

**“I AM NOT DOWN SYNDROME”: A NARRATIVE EXPLORATION OF LIFE AND
IDENTITY IN SCHOOL-LEAVERS WITH DOWN SYNDROME.**

By

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A thesis submitted to the University of Birmingham

For the Degree of Applied Educational and Child Psychology Doctorate

Volume I

School of Education

The University of Birmingham

June 2018

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ABSTRACT

Historically, there has been an effort to improve the inclusion of those with 'disabilities' including Down syndrome (DS). Societal perceptions of DS have been largely negative and may influence how individuals view their lives. Although there has been literature which has explored other people's perspectives, there has been less which has asked those with DS to share their stories.

The aim of the study was to explore the lived experiences and identity of four school-leavers with DS. A narrative approach was employed to elicit stories whilst participants were being recorded on film. A restorying procedure, a narrative tone and thematic analyses were then used to interpret the narratives.

The findings revealed diversity in the way the participants spoke about their lives. All participants experienced factors which would have had a positive contribution on their identity development. However, some experienced other factors which may put them at-risk of foreclosing on their identity development.

The implication of identity development for generating pragmatic or ambitious aspirations is discussed. I recommend that future research explores what is currently happening in educational settings to promote identity formation in those with DS and how this might be refined to harness positive outcomes for this group.

DEDICATION

For George.

ACKNOWLEDGEMENTS

Sue, thank you for believing in me and for encouraging me to pursue my interest in
Down syndrome.

Rachel, thank you for your kindness, invaluable supervision and for supporting me to
achieve my aspiration to become an educational psychologist.

Mum, Holly and Mikey thank you for your continued support and encouragement
through the marathon that has been this thesis.

Hannah, thank you for your friendship, your empathy and your genuine kindness.

Dad, thank you for inspiring my interest in education and for teaching me how to use
a semi-colon.

Laura, Tim and Tamzin, thank you for all the laughs, reassurance and most
importantly for being the other members of my core four.

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CHAPTER ONE: INTRODUCTION

1.1 Background and Context

1.1.1 'Disability' and Inclusion

The term 'disability' is multifaceted. For some it refers to a deficit that causes impairment to the physical body and/or mind (Goodley, 2017); for others, the word signifies the exclusion and oppression an individual experiences as a result of society failing to accommodate his/her differences (Shakespeare, 2006; Dunn, 2016). For those with the latter perspective, disability would be eliminated if action was taken to remove barriers which restrict an individual from becoming an equal and fully participating member of society (McKenzie, 2013). The term 'inclusion' conceptualises the adaptations which may be taken to reduce the segregation of those with differences (Frederickson and Cline, 2009).

Historically, there has been an agenda within educational and wider policy to promote inclusive practice and ultimately improve outcomes for individuals with 'disabilities' (Hooton and Westaway, 2009; Owen and Griffiths, 2009). The purpose of the inclusion drive was to advocate values of self-determination, anti-oppression and equality (Atherton and Crickmore, 2011). Policy included: the Mental Capacity Act (2005) which encouraged empowerment for those with 'disabilities'; 'Improving life Chances for Disabled People' (2005) which aimed to raise expectations and vocational opportunities for 'disabled' people; and the Equality Act (2010) which called for adaptations to be made to lessen the restrictions placed upon individuals due to impairments (Disability Committee, 2010).

The most recent educational policy, the SEND Code of Practice, also aimed to give greater rights to young people with 'disabilities' and to raise their aspirations for when they transition out of school to include, further education, employment and independent living. To achieve this, the policy advised that teaching practitioners and professionals, including educational psychologists, should be guided by young people and in doing so, employ a person-centred approach (Department for Education, 2015). This approach positions the young person's wishes and aspirations at the centre of decision-making processes, which is intended to facilitate change and improve outcomes for the young person (Atherton and Crickmore, 2011; Byrnes, 2012).

Person-centred approaches can be difficult to employ (Heslop and Abbott, 2007). Impairments to the physical body and/or mind are not typically valued, consequently, those with 'disabilities' are at-risk of having their competencies underestimated or perspectives ignored (Skotko, Levine and Goldstein, 2011). For those with physical characteristics of 'disability' inclusion is made more difficult, as the nature of their apparent differences causes them to be segregated from their peers. For those with learning difficulties it may be, albeit wrongly, judged that they do not have the capacity to make decisions about their lives. Finally, for those with communication difficulties it may be challenging for them to express themselves in decision-making processes (Hooton and Westaway, 2009).

