives developed a suitable research relationship to maintain trust (Ely *et al.,* 1991), although this was not sampling to generalise statistically by choosing two participants. The transcripts amounted to over twenty thousand words per person, providing the opportunity to get to know the participants in detail, which, with more participants, would have led to a more superficial analysis. The detailed narrative revealed insights, but these are not claimed to be the experiences of all adults with mild to moderate difficulties, they are elements of truth in the manner of a fuzzy generalisation (Bassey, 2001).

I reflected on both my own experience of working with adults and that of other specialists in the field (Goodson, 2013; McConkey *et al.,* 2009; Kara *et al.,* 2021) to try and understand their individual needs fully from a methodological point of view. I decided that a conversational approach would be the most suitable method, aiming to flatten the hierarchical structure. Although I was not in a position of power in their world, I was aware it could become an issue as they knew I was a teacher and a lecturer. Therefore, I endeavoured to reduce the influence of a perceived hierarchy of prior knowledge (Goodson, 2013) to allow them the freedom to talk about their life experiences, including the time spent in education and beyond. This thesis explores what was learnt from their accounts of their lives and the implications for education and social care arising from this evidence and analysis.

1.7 The structure of the thesis

The research considers the adults’ social experiences and relationships with others and how they could connect with their local community, through the analysis of the transcripts of a series of face-to-face discussions conducted over six months. The research captured essential life experiences related to the research question as isolated snapshots as the individual recalled aspects of their life during their school years, experiences in further education, family support and influences, friendships, social interests, work relationships and romantic relationships established in adulthood. This gradually connected into an overall account of their perceptions of their lives and experiences. This introductory chapter has explained the study's background, aims and purpose.

The theoretical frameworks and socio-political context are explored as the basis for critical discussion within Chapter Two, by investigating what the government policies and guidelines are, relevant to those with a designation of SEND. This is done, alongside an investigation into how the theory of disability and the provision offered through formal education, prepares individuals for independence and the goal of employment. There is also a review of how a community-based approach could assist in developing an appropriate conceptual framework to allow a detailed interpretation of the personal narratives provided.

Chapter Three justifies the methodology and positioning of the study and considers the most appropriate method of inquiry when working with adults previously designated with SEND. Careful consideration had to be made of the approach, location of data collation meetings and frequency, alongside the format of those meetings and the need for constant reflection on the process, to ensure ethical consideration and to limit any influential power dynamics. In this research a qualitative interpretivist approach recognises that narratives of life experiences, including transition, are socially constructed and subjective, rather than objectively measurable. Ontologically, this acknowledges that individuals interpret their experiences in unique and context-dependent ways, making qualitative methods appropriate for capturing the richness and complexity of these narratives. The qualitative methodology needed to support an exploration of the participants’ perspectives through their voices within a relational environment (Van Manen, 2015) to encourage a rich and deep conversation (Clandinin and Connelly, 2000). The research questions focused on the participants’ perception of their social and relational journey into adulthood, including the broader connections outside of their immediate family. The perception of how an individual manages the movement between systems and the types of skills they utilise provided an insight into the types of skills required when navigating their daily lives, and how they interact with systems and structures within the community. As adults transition into the overarching macrosystem where they exist as adults with their own values and beliefs, it is important to recognise the importance of their aspirations and desires. The journey through formal education into adulthood imposes external norms and criteria like personal skills, which are inevitably value-laden. This study discovers the extent to which an individual feels prepared for adulthood and also the implications for both education and social care by using a combined framework to capture the ecological systems that an individual moves between (Bronfenbrenner, 1979) and the personal development skills that ultimately feed into the 5 C's of Positive Youth Development (Lerner, 2009); this is a framework which indicates five strengths that support youth to transition to adulthood (additional information on the 5 C's appears in Chapter Two – section 2.19). The 5 C's are; competence, confidence, character, connection, and caring (ibid). They are used alongside the ecological systems (Bronfenbrenner, 1979) as a combined lens to structure the analysis (Appendix 5). Chapter Three unveils the themes that emerge from the analysis. Chapter Four and Five reveals aspects of the life stories and any implications concerning policy or practice. Chapter Six discusses the revelations and the unique contribution the research has made to knowledge about the lives of adults with a mild to moderate diagnosis of SEND, in relation to the research questions stated in Section 1.4.

Implications for education and social care provision are considered in the light of current policy. The unique approach to the research raises considerations regarding aspects of the process that could be used in future research with adults diagnosed with SEND.

1.8 Summary

This introductory chapter has set out the focus, aims and broad methodological approach to the study, and has outlined the experience and professional positioning that has led to the research questions. This thesis intends to reveal insights into the reality of everyday life as perceived by an independent adult, with a previous mild to moderate designation of SEND.

Once an adult leaves school and college, they can access support through existing agencies, but the impetus to do so relies on a perceived need for support and an ability to access it. The Government SEND policy (DfE, DoH, 2015) describes how, with the proper support, young people can achieve successful long-term outcomes in adult life (ibid, 2015). This narrative inquiry reveals how the adults themselves perceive their lives and experiences and gives an opportunity for their own voices to be heard. Formal education structures anticipated a framework of skills required for a successful transition; through the narrative inquiry, the data collated reveals the reality of their lives and aspirations, exploring both positive experiences and any needs and concerns.

Chapter Two - Literature Review

2.1 Introduction

In this literature review I considered critically three aspects of the literature that relate directly to this thesis. Firstly, the relevant policy environment and any impact on the interrelationships between disability, social care and education. These overarching government policies set the context that the research sits within where the participants' narrative explores their journey, through school, into further education, and then as an individual transition into adulthood.

Secondly, I investigated the theory and research that includes an exploration of the key concepts of disability, ability, inclusion, SEND and social care, relevant to children and young people with a mild to moderate designation of Special Educational Needs and Disability (SEND) through school, into further education and beyond the age of 25 years. This section reviewed the deficit model of disability related to the discourse included within policy, and also critically evaluated the various models of inclusion.

Lastly, a conceptual framework is introduced that offers an ecological community-based model for structuring the narratives. The conceptual framework enabled a critical evaluation of how government policy and associated inclusive practice in education has prepared the two participants in this study for adulthood. The interpretation of their experiences enabled questions to be raised as issues were explored within their narratives.

The original research questions were developed from my experiences as a practitioner, specifically supporting those diagnosed with SEND in further education. The literature explores the extent that skills acquisition underpins the transition to adulthood (DfE, DoH, 2015) and notes the importance of a goal of community integration and citizenship (Abdul Kadir and Mohd, 2021), to enhance inclusion (Morisse *et al.,* 2013; Gilmore *et al.,* 2014; Rahman *et al.,* 2022). The literature influenced the research in seeking an insight into what is deemed to be a successful transition post 25, by including the ecological systems to include an analysis of movement within the broader community.

The overarching research question seeks to discover:

What can we learn about the lives and experiences of independent adults who have previously been designated with a mild/moderate SEND from their personal experiences.

An evaluation of policy clarified the formal support expectations, and the sub-questions became nuanced to extend the research into the narrative of adulthood experiences and how an individual could negotiate the all-important integration into the broader community (Morisse *et al.* 2013; Abdul Kadir and Mohd, 2021). The need for a person-centred approach through the impact on mental wellbeing (Office of National Statistics, 2021) reinforces the need to investigate the fundamental ability to maintain a connection with others as perceived by adults with a diagnosis of SEND.

Sub questions:

How do individuals perceive their social experiences, relationships and connections with the community?

How well do they feel they were prepared for independent adult life beyond the formal provision, which ends at age 25 and what were the implications for both education and social care?

2.2 Policy

Within the field of SEND, there exists legislation that outlines the legal requirements. For instance, when investigating issues pertaining to mild or moderate difficulty, the Equality Act (2010), the Children' and Families Act (2014) and the SEND Regulations (2014) are all relevant to an individual's supported journey through education into adulthood. The SEND Code of

Practice (2015) provides guidance and legal advice on implementing the processes outlined in the legislation as mentioned above. In this section, I will outline the key points of the legislation and reference the relevant detail included within the SEND Code of Practice that has been in place during the educational journey of those with mild to moderate learning difficulties, paying attention to how support eases the transition into adulthood post 25 years.

Additionally, the Mental Health Capacity Act Code of Practice (2005) is a relevant piece of legislation, which is more applicable to the severe to profound range of SEND difficulties, although in certain circumstances any individual might require support related to informed decision-making and a potential lack of capacity to do so independently. The Mental Health Capacity Act Code of Practice (ibid) provides the legal stance for anyone who requires support from another person to make decisions. This act (ibid) includes criteria for assessing mental capacity by identifying an individual's ability to ‘communicate a choice, understand, appreciate, and rationalise with independent reasoning’ (ibid, p.20). Each piece of relevant legislation has something to contribute to the support and well-being of an individual with a diagnosis of SEND with the fundamental principles of inclusivity documented within the Equality Act (2010), and these will be explored in more detail in this chapter.

In order to be able to understand more about the target group of individuals with a mild to moderate designation of difference, the definition of difference needs to be explored. The SEND Code of Practice (ibid, p.15-16) states as follows:

‘A child or young person has SEND if they have a learning difficulty or disability which calls for special educational provision to be made for him or her’.

A more specific definition of moderate or mild difficulties, used in this research, although without specific medical labeling, is defined by the National Association of Disability Practitioners (2015) as being:

'Moderate – People with a moderate learning disability will likely have some language skills to communicate their daily needs and wishes. People may need some support with caring for themselves, but many can carry out day-to-day tasks without help.

Mild – A person who is said to have a mild learning disability can usually hold a conversation and communicate most of their needs and wishes. They may need some support to understand abstract or complex ideas. People are often independent in caring for themselves and managing everyday tasks' (ibid, p.7).

The definition of SEND for both mild and moderate differences also incorporates specific neurological and neurodevelopmental conditions that might impact learning. Those that can be associated with a mild to moderate difference are a diagnosis such as dyslexia, dysgraphia, dyscalculia and attention deficit hyperactivity disorder (ADHD), all of which can impact literacy, numeracy and some aspects of organisational skills, predominantly diagnosed and supported during the time spent in formal education (Westwood, 2017).

Another way to define differences can be to encapsulate the many types of mild to moderate differences under the category of neurodiversity. If an individual is identified as having differences regarding their neurological make-up (Fletcher-Watson, 2022), then those variations can be seen as neurotypes, with the most common being neurotypical. A designation of a mild to moderate difference sits outside the neurotypical group; in this study those differences are at the forefront of educational and social care support needs up to 25 years, after which an individual should have attained the required skills to transition into independence, according to the legislation (DfE, DoH, 2015). However, the differences still exist alongside their strengths, so although an individual is categorised outside of what is deemed to be neurotypical, they are also equally as normal (ibid) and any discriminatory practice would be upheld by the Equality Act (2010) throughout the life cycle.

2.3 SEND in schools and further education.

The key descriptors of SEND previously acknowledged refer to children and young people (DfE, DoH, 2015), as an individual moves into independence and further or higher education; if their designation of difference is mild to moderate (NADP, 2015) they could transition from formal education with limited or no additional support provision (ibid). A designation of difference under the umbrella of SEND refers directly to an individual's ability to learn, in comparison with their peers, requiring a special education provision. An individual might also have a disability which hinders them from accessing the facilities the same way as their peers; both a learning difficulty and a disability would, therefore, exist under the umbrella term of SEND (DfE, DoH, 2015).

The Department for Education's four broad areas of SEND in England are: communication and interaction; cognition and learning; social, emotional, and mental health activities; and sensory and physical needs. A mild to moderate designation of SEND at school would usually refer to a specific learning disability - for example, dyslexia, which impacts an individual's literacy skills; dysgraphia, which can affect writing; or dyscalculia, which impacts mathematics. It could also include attention deficit hyperactivity disorder (ADHD), where it is considered that some supportive accommodations would enable that individual to be able to learn in the same way as their peers. Autism can also come under the umbrella of a mild to moderate designation, where the symptoms allow the individual to manage in their daily life, although they might still experience challenges with social interaction, stimulation of the senses and processing difficulties and have an inability to manage unplanned change (DfE, DoH, 2021). The scale of need for an individual who has a mild or moderate designation would depend on what is being asked of them, linked to the severity of their designation; it is anticipated that a moderate designation would probably require additional day-to-day support, and that their needs remain even after receiving a level of support.

The participants in this thesis have a range of needs; both have autism and dyslexia. The designation of difference, whether it is linked to a learning difficulty or disability, has a similar outcome regarding the barriers to learning. For example, a designation of autism can affect learning through impairments in social skills, understanding, and the ability to respond to social cues, making learning a challenge similar to a learning difficulty.

Once an individual moves into a post-16 provision, a more common overarching terminology is used - Learning Difficulties and Disabilities (LDD) - in the same way that SEND is used within the Code of Practice (2015). In this thesis, I use the term SEND to incorporate all individuals formally designated with a difference, as the challenges that occur refer in the first instance to their educational needs (ibid). As an individual leaves formal education, their difference remains under the umbrella of the Equality Act (2010), where it is stated that physical or mental impairment which has a long-term and substantial adverse effect on their ability to carry out normal day-to-day activities (ibid) requires a level of accommodation. The continuity of provision moves into adult services for those with an Education and Health Care Plan (EHCP) up to the age of 25, including an annual review. The local authorities are also obliged (Care Act, 2014) to continue with a level of support until the individual no longer requires care and support, as they can meet their own needs. As an individual transitions towards adulthood, their curriculum adapts to include more of a focus on what applies to achieving a positive outcome in adulthood (DfE, DoH, 2015). Therefore, a further education institution would offer qualifications and enrichment activities to develop the skills required for independent living, alongside work experience, to prepare an adult for employment (ASDAN, 2023). In some instances, an individual might progress to higher education, where the same designation that facilitated support at school and college would also be used as evidence to obtain the Disabled Students Allowance (DSA) through the provision of relevant hardware, software and additional support provision, known as ‘reasonable adjustments’, which are provided by the institution under the Equality Act (2010).

2.3.1 Equality Act (2010)

The Equality Act (2010) prohibits discrimination across a range of protected characteristics throughout everyone's life journey from the cradle to the grave, including; age, disability, gender, marriage, pregnancy and maternity, race, religion, sex and sexual orientation'. The Equality Act (2010) includes disability and a special educational need concerning a practice or policy that might be discriminatory, alongside issues associated with harassment or victimisation. The Equality Act (2010) uses the term ‘reasonable adjustments’, which appears in education, to ensure that all students have access to the facilities and services on offer, e.g. concessions when taking examinations such as additional time, the ability to leave a classroom for some quiet time, access to pastoral care and other individualised allowances that are relevant to an individuals needs. In adulthood, the concept of ‘reasonable adjustments’ moves into other services and employment, supporting those who are deemed to have a ‘protected characteristic’ or difference. Equality and non-discriminatory practices are legally binding (2010) and form the basis of accessibility to public spaces. The promotion of equal opportunities regarding diversity within both education and employment and other settings address any inequalities and limits the negative impact related to any of the protected characteristics. As an adult moves out of education and into mainstream society, the Equality Act (2010) creates a more inclusive environment that is reflected within the policies of agencies, businesses and institutions outside of an educational setting.

2.3.2 Children and Families Act (2014)

As expected by the title of this act, it covers provisions associated with mediation between parents, young people and local authorities regarding the provision of education, health and care. It also covers adoption and children in a care provision to ensure that a child's welfare and long-term stability are considered, with their needs at the forefront of the process. The Children and Families Act (2014) also covers the reforms to child protection with an emphasis on early intervention and support for the family, again maintaining the child’s best interests at the centre of the process. This act (ibid) also recognises the role of young carers, parental leave and flexible working to all employees to ensure the broader well-being of the family unit. Social work and social care are also covered under this act about the professional standards of social workers alongside the provision of childcare for eligible families. With regards to SEND, the introduction of Education and Health Care

Plans (EHCP), also outlined in this legislation (ibid), replaced the previous ‘Statement of Special Educational Needs’ to extend the support provision from birth up to the age of 25, to support a multi-agency approach and to provide a smoother transition into adulthood. The Children and Families Act (2014) provides improvements for children and young people related to the areas of child welfare, education and family justice across all services. The provision of an EHCP captures the broader support needs, including the opportunity for input from both the child and their family through evaluation and negotiation.

2.3.3 Education and Health Care Plans (EHCPs)

The Department for Education in their green paper on ‘Special Educational Needs and Disability (2012) stated that a 'radical overhaul' was required. According to Norwich (2014), this update was not particularly radical but rather a tightening of existing practices. The more radical aspects were about the model becoming 'user-led’ (ibid) with joint planning and commissioning of the required services. The changes were structured into the Education and Health Care Plan (EHCP) process documented within Part Three of the Children and Families Act (2014), as those with existing statements of SEN transitioned to the new system as part of the Local Transition Plan. The changes included were an extension in the age range from 0-25 years and also that SEN support would be extended to both colleges and sixth forms, and the assessment and issuing process for an EHCP would reduce to 20 weeks from 24 weeks. The importance of including the 'local offer' was also required for children and young people across the education, health and social care sectors. The Children and Families Act (2014) required a cultural shift regarding SEND, as the Special Educational Needs Coordinator (SENCo) became responsible for the strategic aspects within a school, as a key implementer of the new reforms (Curran *et al.,* 2021).

The introduction of EHCPs and the need for an extension to inter-agency collaboration came at a time of austerity in the United Kingdom, where people were being expected to 'do more for less' and the introduction of new systems impacted the teacher's workload (Pearson *et al.,* 2015; Done and Andrews, 2019). Therefore, this focus on freedom of choice was somewhat contradictory to the reality of the economics of the time (Lehane, 2017). There was also a need for a SENCo to be recognised as pivotal, to ensure that a setting could provide best practices (Curran *et al.,* 2021) within their SEND provision. However, historically the role of the SENCo was more varied and the status was not as a key policy implementer (ibid) at the heart of the SEND school process.

As government policies are gradually updated, the evidence of an improvement in provision is not always substantiated by research. The complexity of obtaining a diagnosis and an EHCP led to a 2.5% decrease in those recognised as having a special educational need, alongside fewer EHCPs being issued (Broach *et al.,* 2016). Ultimately, the SEND Code of Practice (DfE, DoH, 2015) is arguably moving in the right direction, albeit slowly, by allowing children and young people to be involved in their plans and transition pathways, which gives additional weight to the decisions being made (Gaona *et al.,* 2020). The EHCP is designed so an individual can share their viewpoint. In some instances, research states that this was not the case and that they also felt that their views were not listened to (Crane *et al.*, 2022). Incidences were reported where the individuals felt their families were the instigators of sourcing the required support, not the educational establishment or the local authority. A late diagnosis was also found to lack support through the EHCP process (ibid).

Within a mainstream setting, individuals with SEND have an Education and Health Care Plan (EHCP) to support their needs while in education, unless the family or significant others suggest otherwise (DfE, DoH, 2015). In some instances, those with a designation of SEND might not have an EHCP due to a lack of a medical diagnosis limiting their access to support from the required agencies. Not all individuals with special educational needs have a disability, and not all of those with a disability have a special educational need, but there can be instances when both are evident, and all the differences are supported by government legislation (Equality Act, 2010; Children and Families Act, 2014). There are many aspects to the successful implementation of an EHCP. The time spent in education by this study's participants will provide an insight into their perception of the systems and access to support during both school and college.

A recent review by Ofsted (2021) noted that even with an EHCP, there were issues with the process of support and the delivery of appropriate education; the report indicated that there were also children with poor literacy skills being wrongly labelled with a learning difficulty. The subtleties of a diagnosis in the mild to moderate areas depends on what challenges the individual is facing and what level of support they have available from their friends and family. For those without a diagnosis, the support available in education and through the social care system has previously been noted as minimal, depending on the available local provision (DfE, DoH, 2015). Parental support and advocacy are elements of transition that are not well documented in government policy. However, they are acknowledged, and at times this was documented as the most reliable type of support during the transition (Essex and Melham, 2019; Gaona *et al.,* 2020; Crane *et al.,* 2022).

Once an adult reaches the age of 25, the EHCP is no longer available; if a severe difficulty remains, an individual could continue with social care and move into adult services. In contrast, if the designation is mild to moderate and they are no longer in full-time education, or in receipt of any additional support through the social care system, the support ceases to exist. In that case, an individual is expected to integrate back into a mainstream existence, where their designation of SEND becomes an historical label that loses its significance. Once they leave education at or before 25 years old, they have completed the education and training available and, therefore, should be able to transition effectively into adulthood. In this study, I investigate these people's perceptions of support and preparation for adulthood and what life was like once these formal structures ceased to exist.

2.3.4 SEND Regulations (2014)

The SEND Regulations (2014) and the SEND Code of Practice (2015) in England relate to support for SEND, but they are different to one another. The SEND Regulations (2014) outline the legal requirements related to supporting children and young people with a SEND designation and the legal process for creating and maintaining an EHCP. They also mentions the same outcomes as the SEND Code of Practice for young people transitioning into adulthood in relation to employment, independent living and community participation (ibid, 2015). The regulations outline the legal framework to ensure that children and young people with SEND receive the required accommodations. The key points covered within the SEND regulations are the definition of 'special educational needs and disability, identification and assessment, the obligations of the local authorities to assess and plan towards providing the required support, the process of creating and maintaining an EHCP and transition planning' (ibid p.13 -14). Since the SEND Regulations (2014) set out the legal requirements, the SEND Code of Practice takes those requirements and offers guidance on implementing the regulations effectively.

2.3.5 SEND Code of Practice (2015)

The SEND Code of Practice (DfE, DoH, 2015) is the overarching guidance document related to the research focus of the journey through education into adulthood for individuals with a mild to moderate designation of difference, focusing on their educational needs up to the age of 25. Within the SEND Code of Practice (ibid), the Equality Act (2010) is referred to as defining the broader terms of difference, as in a 'physical or mental impairment, which has a long-term and substantial adverse effect on an individuals ability to carry out normal day-to-day activities' (DfE, DoH, p.16). Also, the criteria for SEND are defined as a long-term physical or mental impairment that would be experienced for at least a year and should be 'ongoing', with an expectation that the 'symptoms are not expected to improve or change' in that timeframe (ibid). There can also be an overlap between a health condition, such as diabetes or epilepsy, and a special educational need. All relevant conditions would need to meet the criteria previously noted (ibid). The designation of a learning difficulty or disability described in legislation always requires a specialist diagnosis to define the specific difficulties and support requirements.

How the legislation relates to a designation of SEND requires interpretation to define the key points, and then the SEND Code of Practice (DfE, DoH, 2015) sets out the guidelines in the format of practical advice. The remit of the SEND Code of Practice (ibid) is to include the identification, assessment and support for those designated with SEND through the provision of an Education and Health Care Plan (EHCP), alongside the process of collaboration that brings together the young person and the agencies that provide the education, health and social care needs. The SEND Code of Practice (ibid) also outlines the roles and responsibilities of Special Educational Needs Coordinators in schools, aforementioned. The collaborative style of the EHCP is designed to facilitate the most appropriate decision-making process, to provide the most appropriate inclusive setting, based on discussions with all of the relevant parties. It is with regard to the transition phase into adulthood where the SEND Code of Practice (ibid) highlights the crucial steps on the way to adulthood, including preparation for ‘employment, independent living and community participation’ (ibid, p.138) with a reliance on an appropriate curriculum and availability of support through the ‘local offer’ (ibid; Matthews *et al.,* 2023). This area of provision is relevant to the part of the research question that seeks to understand more about social experiences, relationships and a connection within their community and whether access to the outlined support exists as an accessible reality.

2.4 Local offer

Local government provide support and guidance through the dissemination of the SEND Code of Practice (DfE, DoH, 2015) and the expectation that there should be a provision within the ‘local offer’ (ibid). Local authorities like Kent County Council have developed their own local guidelines, such as the Preparation for Adulthood (Kent County Council, 2020) document; this analyses how time spent in schools can support a positive transition into adulthood by identifying taught sessions and learning opportunities across the outlying principles of employability, independent living and participation in society (DfE, DoH, 2015), by placing a local emphasis on the provision and opportunities within the 'local offer'. The Preparation for Adulthood (Kent County Council, 2020) takes the overarching principles and unpacks these into the learning criteria required for a successful transition. The outcomes specify that 'vocational work placements should ensure that activities prepare the young person for healthy, independent living that supports building relationships and engagement in the community' (ibid, p.8) and also that 'Educational settings, schools and colleges should ensure courses enable progression to a qualification or work placement that is meaningful to the student without repeating learning already completed' (ibid, p.8). The Preparation for Adulthood (ibid) document also signposts interested parties to additional provisions available within the area, including an accompanying Preparation for Employment programme available in Kent, accessed through a website that includes information on employability and vocational profiles that can be used when looking at transition steps, to be included within the EHCP (DfE, DoH, 2015). The SEND Code of Practice (ibid) addresses the needs of individuals from 0-25 years and disseminates the expectations of a relevant support provision to the local authorities regarding the education and health care needs of an individual. All of this is covered by the overarching legislation noted previously, which brings together the core principles of inclusion.

2.5 Common ground

The Equality Act (2010), Children and Families Act (2014) and SEND Regulations (2014) work together to provide an environment of inclusion and relevant support for those children and young people with SEND by sharing the idea that all children should have access to the required support and educational opportunities that best suit their individual needs. Since the Equality Act (2010) supports non-discriminatory practice, which is appropriate to SEND, and through the provision of an EHCP and the practical advice and guidance available in the SEND Code of Practice (DfE, DoH, 2015), the required support, negotiated collaboratively, should determine how to meet an individuals needs, in a way that complements the principles of the Equality Act (2010) and the Children and Families Act (2014). It appears that practical integration and specific guidance are provided by the SEND Code of Practice (2015); however, the content is also legislative and where the term 'must' is used within the document, it is also deemed to be a statutory duty. When looking across the relevant government legislation, there are commonalities of purpose and values, to ensure a framework exists of support for children with SEND, including aspects of health and social care up until age 25, with the Equality Act (2010) going beyond and covering the whole lifetime.

2.6 Medical and social model

Alongside the changes to policy, the move from a medical model where impairments or differences are a focus contrast the social model where disability is attributed to the way society is organised. A medical model identifies the difference first and not the accommodations that can be made to limit the barriers (Alderson, 2018). The viewpoints are shifting, but there remains a deficit discourse related to having a difference with the use of words like ‘normal’, ‘disabled’ and ‘impairment’ prevalent within the policy and guidelines that keep it embedded in the medical model of diagnosis (Mueller, 2021), i.e. an associated label that intimates that there is a cure. Language is an integral part of the social model of disability (Oliver, 1996) because language reflects the cultural assumptions and thinking of the society around us. Language is never purely descriptive - it shapes how we see each other, our value of different identities, and sometimes how we behave (McCarthy *et al.,* 2022). The gradual change in emphasis - from referring to a ‘disabled person’ - to a person with a disability provides a power shift, and government policy is gradually moving in this direction, by including those with SEND as decision-makers (Children and Families Act, 2014; DfE and DoH, 2015) when defining goals and the support needed. However, it can be seen that the language remains oppressive and intimates that the power lies with those in hierarchical roles, those gatekeepers to the support systems (Foucault, 1997; Vehmas and Watson, 2014).

I have included the term SEND, related to the description of difference under the umbrella of the Code of Practice (DFE, DoH, p.16, 2015); however, in some further education settings, they may refer to their students as having learning difficulties and disabilities (LDD), with higher education institutions using specific learning difficulties (SpLD) as an overall description of the most common areas of neurodiversity. Once adults move away from further education, they may not need to refer to their diagnosis as a medicalised term - for example, dyslexia - unless they require social or financial support. Many policy decisions regarding an individual with SEND increase feelings of stigma (Abraham *et al.* 2002). Applying for government-funded financial support, particularly any financial benefit scheme, requires focusing on the deficit and meeting the criteria. This negative connotation can impact an individual's self-esteem (ibid). More recently, government policies surrounding the Covid-19 pandemic caused further isolation for the more vulnerable members of our society (The Local Government Association and Association of Directors of Public Health, 2020). More specifically, the National Autistic Society (2020) also called for action related to the impact of the Covid-19 lockdown on exclusion, loneliness and isolation. The symptoms of autism on normal daily life can lead to exclusion through an overstimulation of the senses, and anxiety around unexpected change (DfE, DoH, 2021). The participants in this study would have experienced the government restrictions during the Covid-19 lockdown, and this may also form part of their reflections on their life experiences and how this impacted their ability to connect with others.

2.7 Summary of policy

The aforementioned legislation is relevant to this research question because understanding more about the lives of independent adults designated with SEND, their time spent in education through school, and when and how the designation of a mild to moderate difference occurred, relates to the legal descriptors contained within the legislation. The SEND Code of Practice (2015) states the expectations of an appropriate preparation for adulthood and refers to goals for transition, although any provision of formal support stops at 25 years with the cessation of the EHCP (ibid). In some instances, an individual school or college leaver might enrol as an undergraduate at university and could apply for the Student Finance England ‘Disabled Students Allowance’ (DSA) (2023), where there is a need to provide medical evidence in the same way that an EHCP outlines the required support needs. Students attending university as citizens are covered by the Equality Act (2010), where a provision of ‘reasonable adjustments’ in agreement with the institution could minimise any barriers to learning. Support in higher education is offered through the provision of a DSA support package and also the potential removal of some of the barriers by accessing the university’s policy on appropriate ‘reasonable adjustments’ (Student Finance England, 2023). The Equality Act (2010) protects individuals from discrimination related to many aspects of difference, including disability, throughout their lives. The legislation refers to strategies of on-going support for those with mild to moderate designations, including what is known as the ‘local offer’ (DfE, DoH, 2015).

The 'local offer' (ibid), which is predominantly designed to address the needs of those up to the age of 25, is available in all local areas. I researched the availability in my area using 'Google', and four options appeared; these comprised a supported employment course for post-16 up to 25 years, located 15 miles away from my home, a dance class for all ages, which was not explicitly targeting SEND, an equine class over 30 miles away and a specialist shoe service for SEND individuals. There appears to be a void between the anticipated transitional support and the reality of what is on offer. Other supportive avenues that could be accessed are independent charitable organisations that specialise in a specific area of need - for example, autism, dyslexia, or mental health. The availability of the charitable organisations varies depending on an individual's location within the United Kingdom. As a charitable organisation, the level of support available will also be particularly reliant on their funding streams.

Within the government legislation, the discourse of difference is about medicalising through a diagnosis and labels that categorise what types of difficulties are expected, as a generalised approach. The EHCP and detailed diagnostic reports do describe the specific differences and set strategies in place. However, the language of the legislation remains focused on the medical model of a diagnosed disability and the required support needs. Throughout this study, I refer to SEND as more about acknowledging a difference, which should, wherever possible, be accommodated through inclusive practice. This is particularly the case when referring to those with mild to moderate differences, since this reflects the social model that respects disabled people as valued citizens with legislation that supports their rights to equality and social inclusion overall (Shakespeare, 2014; Den Houting, 2019; Fletcher-Watson, 2022). The theory of disability in this study relates quite closely to government policy and the pathway from school to college, and then into adulthood as the two participants both attended mainstream and also a specialist school on their journey, so they have been privileged to receive the support outlined in the SEND Code of Practice (DfE, DoH, 2015).

2.8 Disability theory

In this section I will explore the key concepts of disability, ability and inclusion within the field of SEND, relevant to children and young people with a mild to moderate designation of Special Educational Needs and Disability (SEND), as they progress into adulthood. As defined by the government policies already explored, in order to access formal support within education, an individual requires a designation of SEND. There are some issues with this evidence-based system, as it relies on perceived difficulties being raised by a third party to commence the investigation (DfE, DoH, 2015). The description of being diagnosed with a special educational need or disability (SEND) is not inclusive in that it instantly labels an individual as being different to the norm (Watson, 2002; Anastasiou and Kauffman, 2011; Ghanouni and Raphael, 2022; Handoyo *et al.* 2022). Yet, without the process of obtaining a formal diagnosis, it might be challenging to provide an appropriate provision of support to be able to access education effectively.

Literature, including policy, notes a need for support for individuals in the context of achieving community integration (DfE, DoH, 2015) as they transition into adulthood. At the time of diagnosis, an individual’s identity is described as having a support need to overcome barriers in their daily life, particularly within areas of additional complexity such as education

(Westwood, 2017). The diagnosis of difference is the key to support, even in adulthood, through self-disclosure (Equality Act, 2010). However, the data revealed that self-identity in adulthood did not align with that of adolescence; the medicalised label faded away as formal support ceased to be a focus, shifting from a feeling of a stigma of difference towards a focus on strengths (DRILL, 2020).

2.9 Deficit model of SEND

For some parents, there can be a dilemma in seeking a diagnosis as they might fear the stigma that labelling could have on their child's self-esteem (Abraham *et al.,* 2002; Arishi *et al.,* 2017). Alongside this perception that a designation of SEND can lead to marginalisation, a diagnosis can be seen as a deficit (Mueller, 2021) rather than a strength (Seale, 2017). Individuals with a mild to moderate designation - for example, those with high-functioning autism - might not exhibit noticeable differences. However, they might have difficulties with social interaction (Hull *et al.,* 2017) and other traits that might go unrecognised and unsupported until they are faced with a social situation within education or in the workplace that raises awareness or triggers their difficulties. This parental dilemma of whether to pursue or avoid a diagnosis is reported in research that comments on the concept of negative connotations associated with experiencing ‘stigma, devaluation and rejection’ (Russell and Norwich, 2012, p.230). Although the designated difference sits with the individual, the stigma can also extend to the family (Gray, 2002) and this can also be factored into the reasons not to seek a diagnosis.

Therefore it appears that a stigma can influence decision-making. This is also referred to as a courtesy stigma (Goffman, 1963), where an association with a difference can impact the parent's decision to seek a diagnosis, as they feel stigmatised by association and potentially discredited for not seeking additional support (Gray, 2002). An ‘enacted’ stigma (ibid, p.737), meanwhile, refers to discrimination and instances of rejection (ibid, 2002). Any potential stigma is uncomfortable for parents to manage. The feelings of exclusion for their child, where invitations to join in community events might not be extended and other examples of avoidance occur, can reinforce their reasons for not seeking a diagnosis. In adulthood, the concept of a stigma can remain, and the external picture of coping with daily life might not be a reality, as an individual conceals their difficulty in order to fit in (Mueller, 2021).