Inclusion and participation may be most challenging for individuals who have impairments to the body and mind (Lalvani, 2013). Down syndrome (DS) is an example of such a 'disability' and is the focus of the present research. It is the most common genetic cause of intellectual disability, is expressed in recognisable

physical characteristics, health complications and impaired communication (Starr et al., 2006; Selikowitz, 2008; Segal and Pesco, 2015). With the inclusion movement there has been a greater expectation that individuals with DS should be included in society (Marshall et al., 2015). Furthermore, researchers have demonstrated the benefit of inclusion in mainstream education for the academic and functional skills of those with DS (Laws, Byrne, and Buckley, 2000; Buckley et al., 2006). However, other literature would suggest that societal acceptance of those with DS has been problematic.

1.1.2 Down syndrome and Society

Historically, representations of DS have been predominantly negative (Gothard, 2002, p.3). Those with DS were once subject to hostile living conditions and in the 1980s there was a proposal that heart surgery should be withheld for infants with DS (Brown, Dodd and Vetere, 2009; Oliver, Woodcock and Adams, 2010, p.135). Negativity has continued to shape perceptions in the past 20 years (Lalvani, 2008). In the year 2000 it was found that parents and medics could hold low expectations of children with DS (Bhattacharya and Sidebotham, 2000). Additionally, in 2003 researchers identified that society held misconceptions, such as DS was caused by complications during labour and that *all* individuals with DS would be affectionate (Gilmore, Campbell and Cuskelly, 2003).

In 2008 mothers of infants with DS shared how they had typically experienced negativity following the birth of their child. The mothers' perceived that society viewed their child as inferior, with the 'disability' considered a burden and something to be feared (Lalvani, 2008). Similar adversity has been identified

in schools which prevents successful inclusion. Cuskelly, Jobling and Buckley (2002) found that 87% of the trainee teachers asked (from mainstream schools) would not be prepared to teach a child with DS. Furthermore, it has been identified that children with DS can be socially rejected in mainstream classrooms (Schwab, Huber and Gebhardt, 2016).

The dominant discourse which has endured through history can be positioned within a Medical Model of Disability (Haegele and Hodge, 2016). According to this paradigm, 'disability' is an inherent characteristic of the individual; a deficit which causes impairment to the physical body and/or mind (Haegele and Hodge, 2016). In the case of DS, the genetic difference is understood as impairment within the individual (Oliver, Woodcock and Adams, 2010, p.135). Those who accept this model would advocate for the impairment to be treated, cured, prevented or rehabilitated in an attempt to 'normalise' the individual so that they are better able to integrate into society (Barnes and Radermacher, 2003; Barnes, 2011).

In the case of DS where there is no cure, preventative measures are considered valuable, such as pre-natal genetic screening (Barter et al., 2017). It is now the case that all pregnant woman in the United Kingdom are offered screening and the option of a termination (up to 40 weeks gestation) if their foetus is believed to have DS (Barter et al., 2017). Statistics would indicate that a high proportion of parents in the past have chosen to terminate a pregnancy of a foetus with DS, and in 2014 termination rates were at 90-92% following a prenatal diagnosis (Morris and Springett, 2014). The elevated termination rates have provoked interest, debate and in some cases outrage.

1.1.3 The NIPT

In 2016 there was media attention on DS following the introduction of a diagnostic procedure called Non-Invasive Prenatal Testing (NIPT) (Verweij et al., 2013). The NIPT was intended as an advance to existing procedures as it allowed for more reliable screening of fetuses for DS, thereby reducing the number of terminations of fetuses who were misdiagnosed (Verweij et al., 2013). Its development was praised by some for promoting public health. However, it has raised concerns from others, who perceived it as reinforcing negative attitudes and suggesting that those with DS should not have the right to life (Grosop, 2016). The conflict in views has fuelled debate, illustrated in media headlines such as ‘Sally Philips: Do we really want a world without Down syndrome?’ (Grosop, 2016).

On the other side of the debate groups have attempted to empower those with DS. Examples include the ‘I am not a disability’ campaign from the charity MENCAP, which seeks to celebrate the achievements of those with DS and promote positive attitudes in society (Cuskelly, Jobling and Buckley, 2002; MECAP, 2018). Campaigns like this conceptualise ‘disability’ as a negative construction imposed on individuals with impairment (Shakespeare, 2006). The additional chromosome expressed as DS is not viewed as impairment but as a ‘difference’ and any difficulties associated with this difference would be overcome by promoting societal inclusion and equal participation (Barnes and Radermacher, 2003).

Although campaigners are attempting to promote positivity, the long-standing negative attitudes, reflected in the current NIPT debate, have the

potential to impair acceptance of individuals with DS. Evidence suggests that these attitudes may be hindering the inclusion and outcomes of those with DS (Lalvani, 2013). Research has identified how young adults with DS are more likely to be unemployed when they leave school, be dependent on their parents and have difficulty forming relationships (Thomson, Ward and Wishart, 1995; Carr, 2008; Nancollas, 2012; Kumin and Schoenbrodt, 2016; Office for National Statistics, 2018). The research indicates that society has a long way to go to improve the inclusion and outcomes of those with DS (Heslop and Abbott, 2007).