Since seeking a diagnosis appears to reinforce a deficit model, this can also limit an association with other agencies that offer support and guidance, as this confirms that a difference exists. In his research, Gray (2002) describes a stigma as being ‘felt or enacted’ (p.737). A ‘felt’ stigma pertains to a fear of failing and relates to a scenario where an individual and their family attempt to portray what they perceive as being a ‘normal existence’ and limit any incidences of additional support. This type of concealment can link with the social camouflaging that exists for those with autism (Hull *et al.,* 2017), where an individual will use techniques to appear the same as people that they interact with (ibid, p.2529), or when those with dyslexia conceal their difficulties (Nalavany and Carawan, 2015) to avoid disclosure and the potential negative impact on their self-esteem. Interestingly this reference to camouflaging appears in this study as the participants describe their challenges while maintaining a sense of ‘normal’ and the idea of being able to ‘fit in’ (Hull *et al.,* 2017, p.2520; Bernardin *et al.,* 2021).

The concept of stigmatisation originates from those personal experiences of being treated as differently to others (Gray, 2002; Nalavany and Carawan*,* 2015), including elements of exclusion through a feeling of devaluation (ibid; Russell and Norwich, 2012; Nalavany and Carawan, 2015). The parents' emotions were captured in the research conducted by Russell and Norwich (2012), where they identified the diagnosis process of their child as a loss of ‘normality’ (ibid, p.233). Statements included in the research (ibid) regarding the diagnosis outcome were referred to by the parents as their child or young person becoming - ‘pigeon-holed’ or ‘put in a box’(ibid), since the language used during diagnosis reinforces the sense of a deficit (Gray, 2002; Russell and Norwich, 2012; Nalavany and Carawan, 2015). The potential exceptions to obtaining support can be influenced by a variety of reasons, including fear of exclusion from what is deemed to be a ‘normal existence’ (Gray, 2002; Nalavany and Carawan, 2015) or through an intentional concealment (Bernadin *et al.,* 2021).

Discussion of the stigmatisation dilemma extends into other literature relevant to the aspirations of adults. In research conducted by the Disability Research on Independent Living and Learning (DRILL) National Advisory Group, ‘See Me as a Human Being’ (2020), the adults with a previous diagnosis of SEND referred to a need for a more strength-based approach in adulthood. The research reported that adults with SEND, as they moved from education into support within social care, required ‘availability of information, positive attitudes and limited stereotyping, the acknowledgement of their strengths from a lived experience as expertise’. In addition, the adults in the study (ibid) wanted to be treated with dignity, trust and to feel valued, with access to choice and control (ibid, p.43). Being able to participate in the community and engage socially is seen as a measure of success (DfE, DoH, 2015; DRILL, 2020), and this links to the expectations within the Code of Practice (DfE, DoH, 2015) that the educational goals documented in an EHCP and the support provided during the transition into adulthood (ibid) will ease an individual’s ability to integrate into the community.

Fortunately, if the stigma is overcome, the need for a diagnosis is not time-constrained, as support remains available throughout the school years and into further education, and it can also occur for the first time in adulthood. In some instances, there can be a delay in the process of receiving a diagnostic assessment (McCarthy *et al.,* 2022), which of course hinders the required support being put in place. The support that is a provision in school and further education associated with an EHCP - for example, additional support through mentoring, access to the use of a computer, or additional time in examinations - continues into higher education, although it is then administered through the Disabled Students’ Allowance (Student Finance England, 2023). Recent research revealed that some students in higher education felt that they were treated more considerately than in school or further education, which was linked to being able to identify their strengths with less emphasis on their weaknesses (Dangoisse *et al.,* 2019). There could be aspects that influence this change of approach in higher education, such as maturity as one leaves the supportive environment of home behind, with the inherent anxiety attributed to the fear of social stigmatisation (Abraham *et al.,* 2002; Arishi *et al.,* 2017).

In adulthood, the Equality Act (2010) refers to strategies of ‘reasonable adjustments' to limit the barriers; the challenges faced in education can prepare an individual for future challenges anticipated, as they transition out of formal education (Dangoisse *et al.,* 2019), through a build-up of repeated incidences of having to overcome adversity, which then becomes a strength (Moriña *et al.,* 2018). Since it is acknowledged that the SEND Code of Practice (DfE, DoH, 2015) refers to the need for skills development to support the transition, a shift in emphasis towards a strength-based approach by acknowledging the development of attributes could provide a perception of what can be achieved, rather than what cannot (Seale, 2017), which also links to the aspirations of those included in the DRILL (2020) research on acknowledging adults and their strength-based aspirations. The deficit model of a diagnosis and support can feel like a limiting factor to some (Russell and Norwich, 2012), and reinforces that a designation of SEND is seen as a deficit. All children and young people can experience challenges during education and into adulthood, regardless of their designation (Dangoisse *et al.,* 2019) and those experiences will influence their self-identity, inform their sense of ability and define any support needs. In this study I am focusing on adults with a former diagnosis of SEND, to gather their life experiences of the years spent in formal education and how this has shaped them into the adults they are today. Within the research conversations, I ensured that a designation of SEND was not seen as a deficit by focusing on a strength-based model of diversity. The data included the participants’ perceptions of any dilemmas associated with their interpretation of incidences that might have been influenced by a deficit or stigma.

2.10 Ability and inclusion

Despite the negative connotations with SEND, inclusive practice is threaded through government policy and the SEND Code of Practice (DfE, DoH, 2015), and provides guidance to be filtered into local policy. Local government provision guidance documents such as the Kent Inclusion Statement (Kent

County Council, 2023) look at the impact on children, parents and carers, and the settings related to the provision of support, and also how the staff managing the systems and services (ibid) should interact. In school, the concept of inclusion in practice (DfE, DoH, 2015) refers to partnership working that provides the required support provisions to ensure that a child or young person can have a smooth transition into adulthood. As noted in the section on policy (p.19) the emphasis on the SENCo (Curran and Boddison, 2021) and an inclusive approach demands that the school, or setting, take a whole-organisation approach to inclusion and the support provided for those individuals with a designation of SEND.

This model of personalisation through partnership working found within the policies and systems in the United Kingdom is held in high regard by other countries (Carey *et al.,* 2018). For example, Australia reformed their disability provision in the light of the UK policy and incorporated the concept that ‘one size does not fit all’ (ibid) into one that offers a more personalised provision of support, although the reality of this relies on the support required being available. In Scandinavia the policy has gone one step further than offering support through access to budgets and a local provision, they have identified a need for personal assistants (Askheim *et al.,* 2014) to enhance the idea of personalisation in the UK. The structure of support in the United Kingdom offers strategies that reflect individual needs, but as a person transitions through their life the needs can change (Dangoisse *et al.,* 2020). The life course described within government policy (DfE, DoH, 2015) expects that an individual will follow a trajectory of attainment with support strategies in place to ensure success. It is anticipated that an individual will attend school and achieve the required skills to be able to gain employment and also be able to develop relationships with others to become embedded as a citizen into their local community (DfE, DoH, 2015).

The issue addressed within this study is what occurs once the formal support mechanisms cease to exist post age 25 (DfE, DoH, 2015) for those with a mild to moderate designation who are not deemed to require ongoing social care (ibid). As previously stated, as long as there is a formal diagnosis, the journey through education clearly has support embedded into the provision with a focus on inclusion (ibid). When this ceases to exist, the provision appears to become more ad-hoc, reliant on a local level of support (ibid) and also the skills developed that have been designed to take a young person forward into adulthood (ASDAN, 2023; Appendix 4). So inclusivity for those with a designation of SEND appears to be reliant on the policies that provide strategies to ensure inclusion (DfE, DoH, 2015), alongside the disseminated policies at a local level (Kent County Council, 2023) that create a process of support which leads towards a transition into adulthood through a focus on citizenship (ibid).

Citizenship is described as the ‘inclusion of some and the exclusion of others’ by Oliver (1996) and he also, mentions that as a society we focus on the deficit, which can create an attitudinal bias (Ruhl, 2020). If access to the provided support systems is not utilised then an individual might well become segregated by their difference (Handoyo *et al.,* 2022), through this process of discrimination or ‘othering’ (Oliver, 1996). Since the process of inclusion is reliant on the availability of support strategies to ensure participation, there can also be incidences where an individual might not fit within the process and will therefore be unable to exercise their agency (Riddell and Watson, 2003; Beyer *et al.,* 2014; Sanders *et al.,* 2017). A successful transition into adulthood relies on support to be able to develop the required skills to integrate into the adult community, as this assimilation is noted in policy as being linked to well-being (DfE, DoH, 2015) and also features in literature (Abdul Kadir and Mohd, 2021). The Office of National Statistics (2021) also state in their data that, **‘**disabled people report lower well-being levels than those classified as being non-disabled’ (ibid, n.p.).
The literature also reveals that a diagnosis of a disability can impact on attaining a good quality of life; in middle-income countries, ‘60% of adults are less likely to enjoy a quality of life compared to those without a SEND’ (Rahman *et al.,* 2022). Quality of life relies on a positive integration through employment and training opportunities (Morisse *et al.,* 2013; Gilmore *et al.,* 2014; Rahman *et al.,* 2022) to allow for a positive contribution to society. Research also notes that as adults mature, they can face social exclusion related to their living arrangements, health needs or socioeconomic status (Hughes- McCormack, 2017; Emerson *et al.,* 2021). For the participants in

this study, their lived experiences included their perception of the skills acquired prior to their transition into adulthood and where the curriculum and structure of their education helped them to prepare for adult life, in order to face the challenges that occurred through building resilience.

2.11 Resilience

The concept of resilience is theoretically complex and appears in the literature, mainly related to those with unique challenges (Yeager and Dweck, 2012; Muniandy *et al.,* 2021; McMenemy and Nicholas, 2022). The development of the required strengths to build resilience (DfE, DoH, 2015) includes a focus on the skills development that will provide access to the broader community (Mueller, 2021) alongside the entrepreneurial human interaction that helps to build a support network (Christensen, 2016; Abdul Kadir and Mohd, 2021). The challenge for those individuals with a designation of difference when formal support ceases to exist (DfE, DoH, 2015), relates to the challenges that occur in adulthood concerning employment, relationships, and the navigation of seeking and securing accommodation, obtaining financial benefits, managing health care and in some instances supporting their own family and the coping mechanisms required in order to be able to persevere.

Current government policy, outside of the overarching SEND Code of Practice (DfE, DoH, 2015), seeks to support those with autism, related to employment. The vision states, 'transitions into adulthood will improve’ (DfE, DoH & SC, 2021) by promoting pathways to ‘lead full and happy lives’ (ibid). These pathways currently exist in the supportive education curriculum (ASDAN, 2023; Appendix 4), identifying personal development skills relevant to the 5 C’s of Positive Youth Development (Lerner, 2009; Carroll, 2015) required for a successful transition into adulthood (DfE, DoH, 2015); however, the policy also notes that work needs to be done to support employers and businesses to be able to accept employees who have a designation of autism.

For all human beings, resilience supports one's ability to recover from setbacks; it is our capacity to cope and maintain a positive mindset in the face of adversity (Yeager and Dweck, 2012), to navigate the ups and downs of daily life, which ultimately supports mental wellbeing (NICE, 2022). Complexities occur in adulthood as many face various challenges in their daily lives which are not solely related to individuals with a designation of difference. The reality for the research participants might be nuanced towards a particular type of experience, and their narratives reveal how they dealt with critical challenges. In this thesis, the themes of the skills development available within formal education are explored through an analysis that identifies the existence of the 5 C's (Lerner, 2009; Carroll, 2015), which offer a positive view of one's actions (competence), a sense of self-worth (confidence), the bonds with others through the development of relationships (connection), and an understanding of right and wrong (character), alongside a sympathy and empathy for others (caring). These strength-based skills can facilitate resilience (Lerner *et al.,* 2013), all of which will be explored in the data analysis.

In some instances, resilience, particularly with those individuals with a designation of SEND, can also be impacted by other factors, such as sensory sensitivities, which could influence the participants' ability to regulate their emotions (Muniandy *et al.,* 2021). In this instance, resilience could be linked to the participant's achievement of perceived positive outcomes by considering to what extent they have embraced their challenges and learned from their setbacks (ibid). In reality, the shared personal experiences expose to what extent challenges arose; in some instances, when faced with a dilemma, an individual could mask any difference (Bernardin *et al.,* 2021) rather than applying the relevant personal development skills. The interrelationship of skills used appeared within the participant's narratives, revealing who, if anyone, mediated the relationship between resilience and a positive outcome (Muniandy *et al.,* 2021). In some instances, a supportive other, such as a family member or close friend, might be driving the solution (McMenemy and Nicholas, 2022).

The complexity of identifying resilience and skills demonstration from a narrative can also be impacted by any decision not to interact with others. Is this resilience actioned by a conscious decision to remain within the microsystem of family and friends (Antony, 2022), where the need to solve problems ceases, or does the individual not have the required coping strategies at their disposal and therefore choose to retract from the issue presented, rather than confronting it? The research conducted by McMenemy and Nicholas (2022) identified how movement between the ecological systems can decrease as adolescents find it easier to stay at home (ibid), when faced with the challenges associated with their designated differences. This could also be encouraged by families who are afraid of stigmatisation associated with a difference (Russell and Norwich, 2012), limiting an interaction outside of the family unit.

All life experiences demonstrate varied abilities to cope with life's challenges and a range of skills required as strength-based coping methods. The reality of the success of this relies to an extent on a continuation of a growth mindset, where challenges are seen as growth opportunities (Muniandy *et al.* 2021). However, this might be an oversimplification when investigating the complexity of human behaviour and what those challenges might be, including the motivation required to take on challenges, particularly when the formal support strategies diminish (DfE, DoH, 2015). A successful transition is documented as the goal within policy (DfE, DoH, 2015). In contrast, the research describes the nuances of transition alongside a designation of difference and how it can influence an exploration of self-identity (Arnett, 2000; Abraham et al. 2002), creating barriers to integration. The transition to adulthood requires an individual to confidently embrace new and complex experiences (Burt and Paysnick, 2012; Gilmore and Cuskelly, 2014), without which community integration and employability could become stifled (Crane et al, 2022).

The development of resilience relates to having the emotional strength to face challenges; there might also be occasions when an individual needs to turn to others for support (Yeager and Dweck, 2012) and their interpretation of the challenge determines what strategies are required (ibid). The ultimate goal of personal skills development for adults moving into independence is measured by how successful their integration into the wider community is, and to what extent - independently or with support - they can attain a 'quality of life'

(Morisse *et al.,* 2013; Montgomery *et al.,* 2019) and resilience reflects the attributes and perseverance needed to get there. There are different ideas about what success looks like; there are the overarching policy goals of employment and integration into the community, but for some individuals, their goals will be determined personally by their own views of success.

2.12 Skills development

As previously acknowledged, a successful transition into adulthood and independence is reliant on having the skills to be able to do so. The SEND Code of Practice (DfE, DoH, 2015) reports that individuals should have friends and supportive relationships. The skills required to make those connections can require a support strategy, but barriers to social interaction and aspects of stigmatisation might hinder these relationships from occurring (Abraham *et al.,* 2002; McConkey *et al.,* 2009; Arishi *et al.,* 2017). Employment options appear in research to be a catalyst for social networks (Macdonald, *et al.,* 2018) as isolation and loneliness is linked to poor economic resources (Osgood *et al*., 2010; Office of National Statistics, 2021). The gap between school provision and the post-16 educational experiences was identified as a deficit which created a low socio-economic status, linked to a designation of SEND (Crane, *et al.,* 2021), with unemployment being prevalent for those with a difference (United Nations, 2018). Since it was noted that a designation of difference could feed the effect that stigma and attitudinal bias have on self-identity, this in turn limits a successful move into employment or any other role within the community (Abraham, *et al.,* 2002; Diez, 2010; Sheffield *et al.,* 2017; Handayo *et al.,* 2022). The employment options for the participants in this study are explored within their narratives, with regard to both their social engagement with others and the impact on their socio-economic status.

The significance of the support needs of those designated with mild to moderate difficulties is that the issues that require support can be subtle (Hull *et al.,* 2017). As noted previously, some individuals with autism struggle to maintain social interaction in new and unfamiliar environments and might rely on camouflaging (Bernadin *et al.,* 2021). A review of employability skills provided to individuals with autism carried out by Bennett and Dukes (2013) revealed a lack of preparation for employment, and although this research was conducted before the SEND Code of Practice (DfE, DoH, 2015) was in place, additional and ongoing support in employment for those with a mild to moderate designation was found to be lacking, related to both employers and their employees (Ghanouni and Raphael, 2022). The type of interventions recommended within the SEND Code of Practice (DfE, DoH, 2015) includes support outside of the family system. In their research O'Connor *et al.,* (2014) found a correlation between a need for skills development and a successful transition that aligns with the SEND Code of Practice (DfE, DoH, 2015). The policy (ibid) defines how an adult is provided with the opportunity to learn new skills and the expectation is that they use those to aid their transition. There is an assumption that an adult without formal support would still be able to maintain their emotional regulation and develop resilience (O'Connor *et al.,* 2014; Moriña, Molina, and Cortés-Vega 2018; Dangoisse *et al.,* 2019). The reality of the move from the formal structures of education (O'Connor *et al.,* 2014) alongside changes to aspects of parental control (Mueller, 2021) will vary for individuals, but the need to be able to integrate into the community is arguably important. However, a sweeping statement that all adults need to integrate is problematic, as every individual will develop and move into adulthood in a variety of ways. Research on emerging adulthood discusses not only what it is to be an adult with brain development finishing by the end of adolescence (Nelson, 2021), but also what is required (ibid), and the theory of emerging adulthood (Arnett, 2000) refers to an exploration of identity and the pursuit of 'love and work leading to a future commitment' (Nelson, 2021, p.181).

Aforementioned government policy sets expectations for the outcomes of this period of transition including 'having friends and supportive relationships, and participating in, and contributing to, the local community' (DfE, DoH, 2015, p.28). The United Kingdom government has recognised that loneliness and isolation are key elements that impact people's well-being (Gilmore and Cuskelly, 2014; Department for Culture, Media and Sport, 2021), this instils a reason why community participation is an integral part of our connection with others (Chan *et al.,* 2020). An individual's sense of community might relate to their immediate family, friends and associates then extend into neighbourhood societies, clubs and shared interest groups. Just because someone exists within their community does not mean they feel part of it (Chan *et al.,* 2020). There is a need for individual skills to be developed during the years spent in education to ensure that employability skills, alongside other factors of social interaction and realistic aspirations of the pathways into adulthood are defined (Abdul Kadir and Mohd*,* 2021). This is more problematic for those with a designation of a mild to moderate difference, as they might be able to cope in education and the workplace within a supportive, structured and familiar environment, but the transition into a community where the available support is minimal could be more of a challenge.

2.13 Theoretical framework

So far in this chapter, I have identified aspects of government policy and how, in adulthood, it expects that the close community of friends and families will continue to support individuals as they transition (DfE, DoH, 2015, p.6). The government's measures of success are related to employability and community participation, associated with the utilisation of skills developed in further education, alongside the informal support that exists within their community. Since emerging adulthood anticipates that there will also be a period of experimentation to consider (Nelson, 2021), the journey from formal education into independence can be problematic, mainly if the anticipated support networks are no longer in place (ibid; Field, *et al.,* 2021). This study investigates how selected individuals perceive how they began to establish life as independent adults and navigate the need to find and maintain employment or volunteering opportunities in line with the government policy (DfE, DoH, 2015). The conceptual framework developed for the study enables a community-based approach to structuring and analysing the narratives shared by the participants; it does this by reflecting on the provision of support and skills development in education, and how this manifests in the perceived reality of the participants. In this section I explore the reasons for using a community-based approach that allows for an investigation into not only the ecological systems an individual moves between in adulthood, but also the skills required for the goal of integrating and connecting with others.

As an individual moves through this transition period, they might struggle with aspects of self-identity. It was anticipated that some of the challenges listed in the literature would appear within the data; for example, incidences related to labelling, low self-esteem, socio-economic difficulties, and troubled relationships (Bynner, 2005; Darling and Heckert, 2010; Burt and Paysnick, 2012; Essex and Melham, 2019). This specific field of adulthood might experience additional levels of vulnerability linked to a mild to moderate designation and to how such people are assimilated into their community (Malkani, 2021), by exploring if they have gained employment, and can live independently and participate in the wider community.

The critical element of the transition to adulthood that the research focused on is to explore whether additional support becomes less essential as an individual extends into new social spaces. The pathway to success relies on acquiring and applying the required skills (DfE, DoH, 2015) and how an individual has developed their strengths through their resilience as they try to ‘fit in’ (Mueller, 2021). Since integration into the wider community relies on building reciprocal relationships alongside the availability of appropriate opportunities (McConkey, *et al.,* 2009; Mueller, 2021), without which they could feel that they remain outside of their extended community (Oliver, 1996), this is an integral part of the investigation. Government policy also describes how supported employment and employers should be available (Department for Work and Pensions, 2022) through grants awarded to local authorities, and this study notes incidences of this type of external support as it arises.

2.14 Community

As an individual moves into a broader community, it is an extension of the microsystem of family life (Bronfenbrenner, 1979), where adult individuals are expected to extend outwards into the workplace and form new relationships, and it is anticipated that reliance on the family unit might diminish (Bynner, 2005; Mueller, 2021). As adults, we live in a multi-faceted world (Bettis *et al.,* 2019), and it is essential to recognise the transient nature of adulthood and the existence of the wide range of ecological systems that we move between of family and friends, education, work and other settings where relational types of interaction occur (ibid). The integration into the community as a citizen is the ultimate goal of the years spent creating an appropriate EHCP that reflects the skills required and relevant support to move along the pathway towards independence (DfE, DoH, 2015). According to the strategies within government policy, those post-25 years are expected to develop their social capital through this extension into the wider community (Holland *et al.,* 2007).

In order to understand how these adaptations to the existing microsystem of family life occur, we need to acknowledge the importance of family in childhood (Bettis *et al.,* 2019). Literature notes that individuals aspire to this sense of increased independence, but are also aware of the need to continue some form of support network (Gaona *et al.,* 2019). In adulthood, this integration into the wider community can support all adults in times of hardship through developing key relationships supporting development and resilience to whatever life ‘throws’ at us (Burt and Paysnick, 2012; Gilmore and Cuskelly, 2014). Therefore, within the conceptual framework, the wider community dimensions that an individual moves within as an adult are crucial, as such people extend beyond the familiarity and structure of family life and move into unfamiliar spaces during the transition into adulthood.

2.15 Goals

A key component of being equipped to transition into adulthood is a reliance on the skills provided in education, which continue to develop during employment or volunteering. This follows the anticipated pathway described in the SEND Code of Practice (DfE, DoH, 2015). The focus of the further education curriculum towards transition at age 25 is on the development of interpersonal skills (ASDAN, 2023), highlighting independent living, employability and social communication; these align with the 5 C’s of Positive Youth Development (Appendix 4) (Lerner, 2009; Carroll, 2015), related to the need in adolescence for enhanced personal ‘competence, confidence, connection, caring, and character’ (ibid; Mooney, *et al.,* 2019; Abdul Kadir and Mohd, 2021). These overarching headings are universal personal development skills required as a key component of citizenship and community integration and a transition into adulthood (DfE, DoH, 2015). The 5 C's of Positive Youth Development (Lerner, 2009) are a valuable lens to identify the individual skills utilised during transition when investigating the life experiences of adults, alongside an acknowledgement of the environmental accommodations an individual moves between within the wider community (Bronfenbrenner, 1979). The ecological systems (ibid) suggest that the environments we encounter over time impact development and Bronfenbrenner states that 'development does not take place in a vacuum' (1979, p.27). These factors include systems from the immediate setting of the microsystem into the wider community of the exosystem. In adulthood, the macrosystem includes social and cultural norms alongside the development of cultural beliefs. I was interested in looking for this in my data.

In research conducted by Morisse *et al.* (2013) on the 'Quality of Life', the influence of environmental variables impacted an individual's experiences. These environmental variables align with the ecological systems model (Bronfenbrenner, 1979; 1986) where in life we move between a variety of systems that can influence our experiences and personal development (Morrise *et al.,* 2013), from the microsystem of the close family interaction that is at the forefront of childhood (Bronfenbrenner, 1979), to the meaningful relationships developed in adulthood. Sets of skills were identified that were required to attain a 'Quality of Life' (Morisse *et al.* 2013), which included 'self-determination, interpersonal relations, social inclusion, rights, and emotional, physical, and material wellbeing' (ibid). Within these overarching factors, there are similarities to the aforementioned skills noted within the 5 C's of Positive Youth Development (Lerner *et al.,* 2005) and the development of these skills are documented as being required for success in adulthood (ibid; Abdul Kadir and Mohd, 2021). The research on resilience in emerging adulthood carried out by O'Connor *et al.* (2014) also focused on the positive attributes of a 'quality of life' (Morisse *et al.,* 2013) alongside the aspirational goal of a 'meaningful life' (Montgomery *et al.* 2019) or a 'purpose in life' (Abdul Kadir and Mohd, 2021). All of these positive descriptions signpost the aspirations of individuals towards the goals of success' and quality, a sense of purpose and having meaning in our lives as adults, in whatever form that takes at an individual level. To be able to ascertain what ‘success’ looks like to the individuals in this study, a conceptual framework is required to analyse life experiences, to identify the utilisation of personal development skills and what life looks like for those individuals and to reveal how that aligns with the expectations and structures of government policy (DfE, DoH, 2015).

For some individuals with a former designation of SEND the reality of their life experiences will also reflect aspects of mental wellbeing and a mental health diagnosis also falls under the umbrella of SEND. Any disability and anxiety-related issues could interrupt an ability to achieve a ‘quality of life’ (Morisse *et al.,* 2013). In research conducted by Montgomery *et al.* (2019), a Community Integration Questionnaire (CIQ) was used to assess the home and social integration of the research participants. The overall focus of this research was on social inclusion (Montgomery *et al.,* 2019), and the outcome was measured by the extent of community integration using the CIQ. The environmental movement of those who were socially integrating with others revealed how they had moved away from the family towards freedom to choose whom they interacted with. Those individuals with a medium CIQ remained more static and only engaged with service providers moving slightly out of their existing environmental system. However, those with a low CIQ remained within the microsystem of their family in what they considered a ‘safe environment’, described as an ‘existence of survival’ as an extension of what they considered to be ‘living’ (ibid, 2019) as their aspiration. The inclusion of mental illness into the descriptor of SEND makes this research relevant; again, the goal of what is deemed to be a move towards a 'meaningful life' is subjective but appears to expand through a connection with others to create a sense of belonging (Montgomery *et al.,* 2019). The movement between ecological accommodations (Bronfenbrenner, 1979) appears to vary in how it extends outwards, as an individual seeks out new supportive relationships in order to make a community connection towards whatever the individual deems to be their acceptable ‘quality of life’ (Morisse *et al.,* 2013; DfE, DoH, 2015).

2.16 Developing skills

The life experience narratives within this study were intended to capture the reality of this adjustment into adult life, and the participants' narratives could include details on to whom and where they could go for on-going support, once the formal interventions ceased to exist. Outside the family unit, adults are expected to interact with others, not just within employment but also with individuals within their own families. The transition to adulthood is a milestone that relies on the ability to forge relationships with others (O'Connor, *et al.* 2014), including new friendships and, in some instances, the development of romantic relationships (ibid). If they are parents themselves, they would be expected to extend their community to include relationships with their child's nursery and school provisions.

Many young people without the additional challenges of a designation of SEND can also struggle with the expectations of adulthood and independence as they experience a mix of vulnerability alongside an anticipation of a move into additional responsibility (Field, *et al.,* 2021). In their research, O'Connor *et al.* (2014) provided an insight into the psychological issues of a transition that, if unsuccessful, can lead to insecurity and incidences of mental health diagnosis (ibid). The incidences of poor mental health in women with autism can link back to the discussion on masking as they might try to obscure their differences, and this can reinforce feelings of low self-esteem, stress and exhaustion associated with maintaining a façade; this in turn leads to feelings of anxiety and the lows of depression (Beck *et al.,* 2020; Cook *et al.,* 2024). The diagnosis of mental health alongside a diagnosis of SEND can be overlooked as the symptoms can be attributed to their diagnosis of SEND. Interestingly, NICE guidelines for schools include a strength based approach for social emotional and mental well-being identifying a need for skills development, including self-care, communication with others and resilience (NICE, 2022).

For all individuals with a former diagnosis of SEND, government policy outlines the steps towards a successful transition (DfE, DoH, 2015) through skills development and an ability to gain employment and interact with others. This leads towards what can be described as a 'purpose in life' (O'Connor *et al.,* 2014; Abdul Kadir and Mohd, 2021), which is similar to achieving citizenship. Citizenship encapsulates the process of integration (DfE, DoH, 2015; Kent County Council, 2020), and this encourages an individual to contribute to society, leading to a purposeful existence and the achievement of social capital through employment, volunteering, supporting others and the ongoing development of personal skills (Holland *et al.,* 2007; O'Connor *et al.,* 2014). The fundamental focus of integration in adulthood is employability (DfE, DoH, 2015), whether paid or as a volunteer. It is within the time spent on seeking employment and maintaining a role as an employee that the skills developed in education come to the fore as an individual extends into the wider community, which is part of the community-based conceptual framework.

2.17 Employability

As the experiences in adulthood develop, the highs and lows instil a resilience; this can lead to a 'turning point' (O'Connor *et al.,* 2014) where through perseverance, acceptance as part of the community and the development of new relationships occur (Burt and Paysnick, 2012), which in turn enhances an individual's experience of social communication. The skills development process at school and college signposts the need for a level of competence and development of social relationships to assist with this stage of their lives (O'Connor *et al.,* 2014), and to facilitate the required wider participation.

Since employment is the goal of a successful transition (DfE, DoH, 2015), and if the required support is unavailable, then a poor experience could ensue with issues related to attendance and the maintenance of an engagement with the workplace (Crane *et al.,* 2021). Local schemes related to funding for supported employment do exist in some instances (Department of Work and Pensions, 2022), but this, like the 'local offer' (Anderson *et al.,* 2022; Matthews *et al.,* 2023*)* relies on being available in the location where the individual resides. Before age 25, parental advocacy remains a key support strategy for those with an Educational Health and Care Plan (EHCP) as a collaboration identifies and targets support (DfE, DoH, 2015); however, on cessation, the individual might not choose to rely on their parents for support.

The research that Crane *et al.* (2021) conducted refers to the Office for National Statistics (2021) data where outcomes for employment for autistic individuals are lower at 21.7% than other disability groups at 53.6%; this again demonstrates that access to employment is a challenge for some individuals. It is also thought that the impact of masking or camouflaging (Hull *et al.,* 2017; Bernardin *et al.,* 2021; Cook *et al.,* 2024) during education and into adulthood might also inhibit the acquisition of skills and performance as an employee (O'Connor *et al.,* 2014; Malkani, 2021). Reliance on a supportive workplace and employer is fundamental to avoiding a negative experience (Department of Work and Pensions, 2022). The conceptual framework has the ability to identify any relevant skills that support an individual to move through the environmental accommodations (Bronfenbrenner, 1979) from the security and familiarity of the family, to the development of extended relationships and new experiences, where individuals need to be able to form allegiances outside of the familiar environments of home as part of their social communication skills.

2.18 Connecting with others

The data provided by the Office of National Statistics (2021), alongside the employment figures (ibid), notes that the percentage of loneliness felt by adults 'often or always' related directly to those individuals with a designation of SEND and has increased since 2014. The data also notes a correlation between those who have limited daily activities and feelings of loneliness (ibid), and reports a rise in cases of mental health diagnoses since the enforced isolation experienced during the Covid-19 pandemic. The government is aware of the risks associated with mental health issues and the link with those individuals existing in low socio-economic situations (DoH and SC, 2021), where unemployment is seen as a factor. In the research carried out by Abdul Kadir and Mohd (2021) they identified a connection between 'confidence and connection' of the 5 C's (Lerner, 2009) and well-being, alongside the goal of a purpose in life (Abdul Kadir and Mohd, 2021), as fundamental components of a successful transition. In supported learning curriculums like ASDAN (2023) students complete modules on 'community action' and the development of 'social relationships', alongside aspects of exploring 'cultural diversity' and 'rights and responsibilities'; these are all important skills required for those individuals transitioning towards independence, in order to be able to maintain that all important social connection with others. Therefore, it is vital to discover the extent to which the transition appears in reality as individuals move into adulthood, and whether they can utilise those skills to integrate into the community, gain employment or enter a volunteer role.

The research questions in this thesis link to the disparity found between the overarching government policy and the availability of a suitable support provision to sustain a connection with others (Gregory, 2017) for those leaving formal education. A move towards a person-centred approach and multi-agency working for those who have had an Education and Health Care Plan (EHCP) during adolescence (Dunsmuir *et al.,* 2020) might provide support for some into adulthood, but not for those with a mild to moderate designation (DfE, DoH, 2015; Malkani, 2021), who are expected to develop their own strategies, alongside a reliance on family and friends (ibid, 2015).

Within the literature search, the language changes as the individual ages, moving from a diagnosis of SEND up to the age of 25 years to a description of having a disability. The diagnosis has not changed due to the age of the individual; it is the cessation of formal support associated with the government policy (ibid) for those with a mild to moderate designation that has come into force. The diagnosis loses its prevalence related to the provision of support, but a diagnosis of difference is part of an individual's identity and does not disappear over time. Each system of support responds to a distinct need; at school, the need is education, which shifts to a need for the required skills to manage into adulthood. The narratives shared were so rich that they required a lens that captured both cognitive development (Piaget, 1972: Vygotsky, 1978) and one that revealed an interaction with others. Maslow (1943) reveals cognitive development towards a quality of life (Morisse *et al*. 2013); however, within Maslow’s theory, these are generalised against capability and independence. In this research for those individuals with SEND, I required a theory that reflects both the environment and the importance of supportive relationships rather than solely a goal of self-actualisation without due consideration of any environmental factors. The theoretical lens had to highlight the skills utilised as they interplay within systems in order to capture the participant’s reality of events.

The lens of the 5 C's (Carroll, 2015; Abdul Kadir and Mohd, 2021) alongside the ecological systems theory can highlight movements and relational influences between life's accommodations (Bronfenbrenner, 1979, 1986) in adulthood. It supports an analysis of how an individual perceives they are coping (Appendix 5). In order to reveal the movements of an individual in or out of the ecological systems and to reveal the extent of their movements, the structure of accommodations that radiate outward from family life, previously associated with their childhood and dependency, provides an appropriate framework to capture information on how an individual might have connected with others and moved towards independence. Access to the required skills during formal education associated with the 5 C’s of Positive Youth Development (Carroll, 2015; Abdul and Mohd, 2021), which includes aspects of a wider connection with the community (DfE, DoH, 2015), is developed to aid a transition to adulthood. The overlaying of the 5 C’s and the ecological systems theory allows life experiences to be exposed to closer scrutiny by providing a framework to support the investigation into the extent of the participant’s preparedness for adult life beyond age 25; this framework will receive closer scrutiny below.

2.19 Bronfenbrenner’s ecological systems theory and the 5 C’s

Bronfenbrenner's model captures individual factors of influence, including sociocultural levels within the environment, highlighting the impact of relationships and events throughout the life cycle alongside acknowledging the existence of ecological systems into the wider community (Appendix 5). The research question focuses on social experiences, relationships, and connections with others by looking at both skills development and the influence of the broader ecological systems towards a goal of successful integration with the community (DfE, DoH, 2015).

Therefore, the conceptual framework of mapping the movement between the ecological systems alongside the categorisation of their skills allows for an analysis of their perceptions of their experiences, focused on their transition, movement between systems from the familiar to the unfamiliar and the role of accessing key support relationships.

The use of an ecological systems theory can help to capture the complexity of environments accessed as an individual develops and expands into the wider community. Bronfenbrenner’s theory was a process of his self-reflection, originating in his earliest conceptions of an ecological systems framework (Bronfenbrenner, 1979). In his later work, he included the person's role in their development rather than looking solely at the environmental factors (Bronfenbrenner, 1986). In this study, I refer to the earlier categorisations of the ecological theory (Bronfenbrenner, 1979) with a focus on the environmental settings, as this provides structure for the journey from childhood into adulthood, noting the movements between the various accommodations. The later work by Bronfenbrenner (2005) moved the theory into the interrelationships between the four elements of the process-person-context-time (PPCT) model (ibid). The detail of proximal processes (ibid) for analysing the life experience narratives moves away from the field of SEND and the educational context of my research. Therefore, the overarching original ecological process model (Bronfenbrenner, 1979,1986) is more relevant and can be used in conjunction with the personal skills development of the 5 C’s for a theoretical framework that supports a thorough analysis, while maintaining the impact of educational content at its core.

The addition of the 5 C’s (Carroll, 2005) is used to identify aspects of personal development within the ecological systems as, without which we ignore the ‘human nature interconnections’ (Elliott and Davis, 2020) as a facet of adult life. The inclusion of the 5 C’s (Lerner *et al.,* 2009; Carroll, 2015) brings the interaction back to a community-based model albeit influenced by the political and socioeconomic aspects of adulthood (Elliott and Davis, 2020). The linear model of childhood development that radiates outwards into the ecological systems (Bronfenbrenner, 1979) can become more fluid in adulthood, with movements back and forth as the social and political influences impact on interaction with others, and relationships build and then breakdown as connections ebb and flow **(**Gobec *et al.* 2022**).** Although the inclusion of resilience is not mentioned within the ecological systems theory (Bronfenbrenner, 1979), it relates to human and skills development as resilience and those entrepreneurial conditions of human interaction are apparent as adults emerge (Christensen, 2016; Abdul Kadir and Mohd, 2021) and develop relationships with others. As adults develop, their character forms, and the values and beliefs that will enable them to function in the community become embedded, while developing the skill of caring and empathy for others (ibid).

Within life experience narratives, a transition to adulthood creates actions to occur within the micro and macro level, as independence grows and reliance on formal support from others fades (Christensen, 2016). Changes to the interaction between family, organisation and society also adapt as the ecological accommodations expand. In this study, the framework of utilising the ecological systems theory captures the impact that skills development has on an individual's ability to confidently transition into the wider community (macrosystem) (Bronfenbrenner, 1979). The theoretical framework will help to identify the ecological systems present in the life experiences of the two participants. The integration of the 5 C’s (Lerner *et al.* 2009) will help to identify the psychological aspects of their perceptions, beliefs and attitudes, alongside the social aspects of any interpersonal relationships and whether or not access to social support is required (Newman and Newman, 2022).

Skills development is the pathway provided by the SEND Code of Practice (DfE, DoH, 2015) towards independence, employability and community participation for those adults with mild to moderate difficulty. The anticipated route for developing those specific skills is to attend supported learning at college, where a variety of personal development skills are offered that are designed to support a transition to adulthood (ASDAN, 2023). The personal development skills within the ASDAN curriculum (ibid) allow the individual to discover more about their own abilities and aspirations through taught sessions, periods of reflection and experiences like work placements to be able to experience what life might be like as an independent adult.
The positive youth development skills, known as the 5 C’s, which include ‘competence, confidence, connection, character and caring’ (Carroll, 2015)

are not a benchmark of the skills that adults must acquire, but are in line with the themes that appear in the modules of the supported curriculum for further education (ASDAN, 2023). These are designed to provide the required skills for a successful transition, including the preparation for employment, which appears as a critical component in the research (O'Connor *et al.,* 2014; Malkani, 2021), reporting that the acquisition of skills can support an ability to cope with life's changes, alongside the development of competence and self-belief, to form positive relationships through a connection with others (ibid). In line with this, ASDAN (2023) also include a focus on independent living skills, community engagement and personal values, through modules on integrity, caring and financial security. Therefore the acquisition of the 5 C's, which are, reported as valuable skills for a transition to the wider community (Abdul Kadir and Mohd, 2021) links back to the transition pathway in place, within formal education as an expectation of government policy (DfE, DoH, 2015).

2.20 Conceptual framework

This thesis will reveal the aspects of the participants' life stories concerning their connection with and reliance on support required and utilisation of skills development by linking Bronfenbrenner's ecological systems theory (1979, 1986) as a framework to show the interplay between the individual, familial and environmental factors that influence human development. The 5 C's of Positive Youth Development (Carroll, 2015) are rooted in the ecological systems theory (Bronfenbrenner, 1979, 1986) in the following manner: competence is connected to the microsystem as it reflects an individual's ability to interact within the family unit; this will develop and extend in adulthood through the interaction with teachers, social clubs and interests as an individual moves outwards, more removed from family members towards other support services and employment that exist in the broader accommodations of the mesosystem and exosystem (ibid). Confidence relates to self-identity, beliefs, and values, and through the positive experience and support that an adult might seek as they move within the broader community of the exosytem (ibid). The aspect of connection is a fundamental attribute, and as skills develop into the broader community in the mesosystem (ibid), relationships build, and a sense of belonging and being part of the community develops. 'Competence, confidence, and connection' (Carroll, 2015) reflect the supportive attributes required in adulthood to connect with others successfully (Abdul Kadir and Mohd, 2021). Character is an overarching skill set that includes values and beliefs, which develop throughout an adult's life. They commence with the formation of family values within the microsystem of family life, expanding through the mesosytem to the exosystem of work, community engagement and other activities that exist outside of the family unit, all interlinked through developmental attributes as a caring trait of being able to contribute, support others, and form and maintain relationships throughout their adult lives (ibid). The ecological systems theory of Bronfenbrenner (1979) will support the understanding of the accommodations an individual moves between, with the skills noted within the 5C's providing a lens with which to analyse and seek insight into the research question of '*What can we learn about the lives and experiences of independent adults who have previously been designated with mild/moderate Special Educational Needs and Disabilities (SEND) from their personal narratives?'*

If we look at the 5 C's (Lerner, 2009) in isolation, the headings are too general to support an investigation into the preparation for adult life specifically related to the input offered within education. The 5 C's are a strength-based model not directly associated with the needs of individuals with SEND, although the ability to deal with the stress of adult life (Lerner, 2009) is a requirement for all adults, regardless of their designation and those informal support networks are fundamental to all (Gobec *et al.,* 2021). Recent research reports that the focus of the 5 C's of positive youth development (ibid) continues to maintain its relevance and builds on the individual strengths to support a transition into the wider community (Abdul Kadir and Mohd, 2021). A connection exists between the 5 C's (Lerner, 2009) and the supported curriculum (ASDAN, 2023) within the modules' descriptions and attainment goals (Appendix four). Education is the main pathway for those with a mild to moderate designation and the further education curriculum is designed to lead them through a series of modules, including experiential learning and workplace opportunities as part of the provision of skills towards independence and employment (DfE, DoH, 2015). Beyond the 5 C's and the positive aspects of development, it is important to note that the focus of a successful transition into adulthood requires an aspiration of purpose and hope (Abdul Kadir and Mohd, 2021). Hence, a variety of strengths and a pathway towards a positive identity are crucial, particularly when we are looking towards the policy goals of employment and community integration (DfE, DoH, 2015). The momentum of reaching the goals determined by policy can be seen to link to a supported curriculum that provides the opportunity for skills development for those with a designated difference (ASDAN, 2023).

2.21 Summary

The literature identifies a need for an overarching policy and practical guidelines to be able to manage the expectations of individuals as they move towards their goals. The journey towards adulthood and independence for those with a mild to moderate designation of SEND is not without problems, and a variety of barriers to inclusion, including stigma (Anastasiou and Kauffman, 2011) and the availability of relevant and appropriate support (Crane *et al.,* 2021), can hinder an individual’s progress. A fundamental dichotomy is also a move between a medical model of a diagnosis to access support and a shift in identity that leaves this behind in adulthood, as the relevance of the previous designation fades once formal support ceases to exist. For some individuals, the concealment of differences can reduce the impact of stigma and labelling on identity (Oliver, 1996; Anastasia and Kauffman, 2011; MacIntyre, 2014; Handoyo *et al.,* 2022) but at the same time mask the reality of their experiences. For those individuals who are struggling to cope in adulthood, their inability to connect with others can impact negatively on their mental well-being (Abdul Kadir and Mohd, 2021).

The SEND Code of Practice (DfE, DoH, 2015) outlines the expectations that college courses and supported employment opportunities will support a transition. In adulthood, a reliance on skills becomes more prevalent as the formal educational support services fade (ibid). The goal in adulthood described by Morrise *et al.* (2013) is for a ‘quality of life’, and the research by Montgomery *et al.* (2019) identifies ‘freedom’ and ‘social inclusion’ as factors of ‘normal life’ approached through a connection with others. The positive aspiration noted by Abdul Kadir and Mohd (2021) also aspires to a ‘purpose in life’ related to acquiring skills. However, as previously noted, an aspiration for a purposeful life is not solely attributed to those individuals living with a difference (Wong, 2020), although the importance of skills acquisition does relate as the challenges that the individual might face could require additional input to reinforce skills development prior to their transition.

This study investigates how each individual perceives their transition from the aforementioned formal support structures within education, as they follow the defined pathway (DfE, DoH, 2015) and identify experiences by investigating the elements of skills and how they are applied in reality within the life experience narratives. The conceptual framework was used to analyse the narratives and look at the accommodations that the individual has moved between, and also note when and how they have applied any of the skills acquired. The ecological framework (Bronfenbrenner, 1979) provided clarity on the ecological systems that adults live within and the 5 C’s (Lerner, 2009) provided a framework of personal development attributes that support transition. This conceptual framework supported an investigation into what adulthood is like for the two participants regarding their social experiences, relationships and a connection with their community. The study identifies how prepared an individual felt they were as they transitioned from education to independent adulthood once the formal support systems were no longer readily available.

Chapter Three - Methodology

3.1 Positioning the research

In this chapter, I explain my position within the research and describe how the ethical considerations underpin both the methodology and the research method due to the potential vulnerability (Aldridge, 2014) of the research participants. The criteria for selecting the participants required adults who had a previous designation of a mild to moderate SEND (DfE, DoH, 2015), and who were now living independently. Due to the potential vulnerability of those individuals and in line with the ethical guidelines, a safeguarding system was required. All names within this thesis are pseudonyms to ensure confidentiality. The most appropriate way to manage this was to recruit individuals who were part of an organisation with safeguarding policies in place.

I approached a local community-learning organisation I had previously completed a case study on for my Masters dissertation (Gregory, 2017). The manager kindly put forward two potential participants interested in participating. They were employed part-time by that organisation and had a previous designation of SEND from their time spent in education. Once the manager had initially approached the individuals, I invited them to a meeting to discuss the study, how the research process would run, and what their contribution would look like. Within this chapter, there will be more information provided on the process of the research method, but during the initial discussion with the potential participants, the method was described as being conversational in order to build trust and to allow the participants to tell their story informally.

During that initial meeting, when the research topic was introduced and the style of the method was discussed, it was initially thought that the conversations could be carried out in a small group. It became apparent at that time that both of the participants would prefer to meet separately. As the discussions unfolded, it was revealed that they had previously been in a romantic relationship and would have been uncomfortable revealing their personal stories in the same space. In this chapter, the style of the research conversations will be explored in more detail, and an explanation of the need for professional boundaries will also be expanded on.

The research question seeks to discover more about the lives of those adults formerly designated with SEND (DfE, DoH, 2015), alongside the sub-questions of exploring the perceptions of social experiences, relationships and any connections with their wider community. Careful ethical consideration (Guba and Lincoln, 1989, 2005) was required when deciding on the most appropriate process, particularly related to the potential ‘vulnerability’ (Aldridge, 2014; DfE, DoH, 2015) of those participating in the research process. This research does not test a hypothesis but instead explores an assumption that formal education provides the required support and tools to succeed during the transition into adulthood and beyond.

When identifying an appropriate research paradigm there are multiple subjective realities to be explored; as everyone’s experiences differ according to recollection, environment, and external and internal influences (Stefánsdóttir and Traustadóttir, 2015). The concept of adopting a measured approach of quantitative analysis (Mertens, 2010) was not deemed to be appropriate, as I required a detailed recount that included the emotional responses of the experience to be able to understand more regarding any perceived barriers and also to celebrate success. Quantitative research has a place in this field and a ‘Perception of Inclusion Questionnaire’ (PIQ) (Venetz, *et al.,* 2015) was considered as an additional method to define the extent of a connection with others as part of a mixed-methods approach. However, I decided not to use the PIQ as the format predominantly applies to children rather than adults, and I wanted a broader perspective of adult life experiences that came from those being researched. In order to reveal an in-depth insight, it was decided that time should be spent on developing a research relationship by building trust within a flexible approach that best suited the needs of those being researched (Aldridge, 2014), particularly being mindful of their additional needs associated with a designation of mild to moderate learning difficulties (DfE, DoH, 2015).

Therefore, the research stance most suited to those taking part in the research was interpretative, leading back to the phenomenological methodology of Husserl (1970) and the interpretative stance of Heidegger (1962), who argued that meaning is interpretative. The constructivist interpretative paradigm relied heavily on the researcher-researched relationship and incorporated ethical considerations alongside the development of ‘reflexivity, rapport and reciprocity’ (Mertens, 2010, p.18). As a researcher, I was aware of ‘first-person authority’ (O’Brien, 2017, p.64), alongside the power differentiation that carried with it from my professional practice. I needed to challenge my intrinsic epistemology to be able to reveal new knowledge (Punch and Oancea, 2014), and to explore existing assumptions that the transition and support in adulthood is adequate to sustain the required connections with others (DfE, DoH, 2015).

Within my research role I acknowledged that my perceptions and assumptions were to be challenged, moving my understanding of their reality towards the margins (O’Brien, 2017) in order to foreground the people whose lives I was interested in. Since defining the research paradigm, ethical considerations remained at the forefront of the research design (DfE, DoH, 2015). There were some challenging research encounters and these will be outlined in more detail later in this chapter.

The development of the required approach (Mertens, 2010; Aldridge, 2014) needed to be one that was relational and supported an in-depth recount of experiences that offered a ‘thick description’ (Geertz, 1973). The research design supported an openness and trust to enable those researched to reveal their emotions, providing a more detailed reality (Mertens, 2010). The research approach also required careful ethical consideration that included a structure of support with links to external safeguarding systems. This approach was fundamental to ensure a research environment of both value and support (Oliver, 2002), without which I could not have been able to conduct the research over an extended timeframe. The research paradigm needed to be emancipatory allowing those researched to speak freely without judgement, and the underpinning ethical considerations supported this approach (Oliver, 2002; Stefánsdóttir and Traustadóttir, 2015). The life experiences were deemed to be gathered in a meaningful order to the participant (Guba and Lincoln, 2005; Flynn, 2019) as the recollections arose within the research encounters, which might not conform to logical time sequencing.

As a researcher, it is my belief that knowledge is socially constructed and can change according to whose experiences are being considered (Crotty, 2015) and the research design had to reflect this aspect. The research design needed to reinforce the trusting relationship (Owens, 2007; Aldridge, 2014), and the constant research reflexivity provided an avenue for any challenging beliefs or interpretative thoughts (Finlay, 2008) that could have influenced the accuracy of the data collation. To ensure accuracy and to assist with the maintenance of an appropriate research relationship reflections were captured in field diaries before and after research sessions to consolidate and reset my researcher positionality.

3.2 Considering alternative approaches

A phenomenological methodology was initially considered, as openness was required rather than seeking answers to a set of questions within an interview. A purely phenomenological approach (Husserl, 1970) relies on the ‘bracketing’ of external perceptions and knowledge. I considered that this approach could limit the ability to share and consolidate incidences, partially due to the power differentiation and also through the subjective nature of focusing on the structure of the experience (Husserl, 1970). There were occasions when a discussion ensued to clarify the experience using the researcher’s experience. Rather than leading or influencing the recollection, the relationship encouraged the train of thought to continue, even if additional time was needed rather than allowing the new information to cease to exist (Laverty, 2003; Finlay, 2008; Willig, 2010).

The detailed consideration of the ethical process, to be discussed fully later, meant that I was prepared to manage the more challenging encounters by acknowledging and challenging my perception of reality (Churchill *et al.,*1998; Van Manen, 2015; O'Brien, 2017). A relational and naturalistic approach (Mertens, 2010) acknowledged the relevance of feelings, allowing an emotive stance to integrate the retelling of life experiences by adopting a hermeneutical approach (Van Manen, 2015). Hermeneutics aligns with the continual reflexive process that was required during the fieldwork (Finlay, 2008; Noon, 2018). A 'hermeneutic reflection' (Finlay, 2008) describes how the research process felt, as I moved between the experience of those researched and my own understanding; this unveiled an awareness of new perceptions that challenged my beliefs and expanded my horizon (Caputo, 2018).

Alternative qualitative methods were considered during the research design phase to validate the data. The addition of an interview with an employer or friend to provide additional insight was explored, but this was dismissed as the trust developed between myself and the key participants could have been compromised (Ely *et al.,* 1991; Foucault, 1997; Riddell and Watson, 2003; Aldridge, 2014; Muhammed, *et al.,* 2014) leading to a breakdown in the research relationship. Meeting together in a focus group environment rather than separately, was also explored (Thomas, 2009), but as the participants were friends I did not want their relationship to intrude on the individual data (Aldridge, 2014); instead individual sessions were planned, as talking about their own lives was the main focus. The addition of creating a piece of art to depict incidences in chronological order was also discussed, as a method that allowed for additional information to be captured that might not be able to be articulated (Theron *et al.,* 2011*)*. Again this was discounted by the participants themselves at the initial discussion regarding how the logistics of the research sessions would be managed. It was important to the research relationship that the process was flexible, so that those being researched felt comfortable in sharing their stories.

Furthermore, an ethnographical study would not have supported the research question, as the data needed to arise without initial interpretation (Crotty, 2015). If the researcher does not have similar designated challenges, they cannot readily absorb themselves into the environment (Thomas, 2009). An immersion into the cultural community would also have been a challenge as the researcher/research participant's boundaries could have become blurred. Ethically the research relationship needed to have clear boundaries to delineate the relationship as that of a researcher and not a friend (Cohen, *et al.* 2007) becoming embedded in their environment. As a researcher, I worked hard to maintain a delineated professional relationship through clear research rules and structures (Thomas, 2009) and this supported the continuation of regular research sessions.

The qualitative methodology was developed after carefully considering a range of alternate approaches - in particular, what would work with these participants who might not be able to articulate their answers in a written form due to their diagnosis of a mild to moderate learning difficulty. As a researcher I did not want to impose a framework to the research process but to start the data collation from the voices of those being researched. Observations of their daily lives would only reveal current incidences, and the power dynamics would be challenging in this instance (Owens, 2007; Chilisa, 2020). A relational approach was sought that offered the participant time to reflect on their life, without the constraints of literacy competency or set questions that could influence the discussion towards a more anticipated response (Chilisa, 2020).

The overarching qualitative relational approach was developed out of my own experience of having informed discussions with higher education students. These discussions were part of the Disabled Students Allowance (Student Finance England, 2023) assessment process regarding students' experiences of successful and unsuccessful strategies of support in school and college. My experience gained in community settings with neurodiverse adults was also relevant. These broader free-flowing conversations had been found to facilitate a more detailed insight into personal experiences, allowing for a reflective and unpressured approach to the recollection (Aldridge, 2014). Furthermore, the research role needed to allow for a reliable and consistent investigation into humanistic values and experiences carried out over an extended discussion period. An extended period was required to build trust (Owens, 2007; Chilisa, 2020) and to enable the research to deepen. Although time was spent in the participants’ chosen environments, the research stance was not to become part of their everyday lives ethnographically, but rather to elicit the stories and relate these from the participants’ perspectives with minimal interpretation at the point of data collation.

3.3 The implications of using a narrative enquiry

Our conversation with others is part of most of our daily lives; it can be with someone we know or a fleeting dialogue with someone unknown. In order to foreground the life experiences of the people whose perspectives I wished to capture and to address the research question, a narrative enquiry was chosen as it would feel familiar to the participants involved. A narrative enquiry can capture the realities of life to provide new perspectives. In this study, the perspectives were gathered from one narrator at a time (Moen, 2006; Grove, 2022), and the decision-making for this will be explored later in this chapter.

In this study, a dialogue provides an opportunity to frame the research question. A narrative enquiry can also be undertaken to address the previously noted issues of vulnerability (Aldridge, 2014: DfE, DoH, 2015) by offering a ‘bottom-up’ approach with the emphasis being on the person sharing their story (ibid, 2014). Maintaining a research design that allows the narrator to speak (Moen, 2006) and be listened to is crucial. In this study, although the stories are captured individually, at times a collective voice can be heard, and the recollection gains additional weight when stories corroborate an incident or emotional response (Vygotsky, 1978; Moen, 2006).

The narrative enquiry had to engage the participants without the stories becoming a co-construction (Grove, 2022) to share any potential counter-narratives (Stefánsdóttir and Traustadóttir, 2015; O’Brien, 2017). It was also imperative that any prior expectations (O'Brien, 2017) I held as the researcher were kept in check so that they did not intrude on the recollection of the life experiences of those in the study, which might have occurred if I had used a set of interview questions. By broadening the scope of the narrative enquiry to collate everyday events through an open conversation, a multi-dimensional insight into their life experiences emerged (Grove, 2022). This focused on recollections of incidences considered impactful by the participants, rather than becoming engaged in a general conversation that could skew the memory into a co-construction (ibid, 2022). The life experiences in those conversations were primarily personal and defined as small-scale (Goodson, 2013) concerning everyday events rather than the overarching, broader narrative of government policy. As a researcher, I did not anticipate that the participants would be aware of the impact of government policy on their daily lives, although I was aware of the potential links and how those broader decisions might have influenced the individual contexts (ibid, 2013; Stefánsdóttir and Traustadóttir, 2015); this is addressed during the analytical phase of the study.

While considering how to reveal the narrative, various approaches were considered, and having a research conversation was one of them (Clandinin and Connelly, 2000). By adopting a relational approach, I could extend empathy to support the participants in revealing those personal experiences (Aldridge, 2014). Rather than looking for a narrative that addresses cause and effect (ibid, 2000), I wanted to create a more ‘invitational quality’ (ibid) which is described by Clandinin and Connelly (2000) as being associated with ‘wakefulness’. As a researcher, this concept of ‘wakefulness’ (ibid, 2000) resonated with my researcher role. I had to constantly reflect on the process and monitor the environment while maintaining a watchful eye on the participants’ well-being before during, and after each session. Furthermore, to ensure that those involved in the study were considered ethically, the research relationship remained at the forefront to ensure that all parties were engaged and keen to remain within the study. By using ongoing reflection, I was more able to ensure that the professional boundaries remained in place (Goodson, 2013: Aldridge, 2014).

As defined by the research question, this study also required the recruitment of participants with a ‘relevant conscious experience of the world’ (Pring, 2015) who were independent thinkers with experience of social relationships (ibid) to provide an in-depth narrative that included aspects of the context and meaning (Geertz, 1973). However, when working with memories, the challenge is to be able to delve deeper and look for the 'rough edges' of the recall (Andrews, 1991), so by taking the time that was needed to describe key incidences and relationships that had impacted on their lives (Finlay, 2008; Aldridge, 2014) the data was able to come directly from the source (Mertens, 2010) without interpretation. There is a notion that those with mild to moderate challenges might be more independent (Adler *et al.,* 2022) than those with more profound difficulties. Therefore the choice of mild to moderate difficulties provided more experienced participants who could relate to transitioning from formal education (DfE, DoH, 2015) into adulthood. As a researcher, I recognise that all adults have some level of vulnerability (Adler *et al.,* 2022), and I understand that this is not only associated with a designation of SEND (ibid, 2015). The relevant life experiences, alongside an ability to articulate memories, gave the study the detail and depth of the recollection, including the emotive content to produce data with additional meaning.

3.4 Selecting a suitable narrative approach

In preparation for the narrative enquiry, I investigated suitable relational narrative development methods. In phenomenological research, there are explorations into what is referred to as the 'lifeworld', where existential themes exist that are relevant to all human beings (Van Manen, 2015). Those themes include spatiality, corporeality, temporality and relationality, also known as communality (ibid), all occurring themes observed during the research conversations. These existential themes include a consideration of the influences of the spaces we inhabit and how we move between and the impact on our feelings, including existence within a research setting. Furthermore, the impact of our home and work environment relates to where we exist as human beings and how it makes us feel. The need to consider these themes meant the research process was holistic in its design, which will be discussed in more detail in the next section.

The environment was an integral part of my role as an ethical researcher (Kara, 2018), ensuring that the participants felt safe. Existentially, our corporeality is where our body exists in the world, how we appear to others, and what we reveal and conceal (Clandinin and Connelly, 2000). The design of the environment of the narrative enquiry had to support the participants to reveal their stories. Although an emphasis was on the researcher-participant relationship, this was not a friendship (ibid). By keeping sight of the holistic nature of the research relationship, the study revealed the reality more holistically (Noon, 2018) from the perspective of those who had received support rather than as a supporter. As mentioned, during any conversations concealed knowledge is possible, primarily if one party exists outside the community and might not be considered to be trustworthy.

While deliberating on how the research relationship could be structured, I reflected on relational research into Indigenous community practices I had observed while living and working in Australia. I found myself making this link because, within the Indigenous culture, the fundamental concepts of trust, openness, mutuality and reciprocity exist in community-focused informal conversations known as yarning sessions (Chilisa, 2020). Yarning means to communicate in a relational manner to share knowledge, (Barlo *et al.,* 2021). The relevant attributes of adapting yarning provided a structure where all parties are equal and have a contribution to make (Chilisa, 2020). The conversations in yarning are community-focused and relational and acknowledge the need for an environment of mutual respect and reciprocity (Bessarab and Ng'andu, 2010), which were the fundamental attributes that the research sessions required.

Although I did not want to cross the professional boundaries into friendship, the relationship needed to develop into one that created trust, not as a friend, but more as a knowledgeable ‘elder’ (Chilisa, 2020), in Australian Aboriginal Indigenous culture, an 'elder' is someone who actively listens and collates the information as presented without any interpretation; this is used in the process of yarning as a relational methodology (Barlo *et al.* 2021), which will be explored in more detail within this chapter. The research relationship was not only required to encourage the sharing of new knowledge in the first instance, but also to extend into a relationship that could make meaning of that new knowledge (ibid) by including an opportunity for reflection.

This study looks at the connections between familial and non-familial with an awareness that relationships can change and are influenced by past experiences, and openness can fluctuate depending on the conversation topic, feelings of security, and any history of similar encounters that might adversely influence the research relationships (Armstrong *et al.,* 2022). This study acknowledges aspects of temporality by building in sufficient time to develop an appropriate relationship enabling time for reflection without needing to fill any periods of silence (Van Manen, 2015), with attention paid to the exit strategy which also required preparation and care (Aldridge, 2014; Stefánsdóttir and Traustadóttir, 2015). The phenomenological theme of relationally (ibid, 2015), refers to interaction with others via our physical self, creating the formation of impressions and preconceptions (Noon, 2018; Van Manen, 2015). In this study, I aimed to transcend preconceptions and labelling by allowing space for individuals to feel comfortable and secure within the research environment (Armstrong *et al.,* 2022). This was achieved, by meeting in conducive environments where the individuals felt comfortable, and engaging in an activity that felt familiar and safe, which also adhered to the ethical considerations discussed later in this chapter.

3.5 What can be learnt from yarning?

The underlying principles of a yarning session, or talking circle, as they are also known, can be used in research. Although Indigenous in its roots, the concept appeared to fit the structure of the required relational conversations (Chilisa, 2020) to address the research conversations in this study in a comfortable and familiar manner. I was drawn into an exploration of yarning to inform the narrative research in this study, where the same principles exist and are of fundamental importance. As a methodology, yarning is relational within a holistic approach, and the process complemented the holistic design I was aspiring to of being able to access an in-depth conversation during the research phase to provide an insight into the acquisition of new knowledge (Barlo *et al.,* 2021). This style of conversation used in yarning focuses on building a respectful relationship with the participants, and in Indigenous cultures this could extend to their ancestors and historical factors. Within this study, the focus is on the relational aspects of the conversational approach and, therefore, it is an adaptation that is used within the research design.

Furthermore, an Indigenous methodology also relates to time and space and acknowledges existence similarly to a phenomenological manner acknowledging that we are all connected holistically (Chilisa, 2020). This narrative enquiry supported a revelation of all aspects of transition and independence (Cohen *et al.,* 2007; Hollomotz, 2012; Barlo *et al,.* 2021) from education to adulthood that may not have been previously considered in detail. While considering a methodology that suits the research focus and the vulnerability of the target participants (Aldridge, 2014), I felt that an adaptation of yarning would provide a relationship with the research process that was trustworthy and maintained the integrity of those involved (Barlo *et al.,* 2021), while also supporting the required flattening of any power hierarchy, which is another fundamental principle of this study (Chilisa, 2020).

I found it interesting that mutual respect underpins the methodology of yarning in Australian Indigenous culture reliant on 'elders' who are knowledgeable and use their knowledge for the 'collective good' (Iseke, 2013). Although I am not considered an 'elder' in Indigenous culture, I do have knowledge of the field of study formed over an extensive period of time. Yarning has fundamental attributes of collecting and sharing stories to inform others, which fit this study well. There is mutual respect in the yarning process (Bessarab and Ng'andu, 2010) that I felt assisted in structuring the research conversations, providing a platform for remembering (Iseke, 2013) to be able to bring these stories back to life. Although not an authentic Indigenous methodology, an adaptation of yarning was chosen to draw on some of the valuable principles and protocols that support a relational approach. As a researcher, I wanted to feel part of the process while allowing others to share their stories to reveal new knowledge (Barlo *et al.,* 2021) while remaining accountable for the research process (Bessarab and Ng'andu, 2010).

The attributes of yarning that were included in this narrative enquiry were the ability to take the conversation to a deeper level by allowing the narrator to talk and the researcher to respectfully and patiently listen. It was necessary to provide an environment that felt comfortable, non-threatening and familiar to deepen the dialogue. Within an Indigenous culture, yarning has numerous layers (Barlo *et al.,* 2021) where the conversations can be informal or social, or they might be designed to be a little more formal to impart knowledge from an ‘elder’ to a community. Whichever type of conversation is being held, protocols exist to structure those conversations, including respect, courtesy and equal participation. In some instances in Indigenous culture, a yarning session can be used to disseminate information (ibid), but this is not what was required in this study, as the stories were multi-dimensional and included a recollection of the emotions of the experience. A protocol that was critical in this study was to build a sense of trust by listening in a manner that is patient (Sharmil *et al.,* 2021), with a sense of mutuality and reciprocity to support the ongoing conversation. As a researcher, I felt that yarning provided a structure within the narrative enquiry and a feeling of integrity that encouraged those more profound reflections (Barlo *et al.,* 2021; Sharmil *et al.,* 2021).

3.6 Issues and implications arising from using narrative enquiry.

This style of narrative enquiry allowed the researcher's voice to appear within the analysis and through some of the reflective pieces. However, the participants influenced the narrative (Cohen *et al.,* 2007: Mertens, 2010: Van Manen, 2015: Adler *et al.,* 2022), and all aspects of the design, including the ethical considerations, ensuring that it is the participants’ voice that is heard. Once the life stories had been collated, a hermeneutic interpretation allowed any significant connections with others to emerge (Willig, 2010) and, with my insider understanding of some of the social interactions, a circle of interpretation (ibid) uncovered aspects of new knowledge. As a researcher existing within a parallel world, the differences in experiences defined my perception of the participants' world, and this study extended my ‘knowhow’ (Lyotard, 1984) by accessing an alternative recollection (Pinar *et al.,* 1995; Finlay, 2008) as the narrative enquiry moved from being purely a one-dimensional descriptive account into one that captured movement. This is described succinctly by Finlay (2008, p.3) as a ‘dialectical dance’ between being ‘removed from, open to, and aware of’ the detail of the narrative; this describes my role within this study as I provided an interpretation from the participants’ perspective, which challenged my existing views of what the stories would reveal.