1.2 Rationale

Having previously assisted a child with DS and currently as a trainee educational psychologist, I have observed how differing attitudes identified in *section 1.1* can influence how a child with DS experiences education. For instance, I have seen how negative expectations of a child with DS prevented him from being included in a mainstream school. As a consequence, I have reflected on the potential effect of that lived experience on the formation of that child's identity, how he sees himself and his future, and this has formed the focus of the present study.

I consider this research timely as it may contribute to the ongoing discussion regarding the acceptance of those with DS in society, illustrated by the NIPT debate. I believe it can achieve this by contributing to informed perceptions regarding DS. Previous researchers have elicited the attitudes of adults with DS toward genetic screening and found that participants echoed negative attitudes, referring to their DS as a tragedy (Barter et al., 2017). Research also revealed that

negative societal attitudes can mediate lived experiences. Alderson (2001) identified that individuals with DS experienced social prejudice and the participants attributed this negativity to their identifiable physical differences. I hope to contribute to this growing literature to explore the contribution of lived experiences on how individuals view their lives, themselves and their futures.

Finally, as a future educational psychologist, working with young people up to age 25, I am interested in applying person-centred approaches to improve outcomes for young people with DS after they transition from school (Byrnes, 2012). Although there is literature which has considered other people's perspectives and/or attitudes towards those with DS, Skotko, Levine and Goldstein (2011) asserts that individuals with DS are rarely listened to in research. (See Appendix 1). In this regard, it is necessary for research to be done to elicit the perspectives of school-leavers with DS. Furthermore, it is seems timely, with the political drive to adopt a listening culture and promote participatory practices for research like this to be conducted.

1.3 Structure of the Study

Consequently, the focus of the study was to explore the lived experiences, identity formation and future life trajectories of school-leavers with DS. Identity refers to who we were, who we are and who we will become (McLean and Syed, 2015). Lived experiences are thought to contribute to identity formation which is an important life process influential for determining life outcomes (Sokol, 2009). Employing a narrative methodology, I was interested in exploring the relationship

between lived experiences, identity formation and desired/expected future life trajectories.

1.3.1 Broad Aims

The initial aim of the study was to add to existing research which has elicited the insider perspectives of those with DS: to consider how individuals talk about their lived experiences in relation to the context of sociocultural discourse and the inclusion agenda (Dunn, 2016). The secondary aim was to consider the contribution of lived experiences, including significant relationships, on the formation of identity and how this identity formation may influence future life trajectories.

1.3.2 Implications of the Research

Transition from secondary education has been identified as a period of sadness for people with DS and it is conceivable that inadequate identity formation may contribute to this unhappiness (Skotko, Levine and Goldstein, 2011). By exploring the experiences of school-leavers with DS, I intended the findings from the study to inform recommendations, which would adopt a person-centred approach, and would facilitate the identity development and subsequent outcomes of other young people with DS transitioning from school. The following chapters will present the literature review, methodology, findings, discussion and conclusion.

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

To provide a conceptual context for the research into the lived experiences and identity formation of school-leavers with DS, this chapter reviews theoretical literature and research. Firstly, it defines the term 'lived experiences'. It then outlines what constitutes the self and how identity can be used as a conceptual tool for understanding the self. It then illustrates how identity might develop, the factors thought to contribute to its formation and how this may be similar and/or different in those with DS. Existing and relevant research is then reviewed.

2.2 Life and Lived Experiences

As established, the general aim of the study is to explore the 'lived experiences' of school-leavers with DS. The course of life is different for everyone and is influenced by a range of factors (Ahsford and LeCroy, 2010). The term 'lived experiences' is thought to refer to the significant experiences an individual has in his/her lifetime (Ahsford and LeCroy, 2010). Sometimes a lived experience will encompass a change or a 'transition', for example the transition out of school during adolescence (Ashford and LeCroy, 2010). Transitions are considered to be meaningful and can influence a developmental path known as his/her 'life trajectory' (Damon and Lerner, 2006; Ahsford and LeCroy, 2010).

The trajectories individuals take are thought to determine decision making and the aspirations they develop for their futures (Ryan and Deci, 2017). The literature would suggest that young people with DS experience the same transitions, for example leaving their school settings, and have to navigate similar

trajectories as their peers (Smart, 2012). Furthermore, like their peers, those with DS hope to achieve aspirations associated with adulthood including: employment, living with greater independence and participating in their communities (Down's Syndrome Association, 2011).

However, it has been proposed that young people with DS can have difficulty with making decisions about their future life trajectories (Down's Syndrome Association, 2011). Nevertheless, with policy driving person-centred approaches it is now more important than ever that those with DS engage in decision making and decide who they are and who they would like to become (Atherton and Crickmore, 2011). Moreover, there is evidence which suggests that young people with DS can lead independent lives and so should not be denied the opportunity (Alderson, 2001).