The professional attributes of having spent so many years working in the field of SEND are crucial to this study, as I utilised my skills of support and nurture in a care-based ethical approach to the study (Chilisa, 2020), leading to a more inclusive approach (Tangen, 2008). The research design allowed for an insight into how the participants engaged in the reality of their world (Van Manen, 2015). Furthermore, in this 'dialectical dance' (Finlay, 2008), previously referred to, research boundaries existed related to the empowerment of others. In this study, it was not my role to empower the participants to tell their life stories but rather to put myself at the participants' disposal so that they could empower themselves to share their experiences (Oliver, 2002), and this resonates with the yarning protocols of sharing the knowledge but still being accountable for the research process (Bessarab and Ng'andu, 2010; Barlo *et al.,* 2021).

As the discussions ensued, experiences were revisited and, at times, adapted as the individual reflected with a more mature gaze, shifting their perspective (Geertz, 1973) on an incident. There were times when I experienced trepidation as I encouraged those involved in the study to share their story, particularly as the relationships developed into mutuality and openness. This type of tentativeness relates to what was documented and, at times (ibid) my positionality as a researcher, as I had to overcome some of the complexity related to the process when exploring the unknown. I decided to document the reflections to remind myself of my role in the process after each session, to ensure that the stories collated were solely the individuals’ perception of their life experiences (Berryman *et al.,* 2013).

As previously noted, the ethical considerations and the complexity of the participants' needs were considered first and foremost; these are threaded through the research design while aiming to maintain a credible study that provided insight into a valid and significant truth (Berryman *et al.,* 2013; Hollomotz, 2014; Grove, 2022). The narrative recollections relied on recalling incidents from memory into meaningful interpretations (Moen, 2006; Berryman *et al.,* 2013) and placed the event in the relevant context (ibid, 2006). It was acknowledged that recall and belief systems can also influence the factual nature of working with memories (ibid, 2013); therefore, the testimony is a reality from the participants' perception, not to be disbelieved or challenged, but to be accepted at face value. The addition of keeping a field diary to note additional ponderings (Berryman *et al.,* 2013; Van Manen, 2015) helped to capture the emotions of the recall.

As part of the session structure, the participants were regularly checked in with to ensure they were happy to continue in the study (Mertens, 2010; Kara, 2018). Their continued enthusiasm for the process was consolidated each time a session was planned. Those involved were asked about their continued involvement and there were always positive responses, as they were aware that they could leave at any time during the process (Clandinin and Connelly, 2000). The motivation to continue was the mutual enthusiasm to share their experiences and to enhance the transition to adulthood and independence for others. Throughout the data collation phase, the responsive methodology supported a relevant researcher-researched relationship (Berryman *et al.,* 2013), without any issues arising that significantly interrupted the process.

3.7 Gatekeepers and commencing the research process

During the research design and the initial discussion with the potential participants, the subject of gatekeepers arose. The impact of significant others could have influenced the engagement and contribution of the individuals sharing their stories, and this required careful consideration. At the initial meeting with the participants, during discussion regarding consent and what the expectations were, it was also essential to discover the potential participants’ level of independence regarding whether there was a need to seek permission from a key worker, and also to determine if they wanted to share any information with a friend or family member prior to agreeing to be involved. It was anticipated that any informal level of support through adult familial or peer relationships would be more reciprocal in nature and less likely to influence their participation (MacIntyre, 2014), but any formal support relationships, like key workers, needed to be identified. In this instance the chosen participants were not in receipt of any formal support and were living autonomously as independent adults. It was agreed at the initial meeting that the manager of their community organisation would be available as a familiar point of contact, if any additional external clarification or support was required.

Furthermore, at the initial meeting, each participant was provided with a research overview (Appendix 1), which was read through, and time allocated for questions, and this information was provided for them to take home. In addition, the consent form (Appendix 2) was also discussed in detail to ensure that they both understood what was expected of them. By reading and discussing the content, it ensured that the detail was understood, and it was at this point that a preference for individual meetings was expressed. The ongoing methods of keeping in touch were also agreed upon; I suggested creating a joint 'WhatsApp' group, but after careful consideration the participants decided that individual text messaging was the most appropriate form of communication. It was agreed that I would send a text message to remind the individual the day before the meeting to ensure they were still available.

The inherent confidentiality required in any narrative enquiry necessitated an unambiguous informed consent process. The discussion, reporting pathways and printed information seemed sufficient at that initial meeting. It was essential to ensure within the research process that on-going consent was consistently provided alongside a regular reminder of the focus of the study, the nature of their individual role, and a check on any topics revealed that had appeared personal to ensure that the participant was happy to include that particular aspect as part of their recollection.

Since defining the research and ethical clearance process, it was noted that the participants would need to be able to clearly articulate their story, which became part of the recruitment criteria. In order to support my comprehension of the content, the participants required appropriate communication skills to reduce some of the potential ambiguity in the narrative (Aldridge, 2014), although not eliminating it all. The life experiences captured in their stories acknowledged their challenges and embraced their successes, and the documentation of the participants’ life stories provided a detailed recount, including emotional connections, in order to create a more holistic description of events (Guba and Lincoln, 1989; Bolton, 2014).

In adulthood, there are a variety of environments or systems that we operate within in our daily lives. This study aims to discover more detail about types of social experiences, relationships and links with the community in the context in which they occur. The systems that adults move within can be wide-reaching (Bronfenbrenner, 1979), particularly as the individuals' engagement with others extends in adulthood from the immediate family to school and close friends, and to the broader systems of work and community engagement where other interactions might occur. Furthermore, the stories revealed aspects of the participants’ personal development (Carroll, 2015; Abdul Kadir and Mohd, 2021) and relationships formed along the way.

3.8 About the participants

As a researcher, the willingness of participants to disclose their experiences was a crucial indicator of the success of the research. My professional background, alongside the ethical considerations, focused on ensuring anonymity. The individual research sessions provided for confidential deeper research conversations that could have otherwise been suppressed. The data was stored and presented anonymously, and details of the narratives were not disclosed to any other party (Appendix 3). As a researcher I felt privileged to have access to their stories and responded to controversial insight from a place of professional concern as the relationship developed. Initially shy, both participants became more confident over time, eager to share their experiences which might provide insights to aid others' transition into adulthood. Collaborating with the community organisation manager ensured compliance with safeguarding policies during the recruitment process. Both participants, in their 30s, followed a similar educational path, starting in mainstream school before transitioning to a specialist school after conformation of their SEND designation (DfE, DoH, 2015). They then pursued further education, participating in supported learning courses that emphasised personal development skills alongside work placements. While one participant transitioned to a mainstream further education course, both faced challenges in securing desired employment opportunities.

The relationship commenced as a researcher with a structured approach to the research sessions to reinforce the researcher/researched relationship (Ely *et al.,* 1991). As time passed and conversations deepened, there were times when the relationship fluctuated into that of a practitioner when a story related to education and employment, and at times extended into a friendship when exploring the complexities of adulthood as I began to feel part of their lives. At times the structured research relationship blurred as I listened to their life experiences, which resonated with my own. This shift in role allowed for empathy to nurture their storytelling. At times, this felt challenging, messy and emotionally taxing, but gaining rich insight into their stories was necessary. Both participants initially volunteered at a community organisation, showcasing their creative skills, before transitioning into paid roles. At the time of the research, they both worked part-time as support workers for one day a week and volunteered for an additional day. Their original SEND designation, primarily associated with Autism Spectrum Condition (ASC), anxiety and aspects of dyslexia, was confirmed by the community organisation manager and discussed during the research sessions.

The openness and trust within the research process negated any aspects of deception (Mertens, 2010), as the participants were aware of how and why their designation of mild to moderate difficulty was a relevant part of the recruitment and research process. Further, part way through the data collation, one participant revealed their embedded coping mechanism of 'masking' their difficulties through a desire to appear the same as everyone else (Den Houting *et al.,* 2021; Cook *et al.,* 2024); the ability to disclose this hidden trait demonstrated the extent of the trust built into the research relationship.

Both participants at the time of the data collation were in a romantic relationship with other people. However, as mentioned, they had also been in a long-term relationship with one another. One of the participants is a single parent, which brought an additional dynamic to the adult life experiences of relationships, childbirth and parenting. During the conversations, it appeared that both participants had social lives linked to their differing interests that formed crucial components of their social interaction with others. There was also some overlap in their social lives, although this was quite limited and their main contact was through working together. The recruitment originated with a need to meet the criterion of SEND within a deficit model focusing on a diagnosis. Although this was not the topic of the discussions, it was an element of their life experiences leading towards independent adulthood (Gerber, 2012; Ledger, *et al.,* 2021).

As a researcher I concentrated on exploring what was illuminated and have not speculated on what was not. The data provided information on many positive aspects of adulthood, including family, friendships, romantic relationships, financial security, and employment. As previously noted, the two narratives provided a detailed insight into daily life, presented as a positive recall without the anticipated problems I expected to reveal. There were glimpses of liaisons with external agencies perceived as authoritative and unfamiliar. Their narratives revealed the support strategies required to cope and highlighted the need to disclose differences to receive adjustments. Navigating life’s challenges and uncertainties requires a level of resilience; evidence for this was less tangible, as there was a tendency for both individuals to shy away from an interaction with perceived authority (Antony, 2022). In both instances, there was limited exposure to major incidences in adulthood, although this might not be the case for all people with a SEND designation.

3.9 Research environments

Both participants worked part-time, and it was apparent through our conversations that they remained within a low socio-economic section of the community, relying on benefits and other concessions. To minimise the cost of travel, meetings were arranged to suit the participants; they always chose the setting as somewhere they felt best suited their own needs. If it was to be in a coffee shop, it was agreed at the start of the initial meeting phase that refreshments would be paid for or provided by the researcher as part of being grateful for the opportunity to hear their story (Mertens, 2010). The research environment was embedded into the plan to allow the location for conversations to be participant-led (Kinney, 2021) and to limit any feelings of inequality. An environment can influence behaviour (Bronfenbrenner, 1979); there was one location that was chosen by me as the coffee shop was closed, and it was apparent that the participant was not at ease in a different setting.

Since I needed to flatten the research relationship to develop a feeling of trust and openness, the attention to the appropriate choice of research environment helped to limit the power differential within the researcher/participant relationship. I was aware that I had contrived the planning process and selected participants who could meet the criteria of the research question; I then relinquished that initial control to provide as much autonomy as possible. In Riddell and Watson (2003, p.30) it is mentioned that, when working with adults with a difference 'a perceived culture of participation could also be a culture of control'. The balance between categorising the research within the arena of SEND during recruitment, and then shifting the focus from a deficit perspective during the research process was a challenge I took on so that I could attend to their story (Bolton, 2014). I acknowledged that I commenced the recruitment with a classification of the participants as a 'kind' (Darling and Heckert, 2010; ibid), but this was to ensure that I recruited the most appropriate participants to address the research question. The data is attributed to the experiences of the participants from their perception of events, and this is where the groundwork of creating a research relationship that felt mutual and reciprocal (Abraham *et al.,* 2002; Darling and Heckert, 2010) supported the process so that ultimately it was their ‘commanding voice’ (Goodson, 2013) that resonated as the expert (DRILL, 2020).

As an experienced practitioner in the field of SEND, I was able to engage with the participants positively, recognising many of the non-verbal cues that could be missed by a less experienced practitioner (McConkey *et al.,* 2009, p.12); the attributes required were those of openness and acceptance with a sense of calm (ibid). In many incidences, the participants revealed their resilience and an optimistic outlook (McConkey *et al.,* 2009), and as their confidence grew and they became more adept at taking the lead, they moved from a place of compliance (Riddell and Watson, 2003) to one where their life experiences and the challenges faced were heard (McConkey *et al.,* 2009). By keeping ethical considerations at the forefront, the vulnerability diminished (Aldridge, 2014) to a point where it became invisible and issues like ‘masking’ (Cook *et al.,* 2024) were no longer required, as the participants became more at ease with the process.

In contrast, when gathering a narrative a biographer might interpret and introduce an unnecessary bias into the narrative (Stanley, 1992), shifting away from the reality of the experience, particularly if there are silences. Periods of quiet did occur in this research due to the inherent challenges of some aspects of social interaction associated with Autistic Spectrum Condition. The narrative process needed to feel comfortable and allow for an adoption of those quiet spaces (Braun and Clarke, 2022) in order to reveal all of the life experiences as 'stored phenomena' (Clandinin *et al.,* 2009). At times the chronology of the life story changed direction as discussions about social experiences, links with others and environments unfolded, triggering other memories (ibid, 2009). One of the strengths of the research was that although the participants were talking separately, their stories had elements of similarity, which provided the recollections with gravitas (Goodson, 2013).

The environment was crucial to enabling the research process to feel natural and uninhibited. As human beings, we share stories to connect with our close network to build relationships (Kara, 2018); this can also be a method of sharing problems and gaining knowledge to support personal growth within the ecological systems we find ourselves in (Bronfenbrenner 1979, 1986). Our stories place us in the world, and each story is unique and expressed through the participants' identity and sense of self. The narrative enquiry was designed to move away from the standard question-and-answer approach into a more free-flowing reflection of life experiences (Kara *et al.,* 2021) as anecdotal stories led to other moments in time (Bolton, 2014), sometimes linked but frequently abstract. Therefore the individuals and the settings worked reciprocally, keeping ethical considerations at the forefront (Kara *et al.,* 2021) and building trust within the researcher/participant relationship (Pring, 2015; Braun and Clarke, 2022) in order to allow a more truthful version of events to emerge

3.10 Meeting the participants

The research conversations offered insight into how the participants constructed meaning from their systems of belief, attitudes, and values (Goodson, 2013). Underpinning the research is the key relational aspect (Ely *et al.,* 1991) of trustworthiness (Goodley, 2021). The lived experiences were explored to include interconnectedness with others and the environment (Goodson, 2013; Chilisa, 2020). This research took place fortnightly over six months, ensuring that the initial momentum was maintained to keep the flow of the stories coming (Braun and Clarke, 2022). There was an inbuilt overlap in the conversation structure at each session that set the scene, and allowed for a recall of the session structure and topics being discussed to refocus on the setting of our research/participant relationship (Riddell and Watson, 2003; Goodley, 2021); this ensured that the participant's voices remained as the expert in this process (Ledger, *et al.,* 2021). There were no set questions or preconceptions of what was to be discussed. However, the research topic of social experiences, relationships and connections with the community was frequently referred to in order to guide the story framework. The conversation generally flowed well. If the conversation was slow at the beginning, I could refer back to previous topics from my field diary notes as a memory aid to glean additional information in some instances, or to build on the concepts in others prior to progressing to another life experience.

A qualitative approach allowed the conversations and sharing to continue for over five months. Since the participants chose the meeting place and took control of the conversation, the research felt participatory (Kara *et al.,* 2021). It was heartwarming to work alongside the participants as they demonstrated a keenness to provide insight into their lives, including sharing any challenges.

The research sub-question of *‘What are the implications for their education and social care beyond the formal provision?’* gave the participants an impetus to identify aspects of their experiences that could signpost potential environments for improvements. Aforementioned the participants' input is seen as an expert in the research process, reducing any power imbalance (ibid, 2021). They were also pleased to take part and had an affiliation with the research focus, which in turn seemed to facilitate a more open discussion.

3.11 Research venues

We met in various venues chosen by the participant; walking in the local area (Kinney, 2021), supermarkets, coffee shops and one of the participants' homes. This venue shift to a home environment was discussed in detail due to ethical considerations. The participant found this to be more suitable as their child required lunchtime sleep, and this was designed to limit the inconvenience to them both. We had previously tried going out, but there were many occasions when the child's needs took priority, and the storytelling was severely impacted. Ethical reappraisal was required at this point and from a relational point of view, this felt like the most appropriate way to proceed (Clandinin and Connolly, 2000). The participant gave their permission for this change of venue and was happy to negotiate to feel more at ease in their own home. It was essential to support the participant to continue to be engaged in the research by honouring their valuable participation (McConkey *et al.,* 2009; Kara *et al.,* 2021). The other participant preferred to meet in the same local coffee shop; we had tried talking and walking, and also a change of venue on one occasion when the café was closed, but it was evident that they felt more comfortable in their preferred venue. This participant liked the familiarity of the venue; we would often start the discussion by looking at the world map on the wall and discussing places we had been to, and also where they would like to travel by identifying the location as a visual. On one occasion I was about to travel to visit family in Cape Town, and they requested a postcard to see some of the main attractions.

3.12 Data capture

After each session, I recorded the conversation into a digital recording device. I had asked for permission to record the conversations, and both participants had agreed to this strategy. After the meeting, I transcribed the conversations verbatim, but there were some subtleties of conversation and nuances of non-verbal language that might not have been captured; these were collated as part of the field diary by documenting my immediate thoughts shortly after the meeting to enhance the reliability of the data (Willig, 2010). It was essential to reflect on the process regarding the ethical considerations (ibid; Braun and Clarke, 2022), ensuring that through the research conversations and associated storytelling, no harm came to the participant or their child.

The process of ethical clearance had been carefully considered with many of the perceived issues previously identified and addressed (Appendix Three). However, when discussing life experiences with a 'vulnerable' adult (DfE, DoH, 2015) it is important to keep a focus on the ethical implications (ibid, 2022), and to ensure that the participant agrees to continue with the thread of a story if it becomes emotive, although in some instances the emotive story might be important to share.

3.13 Exit strategy

The exit strategy was made easier by limiting the amount of sessions to a specific amount with a defined end point, which was discussed at the start of the research process for transparency. Since I did not want to cross the line into a friendship, I maintained a relationship of an acquaintance, but at the same time retained an awareness that the contribution provided by the participants was valuable (Franco and Yang, 2021). Although personal feelings were being shared, an engagement with the topic at a personal level was avoided to limit any sharing of views or amplification of the perceived relationship as one of friendship (ibid, 2020). As the research sessions drew to a close, it was discussed with the participants that I could still meet them for a coffee occasionally if they wanted to, and this did continue with one participant but has now ceased to occur on a regular basis. The success of the research relationship can be measured by stepping out of the process without leaving a relationship that has become one of hierarchical support

(Caine and Estefan, 2011). I have maintained a connection with the community organisation and support their charitable endeavours, not solely to support the organisation but also as an informal way of keeping in touch with the participants. It is apparent that when working for an extended period in a research relationship, there can be a sense of loss from both parties. I decided to maintain a low level of contact to keep connected to the field as an ethical obligation (Morrison, *et al.* 2012), particularly when the project was still ongoing.

3.14 Reflection

The process of constant reflection was essential to manage any power differential. My reflective practice was articulated in informal notes as field diaries (Olmos-Vega, *et al.* 2023) to be able to critique and evaluate my influence on the process, as an additional pause prior to the session, usually while sitting in my car. I did this to focus on what this meant to my role and how I should adapt my behaviour to ensure that I actively listened, and to maintain a narrative that was a true reflection of the participant's incidences being explored (Moen, 2006; Mertens, 2010).

As I commenced the data collation, I revisited the research boundaries; emotionally, the process felt even more complex since I did not step into the 'friendship zone' (Caine and Estefan, 2011). I used my professional experience to create an open dialogue with a purpose, and the frequent references to the research question helped to keep the study at the forefront of why we were meeting, and maintained the link and thread of the conversations (Chilisa, 2020; Braun and Clarke, 2022). In addition, the participants’ contribution was seen as the expert with access to potentially unheard knowledge (Ledger, *et al.,* 2021), my views were cited as misconceptions which structured the power differential in favour of the participants. The impact of our thoughts and experiences creates our perceived reality, which then becomes our actual reality, and this is what this study does; it captures those who have actual life experiences to address the research question (Braun and Clarke, 2022) and challenges the misconceptions of others. I found that actively listening to their stories and reflecting on the emotions of the dialogue frequently challenged my idea of what their life was like (Clandinin and Connelly, 2000).

There was a constant reflective process going on internally as the meetings were being carried out, and also before and after each session, to clarify my role in the research process, consolidating my position every time we met. As I listened, there were come occasions when I required clarification. Any prompting was always gentle so as not to change the story's direction, but rather to clarify the interaction with others and understand what environment they were in at that time, and to reveal any positive experiences or barriers to success. This clarification process at times offered the opportunity for the participants to reflect on the experience being recalled. The process of self-reflective conversations became a valuable tool for both the participants and myself (Lal *et al.,* 2012) to ensure ongoing consent and a clear perception of the research role, to be able to maintain the required boundaries and to keep the purpose of the study at the forefront of the discussion.

By placing the participant as the expert, the power dynamics appeared less intrusive as we settled into a reciprocal research relationship - one that had trust and mutuality embedded (Ely *et al.,* 1991; Riddell and Watson, 2003; Muhammed *et al.,* 2014). The research/participant relationship moved towards friendship, but the professional barriers associated with completing a task helped me retain a professional mindset. As a researcher who was also seen as a practitioner to the participants, it was essential to recognise that the supported practices of social care, with its hierarchical layers, exists as a 'bio-power' (Foucault, 1997), and can be interpreted as controlling and guilty of objectivising individuals. Constant self-reflection was required, and one of the most frequent reflexive thoughts was to remind myself to listen and not speak, allowing periods of silence, so the participants had time to think and reflect before sharing their experiences.

Moreover, as the power differentiation was an ongoing issue related to the planning and ethical process, a creative methodology would always be required (Kara, *et al.,* 2021). The relational conversations suited my communication style, as in my practitioner's role I am adept at quickly building rapport with students with a variety of SEND diagnoses. Advocating for others is also vital within this study. My positionality allowed for a flexible approach to the data gathering (Mertens, 2010), focused on active listening to encourage the participants' full participation (Kara, 2018). Once the research design structure was defined, the critical reflexivity (Mertens, 2010) provided a responsive approach to maintain the required consistency.

The data collation continued over a period of six months. The final sessions reiterated what the study was about, and ensured that both participants were happy for their data to be used. They fully understood that the regular meetings would cease to exist, although I would maintain informal contact with the organisation as previously noted in the exit strategy. After each of the research sessions, the conversations with the participants were transcribed and any reflections were noted in my personal journal.

Both of the participants had attended further education college on a supported education course as a transition from school. The course that they both attended was known as ‘Preparation for Work’; they both progressed to the second stage known as ‘Into Work’, which was designed to assist with the skills development needed for the next stage of independence and employability. As an educational study, I acknowledge the relevance of the ASDAN curriculum as being typical of the type of course content that would be delivered to young people with a mild to moderate designation of SEND (ASDAN, 2023). Although ASDAN is not used in the thematic analysis, I acknowledge that it relates directly to the skills required for the overarching 5 C’s of Positive Youth Development (Appendix 4), as part of the conceptual framework introduced in Chapter Two. The 5 C’s of Positive Youth Development (Lerner, 2009; Carroll, 2015) are relevant as they focus on the overarching skills required for a transition into the wider community (Abdul Kadir and Mohd, 2021), and are also a requirement of the skills required for the pathway into employment (DfE, DoH, 2015).

3.15 Processing the data

The conceptual model used in this investigation of personal narratives, in order to understand more about the social experiences and connections with the wider community, identifies the existence of the 5 C's (Lerner, 2009). This occurs alongside an insight into where the interactions occur within the ecological system (Bronfenbrenner, 1979), particularly as the participants extend into the community beyond the formal provision of support, and this framework structures the data analysis (Appendix 5).

3.16 Coding

A deductive approach provided a structure for analysis that related to personal development, either taught or experienced. The conceptual framework supported the analysis to be able to note where an incident happened by encoding the data in a two-stage approach. Firstly, I was able to pinpoint the ecological environment that could identify what the external and internal influences were at that time, as described by the participant, and secondly to identify which of the 5 C's was being used and why (Elo and Kyngas, 2008) as part of the interaction with others. By encoding the data, the analysis provided an interpretation that was understood by the researcher (Fereday and Muir-Cochrane, 2006), but the content of the personal narratives was taken from the participants' recall of events to ensure credibility using deductive coding derived from the conceptual framework (Appendix 5). As previously noted, the 5 C's (Lerner, 2009) provided broad categories of social interactions, and the ecological systems (Bronfenbrenner, 1979) created a framework to show where those interactions occurred. This allowed for a circle of interpretation (Pinar *et al.,* 1995; Finlay, 2008), leading to an insight into new knowledge that challenged my own perception of what I anticipated the participants' experiences might be (Caputo, 2018).

The first stage of the coding process was to colour-code the individual transcript against one or more of the 5 C's in the context of the situation being retold. The second stage was to go through the transcripts again and colour-code against the four ecological systems to ascertain in what environment the interaction took place (Appendix Eight). The focus on a two-step approach and a hermeneutic approach limited the impact my pre-understanding had on the analysis (Gadamer, 1998) while still acknowledging its use within the analysis of the participants' perceived experience (Mertens, 2010) in creating a space where a deeper understanding was revealed (Gadamer, 1998). The conceptual framework was quite broad in the categories of the 5 C's; the accommodations during the school years predominantly centred on family life and as they transitioned into college, the accommodations extended outwards into a broader community engagement. The two-stage coding process captured most of the data provided (Appendix 8). But it is a model and inevitably some data did not neatly fit into any category; this is noted as an exception as it arose.

3.17 Data analysis

This qualitative analysis was not a step-by-step approach, but I had to start somewhere and for me the first stage was to identify elements pertaining to the 5 C's (Lerner, 2009; Appendix 6) alongside the various ecological systems (Bronfenbrenner,1979; Appendix 7) to give the data a place where it occurred.

The first research sessions were less formal and I did not record but gathered the notes from my recollection of the discussion, alongside a few notes that I had made at the time. This provided the initial data and I also repeated this process without the presence of a recorder to demonstrate the informality of the exit session. The notes and the transcriptions that were taken word for word from my audio were transcribed into Word and anonymised to ensure confidentiality. Alongside the transcription, I also had personal reflective notes made immediately after the session. I brought my own thoughts to the data, but also tried to ensure that the data appeared as it was spoken in the research session. The grounded manner, in which I gathered the data, word-for-word and with reflective notes, enhanced the trustworthiness of the data collation process.

The original transcripts amounted to over 20,000 words from the conversations and some of that material was my own voice in the session. I cut down on the amount by removing my own parts of the discussion and numerically coding each section of the conversation. Then I could commence the coding of this according to my two-stage process. I developed a coding system (Appendix 8) that allowed for the use of colour and number notation to annotate the data.

As I explored the data initially, I made notes on my thoughts through ‘memoing’ - notes to myself. Within the data I needed to make notes on any questions that arose about meaning and key quotes that would need to be referred back to. The coding brought aspects of the data together to reveal the various concepts.

Once the initial coding had been completed on each transcript, I became focused on the bigger picture within the wider body of data. I kept the participants’ data separate as, although there are similarities in designation, the environments that each exists in differ. I identified themes associated with personal skills and also the movement between ecological systems, particularly in adulthood, as they were expected to transition into the wider community. The 5 C’s (Lerner, 2009) also include the developmental skill of making a ‘connection’, and the movement between systems demonstrated the extent of any connection outside of the familiarity of the microsystem (Bronfenbrenner, 1979) of family and friends associated more with childhood.

The way that the stories are shared was important; this was contrived during the planning stage and adjusted as the sessions progressed to minimise any feelings of discomfort or unease for the participants. The constant reflection on the researcher/participant relationship helped to monitor this aspect. The depth of openness that occurred within the research sessions and the transparency offered within the data was also an important factor. The two-stage coding lent itself to an analysis that captured the circumstances of the participants’ perceived experience at multi-levels of what occurred and where. The research environment encouraged a relational approach with a flattened hierarchy to limit a skewed recollection that might have been adapted for the perceived audience – myself as a practitioner. The narrative enquiry allowed my voice to appear within the discussion through some of the reflective pieces, although the raw data was based solely on the personal narratives (Cohen *et al.,* 2007; Mertens, 2010; Van Manen, 2015; Adler *et al.,* 2022).

3.18 Interpretation

As previously noted, the data collation took place over an extended period of time to allow the conversations to become more in-depth and less superficial, as the research relationship developed and the process had sufficient time built in to adjust and move with the participants' needs to allow for a continuation of the narrative sharing sessions. I adopted a 'hermeneutics of empathy' (Braune and Clarke, 2022, p.160) approach as I was mindful of my own perception of reality and wanted to ensure that the analysis stayed as close as possible to the participants' perceived reality (Willig, 2010). The key to the data collation process was to structure research sessions that were relational to encourage emotive recollections to emerge within the recounts. The continual reflexivity required during the research process maintained an appropriate relationship and minimised any obstacles that might have limited the uninhibited sharing of life experiences (Finlay, 2008; Mertens, 2010; Noon, 2018). As previously noted, the time allocated for the sessions, the flexibility of the approach and the extended duration of the data collation period all supported the development of, and sustained, a strong researcher/participant relationship. The reflexive deductive interpretation of the two narrative accounts uses coding as a way of enhancing the validity of the analysis, starting with the collation of the content, which was a product of a flattened hierarchy within a relational environment that supported an open sharing of personal narratives. In addition, the deductive approach used a conceptual framework grounded in existing theory (Mertens, 2010; Braun and Clarke, 2022) to provide a richer analysis.

The research questions investigated the preparation for adulthood, the perception of relationships, and the ability to connect with the community. The identified themes were initially identified within the conceptual framework to handle the quantity of data, but within those themes, additional sub-headings emerged. The transcripts were initially coded against the ecological systems (Bronfenbrenner, 1979) and the 5 C's of Positive Youth Development (Lerner, 2009) to highlight personal skills and the impact of the environment on what literature identified as a successful transition (Abdul Kadir and Mohd, 2021). The next stage was to analyse actual events from the data and identify emerging reoccurring themes by revisiting the transcripts (Appendix 9). This process revealed the richness of their experiences, providing more specific data (Mertens, 2010). These sub-headings include the participant’s perception of their success, self and identity, resilience, dealing with authority and issues associated with employment.

3.19 Summary

The strength of developing an appropriate research relationship was fundamental to the successful collation of the data. The planning and embedding of systems that supported the safeguarding issues underpinned the process. The researcher/researched relationship was formed from taking the planned roles and developing those roles into a reciprocal and mutual relationship that was focused on gathering meaningful data to inform others. Nevertheless the influence of changing environments on the participants was addressed with a degree of flexibility; this supported free-flowing conversations that were unhindered by a need for constant clarification. Moments of quiet were accepted as periods of reflection and the participants felt in control of their contributions. The research was conducted over a period of six months and the consistency of the roles relied on the inbuilt reflective practice to be able to maintain the required research environment. The use of a conceptual framework (Appendix 5) and a reflexive deductive interpretation of the two narrative accounts gave the analysis a structure to work within. A limitation of the analysis is that it was conducted solely by myself as the researcher (Fereday and Muir-Cochrane, 2006); it is this interpretation that drives the conclusion, whereas if the participants or additional researchers had been involved in the coding analysis, the results might have differed.

Chapter Four – Overview of Data Analysis and Narrative Data for Emily

4.1 Presenting the data for both participants

The analysis used the conceptual framework to reveal detail of the social experiences, support accessed, and connections with others (Lerner, 2009), simultaneously interrogating any interactions with the ecological systems. It felt like a conversation with myself as I used the framework to study the narrative. I interrogated the data presented (Ely *et al.,* 1991) to ensure that the themes aligned by reading and rereading the transcript in order to unpick both the ecological systems (Bronfenbrenner, 1979; Appendix 7) and the skills outlined in the 5 C's (Lerner, 2009; Appendix 6) to match the life experiences, the detail of which was enhanced by getting to know Emily and Ben (pseudonym used for participants) over the extended research period.

In this chapter and also chapter Five, I present the narrative for each of the individual participants respectively to limit any diminishment or overlap of experiences. The themes of the ecological systems (Bronfenbrenner, 1979) are viewed as the influences existing within the life course to help understand aspects of the participants' development. The ecological systems within the analysis reveal the systems that the participants have interacted within and those that they continue to move between in adulthood. These ecological systems enhance an understanding of human development across the lifespan (ibid). The second part of the thematic analysis pertains to the Five C's of Positive Youth Development (Lerner, 2009) used to capture the specific skills utilised in adulthood. One of those skills is specific to making a connection with others; the data includes reference to an interaction with supportive others, noting where this might have occurred within the ecological system, as an insight into the need for additional support once formal support mechanisms (DfE, DoH, 2015) have been left behind.

As previously noted and depicted in the diagram (Appendix 5), the conceptual framework merges the two theories, the ecological systems (Bronfenbrenner,

1979) demonstrating movement and developmental opportunities, alongside the crosscutting and bi-directional skills aligned to the 5 C’s of Positive Youth Development (Lerner, 2009). The data reveals, by using this thematical analysis, the extent to which support strategies are required, and how the individuals navigate adulthood towards a goal of independence and community integration (DfE, DoH, 2015).

A pen picture of each participant (Section 4.2.1 - Emily, 5.1.1 - Ben) provides a background on their designation of SEND and what their journey through school, college and work has looked like from their personal perspective.

As previously noted, the sessions were recorded and transcribed and a reflective diary to capture any pertinent observations or descriptive elements to support the data interpretation. The themes were predetermined as described in 2.13, for analytical purposes, although at the data collation stage the narratives did not focus on the theoretical concept of the ecological systems (Bronfenbrenner, 1979) or topics related to the 5 C's (Lerner, 2009). The depth of detail shared was much richer due to allowing the conversation to flow freely without instilling topics or chronological constraints. At the data collation stage, the participants were aware of the research focus and their narrative addressed the following research questions:

‘What can we learn about the lives and experiences of independent adults who have previously been designated with mild/moderate Special Educational Needs and Disabilities (SEND) from their personal narratives?’

While reflecting on those adult experiences, the narrative included the underpinning sub-questions of:

1. *‘How do the individuals perceive their social experiences, relationships, and connections with the community?’*

2. *'How well do they feel they were prepared for independent adult life beyond the formal provision, which ends at age 25, and what are the implications for both education and social care?'*

4.1.1 Definition of ecological systems

The definition of ecological systems adheres to the ecological systems theory developed by Bronfenbrenner (1979; Appendix 7), discussed fully in Chapter Two. The macrosystem relates most directly to the influences of culture and media where overarching beliefs about individualism, family structures, and social issues establish norms and values that permeate an individual’s microsystems.

The exosystem consists of interconnected microsystems that operate without the individual at the centre, but still influence them indirectly. In adulthood, interactions with social services or healthcare can also affect development through indirect experiences.