2.3 Defining the Self and Identity

When an individual asks him/herself who he/she is, the way in which he/she answers this question refers to how he/she views his/herself (Shaffer, 2010). Children (including those with DS) acquire skills at 18-24 months which enable them to recognise themselves as independent beings and categorise themselves according to physical attributes (Hill and Tomlin, 1981). As children develop they begin to understand their inner qualities, for example, their cognitive, social and physical competences (Shaffer, 2009). How children perceive their qualities is referred to as their 'self-concepts' (Shaffer, 2010).

Furthermore, children begin to evaluate their qualities and attributes and this is called their 'self-esteem' (Shaffer, 2010). Those with high self-esteem are

considered to be satisfied with their sense of self; they recognise their limitations but feel positive about their competences (Shaffer, 2010). In contrast, children with low self-esteem view themselves less favourably; they tend to focus on their limitations and do not acknowledge their strengths (Shaffer, 2010). High self-esteem is related to positive life trajectories and mental well-being (Shaffer, 2010). Begley (1999) identified that children with DS can hold positive self-concepts and have high self-esteem when evaluating their competencies which may act as a protective factor for mental health.

When a child enters adolescence the nature of his/her sense of self changes, becoming more abstract (Shaffer, 2009). Adolescents, including those with DS, reflect upon their childhood lived experiences and interactions and better understand the conclusions they have made (Buckley and Sacks, 2002). The end-result of this reflection is the development of a future-orientated self called the 'identity' (Shaffer, 2009). The identity can be described as a conceptual tool individuals use to understand the relationship between themselves, their environment and their social interactions (Shaffer, 2010).

The identity is thought to define an individual and is concerned with his/her past, present and future experiences (Lawler, 2014; McLean and Syed, 2015). Forming an identity brings coherence and illustrates to an individual who he/she was, is currently, and what he/she wants to become in the future (McLean and Syed, 2015). Identity, therefore, can influence and/or determine an individual's goals for his/her future life trajectory, for example, choices for vocation (McLean and Syed, 2015). Moreover, successful formation of an identity is considered to be

another contributory factor to positive mental health outcomes (Erikson, 1968; Georgios and Bosma, 2005).

2.4 Theories of Identity Development

Part of this research is concerned with identity development in school-leavers with DS and so this section will now describe several theories which conceptualise how identity is thought to develop through childhood and adolescence.

2.4.1 Theory 1: Erikson

Erikson is an esteemed theorist in the field of identity development (McLean and Syed, 2015). He developed his theory as an advance on Freud's earlier Psychoanalytical Theory, which proposed that all human behaviour serves biological drives (Thies and Travers, 2006; Freud, 2012). Erikson criticised Freud for over-emphasising biology and for ignoring the contribution of social factors on development (Erikson, 1968; Freud, 2012). Consequently, he coined the 'Psychosocial Theory of Human Development' (Erikson, 1995). His notion was that from birth children socially interact and it is this interaction which determines their development (Thies and Travers, 2006).

For Erikson the formation of identity, or as he called it the 'ego', was the primary outcome of development and was fundamental for a positive life trajectory (Sokol, 2009). He proposed that children are innately programmed to develop and progress through a series of eight linear 'psychosocial stages', during which they relate and interact with others (Erikson, 1995). At each psychosocial stage he believed that an individual will experience a 'crisis' which would end in either a

successful or unsuccessful outcome (see Table 1) (Erikson, 1995; Côté and Levine, 2016). If the individual was successful and resolved the crisis he/she would then proceed with his/her development (Erikson, 1995). The ultimate aim of moving through the stages was to develop a coherent self (identity) (Erikson, 1995).

Erikson considered that it is within his fifth stage 'Identity versus Identity Diffusion' that an individual forms his/her identity (See Table 1) (Erikson, 1995; Duchesne and McMaugh, 2016). The individual, during this stage, has become an adolescent. He/she has acquired new cognitive and physical capabilities, has increased opportunities for independence and has a greater concern for social affiliation (McLean and Syed, 2015). By becoming more autonomous the individual is better able to consider what he/she wants from his/her future (Sokol, 2009). Autonomy, therefore, is perceived as an important prerequisite for identity development (Sokol, 2009).

Furthermore, with increased cognitive skills the adolescent is able to reflect on lived experiences which include how they may have identified with whom they have interacted. They are able to reconcile any contradictions they may have about these identifications and develop a sense of personal coherence or identity (McLean and Syed, 2015). This process illustrates what Erikson understood by the term 'crisis' (Erikson, 1980). Erikson believed that if an individual fails to question his/her experiences in this way he/she may continue to question how he/she perceives him/herself (role confusion) or over-identify with significant others resulting in other people determining who he/she is and will become (Erikson, 1980; Erikson, 1995).

Table 1: Erikson's Psychosocial Stages (Erikson, 1995; Peltier, 2010)

Psychosocial stage	Age	What does the child/person develop during this stage?	Successful resolution of the 'crisis'	Unsuccessful resolution of the 'crisis'	Possible outcome following an unsuccessful resolution
Trust vs mistrust	0-1	The ability to depend on other people and to form predictions for how they may behave.	The child develops trusting relationships with caregivers.	The infant is neglected and this means that he/she mistrusts his/her caregivers, viewing the world as an uncertain place.	• A feeling of persistent anxiety • Difficulty taking risks • High dependency in relationships
Autonomy vs Shame/Doubt	2-3	The ability to do things for oneself.	The child experiences autonomy and is able to explore the environment	The child experiences guilt and is controlled by parents who try to restrain him/her.	• Feelings of shame • Feelings of self-doubt
Initiative vs Guilt	3-6	The child begins to develop independence.	The child experiences greater responsibility, autonomy and independence.	The child feels guilty about his/her growing autonomy and is hesitant to try new challenges.	• May lack self-control • May experience guilt
Initiative vs Inferiority	7-12	An active and satisfying involvement in activities usually in school.	The child feels a sense of competency, achievement and success.	The child feels inferior and inadequate and is unable to experience success at school viewing him/herself as a failure.	• The child may lose interest in trying new experiences

Identity vs Identity Diffusion	12- 18	The formation of an individual's identity through the integration of previous identifications.	The adolescent develops a greater social awareness. Through close friendships as a secure base, he/she begins to question previous identifications and explore choices for identity formation.	The adolescent fails to form a unified identity	• The individual may experience 'role confusion' where he/she question how he/she views him/herself • The individual may experience 'over-identification' where he/she over-identify with significant others. • The individual may experience 'foreclosure'
Intimacy vs isolation	20s	Development of a relationship with a significant other.	The adult develops a relationship with a significant other.	The adult is isolated and fails to develop close long-term relationships.	• The individual may be not accepting of others • The individual may resist relationships
Generativity vs Stagnation	20s- 50s	A consideration of the needs of other people.	The adult procreates and guides the next generation.	The adult experiences depression, self-preoccupation or narcissism.	• The individual experiences selfishness • There may be stagnation where they fail to progress to the next

					stage
Integrity vs despair	50+	A healthy adjustment to ageing and morality.	The adult reflects on life and resolves any unresolved conflicts.	The adult experiences a sense of disappointment and deficiency.	The individual can experience a state of despair

2.4.2 A Critique of Erikson's Theory

Although Erikson provides a theory for how identity may develop, his ideas have been condemned for lacking clarity (Kroger, 2004; Schultz and Schultz, 2017). Furthermore, when formulating his ideas, he relied on observations as evidence of the supposed 'crises' at each stage (Erikson, 1995). His observation has been criticised for being overly subjective and lacking empirical validity and consequently, critics have questioned whether the psychosocial stages may also lack validity (Smart, 2012).

Critics have also suggested, that due to the age of the model, it may have had more relevance at the time Erikson was formulating his concepts (Kroger, 2004). Perhaps the number of stages, linear progression through the stages and the time-frames (ages) associated with each stage may be obsolete in a modern context (Kroger, 2004; Smart, 2012). Consequently, understanding development through a definitive age-related trajectory may be deemed outmoded (Smart, 2012). Lastly, Erikson does not account for influential events in a child's life such as parental divorce which may influence development at each stage (Epstein, 2014).

Despite these criticisms, some consider Erikson's theory to continue to offer insights into how identity may develop, for example how individuals require particular experiences (Kroger, 2004; Schultz and Schultz, 2017). From this, I

judged it a useful theory to apply cautiously when exploring the participants' identity formation in the present study (Kroger, 2004). However, instead of viewing an individual as developing identity through a fixed and defined number of stages, as Erikson did, I view identity formation a long-life long psychosocial process which occurs in *phases* (Kroger, 2004).

With this approach there are considered to be two phases in identity formation (Kroger, 2004). The first phase is 'identification' which is thought to occur during childhood (Sokol, 2009). During identification the child takes on the characteristics of significant others and bases future plans on these identifications (Kroger, 2004). The second phase is 'identity development' where the individual forms their identity (Kroger, 2004). Erikson proclaimed that identity development occurred during adolescence, however, this phase is now considered to be life-long (Erikson, 1995; Sokol, 2009).