The mesosystem connects various microsystems such as education, work, community, friends and family. These systems can either collaborate or conflict with each other. For example, conflicts between employment and childcare responsibilities can affect home life. Both the mesosystem and microsystem revolve around the individual at the centre.

The microsystem, as per Bronfenbrenner (1979), revolves around the individual, encompassing family and close friends, where psychological development occurs primarily through direct contact.

4.1.2 Definition of the 5 C’s of Positive Youth Development

The 5 C's of Positive Youth Development (Appendix 6) further illustrate how skills and strengths are utilised within these close relationships during a navigation of ecological systems. The 5 C’s (Lerner, 2009), are a fundamental way of collating the relevant developmental skills and attributes documented as being valuable in supporting a transition into adulthood (Abdul Kadir and Mohd, 2021). Competence in social skills (Lerner, 2009) allows an individual to seek support and be able to identify from whom and when to seek that help.

The bidirectional movement between the ecological systems shows how the connections function to support the level of contribution required through aspects of a positive family and friend connection (Malkani, 2021), ensuring the required levels of emotional health (Abdul Kadir and Mohd, 2021) through an individual’s ability to communicate and share any issues. The final skill of confidence includes aspects of self-worth, which can indicate positivity in self-development. Resilience (2.11) is also fundamental to coping strategies in adulthood, and self-worth will support an individual to overcome adversity.

4.2 Emily’s data introduction

Emily’s data was gathered over seven sessions. The first session was carried out at an external meeting point after an appointment with a health-care professional. The following six sessions were carried out at Emily's home in order to manage her childcare commitments. There was only ever myself as the researcher, Emily and her daughter Clare at these sessions.

4.2.1 Emily’s pen picture

Emily is aged 33, a single mother to her daughter Clare. Emily has a previous designation of autism and dyslexia. Although no longer with the biological father, she is in another long-term relationship, and her daughter considers him to be her step-father. Emily enjoys creative activities such as making armour and costumes for costume conventions and computer games. She works part-time, two days a week, at a community-based organisation. In her role as an educational support assistant, she aids clients with severe needs to access art projects and curriculum activities. Emily is independent, with occasional interaction with her family, and manages her daily tasks autonomously. She resides in a new two-bedroom ground floor flat, relying on public transport as she does not drive. She lives close to local amenities and her daughter's nursery.

4.3 Ecological systems overview

During the research sessions, Emily’s narrative noted aspects of all of the ecological systems. But her movements remained predominantly in the microsystem, as she interacted with her close friends and family, to whom she had an emotional attachment, where her beliefs, values and identity felt at ease (Bronfenbrenner, 1979).

The exosystem was apparent in relationships between those without a direct connection and neighbours not in her close friendship group. As Emily operated within the closer relationships in her workplace, she became influenced by experiences within the mesosystem. It became apparent when analysing the narrative that these relationships with friends, colleagues and neighbours, formed through an emotional attachment, became a subsidiary microsystem within the mesosystem as a support strategy to manage her interaction with other external, less familiar systems.

Any connections with her support network appear when there is a problem to solve. For example, in childbirth, a relationship with the Midwifery Team could have formed but Emily used her mother as her support, as part of her microsystem. It was confirmed by a qualified midwife from a local Health Trust that a person entering the delivery suite would have to disclose their designated differences to receive any reasonable adjustments (Equality Act, 2010). In this instance, Emily approached the problem by taking her microsystem with her to support her needs in this unfamiliar situation. However, within the narrative, she described her mother's support as taking over her decision-making specifically regarding the need for an epidural. Emily described the interaction, ‘*my mum wanted me to have it, she said “you’ll be in so much pain you should have it”. I could not argue as I was in labour, so I said “OK go on then”.* It appears from the narrative that Emily found her time in hospital overwhelming - not just the experience of childbirth. She reported, *'Yes, it was too much for me. Sensory overload. Yes, I wanted to come home and be able to make a cup of tea.* Emily relies on her mother as part of her microsystem, albeit with the narrative describing her assistance as not always welcomed. The concept of a microsystem travelling with her into this new environment is more beneficial than operating in this system alone. All interactions influence Emily’s opportunity for personal development

(Bronfenbrenner, 1979; Carroll, 2015); in some situations, she might develop or extend her skills or experience a setback that could build resilience, which is more likely to occur if she does not rely on taking her microsystem with her.

Emily is passionate about attending conventions where she creates her fictional character costumes. She attends with her close friends but also has extended friendships through a commonality of interest. However, these relationships only exist in this space while attending the conventions; they are not close friends but offer social support in this space. Within the mesosystem, the manner of interaction decides whether the individual has engaged by their exposure and the extent of the connection. In most situations like work and hobbies, Emily categorises her peers as follows, **'***They're not friend/friends, but we have a chat and have a laugh. They're lovely'*

Emily is an independent woman with adaptive strategies in response to life's challenges, such as making daily decisions. However, she brings the personal connection to the fore whenever possible, as previously noted, by making temporary connections. She is aware of the future and the transition for her daughter of starting school: *'Yes, I'm hoping to get her into xxxx school, where my niece goes'.* Emily is looking forward to a long-term relationship with her partner, although she does not anticipate moving in with him. Emily describes how her partner is expecting her to stay for extended periods with Clare. She notes, '*He's busy decorating. Yes, it's just a paint job and he's got to order a single bed. I can set up Clare's bath there and cook dinner'.* During the research period this relationship ends, with Emily maintaining what she perceived to be his step-parental role. This inability to build and not let go of a connection recurs throughout her narrative; she describes another previous relationship, stating, *'I still love him'*, even though they have both moved on.

Throughout her adult life Emily has faced numerous challenges, demonstrating her resilience. Emily moved out of her existing microsystem and left her support behind when she gained a new job to supplement her income. The interaction with her new employer appeared 'friendly' and she started to create a microsystem of support, as she was struggling to manage the required online work reporting systems. While she was happy to work there, Emily decided to leave as her existing social welfare payments limited the benefit of taking on additional hours, ‘*By the time I got there it wasn’t worth it. I was earning £9.50 and then having a 15-minute walk, which means that the three hours on Tuesday are literally gone and it ends up I only benefit about five pounds*. Emily notes that she did not deal with the exit effectively; she describes how she just stopped attending leaving the microsystem she had started to construct as it was no longer required.

The microsystem becomes a closed environment where Emily can retreat from the overload and complexity of daily life. She makes decisions as to who will be in the microsystem and will develop another one where it does not exist, like in the workplace. Emily retains her connections and relationships with ex-partners, and seeks help from her mother in the absence of any other reliable microsystem members. Some anticipated connections like her daughter’s biological father, did not offer support during the birth, although he did comment on her breastfeeding; ‘*He was jealous, so I stopped.’* Emily has an engagement with the welfare system and government policies that impact her decisions on work and childcare, although Emily prefers whenever possible to keep her decision-making within her curated microsystem.

4.4 Macrosystem evidence: Emily

Emily's narrative includes information that links to the macrosystem; societal and cultural beliefs permeate through to her microsystem, where she acts on her personal beliefs and values. Emily voices her views on drug taking, describing an occasion when she caught her daughter’s biological father taking Class A drugs in her mother’s house, where they were both living. Emily reacted strongly and notes; *‘I told him to fuck off once I found out about the drugs.'* She mentions that he has not seen his daughter since, stating if they pass on the street he ignores them.

Emily had another incident related to Class B drugs in her block of flats. It was brought to her attention by her neighbours that complaints had been made to the accommodation Management Team of someone growing and using cannabis. Emily was aware of her neighbour experiencing severe anxiety: *'That one over there, we got a letter that someone was growing and selling weed. I mean, if someone wants to smoke it, that's OK. One of my neighbours, she has mental health troubles and when her husband comes home she goes right over the field to smoke it.'* Her life experiences have defined her attitudes and values to keep her and her daughter in a safe environment. Emily expresses her views on the broader societal and cultural impacts, although she notes that she is not averse to drug use for medicinal purposes. Although Emily has previously taken a hard line on drug use with her former partner, in this narrative, she reflects on the use of what she considers to be ‘soft drugs’, used for medical benefits to reduce anxiety, as a sociopolitical stance.

Within her narrative, Emily refers to the issues in her life that require attention. In particular she is concerned for her mother’s well-being as her adult sisters primary carer. Emily states that her sister’s symptoms of difference are so severe that the situation at her mother’s home can become unmanageable, with a physical and emotional risk to her mother’s wellbeing. Emily perceives that, due to the severe challenges her sister experiences, she should receive external social support; she feels that her sister's care is too much for her mother to manage. Her viewpoint relates to her understanding of the microsystem of family values, care for siblings and how access to the macrosystem of external support could enhance her mother's wellbeing, by giving her respite from the current situation.

4.4.1 Macrosystem summary

The macrosystem encompasses broader societal and cultural influences and is addressed in relation to Emily's opinions on drug use and her sister's challenging behavioural issues. The influence of societal laws on her choices connects to the ecology of the macrosystem. Emily's stance against her ex-partner’s drug use reflects her cultural values; her sister's situation highlights her understanding of the broader societal impact on families dealing with special needs, and the impact on her microsystem.

4.5 Exosystem evidence: Emily

Within the narrative, Emily refers to her appointment with a health-care professional for a routine check of her daughter's milestones. Emily's difficulties with social interaction and her tendency to mask her true self potentially impacted her experience during the meeting. The influences of the ecological environment created an additional anxiety of not being able to question the advice given; she reports that the health professional was concerned about her daughter Clare’s lack of speech and suggested that she remove her dummy to support her speech. The advice given was then actioned immediately by Emily, without considering the impact on her daughter’s well-being. This meeting originated in the exosystem as a formality, with Emily being influenced by the experience; it then moved into the mesosystem and then her microsystem, as her daughter became negatively impacted. Fortunately, as this happened prior to a research session, we discussed the issue as we walked together, creating a much-needed microsystem of support; Emily's daughter was distraught, so this needed to be addressed as a priority. As Emily repeated what had been suggested, it became apparent that the information gleaned might have differed from what the health professional intended. For many parents, this type of meeting is a positive experience as they gain reassurance that their child is at the correct stage in their development; for Emily it felt like a criticism of her parenting.

In this instance, the health professional was probably unaware of Emily's designation of difference and could not make any reasonable adjustments (Equality Act, 2010). In order to connect with the wider community effectively and to be able to manage the all-important transition to independence as anticipated by policy (DfE, DoH, 2015), some accommodations could remove potential barriers. However, disclosure is at the behest of the individual. Unfortunately, in this instance, the ecological system appeared too formal and unfamiliar and it is likely that Emily experienced heightened anxiety, leading to camouflaging (Bernadin *et al.,* 2021). Emily rectified the problem when she realised that an immediate removal of the dummy exacerbated the problem in the short term.

Emily describes how, for financial reasons, she was keen to gain additional hours at her current place of employment, and she reports being interested in other roles, but feeling unsure how to access them. Emily's work exists in her mesosystem, but her inability to gain additional employment is an exosystem issue where she feels ill-equipped to prepare, seek and maintain employment (Bennett and Dukes, 2013), even though she has received some support at school. Emily describes her employability experience at school with a negative stance; *'Yes, if they sat everyone down and told them how to move on and do a CV, but instead it was just finish school and then go to college.'* For those with a designation of autism, findings have suggested that individuals require support to 'strengthen and promote appropriate routes into employment' (ibid), linked to both the macrosystem of government policy and the exosystem of local implementation. Emily recalls supported work placements at college and subsequently while under the umbrella of formal support. She experienced an abusive relationship and accommodation issues; Emily recalls being supported by a key worker as she was living in supported accommodation. A work placement was arranged by the key worker at a cat sanctuary and Emily recalls; *'They were really harsh to me. I worked really hard cleaning.'* Emily states that she felt '*bullied'* and that she was being subjected to *'mind games'*, stating that what she did was never good enough. There were other placements that were positive; *'I got a job on a farm, and I loved that. I worked in charity shops and other places.'* As she recalls examples of where social support existed in the exosystem, coercing her into the mesosystem without providing formal support, Emily reports; '*I was in supported living for a while, but there was no help after.'*

Emily's experiences when receiving support moved from an exosystem of social care systems to the centre of her mesosystem, where she settled into her new living arrangement and started to develop a microsystem of emotional connections. She recalls that at that time, she was socialising, staying out late and drinking, returning to the accommodation to sleep it off; '*I was the only one that went out to 3-am, and I used to ring up and see if someone could pick me up. The staff used to come on at 9-am, they loved* *me. They used to look around the door and ask if I was OK? I'd say go away! It was a good laugh, but it was the wrong place.'*

In contrast to living in a supported environment, when Emily became a mother, she focused on obtaining her own home and engaged with the local authority within the exosystem. She describes the online process of 'bidding' to secure her flat: *'I was on the list and lived with my mum for 19 months. I constantly bid on apartments. I was on the loo looking at my phone a call come through and they said I had an apartment. Clare was only one just last year. It was the most amazing thing ever. I love my mum but living with my mum is difficult, I was crying.'* Emily appears to be conflicted by a need to have the microsystem of support for security and her desire for independence.

During this period of transition to parenthood, Emily developed her integrity and responsibility, becoming accountable (Weiss and Riosa, 2015). She is open and sincere when describing her experiences. She relates the outcome of some of the more challenging experiences demonstrating an enhanced competence in coping, and through the many setbacks, she has developed a level of resilience (Catalano *et al.* 2004). A preferred method of problem-solving frequently appears within the narrative if an issue arises in a wider system; Emily brings it into her mesosystem to deal with it, bringing support from the familiar people and her existing microsystem of friends. This appears to be a more comfortable process, although as noted previously this can also become conflicting as she seeks independence as an adult.

4.5.1 Exosystem summary

The exosystem involves the external environments indirectly affecting Emily in her daily life. Emily's engagement with social services and financial struggles are all part of the exosystem. As stated, Emily takes problems that arise in other systems into an arena with familiar people, as she feels more comfortable with people who understand her needs and who can support her with decision-making. When Emily moves out of the comfort zone of her microsystem, the ecological transitions and the bi-directional contact additionally influence her skills development (Bronfenbrenner, 1979).

According to government policy, participation with others outside of the microsystem supports the all-important transition into independence (DfE, DoH, 2015).

4.6 Mesosystem evidence: Emily

Emily moves into the broader ecological settings, but choosing to favour the microsystem with access to her support system. This support system follows her in smaller circles; she constantly reconstructs the microsystem as she moves into the wider ecological context. The mesosystem becomes a collection of microsystems that expand as Emily becomes more active in community life; as her network expands, more interconnections occur. The ecological schema allows the data to be interpreted to reveal the interconnections that occur in the middle years of life (Bronfenbrenner, 1979), where dramatic shifts in development can occur - for example, homelessness, abusive relationships and sole parenthood. Emily describes her existence as an adult as building on her connections. In her narrative she notes that she was once a client at the community organisation, which influenced her development, and now she has the confidence and skills to be an employee. The narrative describes her journey from home to supported living and into independent accommodation with her daughter. Emily appears to be able to expand outwards, as long as she retains access to her microsystems. The adaptations regarding her relationships are described in her narrative; her work colleagues are not *'friend friends, but friends'*, which shows an adaptation of her understanding of relationships through experience and the influence of her environment.

Emily also shared information on issues with the Estate Management Company for her accommodation regarding access within the shared hallway and complaints about her buggy being in the way. However, although she acknowledged the issue in the mesosystem, Emily brought the communication to a personal level attributed to the cleaners that she connected with, rather than dealing with a higher, more removed authority. The mesosystem exists in the revelation of relationships with neighbours, where Emily also shared her knowledge of the new local community plans, such as the new Medical Centre and other community facilities. Having to engage with the mesosystem and other wider systems can trigger Emily's inability to cope, and she will drop into masking (Russell and Norwich, 2012; Nalavany and Carawan, 2015) in order to 'fit in':, *'I don't always understand what people say to me. I make out I have.'* This is Emily's coping strategy and as an adult, it can have negative implications. The recollection of the time spent in childbirth where the staff were unaware of her designation of difference, and her misinterpretation of the advice provided by the health professional, highlight an inability to disclose her limitations in unfamiliar contexts.

4.6.1 Mesosystem summary

Through sharing her narrative, Emily demonstrates how she observes events outside of her microsystem then engages with them in her microsystem; she recalls conversations with neighbours about local incidents. There appears to be a lack of interaction outside of her microsystem unless Emily receives support to do so; without the opportunity to enhance her skills, her confidence could be impacted when she is required to operate in another system.

4.7 Microsystem evidence: Emily

Emily exists predominantly in the microsystem. She mentions her mother frequently during the narrative session; she recalls her reliance on her support in hospital, where she advised Emily to have an epidural: *'She said you'll be in so much pain you should have it.'* Emily reports that she would have preferred not to have the procedure that has resulted in ongoing back problems. Emily has a mixture of positive and negative stories related to her mother's support although she is grateful overall for her support, particularly with childcare.

Emily speaks about her health concerns, noting that she also has epilepsy and can experience symptoms of *petit mal*, *my absences can come at any time. I had one nearly then [Emily looks vacant] I can still talk but I stare, I go – what did you just say?'* - Emily notes that this interferes with her ability to remain in the moment, but appears unconcerned and does not feel that this impacts on her ability to manage her daily life.

Emily is annoyed and feels targeted regarding the complaints disseminated through the Management Company at her accommodation. She feels that the cleaners were not doing their job effectively, so here the dialogue becomes one of blame and reciprocal aspersions. However, it appears any discussion was solely between Emily and her neighbour. Again, this confirms her need to rely on the microsystem, which, according to Bronfenbrenner (1979), could be associated with the challenge and support presented in the new environment by maintaining her connections with the more familiar (ibid). There appears to be a tendency to remain where Emily feels in control and safe, relying on her support network to help her navigate any influences from other systems.

4.7.1 Microsystem summary

Emily shares her positive experiences of her relationships with others, with exceptions when dealing with the mesosystem or exosystem; familiarity, connection and friendship are very important to her. Emily appears to be more comfortable in her microsystem, and she enjoys a positive relationship with those who fit within this system, demonstrating competence in her social skills (Catalano *et al.* 2004).

As Emily's narrative unfolds, it reveals a focus on the transitions between her personal life, work and family, emphasising the intricacies of her microsystem. The nature of adulthood can force a movement into a broader community (Bronfenbrenner, 1979), where the interactions are no longer mediated after reaching the threshold age of 25. Emily consciously collaborates with her friends and family rather than extending her network to include what she sees as 'others', whom she would tend to mask her difficulties from. The movement between ecological systems can sometimes be forced by personal circumstances, employment opportunities and social care factors that need to be addressed outside of the microsystem.

4.8 Summary of ecological systems

The systems identified in the narrative describe an existence predominantly within the microsystem. The nature of adulthood expects a movement into a broader community (Bronfenbrenner, 1979) through the need to access external support. Emily experiences the broader systems by travelling in her microsystem ‘bubble’ and interacting with other systems by remaining connected to her microsystem. A lack of engagement with other systems limits any opportunities for extended interactions with others. The impact of restricting her movement into broader systems negates the opportunity to experience new things, test her competence and experience the setbacks that can occur in adulthood, which help to develop resilience.

As Emily navigated her new job as a cleaner in a factory, describing the interactions with her new colleagues, the dynamics between her work environment and personal life were revealed, reflecting the interconnectedness of different spheres. In her new job she was unknown to her colleagues and she went into the role without her microsystems of support; as she encountered problems, she developed a support connection with her manager to manage the reporting difficulties. Other examples of a temporary support network relate to attendance at a large comic convention, where contact was with those she had met previously. She also returned to the occasion of her daughter's birth and the influence of her mother on her treatment. Emily refers to her experiences as a journey influenced by the exosystem, with interaction within the mesosystem, but always with a journey back into her microsystem, or the development of a new microsystem in order to manage the interaction. Interestingly, in contrast to relying on the microsystem for support, Emily describes her ideas about alternative careers after attending a job fair where she was introduced to a role within elderly care. This demonstrates how Emily enters wider systems on her own terms, but the reality of this idea is not explored further, maybe due to the associated complexities of moving away from her existing support systems.

4.9 The 5 C’s of Positive Youth Development

The introduction to the 5 C’s of Positive Youth Development appears in section 4.1.2.

4.9.1 Overview

Analysing Emily's traits using the Five C's framework revealed her competence in navigating the microsystem and the mesosystem, managing relationships and exploring work opportunities. Caring aspects were evident in her relationships with family, including demonstrating empathy. The connections were highlighted through family interactions, friendships and the extent of her support networks, reinforcing the significance of relationships in Emily's life. Emily displayed confidence in parenting, seeking support and exploring new opportunities alongside a microsystem of support.

4.10 Competence: Emily

The data provides examples of Emily's competence in managing her and her daughter's daily lives. She works, her daughter attends nursery, and she manages the daily tasks of shopping, household chores and additional parental responsibilities.

Instances of competence in the narrative are linked to Emily's social, academic, cognitive and vocational capability. However, there are areas of her life experiences where she does not exhibit independent decision-making. Emily touches on the birth of her daughter; she reports that the decision to have an epidural caused her some ongoing back issues, noting: *'Yes, my back has been bad. I pulled it picking things up. When I gave birth, five weeks afterwards my back went.’*

Emily can navigate incidents that are outside of her usual routine. She was able to take her daughter to attend the meeting with the health professional at an unfamiliar location. Emily had an understanding of what the meeting was about. Although she appeared to approach the meeting confidently, her challenges caused heightened anxiety and masking became her coping mechanism (Beck *et al.,* 2020).

Emily reflects on her social relationships and her transition to a specialist provision at school. She reports: *‘It was what I needed; I would have struggled there' (in the mainstream).* Emily appears to have an awareness of her need to develop strengths in her social communication, recalling that at school she would not have *‘said boo to a goose’.*

Interestingly, throughout her narrative Emily describes her competence in building relationships and reveals masking as a strategy she uses to cope. Therefore, some of her experiences could be based on fake competence. Still, she is consciously deciding to do so: ‘*Yes, I want to fit in and not to be judged’*, which is a skill in itself.

In her actions and narrative, Emily demonstrates competence in understanding her access to childcare**:** ***‘****I only get 15 hours free. I think if I needed get another job they will reimburse me for the childcare? Yes so hopefully in a year or two if I have found the perfect job.’*

Emily is creative and excels in costume design and weapon-making, supported in the session by photographic and actual examples of her artistry. Emily is aware of her skill and the social side of the convention, and plans to involve her daughter in her hobby going forward. *‘I have got friends, my mates who go to xxxx. I bring Clare she plays with the cool teddies and stuff. Yeah, like costumes, I would love to design a really big dress, so I don't do it and put it off. I feel better at doing things I'm used to. Yes, this is another one, there is one in a couple of weeks but the main one is xxxx. I’ve made the holster, it’s up there with my figures’.* Emily shows me some of her creations; she is very talented, particularly when repurposing recycled materials.

4.10.1 Competence summary

Emily describes her competence in social situations, preferring to keep her friendship group to her close friends. Competence is an area of personal development that is deemed to enhance access to social relationships (O'Connor *et al*., 2014; ASDAN, 2023). As previously identified, there is a connection between being able to achieve a purpose in life and being competent to connect with others. In some of Emily's interactions with those outside her friends and family, a false sense of competence can occur, related to her masking in some situations (Hull *et al*., 2017; Bernardin *et al*., 2021). Fortunately, within the research session, as we had discussed masking, it was evident that Emily was being her authentic self. This is important to the research process, as I did not want to portray a narrative that was not true to her experiences (Den Houting *et al.,* 2021).

4.11 Character: Emily

The narrative reveals aspects of Emily's character by unveiling her challenges in dealing with societal rules due to her autism. Her openness about masking and its impact on her anxiety provides an insight into her character and how she struggles to disclose her autism to others. Emily’s narrative reveals her values, resilience in coping with challenges, and how her decisions align with her principles. She made a stand against her ex-partner's drug use, emphasising her principles and demonstrating her protective instincts towards her family. Her development through her life experiences has defined her attitudes and the values that keep her and her daughter in a safe environment. Emily communicates with an honesty that provides sincerity in her recollections; her ability to weigh up the risk of her neighbour's use of cannabis for her mental well-being is a balanced view when she has collated all of the factors of the situation.

When moving outside of her microsystem into the realms of social support, Emily appears less competent in the appropriateness of her parental skills; she appears uneasy when dealing with those that she considers to be the 'expert', regarding receiving a possible criticism related to her parental skills. She reflects on her previous experience during her meeting with the health professional and the lack of focus on her child’s development: *‘Yes, she didn’t ask me many questions and she didn’t ask me about Clare’s progress.’* There is an air of uncertainty when Emily reflected on the purpose and outcome of the meeting.

Emily notes that she is struggling financially and looking to enhance her socio-economic position. Emily reflects on the past experiences that were designed to support her skills development and employability; she mentions that she moved from school into supported education, firstly ‘Preparation for Work' and then ‘Into Work'; both courses were designed to provide skills development opportunities and work placements. Emily reflects on that time and the limited choice available: *‘I wish I had gone into sewing or something like that.'* She perceives that the time spent at college did not best suit her needs and career aspirations.

She commenced as a participant in the community organisation and is now employed part-time. Emily has experienced a setback at work: *'I had three days a week in the community organisation due to Covid. I had a mental breakdown, Clare was six months at that time; it was shit, depression really hit me. I felt trapped, I went out for walks everyday. I met people outside, probably shouldn't of but….'* Emily reflects on her behaviour when she was experiencing a breakdown and hiding her true self: *‘To some outside of my close friendship and family group, it looked as if I was panicking.'* Emily describes masking as hiding her true feelings, which leads to an increase in anxiety, and her reflection on these experiences demonstrates self-awareness.

4.11.1 Character summary

Emily's character includes respect for societal rules, and she shares her knowledge of right and wrong, particularly related to her parenting skills. There appears to be an apprehension related to less familiar environments, where she applies her sense of standards for the expected behaviour, but does so with less confidence.

Emily has a viewpoint of what might be in the best interests of others; for example, her mother and her sister's care needs. Emily describes several instances where she was provided with the support she needed through the social support system and education. Due to her low socio-economic situation, Emily is constantly looking at ways to increase her income by attracting more hours at her current workplace. However, she is also aware that in the past, she was not functioning effectively as an employee; her narrative describes how she is trying to change that around highlighting her resilience, proactivity, self-awareness and ability to be reflective.

4.12 Caring: Emily

Caring for others and the relational aspects of being an adult are a priority for Emily, and she does this by sensing how other people might be feeling from their perspective, showing emotional maturity. Emily describes the relationship with those at work: *‘We have Christmas do’s, we used to do a lot. It all packed up during Covid’.* Emily also refers to her neighbours: *‘My friends up there [points upstairs to the flat above] xxxx has a three-year old and a four-and-a-half-year-old. I’m really close to xxxx and xxxx***.’** Emily has a strong sense of social concern, and she holds friendship in high regard.

Emily's caring nature is evident in her relationships with her daughter and her close connections with her ex-partner, and also in the care that she shows for her mother and the support she provides for her sister (see Section 4.4). Her vigilance regarding her daughter's health and well-being underscores her caring disposition. Emily’s maternal relationship reflects a deep and enduring caring attitude in her parent-child relationship. Furthermore, the narrative expands beyond the mother-daughter relationship, noting that Emily exhibits a cheerful and caring disposition towards her daughter, work colleagues, neighbours and friends. This broader expression of care suggests that Emily's caring nature extends beyond her immediate family to encompass her social and professional circles.

4.12.1 Caring summary

In summary, the text indicates that caring is a prominent aspect of Emily's character, evident in her relationships with her daughter and others in her life. Emily describes how her confidence has grown as an adult, and she enjoys a strong bond with her family and friends. She empathises with others showing an emotional maturity.

4.13 Connection: Emily

Emily likes to have a positive bidirectional bond, which helps her to feel supported. She has a close unit of friends, including her immediate neighbours; she prefers not to enter into a dialogue with those she does not know, but rather discover information through conversations with her peers.

Emily describes during our first meeting how her relationship with her partner was as a father figure to her daughter; she states that he feels more like a father to Clare than her biological father. Interestingly, this relationship with him as a partner ends during the period of the data collection process, but Emily maintains that he continues to have regular childcare responsibilities for Clare.

The interactions with social services and the health professional showcase Emily's connections beyond the immediate family, indicating potential for additional support. By viewing the interactions through an ecological systems lens, and the connections between Emily, her daughter Clare, partner, friends, colleagues, and associated agencies, Emily’s perception of events shows how she is able to shape her decisions and access her support systems.

Emily values the connection with her friends and the camaraderie they have with shared experiences of children of similar ages. Emily is close to her immediate family but understands the difference between work colleagues, friends and family relationships, *‘I have got friends, my mate who goes to xxxx’,* regarding her confidence and ability to connect with others. She describes how her confidence has grown in adulthood compared to when she was at school. Emily enjoys a range of relationships that are bi-directional and positive (Lerner *et al.,* 2009); she shows an awareness of her growth in confidence as an adult, referring frequently to positive connections.

4.13.1 Connection summary

Emily describes how her confidence has grown as an adult and she enjoys a strong bond with her family and friends. Emily can become conflicted in some unfamiliar situations, which could be related to her masking, where she cannot function in some environments so she becomes unobtrusive.

4.14 Confidence: Emily

Emily shows aspects of her self-worth and self-esteem within the theme of confidence. Emily's clear decisions, understanding of her daughter's needs and ability to handle challenging situations indicate her confidence in motherhood.

Emily appears confident in understanding her rights as a tenant, and she vocalises her thoughts about what was appropriate when faced with a complaint about the shared hallway: *‘They need a bike rack or something, I understand that, but was trying to keep it tidy.’*

As an adult**,** Emily has an optimistic view of her ability to manage in the work environment, although she draws attention to some skill areas that could be enhanced. Specifically, she reports that she would benefit from support to investigate what courses or roles are available to her and how she can start the process of seeking a career change.

Emily describes herself as being part of a community of single parents who rely on each other for support. She has a routine of living in her close community, with the nursery care for her child, the workplace where she feels secure, and her accommodation where she has friends around her for additional support. The influences of other systems outside of her microsystem appear to put Emily under additional pressure.

4.14.1 Confidence summary

Within the skills area, Emily portrays positive attributes across the skill set. She has some difficulties managing interactions with those she is not familiar with, and uses masking, as a barrier to genuine social interaction. If Emily remains in her microsystem, she is confident, and she has a high level of self-esteem that facilitates her life as an independent adult. Emily draws attention to some skill areas that could be enhanced. Specifically, she requires support to investigate what courses or roles are available to her and how she can start the process of seeking a change.

4.15 Summary: Emily

Emily's narrative offers valuable insights into adult life's complexities, especially in navigating different systems. Emily's experiences underscore the significance of engaging beyond her immediate circle, as per Bronfenbrenner's theory (1979). However, her tendency to remain within her comfort zone limits her exposure to growth opportunities.

In her employment journey, Emily's interconnectedness with various aspects of life becomes evident. While she excels socially, her reluctance to step outside her familiar circle may hinder genuine interactions. This emphasises the importance of social competence, though Emily's authenticity in research sessions ensures accurate portrayal.

In summary, Emily's journey highlights adulthood's multifaceted nature, emphasising the importance of authenticity, resilience and self-awareness. Her experiences serve as a testament to the complexities and opportunities in the journey of self-discovery and development.

Chapter Five – Overview of Data Analysis and Narrative Data for Ben

5.1 Ben’s data introduction

Ben’s data was gathered over six sessions. The sessions were mostly conducted in a local coffee shop where we had our initial meeting; we also tried walking and talking with a different place for refreshments. This went well regarding the setting and the ease of conversation, but when we discussed the meeting place for the subsequent session, Ben requested that we return to the coffee shop. The coffee shop was a busy setting with customers coming and going, which did not stifle Ben’s ability to share his story.

5.1.1 Ben’s pen picture

Ben is also in his mid 30s, with a previous designation of autism and dyslexia. He is in a long-term relationship and his partner has adult children. He lives independently and works in a local community organisation, where he commenced as a client and is now a part-time employee. Ben works as a support assistant, accompanying clients on days out and also supporting them in the classroom with their practical activities. Ben's hobbies are listening to heavy metal music and attending concerts and festivals. He lives independently in his home, which he shares with his partner Bess. He enjoys practical activities, both at work and at home, and is proud of the skills he learnt on a construction skills course at college. Ben is close to his family and is supported by both his partner and his family members.

5.2 Ecological systems overview

Most systems identified within the data pertained to the mesosystem and microsystem, where relationships develop and extend outside the family but remain in groups of microsystems. As I delved into the layers of Ben's ecological systems, there was an absence of engagement with the wider societal impacts of the macrosystem and exosystem in his narrative. His focus remained on his immediate surroundings, relationships and regular activities. Within Ben's narrative, there are some influences of societal and cultural factors that might be operating more subtly. For instance, Ben is very interested in travelling to other countries, and he notes that he has done so with his family in the past: *'Been to Los Angeles, that was a birthday treat.' […] - When we got to the hotel and the reception reported a gunshot, we thought it was fireworks.'* These experiences have developed an interest in other cultures for Ben. He describes his desire to travel overseas in the future *'I have Dane blood in me – it's so expensive to travel there. […] Seen them all, 'Vikings' [TV Show] I'd like to go and a name that I can't say…Norway, Denmark area I suppose.'* Ben's travel plans focus on a geographic area he feels connected to through popular media and his self-identity. He identifies being connected to the Vikings as part of his social identity.

5.3 Macrosystem evidence: Ben

Ben demonstrates his insight into societal and cultural differences related to his visit to the United States of America and their more liberal access to guns: '*We went to a gunshop, and they sell crossbows!'* Ben describes how he felt that this was dangerous and unacceptable, with a risk to the safety of members of the public. Ben describes his unease: *'I don't like guns'.*

Ben relays his interest in new trends in technology, commencing with a discussion about smart watches: *'I'd like to get one; someone at work has a really thin one' […] They said you could get a chip in your arm! I wouldn't like that' […] That would freak me out.'* Ben is interested in the developments of technology as being linked to 'science fiction'. He reflects on the fast pace of technological advances in gaming. Ben described how his nephew became confused as he was only used to touchscreen technology: *'My nephew, you know the old Game Boy, he was trying to swipe instead of pressing the button.'* Ben notes that although he enjoys gaming on his console, he does not interact with fellow gamers online. If he did interact online, he could be making connections with people from all different walks of life and also those living in different countries. Ben has made the decision to enter the virtual world and interact only with fictional characters rather than real people, remaining in his microsystem.

In his narrative, Ben responds to the impact of the societal influences during the Covid-19 pandemic, particularly about the government guidelines and the impact on his daily life: *'I was staying with my partner. I didn't want to be on my own.'* Ben was aware of the Covid-19 guidelines, and early on he made a decision with his girlfriend to move into her house: *'No it was Bess's idea. She's got a house and she has two daughters […] It was really nice - […] I did enjoy it.'*

Ben reflects on obtaining his designation of difference: *'I was born with autism and stuff. My mum was on it.'* Ben received his diagnosis and moved from mainstream to a specialist provision: '*I'm good at like practical stuff. My reading is better than my writing and my spelling.'* After leaving school, he moved into supported learning at college; once completed, he then progressed to construction skills and then a music course. Ben recalls: *'At college, I loved it. I did level 1 and level 2, I wanted to level 3 I wasn't able to do it. What was the reason I can't remember…oh yeah, I was too old [Sic]'.*

5.3.1 Macrosystem summary

Ben is aware of the broader societal and cultural norms related to adult influences on his daily life. Ben chooses not to engage with wider communication and relationships although he has developed clear opinions, values and identity in relation to society and culture. Ben is very close to his family and his partner Bess; he relies on those close to him for support and guidance as a microsystem of support.

5.4 Exosystem evidence: Ben

Ben interacts with other systems indirectly and is more emotionally connected, rather than physically. The decision to move to a more supportive educational environment used the external systems that affected Ben's microsystem life. Ben refers to a local agency called 'Connexions' (Sheehy *et* *al.,* 2011), and when asked what ‘Connexions’ offered him Ben replies: ‘*A helping hand to get up’*. The support that Ben accessed existed in his exosystem, as part of a government initiative of external support available at that time. The provision guided Ben towards a music course that met with his interests: ‘*I play guitar, bass, a little bit on the drums. I was in a band at college, went our different ways and stuff.’* Without this intervention, he would have found the application process challenging to manage.

Ben's experiences during Covid -19 refer to the exosystem of government guidelines, where everyone was expected to socially distance (United Parliament, House of Commons, 2022) and Ben had to make a decision about who he would remain in close proximity with. ‘*I was staying with my partner I didn’t want to be on my own.’* When asked if he was already staying there he says, ‘*No, it was Bess’s idea, she’s got a house and she has two daughters.’* He recalls seeing his family online: *‘we what’s it called, face-timed.’* Ben also notes, *‘I went back to the house sometimes to get a bit of space.’* Ben also talks about the influence of mass media at that time and now, suggesting that it can impact his perceptions and views. He states that he avoids the news, as it causes anxiety: *‘I don’t like watching it. You just don’t know what’s true.’* In his narrative Ben describes how being unable to clarify the truth unsettles him. His avoidance of media access means Ben gathers information from his partner, close friends and family - the sources that he trusts to influence his development, societal attitudes and beliefs. Ben refers to a television programme that sparked his interest in the Viking culture: he felt his identity and interests aligned with this culture, and he made self-identity connections without any substantiation.

Ben describes the neighbourhood where he lives and recent issues with anti-social noise: *‘Well last night there was this noise it was music […] it was near but it was loud […] It was about an hour.’* When asked what his response was he says: ‘*I tend to avoid it, go the other way.’* He notes that when he attended a concert there was conflict between opposing fans: *‘At the station there was trouble, people were throwing bottles at each other […] I keep myself to myself.’* Ben feels safe in his own environment; he reiterates a fear of the unknown and makes decisions to keep himself safe. Within the exosystem factor, any elements outside Ben's direct control impact on his feeling of comfort; he prefers to avoid any negative interaction or confrontation, although this does not result in total avoidance.

5.4.1 Exosystem summary

The exosystem involves external settings that indirectly impact Ben's life experiences. He has received support from social services, workplace dynamics and broader life experiences. The exosystem is a system without Ben at the centre; it brings together the microsystems of influences of systems on his daily life with access to social support and the influences of local politics and media.

5.5 Mesosystem evidence: Ben

Ben engages with work within a mesosystem where his microsystems of work, friends, and the local community come together. He appears not to seek interactions outside of his community, maintaining his interactions as a bidirectional microsystem of close friends and family.

Ben describes how he was bullied at school: *‘When I was in mainstream I was picked on everyday, because I was different.’* He notes how he was able to receive formal support once he moved to a specialist provision: *‘They were all good; I’m trying to remember their names.’*

Ben’s passion for music includes the need to travel to concerts and he also attends a festival each year. Ben expresses his excitement when he describes the festival where he camps with his partner: ‘*It’s four days, Friday, Saturday, Sunday and Monday. We can’t wait.’* He describes their accommodation, ‘*It’s a four-man tent, room for two! It’s got a place to sit and bedrooms.’* The festival is held outside of his local community and Ben and his partner travel together to get there: *‘Derby, yes two trains.’* Ben notes that they stay in a quieter area for those designated with a difference: *'We stay in 'hell. It's much quieter.'* ('Hell' is a camping area designated for those with disabilities.) This is the first time that Ben has mentioned his difference in adulthood. He cannot recall how this concession was sourced but notes that it benefits his needs, as the campsite is much quieter. Ben refers to a friend who supports him with this type of event; when asked what his role is, Ben states*, 'A bloke I know will help. He's a student something teacher?'* This relationship reveals the interconnectedness of the supportive microsystem network existing in his mesosystem. Although I was unable to clarify who this person was, he appeared to be an experienced adult who was available to offer advice when required.

5.5.1 Mesosystem summary

Ben prefers to remain within the microsystem, where he has control of his own decision-making and knows who to talk to for issues outside of his expertise. This approach facilitates his connection and interaction with his microsystem network, established to protect him and support him when venturing into other systems. Ben's life is influenced by connections and interactions between different microsystems, which are characteristics of being within the mesosystem. Ben is fortunate to have been able to access paid employment at the community organisation where he started as a client, which is also part of his microsystem: *'I was a student first then I spoke to xxxx and said is there any volunteering to do? She spoke to John (Pseudonym) and he said "Yep go for it." John gave me a payday and I volunteered as well.'* During the time spent on the research Ben remained part-time*.*

5.6 Microsystem evidence: Ben

Ben resides predominantly within the microsystem of friends and family, where the more significant influences occur, which is the same for any adult with or without a designation of difference. His interactions within his microsystem relate to support provided and access to other support within the mesosystem, where he takes his microsystem with him. From his narrative, it appears that Ben is more reliant on his partner for support than his family; he notes: *'I am better with people that I have something in common with.'*

Ben recalls his journey through education from mainstream to a specialist provision, then into college, again on a supported course, and then his move into the mainstream curriculum, where he studied construction skills and music. The education provision belongs to the mesosystem, but the relationships with those he meets and interacts with cross over at times into his microsystem of friendships. Ben recalls that when he was on his construction course he experienced issues with the staff: *‘It was good, but the boss people were awful.’* He describes how he felt isolated and unable to feel at ease in the mesosystem. Ben describes this as a negative experience: ‘*Apart from three people* [helpful] *out of how many there were there really’,* the others were not supportive. It is unclear as to why Ben did not receive formal support at college linked to his designation of difference.

Ben has been living independently for a long time: *‘I’ve got my own place about five to six years ago’* and this was with his ex-partner. Ben can look after himself and although he does not like cooking he can, stating takeaways are *‘not healthy’*. Ben also reports that he is visiting the gym, as he is aware that exercise is essential to his well-being. Ben has chosen a gym where the membership is more flexible - *‘you can cancel anytime’* - demonstrating his ability to make life decisions.

Ben's focus on preparing for the festival, camping plans, and travelling with his partner all involve personal, immediate aspects of his life. These activities are all part of his microsystem as they directly relate to his personal experiences and preferences.

5.6.1 Microsystem summary

Ben maintains close contact with his friends, family and partner. Ben's tendency to avoid confrontation is a personal characteristic within his microsystem. It reflects his approach to interpersonal interactions and conflict resolution in his immediate social context. Ben has learnt to keep himself safe and well through his preferences and his conscious decision-making related to self-care, by booking a designated camping site that best suits his designation of difference. All of these elements are part of Ben's microsystem, as they involve immediate and direct aspects of his life, personal experiences, relationships - and how he manages his immediate surroundings.

5.7 Summary of ecological systems

Ben retains a connection with his support network, including his partner, friends, family and work colleagues. Ben is aware of the broader societal issues, but he chooses not to engage with mass media or conflict as he prefers to remain where he feels most comfortable and in control. As noted, he uses his life experiences to remain safe; he has also developed coping strategies to support his ability to manage if things do go wrong.

5.8 The 5 C’s of Positive Youth Development

The introduction to the 5 C’s of Positive Youth Development appears in section 4.1.2.

5.9 Competence: Ben

Ben demonstrates how he has competence in decision-making, and an ability to make friends and develop his microsystems of support. The narrative provides examples of Ben’s confidence growing once he moved to a specialist provision on receipt of his diagnosis: *‘It was what I was diagnosed as a kid. […] Smaller classes, yeah, mainly to do with my speech. I couldn't speak very well as a kid, and I went to Speech and Language’.* Ben is aware that his designation of difference put him on the pathway of supported learning at school and further education, where he returned to the mainstream when he studied Music and Construction. He recalls that his mother was active in obtaining his diagnosis: *'Yes, I've moved around a bit, then we found a nice place to stay for schools and colleges […] First of all I was like a main, oh I can't say the word* [I prompted with the word mainstream]*, cos at mainstream I wasn't coping well with it yeah, yeah.’*

Ben is a fan of heavy metal music and follows his favourite bands with his partner. He was keen to describe the aspects of Battle of the Bands that he attends: '*You've got four of them are playing and two go through finals and semi-finals […] We vote and at the end of the night they say who's got through.'*

The narrative provided information on Ben's travels overseas, to concerts and the festival in Derbyshire he attends every year. He travels to concerts with his partner; the venues are mostly local and within walking distance or on local train journeys. Ben supports his partner when they travel; as he notes, *'she gets nervous when travelling'.* Ben appears to offer a behavioural response, where he steps up and supports his girlfriend's anxiety.

Ben reports that he likes making things and describes how he has been building a shed in his garden to play music and create woodwork items in; he notes that items could be for sale, *'guitar cases and guitar stands'.* This entrepreneurial idea appears to be in response to desiring an additional income: *'I'd still do my one-and-a-half-days. I'd like to do the woodwork, find someone'* (this refers to selling the items he has made*).* He also recalled construction techniques learnt at college associated with his use of tool techniques: '*Yes, like plumb level, I think it is this, levels, spirit level, and joints 10mm […] you can get a builder's tape measure that tells you how many courses and levels […] a string line keeps you straight'.*

Ben describes his competence with technology as '*not good at tech',* although he has a good knowledge of current developments in the field. He shows an awareness of the rapid changes in technology and the generational gaps in knowledge between himself and his nephew.

Related to his designation of difference, Ben notes that he used to find it more challenging: *'I've gone through that stage - it was uncomfortable, and I've got used to it.'* He mentions that if he requires additional support, his mother and girlfriend help him. He mentions that the partnership with his girlfriend is reciprocal: *'Some bits she finds difficult I then help her out',* and he states that he would choose Bess for support rather than his family. During the research sessions it was not apparent whether or not Bess had a designation of difference, except for mentions of her social anxiety and that she does not enjoy travelling as this also makes her feel anxious.

On one of the research sessions, Ben cancels and does not give an explanation; when we meet the next time, I ask him if everything is all right and anticipated that he will tell me why he had to cancel. Ben responds to the question about the reason with clarity: *'I had to be somewhere […] No things just happened.'* This response demonstrated that Ben is able to make decisions and prioritise his time.

5.9.1 Competence summary

Ben demonstrates his competence as an independent adult as he can maintain a relationship, even with the stress associated with the government lockdown during Covid-19. He has built up a social support structure, and he is supportive of his family and partner. He engages with numerous interests; he pursues his passion for music by attending concerts and uses his construction skills at home on do-it-yourself (DIY) projects.

5.10 Character: Ben

Ben understands societal and cultural rules and what is expected as appropriate behaviour. He recognises the challenges of being designated with a difference and how this can be a barrier in some situations. He has a positive outlook and has left behind his previously designated difference, as he is no longer in education. He mentions that his autism challenged his ability to become '*accepted and confident'.* He describes how he has been associated with the community organisation where he has worked part-time for six years. He recognises the impact of positive work relationships and fondly describes one of his ex-colleagues: *'He was hilarious! I think he was retiring […] reminded me of Tommy Cooper, lovely man.'*

Ben’s engagement with others demonstrates his positive attitude, relevant skills and emotions to work alongside clients with more profound differences and who require a high level of emotional support. When Ben describes the types of people he likes to spend time with, he reports that he prefers *‘people that I have a lot in common with’.* Ben demonstrates his emotional maturity and care for his partner when he notes that he appreciates the hard work she is putting into decorating their home: ‘*Some bits she finds difficult I help her out.’* Ben speaks about his family more in the past tense, when he required support. He notes that during the Covid-19 lockdown he kept in touch, but he does not refer to current interactions other than to say they loved his partner and her family. It appears that Ben refers mostly to more recent aspects of his life experiences, unless prompted.

5.10.1 Character summary

Ben is a quiet person with a high degree of self-awareness, and he is also aware of his partners needs. Ben's understanding of societal rules and a keenness to keep out of trouble, alongside an awareness of his strengths and challenges provide him with a character that fits well into his life and work role. He also reflects on his care for his younger self and recognises the impact his designation of difference has had on his educational journey, all of which have contributed to developing his character.

5.11 Caring: Ben

Ben’s narrative highlights a sense of care for his younger self related to bullying and his struggle associated with his difference. He describes his friendships from school: *'Loads, I still see one, actually two, but he's busy.’* Ben has a social concern for others; if they are in his friendship group, he understands the etiquette and describes how he would act: *‘I’ll just give them a nod or buy them a drink or something.’* He also understands when others have offered support - for example, when he was provided with his first house:

‘Err…me mum helped.’ Ben also notes: *‘A keyworker – yes there was one […] yes they used to come in and check things.’*

Ben has a close relationship with his brothers and mentions their designation with a difference: *‘Oldest brother has it and my youngest brother he’s dyslexic, and he’s a plasterer’.* He notes that his own role at the community organisation is enjoyable: *‘Yes working there, I don’t want to leave […] It’s nice working with everybody.’*

Ben has a long-term partner, and he describes how she has been decorating their home: *'Bess, my girlfriend, has been wallpapering; it's getting the right paper.'* He speaks fondly of the relationship and their shared interests, *‘Music and gardening’*; interestingly this is the only time Ben mentions gardening. He also notes that he supports his partner as she - *‘gets nervous when travelling’.*

Ben describes his caring and reciprocal relationship with his parents, siblings and nephew within his narrative. This data appears within the section on connection. The friend Ben refers to in the section on character also relates to his skills in caring. Ben has developed a supportive relationship with someone as his 'go to' person if he needs help, particularly with travel.

5.11.1 Caring summary

Ben's expressions of care include a demonstration of his empathy for others and an awareness of his connection with others at a friendship level. Ben also reflects on his own experiences as a young person who faced bullying, although the majority of his narrative depicts the positivity of his relationships.

5.12 Connections: Ben

Ben is clear about his connections within his narrative through his description of relationships with family, friends and colleagues. His ability to establish and maintain connections has played a role in his educational and vocational journey. He outlines the connection between in-class support and his move to a specialist provision: *'I was in one class, then they put me in another class,* *I'm trying to remember now.'* Ben reports that he completed some of his supported course at college and left before the end, also exiting his work placement: *'No, I didn't do the course any more. I was so into my music. Somehow, I got connected to "Connexions" yeah, and they helped me get into a music course. It was a BTEC.'*

While the research session was underway, it was discussed that using WhatsApp might be a useful way for us to communicate. Ben notes that he is not a social media advocate: he reports: *'I sort of don't. It's easier in person.'* Despite this, Ben can respond to text messages and lets me know if he cannot make one of the sessions.

Ben describes his interest in construction as linking to his memories of time spent with his grandfather. One day, when we are walking along, he starts talking about bricklaying and says he would have liked to have *'followed in his footsteps as a bricklayer'.*

Ben understands that networking can help with a job search and that making connections with others can be helpful in life: *'Depends where you go like I go to pubs and meet people in there and chat with them.'* Regarding being able to find employment, he notes*: 'I did say it to the people at college, they said they'd get back to you but they didn't.'* Despite requiring more paid hours, Ben describes how he feels comfortable and supported in his workplace, and he enjoys the creative side of his role, *'doing pottery or just painting'.* Ben also supports clients with outside activities, such as sports and travelling around the local area.

Ben has a long-standing romantic relationship, is aware of his partner's interests, and speaks positively about their relationship: *'We met at the pub, a local band playing…it was a rock band.'* When Ben is asked if he knew his girlfriend before, he says: *'No, we have been in the same places' but were unaware of each other […] We'd crossed paths but never met'.* He notes that his parents *'really love her and the girls as well'.* When asked about making new friends and speaking to strangers, he replies, *'Ummm, a bit nervous.'* Ben describes how he can mix with people who are unaware of his challenges, *'No, I've gone through that stage. It was uncomfortable, and I've got used to it.'*

Ben cancelled one of the research sessions by text message. When I ask him about this, he replies: *'I had to be somewhere.'* I ask if he had been unwell and he responds: *'No things just happened.'* I feel concerned that Ben might not be keen to continue with the research, but when I ask about booking the next appointment, he responds positively, '*Next week?',* and we agree on a date for the next session in three to four weeks' time.

The scenario of seeking help when faced with outside influences of formal meetings, like the Job Centre, Medical Appointments etc. was explored, and Ben notes that he would take a support person with him, *'Mum or Bess'*.

5.12.1 Connections summary

As noted throughout the narrative, Ben is aware of the need to make connections with others. He has his microsystem of family, friends and his partner to rely on for support, and he does not readily connect with others outside of his secure network. However, he did meet his current partner at a pub, demonstrating his ability to form relationships without support. It appears that his reticence to do so is more of a personal choice, rather than a limitation of his skills.

5.13 Confidence: Ben

Ben demonstrates his confidence in providing a narrative and recalls pertinent information from when he was at school to give a chronological structure to his narrative. He recalls positive work relationships - *'Loads I still see one, actually two, but he's busy'* - and relates his journey from supported education to independence as being more confident: *'Its hard to explain, now I am being accepted and confident.'*

The narrative reveals an interest in making things with wood and he recalls the skills gained at college: *'Woodwork I can't think of anything else.'* (Notes are reported on the use of tools in the section on competence.) Ben decided to keep me updated on his progress with constructing his outside space each time we met. He had built and was organising his own space in his garden, describing the jobs as, *'just sorting it out, moving things around, put extra boards and seats in.'*

Ben has independent travel experience and bases decisions on his knowledge of a journey when deciding to see a gig: *‘depends how far it was’.* He recalls how he is confident when travelling to gigs that are not just local but also in London, and states that his boundaries are *‘Everywhere, London, locally’*. Ben also notes that with the festival that he attends and camps at, *‘My mate told me about it. I thought let’s go’*. Regarding drinking alcohol at the festival Ben reports: *‘We get it there. I can’t really remember drinking too much [laughs]’.*

5.13.1 Confidence summary

Ben’s confidence appears in his narrative: he can travel, attend gigs and music festivals and camp. He works and makes decisions about most aspects of his daily life in partnership with his girlfriend. He has designated support networks that he can call on when required, allowing him to tackle those challenges of adulthood that would otherwise be insurmountable.

5.14 Summary: Ben

Ben's narrative reveals his inclination towards his microsystem for security and familiarity. He showcases clear opinions, values, and an identity shaped by societal norms. He describes his support network as influencing his decision-making.

Experiences within the exosystem, such as social services and workplace dynamics, indirectly contribute to Ben's development and outlook. His reflections on past experiences highlight both positive and negative influences, underscoring his resilience and positive outlook. Ben's competence as an independent adult is evident in his ability to maintain relationships, engage in various interests and support his family, even during challenging times like the Covid-19 lockdown. While he prefers his secure network, he can form new relationships when necessary.

Throughout his narrative, Ben demonstrates empathy, self-awareness and an understanding of societal rules, contributing to his character development. Despite facing challenges like bullying, he maintains a positive outlook, focusing on supportive relationships.

In summary, Ben's story reflects his confidence, resilience and ability to navigate the complexities of adulthood with the support of his close network. His narrative highlights the significance of personal choice and designated support networks in overcoming challenges and thriving in life.

Chapter 6 – Discussion and Conclusion

6.1 Introduction

In this chapter, I delve into Emily’s and Ben's perspectives on life beyond the world of policy outcomes, as discussed in Chapter Two, and draw out what has been learnt from the narratives and the implications of this new knowledge. The conceptual framework was used to systematise the analysis of Emily’s and Ben's experiences of adulthood, including social interactions, relationships and community connections. While acknowledging professional frameworks derived from policy that defines intended outcomes for education provision. This chapter analyses real events to uncover themes from their narratives, aiming to accurately represent their views and discover how they perceived their experiences.

To evaluate the data further, I used an inductive process to identify the emerging themes. It can be seen that revisiting the transcripts and highlighting key categories that were repeated throughout (Appendix 9) provided a richer insight (Finlay, 2008; Caputo, 2018). This process allowed the data to guide my analysis of the perceptions revealed within the emerging patterns, themes and concepts.

The narratives revealed the participants’ perception of their experiences identifying recurring themes, such as the participants’ definition of success, their self and identity, and resilience. Additionally, the participants described complex interactions with authority, and their personal stories related to their employment while threading through their reliance on personal support networks. Both Emily and Ben have a reliance on their microsystem of support as previously noted, and this is really no different from any other adult who experiences vulnerabilities from time to time, without a previous designation of SEND. There are some aspects of adult life that are unfamiliar, and this is when additional support systems are required to engage with the wider world. The conceptual framework was useful to identify where the participants interact across the concentric circles of systems (Appendix 5), while remaining in contact with their microsystem of support. The inclusion of the 5 C's (Lerner, 2009) in the conceptual framework identified overarching skills, which allowed for an insight into where skills existed and who they were connecting with (Abdul Kadir and Mohd, 2021; Malkani, 2021). Ben and Emily describe their ability to evaluate risk and make decisions on issues of safety.

To summarise, both participants have achieved a level of independence in adulthood, and through their narratives they identified several reoccurring themes to be explored within this chapter. The themes include the participants' perception of success, self and identity, resilience, authority and employment.

6.2 The participants' perception of success

In this research I am reflexively aware of what the participants' voices are saying to define their perception of success. Although both Emily and Ben have followed a structured skills development pathway up until 25 (DfE, DoH, 2015; Carroll, 2015), the measure of their success relates to their perception of their life experiences and the value, if any, that they place on previous support provided. The literature is clear in the requirement of skills development as a catalyst for a successful transition, and the aspiration of a meaningful life, as noted in the research by Montgomery *et al.* (2019), where individuals need to belong and have a connection with the community. These important factors facilitate integration, without which individuals could become isolated (O'Connor, 2014; Nelson, 2021) and this research provides an insight into how connection with the community and the development of relationships occur.

The experiences and perception of success from the viewpoint of each participant influences their identity (Nelson, 2021) by building the required life skills as adults. If success in adulthood is measured by employability and community integration (DfE, DoH, 2015; Chan *et al.,* 2020), then the narratives describe how a version of success has been achieved. Emily and Ben have become experts in their own lives (DRILL, 2020), taking control of their employment, travel, daily tasks and parenthood, demonstrating a good quality of life (Morisse *et al.,* 2013). Both Emily and Ben also described how important it is for them to actively pursue their hobbies and interests as a creative outlet.

The stigma of a previous designation of difference became irrelevant in adulthood, no longer a catalyst for attracting formal support. Rather than continuing to focus on the deficit they both focused on their strengths (Dangoisse *et al.,* 2020), which provided them with enhanced self-esteem as the loss of the former designation of difference allowed them to ‘fit in’. Ben refers to his childhood struggles, which impacted on his confidence; he described feeling ‘held back’ regarding his label. Emily notes that her designation of difference was most prevalent when she moved from mainstream to a specialist school provision. This suggests the impact of a designation of difference and labelling up to age 25, alongside the focus on skills development at school and college, related to a perceived deficit that if accepted could mitigate against success (Malkani, 2021). An increased focus on any difference contributes to reinforcing a ‘felt’ stigma (Gray, 2002), leading to an increased fear of failure. The move away from the deficit of a designation of difference appeared to empower Emily and Ben to look towards their strengths, without a constant reminder of their limitations. Their coping strategy of developing a support network facilitated the focus on their strengths and created a ‘can do’ approach to life.

While receiving formal support the language predominantly related to a designated difference and the potential challenges that they could face as adults with a focus on generic skills enhancement. Emily reflected on her need at that time; she noted that the most valuable aspect for her was employability skills and acknowledged the value of volunteering. Ben reported having negative feelings about his diagnosed deficit that remained with him, stating, ‘been through that stage and got used to it’. He referred to his diagnosis as a stigma (Handoyo *et al.,* 2022), also reinforcing issues with his literacy skills at college, where he received some additional support.

In adulthood their focus was on managing everyday tasks and social interaction; where their diversity became more inclusive, it was when challenging engagements with formal processes allowed differences to resurface. Success in adulthood consistently relied on their support network, mentioned in all of the research sessions. The network of family and friends were aware of their challenges and were turned to, not just because they had a close relationship, but because they understood the impact of specific differences, and could offer appropriate support as an integral component of their coping strategy (Christensen, 2016).

However, there were some examples of events where support was not readily available leading to a concealment of a perceived deficiency (Hull *et al.* 2017). Emily reported this was her embedded strategy where she portrayed an identity of equality (Nalavany and Carawan, 2015; Hull *et al.,* 2017), dismissing any need for a disclosure. It appeared however, that the strategy of concealing her challenges with social interaction introduced additional barriers, resulting in an unsuccessful interaction and an increase in her anxiety levels (Beck *et al.,* 2020; Cook *et al.,* 2024). There is limited evidence of whether or not, if she had disclosed her challenges, she would have received an adaptation through the provision of reasonable adjustments (Equality Act, 2010), although through disclosure it is anticipated that support might be available to reduce discrimination, which in turn could have made the interaction less confronting.

Both participants noted that they have consciously moved away from the focus on their perceived limitations (Oliver, 1996; Anastasia and Kauffman, 2011; MacIntyre, 2014), which reduced access to an emancipated existence (Wong, 2020). Both Emily and Ben cite examples in their narrative where they have forged new social interactions, citing their work colleagues as friends. Ben describes how they, ‘have a laugh’ and it ‘feels like family’. Their work roles embrace the opportunity for additional responsibility, with Ben describing his integral role in a project where he was travelling with some clients and had to ‘walk with them into town’, further enhancing his levels of confidence (McConkey *et al.,* 2009). These examples show an increased confidence enhancing a quality of life and a positive interaction, rather than their designation of difference instigating negative connotations.

They are mostly fulfilled in their roles but identify that the educational pathway followed a more generalist route, from specialist school to supportive education at college, with a focus on life skills (DfE, DoH, 2015). It appears from their narratives that wide-ranging career advice and guidance appeared to be missing from that stage of their transition to adulthood (Banks *et al.,* 2022). Although Ben did receive some initial guidance and support from "Connexions", this support was short-lived as the service ceased to exist alongside funding issues, and he was unable to complete the required level of qualification to work in construction. For both Emily and Ben, they embrace the utilisation of their skills in their hobbies for creative satisfaction. Emily uses her talent in costume design, and Ben embraces his love of music by attending gigs, and also utilises his construction skills at home on do-it-yourself (DIY) projects. The issues around their current employment will be explored further in the section on employment (6.6). The success that Emily and Ben have described in their narratives relates to achieving a quality of life (Morisse *et al.* 2013), where they feel included, made safe by the choices they have made; they also acknowledge the security provided by employment, albeit they would both like a higher income.

The provision of a support network safeguards Emily's mental health and well-being (Muniandy, 2021), as she becomes overwhelmed and can appear to panic. Emily's experiences in adulthood have given her the opportunity to develop her life skills, understand her own needs in order to manage her more challenging relationships (Mueller, 2021), and be able to cope as a sole parent. Emily's narrative provided a positive spin on her life to date. She was mostly upbeat, even when her most recent relationship broke down, keeping a positive outlook on life and maintaining a connection with her ex-partner for her daughter's benefit. Emily has entrepreneurially developed her support network (Christensen, 2016); she has a good understanding of her own needs and is aware that there are times in her life when she needs support, although she recognises concealment is an embedded reaction to unexpected change.

In comparison, Ben was not quite as forthcoming regarding his personal experiences, but he did share details related to his current romantic relationship and described a previous long-term relationship, where they had remained friends. He is content working at the community organisation, and he describes his colleagues as close friends, and part of his support network (O'Connor *et al.,* 2014).

Ben's creative skills have been channelled into home improvement as no career route was available to him at college. He was keen to share his recollection of specific knowledge related to bricklaying and measuring techniques; he also described some entrepreneurial ideas about a possible craft business based on his woodworking skills. While the skills increase his quality of life and may save him some money, this results in a reduced income overall. The overarching outcome of employment is success; however, both noted that they would prefer to be working additional paid hours for financial security, with a preference for this to occur in their current role, although as a community organisation with limited funds they cannot just add extra hours of employment.

Hobbies and interests are an outlet for their creativity and skills: For Ben the main things are his interest in music, and his hobby of DIY; for Emily, her passion for costume design and attending character conventions appear to mostly satisfy her creativity. Both Emily and Ben identify their outcomes as being broadly successful, although they would have preferred a career choice that aligned more with their interests. As Ben was reflecting on his journey into adulthood he made a note to his younger self, *'Don't give up on your passions, keep going, it will all work out'*, which demonstrates his feelings about his success to date.

The successful outcomes described by Emily and Ben mirror the goals within policy (DfE, DoH, 2015). Post 25, they entered a void in support where the focus of help reverted back to their family and the development of their own support network. Both have obtained permanent accommodation, providing them with a safe space. Interestingly, both of their employment outcomes were initiated through a prior association with the local community organisation at a time when there were limited supported employment options available (Kent County Council, 2020). The organisation that employs them did not appear in the ‘Local Offer’ and it was by chance that they made the initial connection. Employment is a successful outcome, facilitating community integration and developing additional friendships and the role balances their ambitions with realistic expectations.

6.2.1 Implications: Success

The narratives reveal two important points about the deficit surrounding the stigma of a designation of difference (Oliver, 1996; Anastasia and Kauffman, 2011; MacIntyre, 2014; Handoyo *et al.,* 2022). There is strategic cut-off point at age 25 with an expectation that a need for skills development has been completed (DfE, DoH, 2015). The previous designation of difference fades away by losing the ‘felt’ stigma (Gray, 2002), as formal support ceases and informal support becomes embedded. There is an expectation that a transition will lead to integration into the community (DfE, DoH, 2015), although it is not explicit that this would form a sustainable support network. There is also an assumption that an individual will have the entrepreneurial skills required to develop such a network (Christensen, 2016). For those individuals who do not have established relationships with partners, friends and family, the reality of social integration could be more challenging.

Any reference to the previous designation of difference becomes more apparent when an interaction occurs with an unfamiliar person or agency, where without a provision of disclosure (Equality Act, 2010) accommodations remain unavailable. In this professional capacity, the agency or authority might be unaware of any barriers due to the camouflaging of needs that occurs. In these instances, a reference to the previous designation could be helpful to be able to receive support solely for that interaction. The challenge for those interacting with an adult with a mild to moderate designation is recognising the subtlety of potential barriers to a successful interaction (ibid).

The preparation for adulthood does not include the management of interactions outside of the more familiar environments. There are structures in place within the health service and other authorities to be able to offer reasonable adjustments (Equality Act, 2010), when required. However, the process of being able to trigger support is more complex, as the participants' have become distanced from acknowledging that potential barriers exist in an attempt to fit in, to limit any additional complex interaction and blend in with the norm.

Within the narratives, as the designation of difference becomes irrelevant related to a withdrawal of formal support (DfE, DoH, 2015), it is also deemed that there is an absence of specific career choice, with generic skills development and work experience being the main focus for individuals with a designation of difference, leading to a lack of opportunity to pursue their career interests (Banks *et al.,* 2022). It appears that there is a need for an audit on the progression of adults with a mild to moderate difference, to signpost available career development and employment options.

In order to summarise what is required for success, the narratives revealed an informal support structure that is essential in adulthood. The structured focus on the transition into adulthood (DfE, DoH, 2015) post 25 refers to the development of an entrepreneurial support network to support problem solving while understanding their limitations, which can occur if there is an established relationship with family and friends to build upon. Furthermore, the designation of difference relates to a deficit discourse of need, and once the formal support ceases the relevance of a label diminishes. In addition, the loss of a perceived designation of difference limits the need to focus on disclosure, allowing for more social interaction, increased confidence and aspiration related to their skills and preferences.

6.3 The participants' perception of self and identity

The previous section on perceptions of success influences identity as Emily and Ben move into a space where they embrace their strengths (DRILL, 2020). Aspects of their self-identity revealed in their narratives are of adults who are confident in their workplace, are able to pursue their hobbies, show competence in their skills and have confidence in their social engagement with romantic partners, in parenthood and as friends. They can also integrate with their local community through work and neighbourhood relationships, and retain strong family ties.

Employment is a requirement for independence and community engagement (DfE, DoH, 2015); it is also a way of countering isolation. The positive aspects of being employed enhance their self-esteem. However, it has not always been like this for Emily and Ben; they have both reported being bullied - for Ben at school, and for Emily, during a supported work placement. Being poorly treated impacts self-esteem (Beck *et al.,* 2022; Cook *et al.* 2024), causing a negative feeling of self (Dangoisse *et al.,* 2019), which can then be triggered by similar incidences in adulthood.