2.4.3 Theory 2: Marcia

In reconceptualising Erikson's theory as a phased approach, it is helpful to examine the work of theorists such as Marcia (1966). Marcia developed the 'Identity Status Paradigm' (based on empirical interviews) to describe the processes which Erikson describes as the 'Identity vs Identity Diffusion' stage (Marcia, 1966). Erikson proposed that individuals, through unsuccessful resolution of the crisis during this stage, can experience 'role confusion' (See Table 1). Marcia considered how individual differences in the experience of identity formation could result in varied outcomes he called 'statuses' (Marcia, 1966; Bjorklund and Blasi, 2012).

Marcia proposed that individuals will arrive at identity formation via different trajectories (Marcia, 1966). Individuals may or may not have a 'crisis' which involves them exploring different alternatives for their identity and then committing to an alternative (Marcia, 1966; Martin and Fabes, 2009). The resolution of a crisis and the way in which an individual has explored and/or committed, will determine his/her development in accordance with one of the four identity statuses (see Table 2) (Marcia, 1966).

Table 2: Marcia's Identity Statuses (Marcia 1966; Bjorklund and Blasi, 2012)

Identity Status	Explanation
Identity Achievement	• The individual commits to values and goals after freely exploring alternatives. • The individual is autonomous and less reliant on others to make decisions and has parents who support his/her autonomy. • The individual is satisfied with who he/she is and is not vulnerable to negative information about him/herself.
Identity Foreclosure	• The individual has committed to an identity conclusion without exploring alternatives for his/her identity. He/she may not have experienced a crisis where he/she have explored alternatives. • The individual has accepted the values and goals of parents or other authority figures. • The individual has low autonomy and appears to be seeking the approval of others.
Identity Moratorium	• The individual is currently exploring different alternatives and has not made firm commitments but is working towards these decisions. • The individual does not conform to parents and has difficulty with detaching him/herself from his/her parents.
Identity Diffusion	• The individual has not made a commitment to an identity conclusion but unlike those in moratorium is not exploring alternatives. • The individual lacks autonomy and may appear distant or withdrawn. • The individual may or may not have experienced a crisis but has not committed to anything.

Although Marcia's research can be used to extend Erikson's original assertions, the model has been criticised for being simplistic (Kerpelman, Pittman and Lamke, 1997). While Marcia recognises individual differences in the formation of identity, the theory does not provide enough detail regarding the specific mechanisms involved (Kerpelman, Pittman and Lamke, 1997). Consequently, other theorists have built upon Marcia's work. Three models are presented in Table 3 (Grotevant, 1987; Bosma and Kunnen, 2001; Luyckx et al., 2006). The models may be perceived to be advantageous as they elaborate on how exploration and commitment may occur in identity formation.