Fortunately their workplace supports a feeling of positivity as both Emily and Ben feel valued as part of a team; their current experiences build on their positive sense of self by reinforcing their achievements (O’Connor *et al.,* 2014). Emily’s and Ben's employment contrasts with many of the research and government initiatives, reporting employability as one of the more significant challenges to those with SEND, leading to isolation (Malkani, 2021). Emily describes how she is part of the workplace decision-making process and feels competent in this field. She also embraces the practical aspects of her role, acknowledging that she is unable to ‘sit still and do nothing', showing her self-awareness.

Furthermore, Emily and Ben are now navigating the complexities of the additional identity of parenthood. Emily is a confident mother and focused on Clare's well-being during the research sessions. In education there is an emphasis on becoming confident individuals who are physically, emotionally and socially healthy, responsible citizens and able to manage risk and make decisions (ASDAN, 2023), but the complexity of romantic relationships and parenthood were not included when studying for adulthood. Ben is by default a step-parent to his partner's daughters, whom he lives with, although during the research sessions he appeared reticent to note his role, referring to the girls as ‘Bess’s daughters’.

Emily and Ben's narratives provide insight into how they have successfully transitioned into these adult roles, feeling equally competent compared to their peers. Although their support network is relied on for the more complex decision-making, this appeared minimal in the narrative. However, a need for a coping strategy could also be a learned behaviour, moving from a reliance on a supportive environment during education, in a similar way that camouflaging or masking occurs as an embedded way of depicting normality (Russell and Norwich, 2012; Nalavany and Carawan, 2015).

Despite some unique challenges, Emily and Ben demonstrate internal strengths in the data. They both value their independence and note their pride in their achievements. Ben carries out his daily tasks and supports his partner; he is developing his outside space. He recognises his emotional limitations and describes how engagement with the news and social media can make him feel overwhelmed, as he is unsure of the truth. Ben is aware of the risks and manages his self-knowledge effectively by limiting his interaction with external media to maintain his well-being.

Emily as a sole parent enjoys motherhood, appearing confident and prioritises her daughter's needs by making the decision to take the research sessions to her home as the best option for her daughter. Emily is very proud of her integration into her local neighbourhood; she knows many of her neighbours and interacts regularly, sharing childcare responsibilities and engaging in local issues. The concept of integration (DfE, DoH, 2015) is an outcome that ensures a connection with others as a result of skills development (Lerner, 2009). Emily does not exhibit the same barriers that could limit her engagement with others, as noted in the literature regarding individuals with a designated difference (Montgomery *et al.,* 2019), although it is difficult to know how frequently she masks her true self. Emily provided an insight into an interaction with authority, where she used masking as her coping mechanism (Beck *et al.,* 2020) to maintain her self-esteem (Field *et al.,* 2021). The literature refers to the impact of additional responsibility and how feelings of vulnerability can also cause a feeling of inadequacy (ibid). Both Emily and Ben limit their periods of vulnerability by remaining in a familiar and friendly environment; if they venture out of their microsystem, this can challenge their perceptions of their capabilities.

On several occasions in Emily's narrative, if she had disclosed her designation of difference, she could have sought support through the provision of reasonable adjustments (Equality Act, 2010). Emily is open about her need to fit in and by masking, limits her visible anxiety. However, internally her anxiety is exacerbated (Field *et al.,* 2021) as she becomes increasingly uncomfortable, particularly if she has to maintain the camouflage for an extended time. Ben did not describe his concealment of differences; however, he reports that his autism was initially a barrier to becoming 'accepted and confident'. He no longer identifies as a victim; he described how he removes himself from any perceived risk related to confronting behaviour, where he has decided that aggressive behaviour does not align with his identity; he notes that he is ‘not that type of person’ and ‘likes to keep away from it’. By avoiding situations that he finds challenging, he is choosing what thoughts and actions fit with his own values and characteristics (Nelson, 2021). Ben exerts his confidence, pushing his boundaries by travelling to unfamiliar venues, and is engaged in voting for ‘Battle of the Bands’.

Emily excels in her creative interests, as demonstrated by her frequent enthusiastic references to costume-making in our conversations. She pays attention to being able to portray the characters accurately, so much so that she is now invited to attend as one of the characters showcasing their costumes alongside her convention friends. She portrays the character and is both accepted and admired as an expert in the field, which is a boost to her confidence.

The beliefs that both Ben and Emily hold originated in their upbringing and education. Their experiences in adulthood consolidate those values and beliefs by guiding their choices, influencing their decision-making and creating their quality of life. Their social interaction with others, at work; and during the events they enjoy as hobbies, bring to their identity a sense of achievement and enhance their creativity and self-expression. The Office for National Statistics (2021) reported that the well-being of those with a designated difference could lead to social exclusion; however, this was not the case as both Ben and Emily have achieved stability in their lives, and they are not socially excluded (Morrisse *et al.,* 2013; Gilmore and Cuskelly, 2014; Rahman *et al.,* 2022), and have achieved a good quality of life. Their self-development is optimistic, and they can live independently and positively contribute to their community (DfE, DoH, 2015). According to Nelson (2021), the journey into adulthood equates to the proper steps to move towards a future commitment as an adult. Both Ben and Emily appear to have those proper steps in place as they have developed self-awareness to maintain their interests; they manage their interactions in line with their capabilities and values, in order to live their lives on their own terms.

6.3.1 Implications: Self and identity

The traits associated with identity and self from the data need to be correlated against what particular traits Emily and Ben could be exhibiting attributed to a designation of autism, however mild or moderate. Furthermore there might be a limit to a wider generalisation related to a sense of self from the data, as all individuals have different needs. The data shows that a sense of identity relates to how an individual sees themselves amongst their support network, and also externally in the community, at work, and when taking part in their hobbies and interests. The narratives dwell on the positive attributes of their social interaction with others: positive self-identity related to their role as friends, employees and parents, without any hint of being constrained in life’s experiences related to a designation of difference.

An important aspect of self is the demonstration of confidence in their workplace, competence in their skills and a strong sense of social engagement. Despite setbacks in childhood the narratives reveal a positive sense of self, attributed to integration into a workplace, where competence fosters feelings of positivity and achievement. Personal relationships and an ability to navigate the complexities of relationships and parenthood reinforce internal strengths and resilience. The narratives demonstrate the value of independence and their achievements.

However, the positive aspects of self-esteem can be impacted by instances of concealment highlighting the need for continued support and understanding, in those instances where a unfamiliarity of experience and unexpected change occur. Any unfamiliar experiences can impact on embedded coping strategies, and require additional support from their network or by seeking reasonable adjustments (Equality Act, 2010); this can be seen, as a positive attribute by being proactive in eliciting support to keep the required strategies in place (Nelson, 2021), ensuring personal agency and control.

6.4 The participants' perception of resilience

Resilience is required in independent adulthood, influenced by life's experiences (NICE, 2022) where the development of various coping mechanisms is needed to manage life's challenges. Both participants show an adaptability to cope with change by embracing individual strengths (Yeager and Dweck, 2012), and despite challenges they also exhibit a positive self-concept (ibid). During the insight into their life experiences, they both exhibit adaptivity to change and have indeed driven most of those changes.

Entrepreneurial skills and resilience support an ability to cope with life's challenges, which otherwise result in setbacks (Burt and Paysnick, 2012). Skills development and life experience can provide the necessary tools and growth mindset to manage those setbacks (Yeager and Dweck, 2012). The experience of negative incidences impacts the concept of self, potentially causing a setback, like bullying or feeling discriminated against. According to the literature (Yeager and Dweck, 2012), the ability to bounce back from a negative experience, rather than let the transgressors win by impacting their actions, supports an adult's well-being (NICE, 2022).

Furthermore both Emily and Ben have not only shown resilience, but have also taken positive action, to enhance their strengths (Yeager and Dweck, 2012); learning from their experiences (Christensen, 2016; Abdul Kadir and Mohd, 2021). Ben has left behind his designation of difference, where he felt 'held back' and hindered in his goal of working in construction, by utilising his construction skills at home. He has an emotional connection to the building trades, describing how he would have liked to 'follow in his [Grandfather’s] footsteps' as a bricklayer. During the Covid-19 lockdown, Ben drove a change by moving in with his partner rather than being alone, noting that he returned home when things felt overwhelming. Ben has a clear sense of self and what aspects of his life require a coping strategy.

Emily's narrative included many challenging events, including complex relationships that she ended based on her values and beliefs by prioritising her well-being. Emily became displaced from her family home as a young adult, moved around from place to place with a range of support strategies; eventually she became a parent and obtained her own flat. Emily has managed all of this independently, initially with some support from social services while at risk of being homeless, until she obtained her own flat. During the Covid-19 lockdown, Emily also reveals how she had a mental health ‘breakdown’ which negatively impacted her work performance, but she made a concerted effort to turn this around to demonstrate to her employer that she was worthy of her role.

Emily’s decisions related to managing relationships have shown her need for self-protection, reducing any impact on peer relationships (Antony, 2022), as she endeavours to keep her relationships platonic whenever possible. In both Emily and Ben's narratives, their capacity to demonstrate resilience and safeguard their emotions is described when faced with challenges (Antony, 2022), which positively impacts their self-esteem by refusing to be set back (ibid). The existence of a supportive network taps into the skills of others through a reciprocal relationship that understands the personal challenges that both Emily and Ben can experience, knowing there is someone to turn to for support (Yeager and Dweck, 2012).

Ben chooses not to engage with external factors where he cannot decipher the truth, preferring to gain his version of current affairs from his close family and friends (ibid, 2012; Muniandy *et al.,* 2021). His deliberate avoidance of confrontation and anti-social behaviour demonstrates a resilience that keeps him safe. Resilience relies on maintaining a positive growth mindset (Yeager and Dweck, 2012) initiated in education (Lerner *et al.,* 2013), which continues to be associated with life experiences, where they make decisions to limit instances that create additional challenges. The incidences they experience in their daily life allow them to enhance their emotional intelligence (Antony, 2022) and, strengthen their resilience associated with social interaction and relationships, alongside a continued relationship with their informed support network (McMenemy and Nicholas, 2022).

6.4.1 Implications: Resilience

Life experiences, including setbacks like bullying and discrimination, shape resilience (NICE, 2022). The data provided an insight into the proactive approach adopted to overcome challenges and setbacks by continuing to develop their resilience (Christensen, 2016; Abdul Kadir and Mohd, 2021). The narratives reveal skills gained through life experiences; the ability to develop resilience also helps to drive change by not allowing setbacks to impede progress. Resilience links to identity and self-esteem by adopting a positive growth mind-set, being able to recognise success (Yeager and Dweck, 2012; Lerner *et al.,* 2013; Antony, 2022), continue to develop their skills (McMenemy and Nicholas, 2022), reach their goals and maintain well-being in order to live the lives they choose to live.

Once the fundamental aspects of taught sessions and reflections on experiences in a work placement are completed (ASDAN, 2023), the need to continue to develop resilience becomes part of daily life. In the absence of mediation and without the shelter of a support network (Muniandy *et al.,* 2021; McMenemy and Nicholas, 2022), an individual might shy away from pushing the boundaries due to a fear of failure, impacting on self-esteem and well-being. Therefore, to encourage interaction with others and a growth mindset (Yeager and Dweck, 2012), it is important that adults are able to receive a level of support not to drive the solution (McMenemy and Nicholas, 2022), but to support on-going skills development.

6.5 The participants’ perception of interacting with authority

The definition of formal relationships within this research refers to those organisations that are formal and unfamiliar to Emily and Ben, and where they are not themselves known to the people they are interacting with (Riddell and Watson, 2003). Within the narratives, there were occasions when interactions with authorities were required to source an external service - for example, accommodation, financial support, managing health issues, and being able to gain and maintain employment (Christensen, 2016, Crane *et al.,* 2022*)*. These interactions are aspects of citizenship (Oliver, 1996), and they relate to Emily's and Ben's perceptions of success, identity, resilience and inclusion in society as disclosed in previous sections of this chapter.

Emily reveals her confidence in her daily social interaction until she encounters unfamiliar people in a position of authority, where she is more likely to conceal her true identity by masking (Beck *et al.,* 2020; Cook *et al.,* 2024), as she perceives that instantaneous decisions and accountability are required (Field *et al.,* 2021). To illustrate the complexity of Emily's perceived barriers to interacting with authority, she describes a formal complaint related to her daughter's buggy parked inappropriately in the shared hallway. To gather support after her perceived wrongdoing, Emily sought validation by discussing this with her friends and neighbours to build a consensus of support, rather than confront the originating authority. By choosing not to interact with unknown instigators and concealing her difficulties (Mueller, 2021), Emily remains unaccountable and her self-esteem is not negatively impacted.

The dichotomy for Emily and Ben is that limited experiences reveal a fear of engaging with unfamiliar territory (Field *et al.,* 2021), although in some instances, such as attending music festivals and character conventions, they have persevered until the unfamiliar becomes familiar. In order to maintain their ability to fit in and cope, the preference appears to be for those environments closer to their support network (Gobec, *et al.,* 2022). However, there will be incidences where an unfamiliar interaction is required and the decision needs to made as to whether they take their support system with them, as in the example of Emily's interaction with healthcare agencies related to her daughter's birth.

Therefore, their aversion to risk could hinder the development of resilience; it is unclear as to what extent this is attributed to their previous designation of autism, or a skills deficit. There is also a risk of isolation from a limited section of community interaction (Office for National Statistics, 2021). Both Emily and Ben appear to engage with a limited number of agencies outside their immediate community, in order to protect themselves from an impact on their emotional well-being (ibid, 2021). As discussed previously, issues around their success in developing skills, pushing outside of the comfort zone to develop resilience (McConkey *et al.* 2009) and fostering the ability to disclose in formal interactions to obtain the available support are all relevant to managing an unfamiliar interaction.

6.5.1 Implications: Interacting with authority

Emily and Ben, as independent adults, have a positive perception of their relationship with others and their integration into the community (Goodley, 2021). However, this is not the case in relation to authority and communicating with unfamiliar people. By choosing a limited engagement, they protect themselves against a negative interaction that can trigger issues around identity and impact societal inclusion.

The loss of the identity of a difference limits the option to restore a need for additional support when interacting with unfamiliar individuals and authorities without the option of disclosure, all interactions remain a challenge. If the individual is unable to engage effectively then the implications could undermine the safety and security of their accommodation, or incur a potential health implication to themselves or their family. The options represented in the narrative were avoidance or masking (Hull *et al.,* 2017), as the processes as they exist might not be suitable to meet the needs of neurodiversity (Equality Act, 2010).

6.6 The participants' perceptions of employment

Employment is one of the overarching measurements of success in policy (DfE, DoH, 2015) and underpins the taught curriculum (ASDAN, 2023) by identifying the skills required to gain employment and achieve a quality of life (Morisse *et al.,* 2013). The narratives suggest that for both Emily and Ben their engagement with employment provides them with a fundamental aspect of their self-identity, providing opportunities for personal growth. Through their work relationships they are able to enhance social interaction, and develop their skills, including resilience.

The community organisation that Emily and Ben work for has a culture of support for colleagues by providing a familial approach to managing difference (Gregory, 2017). This workplace is aware of Emily's and Ben's challenges, as they have known them from when they entered as clients. Both of their narratives describe their integration into the workplace, where they identify as being successful in their roles and popular with their colleagues, whom they socialise with on equal terms, which is an important component of community integration (Macdonald, *et al.,* 2018). Although not mentioned explicitly in the data, it is important to recognise that this specific supportive context is influential in their lives and reflects what is required from employers and organisations to support inclusion (Department of Work and Pensions, 2022).

The field of social care that they are working within suits their individual needs and they are fully integrated into the organization, although, Emily cites a time when she was struggling with her mental health and she refers to having a 'breakdown'; she notes this impacted on her relationship with her workplace and it required some effort on her part to reintegrate (Abdul Kadir and Mohd, 2021). Emily and Ben both feel at ease in their workplace, alongside colleagues specifically trained in neurodiversity (O'Connor *et al.,* 2019), allowing Emily and Ben's roles to extend into social relationships (Morisse *et al.,* 2013) through the inclusive nature of the organisation (Mooney *et al.,* 2019) with a clientele of moderate to severe disabilities SEND. The literature refers to employability as the pinnacle of success for those with a designation of difference (DfE, DoH, 2015) as it brings together aspects of social engagement and being able to feel valued (DRILL, 2020).

Emily and Ben both describe their involvement in workplace decision-making, discussing their input and key role in getting tasks underway by taking responsibility for artistic projects. Emily notes her role in leading art projects within taught sessions, and Ben is responsible for supporting the clients with creative and sporting activities. He is also tasked with carrying a large sculpture for a local carnival.

Interestingly both Ben and Emily have expressed a desire to work elsewhere for financial reasons, as their current paid hours are limited. A low socio-economic status is noted alongside the challenges of a successful move into employment for those with a designation of difference. Government policy (DfE, DoH, 2015) states that employment is an outcome, but the steps along the way are not enabling (Osgood *et al.* 2010), where a stigma of difference can also limit the available employment options (Sheffield and Morgan, 2017; Handoyo *et al.,* 2022).

New environments and unfamiliar procedures increase feelings of unease. In Emily's new work role she struggled to manage the work reporting process, which impacted her confidence. In a work situation Emily is reluctant to disclose her difficulties in case this leads to discrimination; she notes that her dyslexia was also making her additionally anxious in the new environment. Emily soon discovered that due to the rules of her benefits scheme and her inability to access additional childcare, the financial reward for the new role was negligible and she resigned. Emily describes another potential specific skills deficit related to poor numeracy, noting additional employment limitations, demonstrating that she can navigate opportunities in relation to her perceived limitations.

In employment, success is not solely associated with gaining a job, but the sustainability of that role, leading to community integration (DfE, DoH, 2015). It is apparent that the role that both Emily and Ben are in at the community organisation suits their needs; they feel comfortable and their support needs are being met. Emily and Ben have achieved a good quality of life (Morisse *et al.,* 2013), where they have established themselves as part of a team and feel valued. Their experiences contrast with broader research and government initiatives, which often identify employability as a significant challenge for individuals with a designation of difference, leading to social isolation (Hughes-McCormack *et al.,* 2017; Emerson, 2021). There remains a need to enhance the overall opportunities for employment and allow these transitions to improve for those adults designated with a difference (DfE, DoH and SC, 2021). Emily and Ben perceive employment as fundamental to their independence and community engagement, and as a requirement for enhancing self-esteem and countering isolation (Osgood *et al.,* 2010; Office for National Statistics, 2021). It appears that, in comparison to other adults with similar difficulties (United Nations, 2018; Crane *et al.* 2021) Emily and Ben have been fortunate to obtain the role that they have (Ghanouni and Raphael, 2022).

6.6.1 Implications: Employment

The exploration of the significance of employment as a measure of success and a pathway to independence and community engagement for individuals like Emily and Ben highlighted how employment provides a positive self-identity, opportunities for personal growth, and through the friendships made and the tasks undertaken, also provides an integration into their local community. As noted, the community organisation accommodates their differences but is unable to employ them full-time. Other organisations might not be so accommodating to their differences, but pay higher salaries, although the sustainability of other employment options might not be as realistic. There are currently government moves to provide additional supported employment opportunities, but the reality of accessing these roles at this moment in time is unlikely (Ghanouni and Raphael, 2022). There is no doubt that being employed, even part-time, promotes independence, enhances self-esteem and provides inclusion in society. Employment is an aspect of society; therefore if we were more inclusive in society then fewer adjustments would be required in an employment setting. Government policy is striving towards inclusion and an acceptance of difference, specifically focusing on autism (DfE, DfH & SC, 2021), where pre-employment support and the creation of innovative approaches to disability support related to job search and employment options will be provided. The policy strategies go some way to structuring the required support (ibid), but these strategies rely on an individual continuing to focus on a deficit by disclosing their needs. The narratives reveal a reluctance to continue to retain a designation of difference once formal support ceases to be available.

6.7 Conclusion

The narratives have revealed important insights to address the research questions: 'How do the individuals perceive their social experiences, relationships and connections with the community?' and 'How well do they feel they were prepared for independent adult life beyond the formal provision, which ends at 25, and what are the implications for both education and social care?’

Both participants feel fully integrated into their communities, enjoying a high quality of life and a positive self-concept. Their stories emphasise the significance of supportive networks, personal coping strategies, and the pursuit of personal interests and hobbies; these are crucial for their well-being, especially given their need for creative outlets.

Employment is crucial for adult independence, fostering integration, combating isolation and boosting self-esteem through recognition of one's contributions. Despite challenges faced by individuals with designated differences in obtaining and retaining employment (Office for National Statistics, 2021) with outcomes for autistic individuals at 21.7% against 53.6% for other disability groups, the experiences of Emily and Ben highlight a fortunate exception to this trend. They are employed and have attained integration into the community organisation, providing social interaction and a feeling of contribution; however, the employment is part-time without the potential of an increase in hours, leading to an associated economic disadvantage.

Emily’s and Ben's resilience aids them in navigating life's challenges, crucial for maintaining well-being in adulthood. Selective interactions contribute to this resilience, although their own restriction of unfamiliar interactions also counters an opportunity for skills development and required support. Avoiding unfamiliar authorities helps them manage emotional regulation; when there is an encounter, masking their limitations occurs, reducing the risk of negative interactions that impact on identity and societal inclusion. It is essential for those in education to acknowledge the persistence of challenges into adulthood, and to promote options and strategies to manage the interaction and support disclosure. This will ultimately lead to a more open and effective social interaction with external agencies and authorities, removing potential barriers through reasonable adjustments (Equality Act, 2010).

Employment preparation starts in education. Both participants experienced a lack of appropriate career guidance within the supportive courses at college, focusing more on general life skills and basic literacy/numeracy. The analysis highlights the lack of specific career choices and mentoring for adults with designated differences, revealing insufficient preparation for life beyond formal support; this indicates a need for on-going employability support, career guidance, and targeted training.

In order to cope with life’s inevitable setbacks, resilience is a necessary attribute to manage change and adversity. The development of resilience is introduced in supported education, but it is life’s experiences where individuals develop the required coping skills. Resilience is an attribute that requires both input and awareness, alongside a support structure to move outwards into the wider ecological systems, in order to embrace unfamiliar experiences.

Without the above strategies, there is an assumption that these adults will be solely reliant on their support network. The SEND Code of Practice (DfE, DoH, 2015) defines participation in society as. ‘having friends and supportive relationships, and participating in, and contributing to, the local community’ (ibid, p.28), but the steps to get there are undefined for those with mild to moderate needs post 25. Adults without a support network could experience isolation (Osgood *et al*., 2010; Office for National Statistics, 2021). For those adults like Emily and Ben, access to the ‘Local Offer’ is also obscured, as not all local provision is documented (Gregory, 2017; Anderson *et al.,* 2022; Matthews *et al.,* 2023), specifically for those post 25 years. An audit of local provision should be carried out to collate all of the available services, including voluntary and charitable organisations, that could support those adults who are not fully employed or engaged in social spaces to facilitate their community integration.

The provision of local mentoring for those adults in the community without access to support could provide signposting to employment opportunities, financial support, training and volunteering options. The role of the mentor could include a guided introduction to available services, so that the individual has support when making the initial contact. By offering this service, the availability of opportunities could be made more accessible and centralised, in a similar way to what was previously offered by the “Connexions” service to young adults with SEND, prior to budget cuts. Such an investment could reduce other spending such as on mental health services, by building capacity to prevent issues occurring (DoH and SC, 2021).

6.8 Recommendations for education and social care

The research provides data supporting several recommendations for education and social care:

1. The ‘Local Offer’ should reflect the local opportunities related to adult needs with a focus on careers development and employability, including access to supportive employers and to include post-25.

2. Training on awareness and inclusion could be offered to employers, alongside trained workplace mentors to support integration.

3. Careers development in education provision should facilitate realistic career aspirations, as well as generalised skills development.

4. Specific skills and interests should be considered not just generic courses on life skills.

5. On-going support should be available post 25 on a needs-led basis. This provision could be the role of a community mentor who checks in regularly to ascertain how the key factors of employability, financial security and health issues are for an individual with mild to moderate needs. This would ensure that those adults without a support network could pursue success, integrate with others and receive support to engage with formal authorities.

6.9 Original contribution

The research foregrounds the participants as experts, allowing their voices to be heard by using a relational approach rather than a hierarchical interview style. The researcher/researched relationship drew on my personal experience of the Indigenous practice of yarning to create a flattened hierarchy over a longitudinal study period.

The research provides rich insights into these people and their lives and challenges a deficit model of living with a difference. The narratives showcase their success, and reveal that as formal support ceases the stigma of a designated difference fades away, allowing the individual to perceive a positive identity. A positive identity leads to a positive interaction with others; the only time this becomes negative is during interactions with unfamiliar authority, where any perceived barriers to interaction impact on the effectiveness of the engagement. Any negative interactions can also create a fear of failure, and this is why the support network is so important in facilitating decision-making, and supporting the ability to build and maintain relationships.

It was identified that the crucial support network is initially created in the microsystem, appearing as a ‘bubble’ of support from family and close friends. This bubble travels alongside the individual outwards into the broader and less familiar aspects of adult life, then returns into the perceived safety and comfort of their microsystem, stretching the microsystem into those wider systems. There are incidences as they travel into the broader systems where strengths in confidence, competence and connection fade requiring additional support to consolidate their success. For those individuals who do not have access to an informal support network, this is where access to a mentor could enhance their life experiences.

The participants' narratives reveal a life that is both successful and fulfilling, with many positive aspects; these include a connection with their community, the development of romantic relationships, friendships, connections with work colleagues, wider relationships with neighbours and interactions with likeminded individuals when engaging with hobbies and interests. Their work life could be enhanced by a more specific career choice that meets their interests, but the reality is that there is an absence of career guidance and development opportunities currently available.

The conceptual framework was extremely helpful in considering how skills are called into play across the widening spheres of activity, which may be valuable in designing future education in preparation for transition, lifelong learning and social support.

6.10 Further research

A limitation of this research is only having access to two research participants who work in the same organisation. It would be useful for future research to include additional stories of those who are not employed in supportive environments, making use of the same kind of relational methodology. It would also be useful to have a range of ages to identify aspects of development in adulthood. The narratives in this research were unguided and evolved through naturally occurring narratives; therefore the inclusion of observations, discussions with employers and peers, and the individuals' experiences of disclosure could add extra detail.

More research is needed to challenge the deficit-based, needs-focussed process of living with a previous designation of a difference to give individuals the opportunity to affirm their agency and define their own success criteria.

In conclusion, the two narratives reveal a perception of successful independent lives in the same way that the narrative of any adult without a designation of difference would do. The combined framework of ecological systems and skills allows for an exploration of how skills change in relation to the movement out from the microsystem. An example of this is where aspects of competence, confidence and connection fade as the individual moves into an unfamiliar system, particularly if their established support network is unavailable. The narratives challenge the deficit-based, needs-focussed view of SEND, with these individuals affirming their agency, being proactive and creative, and choosing how to live their lives.

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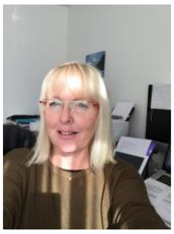
Appendices

Appendix One

Canterbury
Christ Church
University

Lived Experiences of Adults with Special Educational Needs and Disabilities: Listening to their voices.



PARTICIPANT INFORMATION (to be talked through individually)

My name is Bernadette Gregory. I am a friend of ‘xxxx’ and have known xxxx for a long time. I am studying at Canterbury Christ Church University and as part of my course I am doing a research project about people in our community. I want to find out more about what you have been doing since you left school or college. I am interested in finding out what are the activities that you do each day and who you talk to and go to if you need any help. By sharing your story you can help others to get the support they need in our community.

How will we do it?

I have found in my life that the most fun you can have is when you are sitting and chatting to people. It’s a good way to share our stories and we can build friendships by chatting to others.

You can help me to understand who you go to in your community, who are your friends and who are those people that support you.

As we go through our lives we have lots of changes, we go to school, then maybe move to college, perhaps start work and possibly move house. These are aspects of your life story and different people are around to support you as you become and adult and are more independent.

If you take part we will meet up, just you and me, and have a chat to share our stories and then to start to document yours. If you like drawing you could do a picture of your experiences. As we work together to collect information about your life story it will show what you have done, who you connect with and what parts of your community are important to you. We will continue to meet up to five times and then we will have gathered enough information to help me with my project. We may meet at ‘xxxx’ or go for a walk or to a café.

To participate in this research you must:

- Be over twenty-five years old.
- Be living independently (although you may have help from carers).

- Able to give consent to take part in the story telling now you know more about it.

After we have finished

At the end of the project I will meet up with you to tell you what great information the stories gave me and we can take another look at your story. All of your information will be stored safely and I will not share the details with anyone else because of the rules of Confidentiality and Data Protection.

Confidentiality and Data Protection

Any stories saved will have the names changed so that nobody knows it is your story. The recordings will be stored on a password-protected computer in a locked cupboard.

Once the project is done

I am going to write about what you have told me. This is for my ‘doctorate’ and I will get a certificate from the university. I hope that this will help people to understand the lives of people in my study. It is important they know what it is like to be you. This completed project will be published in the Canterbury Christ Church University library.

If you want to stop being part of the project

You can stop taking part in the sessions at any time without having to give a reason. I will make sure that every time we meet we will have time to talk about any worries you have about what we are doing. You can also ask xxxx or other members of staff if you have any questions. If you don’t want me to write about you, just let me or xxxx know.

Any questions?

Please talk to me when we meet if you want to send me a message talk to a member of staff and they will pass it onto me by email.

Appendix Two

Canterbury
Christ Church
University

CONSENT FORM

Title of Project:
Lived Experiences of Adults with Special Educational Needs and Disabilities: Listening to their voices.

Name of Researcher: *Bernadette Gregory*

Contact details:

Address: *Graduate School*
Canterbury Christ Church University

Tel: *01227 923640*

Email: *[bg176@canterbury.ac.uk*

This consent form will be worked through orally with the participant to ensure that they are fully aware of their commitment.

Please tick the box if you agree.

1. I understand that Bernadette is studying people's life stories and she wants to listen to mine. I would like to share my story with Bernadette.	☐
2. I know I can stop if I change my mind.	☐
3. I am happy for Bernadette to record my story. Bernadette will not share my name with anyone else who reads my story.	☐
4. I will meet Bernadette up to five times and then the project will be	☐

finished.	☐
5. I know that if I am worried I can talk to Bernadette or another member of staff at xxxx or a friend. 6. I agree to take part in the above project and I know that I will be able to ask questions as we go.	☐

Name of Participant:	Date:	Signature:
Name of support person (if relevant):	Date:	Signature:
Researcher:	Date:	Signature:

Copies: 1 for participant
1 for researcher

Appendix Three

Ethics Application

Ethics ETH2021-0329: Mrs Bernadette Gregory

Date Created	05 Jun 2021
Date Submitted	15 Dec 2021

Date forwarded to committee	05 Jan 2022
Researcher	Mrs Bernadette Gregory
Student ID	GRE97D51957
Category	Postgraduate Research Student
Supervisor	Dr Judy Durrant
Project	SEND - their voices: adult learners lived experiences of their transition into adulthood
Faculty	Faculty of Arts, Humanities and Education
School	School of Humanities and Education Studies
Current status	Approved

Ethics application

Personal details

Applicant name
Mrs Bernadette Gregory

Status
Postgraduate Researcher

Faculty
Faculty of Arts, Humanities and Education

School/Team
School of Humanities and Education Studies

CCCU email address
b.gregory176@canterbury.ac.uk

Are you the principal researcher?
Yes

Course Type
Doctorate In Education

Study level
PhD

Name of CCCU academic supervisor/tutor

Dr Judy Durrant, Dr Sue Soan

Email address of CCCU supervisor/tutor
judy.durrant@canterbury.ac.uk, sue.soan@canterbury.ac.uk

Project details
Project title
SEND - their voices: adult learners lived experiences of their transition into adulthood

Estimated start date of data collection
17 Jan 2022

Estimated end date of data collection
30 Jun 2022

Estimated end date of project
01 Sept 2023

Does your project involve human participants?
Yes

Does your project involve interaction with animals?
No

Does your project involve the processing of data not in the public domain?
No

Will the study involve participants who may lack capacity to consent or are at risk of losing capacity to consent as defined by the Mental Capacity Act 2005?
No

Will the study involve recruitment of participants through the NHS?
No

Will the study involve participants (Children or Adults) who are currently users of social services including those in care settings who are funded by social services or staff of social services departments?
No

Project summary
Briefly explain the purpose and intended outcomes of your project.
During my career, I have worked alongside young adults with Special Educational Needs and Disabilities (SEND) on supported courses with work placements, with a view to them gaining employment as an outcome. This raised the question of what happens to them as they leave

supported education and transition into the community as independent adults. My proposed research will investigate the life experiences of adults with Special Educational Needs and Disability (SEND) for whom a learning difficulty and/or a disability has warranted health and/or education support. The participants that will be the focus of this research will have received support during their time spent in education with their, communication and interaction, cognition and learning, social, emotional and mental health, and sensory or other physical needs (Department for Education, Department of Health, 2015). The participants will need to have the ability to verbally share their story unsupported and I would expect that their needs would be classed as mild to moderate. The data collation will be conducted by adapting a process of relational communication based on the indigenous method of 'Yarning', which means to sit down and chat. The importance of adopting an appropriate method of communication was a finding in my previous dissertation (Gregory, 2017). I need to adopt a communication style that flattens the power dynamic, with caring conversations that facilitate an insight into the participant's perspective of their social experiences, relationships, and connections as they live their life in adulthood.