Table 3: Additional Models for Understanding Identity Development

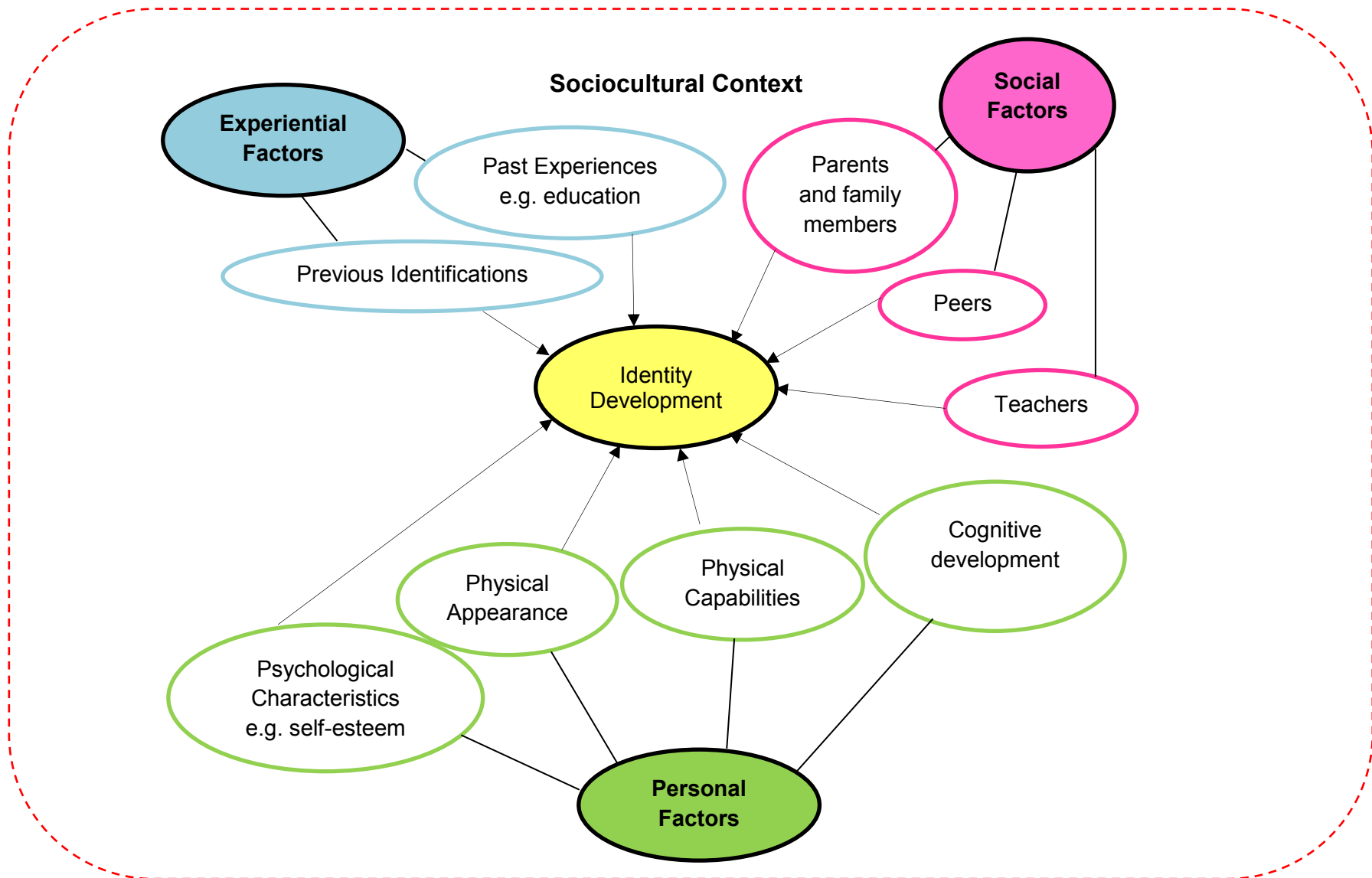
Model	The process of identity formation	Factors which contribute to identity formation
1. Grotevant's Process Model (1987)	• The individual participates in elaboration or problem solving where information is elicited about him/herself and his/her environment in order to make commitments about identity and life choices. The individual engages in hypothesis-testing and through assimilation incorporates information into an existing identity or through accommodation transforms the existing identity; • Commitments are the result of exploration (identity consolidation) and if they are judged unsatisfactory through identity evaluation the process resumes.	• Personal attributes (cognitive ability and self-esteem) • Life experiences (e.g. parental divorce); • Culture, society and social expectations of others (e.g. teachers, parents and peers); • Affective factors (e.g. anxiety and feelings of failure);
2. Bosma and Kunnen's Transactional Model (2001)	• Identity development is the result of interactions between a person and his/her context. • During interactions the individual receives information which is either assimilated or adjusted and then assimilated into identity conclusions (conflict). If the individual fails to overcome the conflict, the process may continue until accommodation occurs.	• Experiences; • Developmental history; • Social interaction.
3. Luyckx et al. (2006); A Process-Oriented Approach to Identity Formation and Evaluation	• The process begins with exploration where the individual receives information on various identity alternatives, actively exploring these alternatives; • Then the individual commits and makes a choice; • The individual may continue to explore and evaluate their identity choices. • The individual then commits to an identity alternative.	• Experiences; • Social Interaction.

2.5 Identity Development: Contributory Factors

Erikson's emphasis on psychosocial rather than the preceding psychosexual development (from Freud) enabled him to acknowledge the role of social influences (Erikson, 1968; Freud, 2012). However, later theorists have extended this to recognise how development is assumed to be embedded in a wider sociocultural system and how identity formation may be subsequently mediated by sociocultural influences (Farenga and Ness; 2005): for example, how it may be more difficult to develop identity successfully in a culture which provides fewer opportunities for exploration and autonomy (Farenga and Ness, 2005).

Bosma and Kunnen (2001), claimed that the formation of identity should be understood as a process of person-context interactions and so identity formation is influenced social context and interaction. The context in which an individual resides (sociocultural context), therefore, is deemed an important contributory factor on how the types of interaction a person has and whether his/her identity formation is successful (identity achievement) or unsuccessful (identity foreclosure, moratorium or diffusion) (Marcia, 1966; Bosma and Kunnen, 2001). Figure 1 provides an overview of the factors I have identified from the literature which may contribute to identity formation and those I now discuss.

Figure 1: The Contributory Factors on Identity Development



2.5.1 Social Factors

The first factor is the contribution of social relationships and interaction on identity formation (Watts, Cockcroft and Duncan, 2009). Kroger (2004) writes that social interaction occurs at every phase of psychosocial development. The relationships a young person develops in his/her life are assumed to stabilise his/her identity formation as he/she is better able to identify his/her social role through interacting with others. (Kroger, 2004). Furthermore, during the identification phase, children interact and then identify with people in their lives, such as their parents, which forms the basis of how they see themselves (Kroger, 2004).