Briefly explain your methods, research design and data analysis in lay terms.
The research question is 'What stories do individual adults with SEND tell of their lives and experiences'? Additional sub-questions can also be posed regarding how the individuals perceive their social experiences, relationships, and connections and how have they changed over time. During my career as a practitioner, I have spent some time in Australia where I worked in community education, predominantly supporting adults with their literacy and numeracy needs. During that time I worked in a variety of rural settings and I became interested in a more relational and engaging method of discussion. In Australia in the Aboriginal communities, this is known as 'yarning', where those taking part sit together, sharing stories to impart new knowledge. I am sensitive to the idea of engaging with a methodological approach from another culture and I approached Dr Marnee Shay, a Senior Lecturer at the University of Queensland, who has endorsed the use of this yarning methodology in new contexts including my research. The process of 'yarning' provides a sense of equality that exists as an integral expectation of the environment, designed to share experiences and to create new knowledge. My adaptation of 'yarning' will allow the participants to tell their stories, without judgment and with a sense of fluidity that will encourage a more detailed description of their journey. The adaptation of a 'yarning' process facilitates a sense of equal participation in an adult to adult setting. Within Aboriginal culture 'yarning' allows stories to unfold and the sense of journeying together through the past, present, and into the future allows people to be together in a manner that is relational. I intend to carry out between four and five 1:1 sessions with the participants to document their journey, these discussions will not last more than one hour and will include a discussion at the beginning to reiterate the style of communication we are using with the 'sit down and chat' method of discussion and a de-brief at the end to ensure that the participant is happy to continue next time. If the participants are willing they will be supported to produce a collage of their discussion, this can be done as part of the discussion to highlight key incidences and this will build up as the story progresses. Again, this is an adaptation of Aboriginal artistic storytelling where they create images that can document a journey from the past or capture a moment in time. If a collage is produced the visual images can be collated at the end of the project as a visual documentation of their life experiences.

Please indicate how you may disseminate the findings from your project.

Thesis/Dissertation Journal article Conference paper

Ethics & governance checklist
Does your project involve collecting and/or processing Personal Identifiable Information/personal data?
Yes

Does your project involve processing security-sensitive data?
No

Is this an externally funded project?
No

Will your research/any part of your research be carried out in a location outside of the UK?
No

Is the research taking place primarily within an organisation external to CCCU?
Yes

Does the study have the potential to impact on professional relationships?
No

Does the study involve participants who are particularly vulnerable or unable to give informed consent?
Yes

Does the project involve any patients and/or service users of a health and social care organisation?
Yes

Will the study require the co-operation of a ‘gatekeeper’ for initial access to any vulnerable groups or individuals to be recruited?
Yes

Will the study use deliberate deception?
No

Will the study involve discussion of, or collection of information on, topics of a sensitive nature personal to the participants?
Yes

Is it possible that criminal or other disclosures could be made by participants in the research that will require action?

Yes

Are drugs, placebos or other substances (including but not restricted to food substances, vitamins) to be administered to human or animal participants?
No

Does the study involve invasive or intrusive procedures, such as blood taking or muscle biopsy, from human or animal participants, or the storage of human tissue?
No

Is physiological stress, pain, or more than mild physical discomfort to humans or animals, beyond the risks encountered in normal life likely to result from the study?
No

Is it anticipated that there will be any discomfort or distress caused to participants and/or animals (as appropriate), the researcher or organisations as a result of this research?
No

Will the study involve prolonged or repetitive testing?
No

Will financial inducements be offered to participants?
No

Research host (external)
You have indicated that your research will be taking place primarily within an organisation external to CCCU. Do you have permission from the relevant organisation to carry out your research?
Yes

Please attach the relevant management and/or R&D Department permission(s).
Human participants
Who are the participants?
The participants will be adults who identify with the overarching title of Special Educational Needs and Disabilities (SEND) who have been through supported learning associated with one or more of the four areas of SEN, albeit to a mild or moderate extent, in one or more of the categories listed below:
-Communication and interaction;
-Cognition and Learning;
-Social, emotional, and mental health;
-Sensory and/or physical needs.
I require the participants to be able to verbally articulate their life story and I anticipate that through the recruitment process I will be able to identify those individuals with a mild/moderate difficulty.

I would expect the individuals to be living independently and they might be working. They may have an element of occasional additional support but are not registered with social services.

How many participants will there be?
Two to three participants

Please detail the rationale for the number of participants including if necessary a power calculation.
I require a small number of participants to be able to obtain sufficient data to gather rich individual data. I do not need to generalise from the data.

What are the selection criteria for participants?
The participants need to be able to be independent, articulate adults who are capable of orally describing their stories. They will fit the criteria of SEND and will have had the provision of supported learning during the time they spent in education. The participants must have had sufficient life experience of education, further education or training, and possibly work experience or employment to draw on. The participants will be part of a community organisation to provide access and gatekeeping so that the policies and procedures are available, such as safeguarding.

What will the participants be expected to do?
There will be an initial meeting to describe the process and to gain agreement related to their participation, the Manager of the community organisation will be invited to attend so that any issues can be addressed regarding the participant and their participation, logistical decisions regarding an appropriate meeting place, and a clear and documented discussion regarding the participant's role and their ability to cease participation will be discussed to ensure that all parties are clear about the process. If they wish to participate additional consent will be gained, eg. from a family member, on the advice of the community organisation. Once an agreement has been reached the research based on an adaptation of 'yarning', will commence. I plan to engage with the participants on a 1:1 basis to ensure confidentiality and privacy is paramount during the storytelling process and we will meet between four and five times. The sessions will last no longer than one-hour and there will be some flexibility of timing to ensure that the individual's needs are catered for regarding the need for a rest break, refreshments, and also to ensure that they are finding the session a positive experience. The environment is important as it needs to be neutral, there may be a location within the organisation that is private and without external distractions, or weather permitting the sessions can be held outside, either sitting or walking and talking, and this will be developed to best suit the individual's needs. I intend to organise the sessions in a location convenient to the participant, to minimise any travel costs. An initial introduction to the 'yarning' process will include an example formulated around my own life experiences as an example of storytelling, this may be in the form of a social story with visual aids that can be used, keywords will be introduced that can support a continuation from a previous discussion. Food and drink are also important aspects of 'yarning' so I intend to provide light refreshments that add to the relational, caring supportive approach. The sessions will be digitally recorded, with permission to ensure that the data is available for analysis. Any restrictions due to Covid-19 will need to be adhered to, both considering the national and organisational guidelines.

How will the participants be recruited?

The participants will be recruited in collaboration with the community organisation that I have a connection with from conducting my Masters dissertation with them. The manager of the organisation is an ex-colleague and his community group is planning to share some of my vegetable gardens to gain horticultural skills. Since completing my previous research with the organisation I have maintained a good relationship with both the staff and the clients. The manager has identified members of his group that meet my criteria and they will be approached individually by myself to ascertain whether or not they would like to participate in this research. I will ensure that the individual is aware that they have a choice and it is not a requirement of the organisation that they take part..
New members join the group periodically so I will ask the manager to keep me updated on any potential participants as he understands the selection criteria. I will then arrange to talk to them to inform them about the project and ascertain whether or not they may be interested in taking part and gain necessary additional consent as appropriate. The manager of the organisation will share with me if there are any additional gatekeepers that need to be informed as he has the working knowledge of his group.

Please upload any advertisement materials (ie posters, flyers etc).
Will it be necessary for participants to take part in the study without usual informed consent procedures having been implemented in advance?
No

How will you record consent?
I have produced a fact sheet that uses clear explanations to limit any confusion regarding the research focus and the methodology of 'yarning' for all participants and relevant gatekeepers. This will be talked through at the recruitment stage to ensure that those involved are clear about the focus of the research and the method being used to share their stories. I will also ask the participants, the manager (and any additional gatekeepers if relevant) to sign a consent form.

Please upload the consent materials.
How will participants be informed of the research project and what is required of them?
The first face to face meeting will consist of an outline of the project, timescales, expectations, and a description of the process and the data gathering methods to be used. As previously mentioned I will commence the initial 'social yarning' stage by sharing my own life experiences, with a focus on my journey to allow the participants to understand what the 'yarning' story-sharing process may be like for them and be able to experience the secure and informal environment.

Please upload the participant information materials.
Please describe any expected benefits to the research participant.
As a researcher, I am hoping that being part of the research process will allow the participant and myself to connect, to allow them to reflect on their experiences, by documenting their life story as independent/supported adults within our community. The purpose of the research is to allow for real stories to be heard that may challenge preconceptions, and the documentation of social experiences and connections will highlight what is available and also identify if there are any suggestions for additional support strategies to be developed.

How will participants be debriefed following their participation in the research?

The participants will be able to listen to an anonymised summary of the outcomes. This will be fed back during an exit meeting where the discussion will be centered around the key conclusions of the data collation, suitably phrased so that they understand. I hope that they will be interested and that they will feel proud to have taken part. There will also be an opportunity to review any artwork that has been produced as an overview of the complete journey.

Please upload any debriefing materials.

How will individual participants be made aware of the results of the project?
As a researcher, I intend to feedback to them on the anonymised key points of the research and to share any anonymised artistic interpretations (if available). If the participants agree this could be presented to the participants, the manager, and any additional gatekeepers identified as a small group, or if they prefer, an individual approach can be carried out.

Please detail the process for participant withdrawal and what is to be done with their data once consent is withdrawn.
At each 'yarning' session the participants will be asked whether they are happy to continue. If anyone is not their data will be removed from the research project. It may be that the participant is unwilling on the day to take part but wishes to continue being involved with the process, this is acceptable and an alternative date can be made to facilitate their continuation. I will also be in continual discussion with xxxx the centre manager who will pick up on any concerns.

CCCU participants

Will your study specifically target staff or student participants from a Faculty other than your own?
No

If yes, please select all relevant Faculties.

Will your project involve the recruitment of 100 (or more) CCCU student participants?
No

Vulnerable participants
Will participants be purposefully selected from any vulnerable groups?
Yes

Please provide details of any vulnerable participants.
The participants are deemed to be vulnerable due to the definition of living with a difference (SEND). They will be recruited and the target group is those that are living independently, although it is expected that there may be some level of support being provided by a family member, carer, or friend to manage some of their life skills. It is not possible to explain further yet as this will vary individually.

How will voluntary informed consent be obtained from individual vulnerable participants or those with a right to consent for them?

Voluntary consent will be sought by those who are living independently and the consent form will be talked through to ensure clarity. A discussion will be had with any other interested parties, if applicable to ensure that they are also aware of the involvement with the research project. A copy of the Participation Information Sheet can be used to inform those that are not directly involved in the process. The researcher will work closely with the centre manager and be available for questions or concerns to be raised.

Please upload any correspondence to vulnerable participants, parents, guardians, carers, keyworkers etc.

Service users

Please provide evidence of how patients/service users/the public have been/will be involved in the design, management, conduct and/or dissemination of your research or a rationale for non-involvement of patients/service users/the public.

The participants will be providing the data and they will be identifying areas of need, if applicable.

Gatekeeper

Who is the ‘gatekeeper’?

The main gatekeeper is the manager of the community organisation. It is important to ensure that any additional gatekeepers are identified and this can be done through a discussion with both the participant and the manager. It is important to identify any formal or informal arrangements to ensure that everyone is clear, eg. friends and family members, about the project and the role of the participant.

What data/access to individuals will the ‘gatekeeper’ provide?

The participants are part of a community group and therefore the Manager of that group will provide access to the participants. The manager will also be able to inform me about the need to involve any additional people at the recruitment stage, as he already has a working relationship with the participants.

How do you intend to approach the 'gatekeeper'?

The main gatekeeper is the Manager of the community organisation who will allow access to the individuals. We have a professional relationship built on trust and he has previously allowed me access to his organisation for my Master's dissertation. We have an ongoing professional relationship and I am providing space (free of charge) for the community group to develop a small horticultural provision as they have been unable to source a suitable piece of land. The manager has agreed that he is supportive of this research and he will support me to inform any interested parties about the project details, to ensure that they are clear about their family member. friend or clients involvement.

Sensitive and personal topics

lease list and explain how you will respond to participant discomfort due to topics of a sensitive nature personal to the participants.

The research is not asking for the sharing of difficult or sensitive topics. Some may occur during the course of the conversation initiated by the participant as they recall incidences that were challenging, for example, employment or social relationship issues. It will be made clear within the initial discussions that we are not including personal or sensitive material. I would intervene if the focus became too revelatory.

Criminal disclosures
Please list any possible criminal disclosures that could be made by participants in the research and explain the processes in place to deal with this.
Any disclosure of criminal activity is unlikely to occur. If any criminal disclosures were apparent they would be dealt with under the community organisation's policies.

Research materials & additional information
Please upload any research materials or tools e.g. surveys, interview questions, focus group guidelines.

Please provide details of any other ethical issues that you think are relevant to your project that have not been covered elsewhere within this application.
I am an experienced SEND practitioner. I have worked for many years supporting vulnerable adults with a variety of needs and I have never had a negative incident due to my communication style. I am currently working in a role where I assess students with a multitude of difficulties including mental health, physical disabilities and also learning difficulties. I am able to put them at ease, source the relevant information and keep the conversation focused, professional, and positive. Many of the people that I work with are surprised how quickly I can build rapport and I always treat all of my clients with the utmost respect and I adapt the communication style that I have found most beneficial for all parties. I am genuinely interested in discovering more about the reality of living with a difference and I intend to give each participant the space, support, and encouragement to be able to share their experiences. I believe it is important ethically for these voices to be heard.

Please upload any additional documentation to support the submission.

Data protection
Will special category personal data be collected?
Yes

What types of personal data will be collected?
Name and contact details and the contact details of any supportive friends, or family, if applicable. The stories are also personal data alongside any collage, but this will be anonymised.

What is the lawful basis for the collection and processing of personal data?
Consent

Please provide details of any arrangements in place to respond to individual requests for access to their personal data (Subject Access Requests).
The participant's stories will be available for them to access if required. The participants can request access to any information stored, including recordings, transcripts, artwork.

Will participants be able to withdraw consent at any stage of the research? If not, what is the cut-off date and the reasoning for this?
Yes, they will be able to withdraw consent at any time during the data collection and their data will be deleted. They will remove themselves from the 'yarning' process immediately. As the researcher, I will build in a regular checking process to ensure that the individual is happy to proceed, with regular reminders of the focus of the research.

What is the process for participant withdrawal?
This can be done informally in a conversation or by any other method of communication that is appropriate to the participant. As mentioned above a process of revisiting the research focus and checking in with the participant regarding how they feel will be a regular part of the discussion. I will also involve the manager in regular conversations to ascertain whether there have been any additional issues or concerns raised outside of the data collation process.

Who will have access to the personal data?
By the examiner with personal information anoymised.

Please provide details of any third parties involved in the collection or processing of personal data.
None.

If relevant, have you ensured that all third party involvement in the processing of data is/or will be covered by a Data Sharing Agreement (with a data controller) or a Data Processing Agreement (with a data Processor)?
Not applicable

Will personal data be collected from or shared with parties outside of the UK?
No

If yes, please list the country/ies involved.

Detail the additional safeguards that are in place to ensure the personal data is protected.
The data will be anonymised and will be stored on a secure device that is password protected.

re you using social media/online forums to recruit participants? If so, how are you gaining informed consent?
No.

Are you using social media/online forums as a source of data collection? If so, how have you ensured the security surrounding your use of personal data in social media/online activities? No.

Are you undertaking any activities that could create privacy concerns for individuals due to personal intrusion? If so, please provide details of the activities and how the privacy concerns will be addressed to reduce the impact.
Any photos, life stories, or artwork stored or published will not include any links to personal Information including names or locations. Photos that indicate identity will not be included in the thesis but will be used to stimulate storytelling.

Please provide details of the processes in place to ensure confidentiality.

All data will be anonymised prior to storage by using pseudonyms and will be stored on a password- protected device stored in a locked facility. Any identifying details will be reviewed and every step will be taken to protect anonymity.

Please detail the processes in place to check the dataset received or processed is, and will continue to be, relevant, adequate and not excessive.
The research is focused on sharing stories, their life experiences related to social interaction. As the researcher, I will keep a clear focus on the research question.

Where and how will personal data be stored?
The 'yarning' will be audio recorded. The process of 'yarning' will include a reminder of any joint sessions of storytelling must include confidentiality to discourage participants from discussing the content outside of the session. All data gathered will be stored on a password-protected device that is only accessible to the researcher. If any of the discussions become worrying to the participants the discussion will cease.

How are you ensuring that personal data is safely stored, processed and disposed of securely when no longer needed?
Personal information and contact details will be removed at the end of the project, deleted electronically so that they are unavailable.

How long will personal data be kept/stored for after the project has completed and in what format will this be?
As above, any personal information will be removed as the need to contact individuals comes to an end.

Research health & safety risk assessment
Have you completed a Research Health & Safety Risk Assessment form?
Yes

Has your supervisor reviewed your Research Health & Safety Risk Assessment form?
Yes

Has your Research Health & Safety Risk Assessment form been approved by the relevant Head of School/Department or delegated member of staff?

Yes

Appendix Four

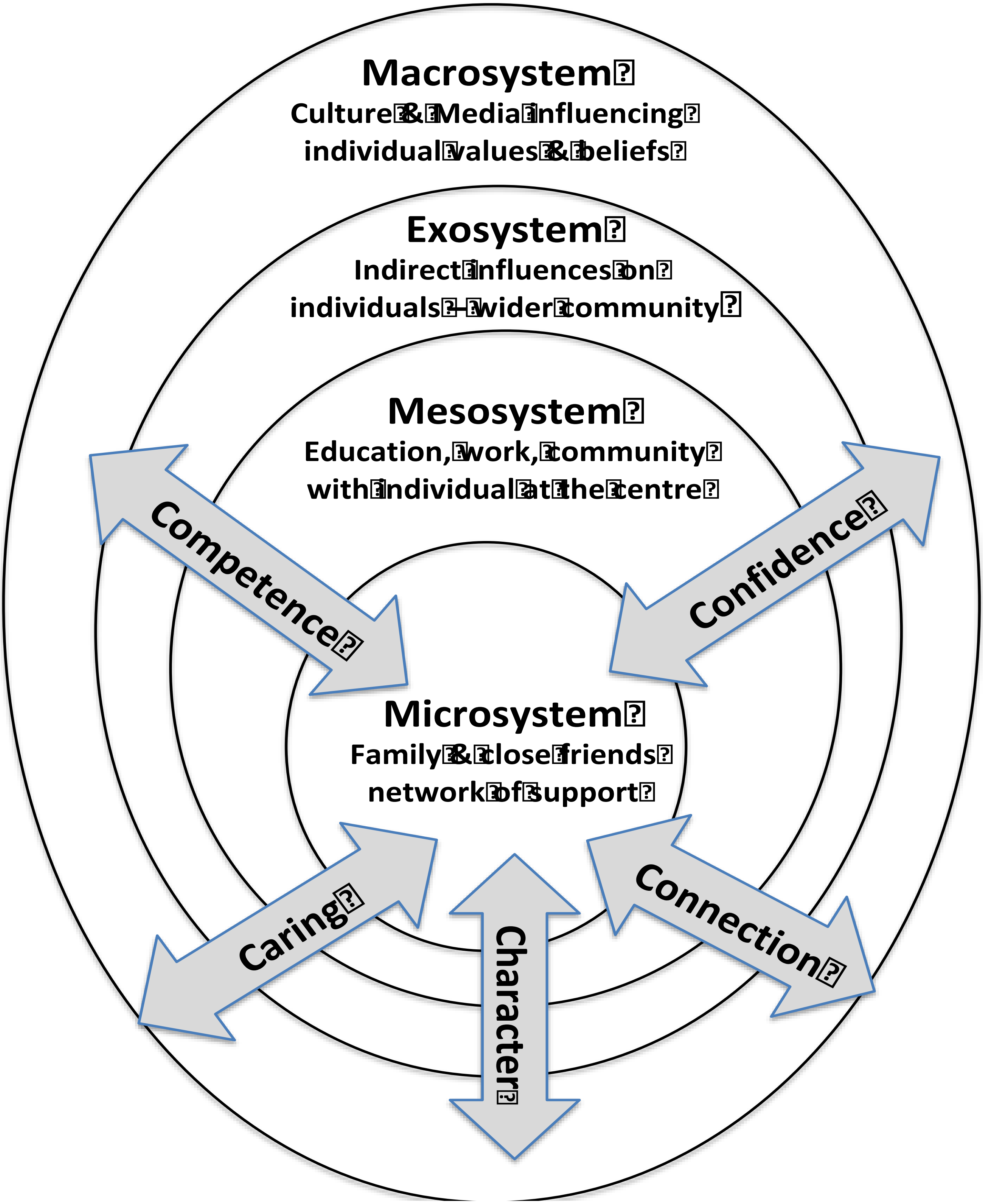
5 C's of Positive Youth Development	ASDAN Level 1 Award Modules in Personal and Social Development

Competence	• Food Safety in the Home and Community • Healthy Eating • Healthy Living • Managing Own Money
Character	• Identity and Cultural Connection • Individual Rights and Responsibilities • Environmental Awareness
Caring	• Environmental Awareness • Healthy Eating • Healthy Living • Making the Most of Leisure Time
Connection	• Managing Social Relationships • Food Safety in the Home and Community • Identity and Cultural Connection • Individual Rights and Responsibilities • Environmental Awareness
Confidence	• Community Action • Food Safety in the Home and Community • Making the Most of Leisure Time • Managing Own Money • Identity and Cultural Connection • Individual Rights and Responsibilities

Appendix Five

1.Competence and Confidence taper off as an individual move outwards into the exosystem and macrosystem. Connection also tapers depending on the support available.

2. The microsystem stretches out moving onto the wider systems as the individual takes their circle of support with them.



Appendix Six

5 C’s of Positive Youth Development (Lerner, 2009)	
Competence	Positive view of ones action (capability) in specific areas of, social, academic, cognitive and vocational. **Cognitive competence** – pertains to abilities like decision-making, attainment, and attendance at school and test scores. **Vocational competence** – relates to work habits, career choice, exploration and entrepreneurship.
Character	Respect for societal and cultural rules, possession of standards for correct behaviour – a sense of right and wrong (morality) and integrity.
Caring	A sense of sympathy and empathy for others.
Connection	Positive bonds and bidirectional exchanges (reciprocal) between the individual and peers, family, school and community in which both parties contribute to the relationship.
Confidence	An internal sense of positive self-worth and self-efficacy i.e. belonging to a domain i.e. political, understanding a procedure. Ones global self-regard (A capacity to achieve).

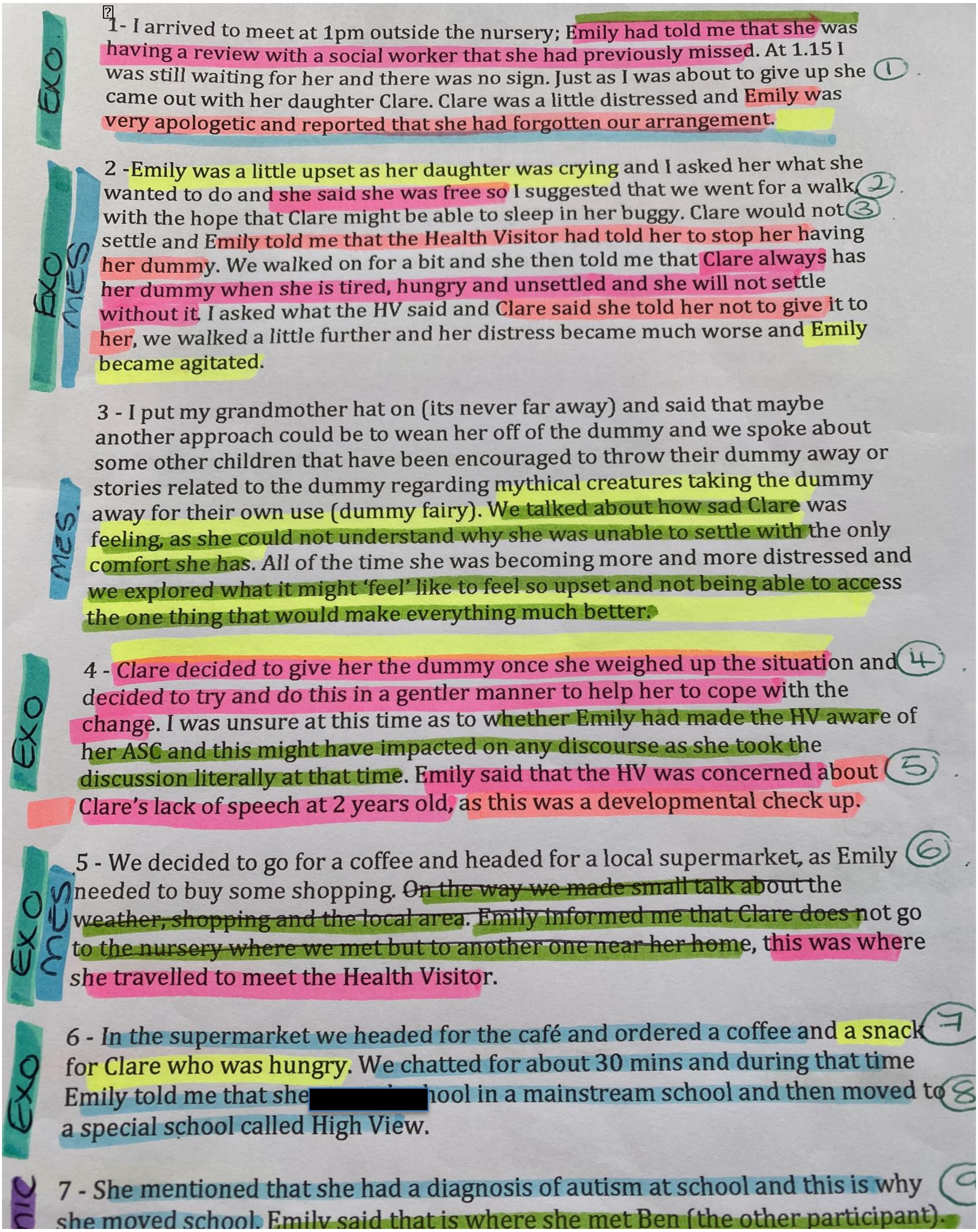
Appendix Seven

Ecological Systems (Bronfenbrenner, 1979) for Data Analysis	
Macrosystem	This is where the broader societal and cultural impacts occur and contribute to development. The values, norms, traditions and beliefs are shared with others of a similar identity. Beliefs can shift and change over time and they can also be influenced by geographic location and socioeconomic status. Influenced by – values, attitudes, law, customs, policy and identity.
Exosystem	The is system is not where the individual exists in a social context, but rather where they live, the impact of Government policies, social services and community resources, The context is indirect, although they will possibly move onto these realms in adulthood, like the workplace and others areas of community engagement. Influenced by – Mass media, social services at a community level, local Government, workplace and broader relationships.
Mesosystem	This system is where the relationships and interactions move from the family, towards friends and wider family. It also

	includes others outside of the family that has a relationship with the individual. For example, when the developing person moves into a new setting they might gain new knowledge and can now exist in either setting having made the links outside of their immediate family and friends. The relationship between the family, school and college can impact on learning and as an adult moves into other systems they might discover the links between the various systems and this in turn could impact on development, through their experience of other networks. Influenced by – interactions between the individual, parents, educators, friends and siblings and other members of their close community and family.
Microsystem	The individuals' immediate environment, those they interact with daily, including family, friends, classmates or work colleagues. It is the microsystem that has the most direct impact on the individual. The relationships and interactions are also bidirectional, as are the 5 C's of Positive Youth Development, regarding personal development. Individuals are influenced by the close relationships. A close virtual relationship can also be part of a microsystem – this system is

	where experiences directly affect behaviour, learning and values. Influenced by – Parents, friends, siblings, close settings like school, college, childcare, work colleagues.

Appendix Eight – Example of Initial Coding



EXO

1- I arrived to meet at 1pm outside the nursery; Emily had told me that she was having a review with a social worker that she had previously missed. At 1.15 I was still waiting for her and there was no sign. Just as I was about to give up she ① came out with her daughter Clare. Clare was a little distressed and Emily was very apologetic and reported that she had forgotten our arrangement.

EXO MES

2 -Emily was a little upset as her daughter was crying and I asked her what she wanted to do and she said she was free so I suggested that we went for a walk ② with the hope that Clare might be able to sleep in her buggy. Clare would not ③ settle and Emily told me that the Health Visitor had told her to stop her having her dummy. We walked on for a bit and she then told me that Clare always has her dummy when she is tired, hungry and unsettled and she will not settle without it. I asked what the HV said and Clare said she told her not to give it to her, we walked a little further and her distress became much worse and Emily became agitated.

MES

3 - I put my grandmother hat on (its never far away) and said that maybe another approach could be to wean her off of the dummy and we spoke about some other children that have been encouraged to throw their dummy away or stories related to the dummy regarding mythical creatures taking the dummy away for their own use (dummy fairy). We talked about how sad Clare was feeling, as she could not understand why she was unable to settle with the only comfort she has. All of the time she was becoming more and more distressed and we explored what it might 'feel' like to feel so upset and not being able to access the one thing that would make everything much better.

EXO

4 - Clare decided to give her the dummy once she weighed up the situation and ④ decided to try and do this in a gentler manner to help her to cope with the change. I was unsure at this time as to whether Emily had made the HV aware of her ASC and this might have impacted on any discourse as she took the discussion literally at that time. Emily said that the HV was concerned about ⑤ Clare's lack of speech at 2 years old, as this was a developmental check up.

EXO MES

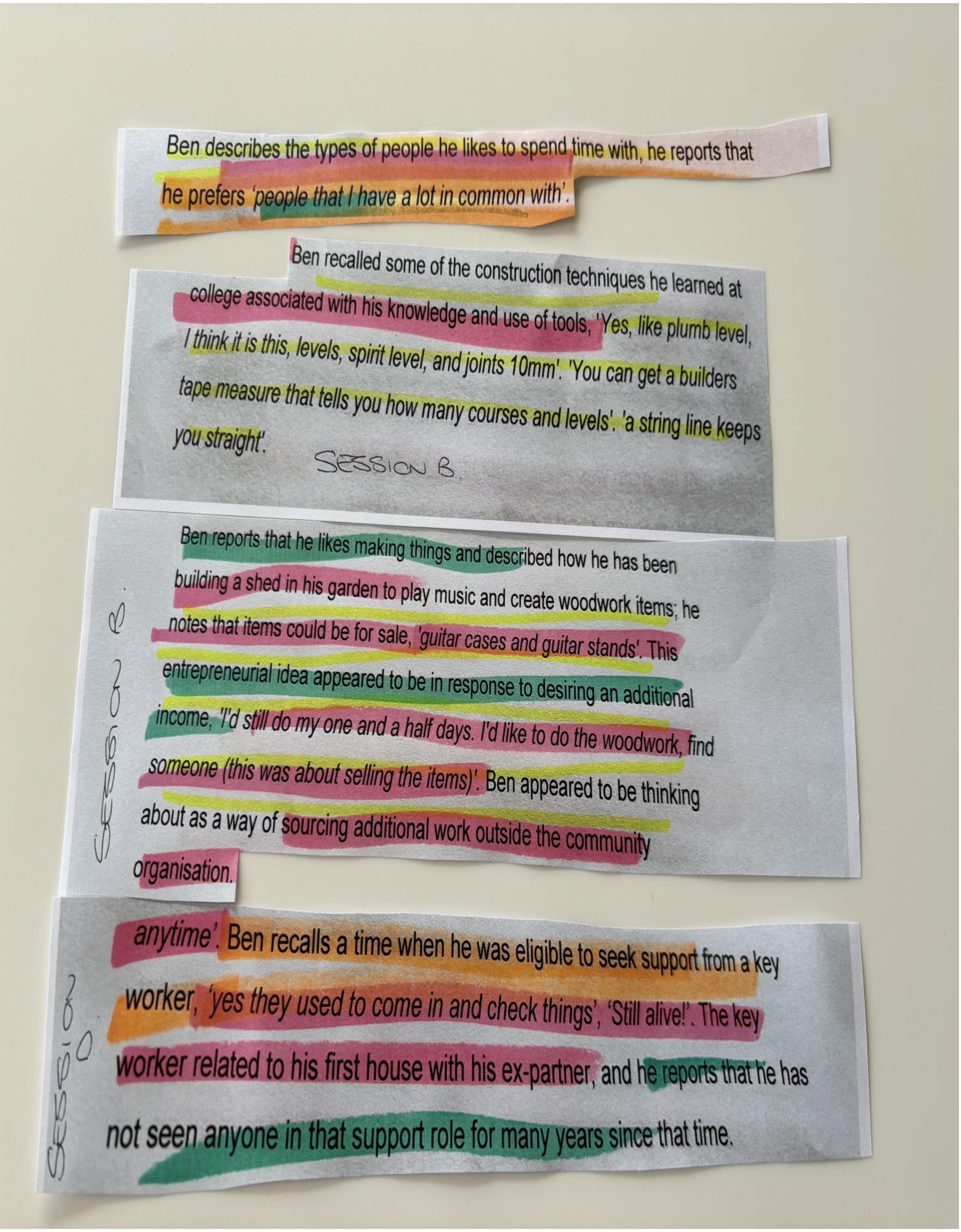
5 - We decided to go for a coffee and headed for a local supermarket, as Emily ⑥ needed to buy some shopping. ~~On the way we made small talk about~~ the ~~weather, shopping and the local area. Emily informed me that Clare does~~ not go to ~~the nursery where we met but to another one near her home~~, this was where she travelled to meet the Health Visitor.

EXO

6 - In the supermarket we headed for the café and ordered a coffee and a snack ⑦ for Clare who was hungry. We chatted for about 30 mins and during that time Emily told me that she [redacted] hool in a mainstream school and then moved to ⑧ a special school called High View.

7 - She mentioned that she had a diagnosis of autism at school and this is why ⑨ she moved school. Emily said that is where she met Ben (the other participant).

Appendix Nine – Example of Participant's Perception Themes (Success)



Ben describes the types of people he likes to spend time with, he reports that he prefers *'people that I have a lot in common with'*.

Ben recalled some of the construction techniques he learned at college associated with his knowledge and use of tools, 'Yes, like plumb level, *I think it is this, levels, spirit level, and joints 10mm*'. 'You can get a builders *tape measure that tells you how many courses and levels*'. *'a string line keeps you straight'*.

SESSION B.

Ben reports that he likes making things and described how he has been building a shed in his garden to play music and create woodwork items; he notes that items could be for sale, *'guitar cases and guitar stands'*. This entrepreneurial idea appeared to be in response to desiring an additional income, *'I'd still do my one and a half days. I'd like to do the woodwork, find someone (this was about selling the items)'*. Ben appeared to be thinking about as a way of sourcing additional work outside the community organisation.

SESSION B

anytime'. Ben recalls a time when he was eligible to seek support from a key worker, *'yes they used to come in and check things'*, *'Still alive!'*. The key worker related to his first house with his ex-partner, and he reports that he has not seen anyone in that support role for many years since that time.

SESSION D