When a child progresses out of this phase and commences adolescence, he/she develops relationships and shares more meaningful interactions with peers (Shaffer, 2010). During this period, friendships can provide what is called a 'secure base' where they support the adolescent to explore alternatives for his/her identity during an uncertain time (Underwood and Rosen, 2011). Furthermore, through interacting with peers individuals learn about themselves and begin to question how they are perceived. This information is then either assimilated or accommodated into their identity (Luyckx et al., 2006). Peer acceptance is associated with the development of a positive self-concept (Huck, Kemp and Carter, 2012). However, if young people fail to develop friendships during adolescence or have negative interactions with peers, it is believed that they will not have a secure base or the positive social feedback required for establishing successful identity achievement (Marcia, 1966).

In addition to friendships, parental relationships may also contribute to a young person's identity formation (Underwood and Rosen, 2011). During childhood,

parents are able to control how much they allow their children to explore the environment (Underwood and Rosen, 2011). During adolescence, parents who encourage identity formation continue to provide their children with opportunities for exploration, a greater sense of autonomy and support (Schwartz, Luyckx and Vignoles, 2011). Those who have more stable relationships with parents typically find it easier to experience identity achievement (Marcia, 1966).

However, some young people may over-rely on their parents for support which may restrict their opportunities for exploration and autonomy (Kroger, Martinussen and Marcia, 2010). As a consequence, individuals may experience identity foreclosure where they make commitments regarding their identities without a period of freely exploring alternatives (Marcia, 1966; Bjorklund and Blasi, 2012). These commitments may be made for them by their parents (Marcia, 1966). In contrast, those who fail to develop secure relationships with parents may experience identity diffusion where they have not made any commitments to identity conclusions and are not exploring alternatives (Marcia, 1966; Underwood and Rosen, 2011).

2.5.2 Experiential Factors

In addition to social relationships, the lived experiences a person has in his/her lifetime may contribute to identity formation (Erikson, 1968). For Erikson, these experiences were 'crises' and were fundamental to successful identity formation (Erikson, 1968). Farenga and Ness (2005) suggest that identity forms by a young person synthesising previous experiences where they have identified with others during childhood. Accordingly, the experiences a child has of interacting with significant others are likely to influence identity formation (Shaffer, 2009). Furthermore, as development is embedded within a sociocultural system, cultural

norms may play a role in shaping a child's experiences within his/her family which then affect subsequent identity formation (Farenga and Ness, 2005).

In addition to experiences within the family unit, experiences in educational settings can influence identity formation (Kroger, 2007). Teaching practitioners can provide school pupils with opportunities to participate in self-discovery and exploration (Underwood and Rosen, 2011). By engaging students in discussions regarding options for future vocations and facilitating opportunities, such as work experience, teachers can support young people to consider alternatives for their identities and aspirations (Shaffer, 2009; Underwood and Rosen, 2011). Moreover through pedagogic practices teachers can offer students the opportunity to engage in self-reflection (Underwood and Rosen, 2011).

2.5.3 Personal Factors

Theorists have also proposed that factors inherent to the individual, may contribute to how he/she develops identity. For Erikson, this included an individual's biological and psychological characteristics (Erikson, 1968). More recent theorists have identified additional factors such as an individual's ability to use operational reasoning and inference skills (Grotevant, 1987). Moreover, self-esteem has been linked with successful identity formation in that high self-esteem is related to greater motivation to explore identity alternatives (Grotevant, 1987). Finally, reflection is important to enable individuals to attend to and explore incoming information regarding their identity (Grotevant, 1987). It is conceivable that the identity statuses depicted in Marcia's theory are associated with different personal characteristics (Marcia, 1996) (illustrated in Table 4).

Table 4: Personal Factors associated with each of the Identity Statuses (Marcia, 1966)

Identity status	Personal Factors associated with this status
Identity Achievement	• Individuals who achieve identity often demonstrate decision making where they have employed operational thought and reasoning skills. • They persevere when faced with difficulties. • They exhibit prosocial behaviours such as helping others. • They have stable relationships with others.
Identity Foreclosure	• These individuals are more hesitant to try new experiences. • They do not engage with the same level of operational thought and reasoning as those who establish an identity achievement status. • They are more likely to conform to authority. • They demonstrate low levels of autonomy and high reliance on parents.
Identity Moratorium	• They do demonstrate with operational and rational thinking. • They tend to avoid making decisions about their identity. • They have close relationships but are not committed to a partner.
Identity Diffusion	• They demonstrate less operational thought than the previous statuses. • These individuals are often reluctant to trust others, lack close relationships and may be isolated.

2.5.4 Identity and Future Life Trajectory

Identity formation is considered to be important as it influences future life trajectories, directing vocational and ideological choices, and is related to positive mental health (Erikson, 1995; Sokol, 2009; Georgios and Bosma, 2005). However, it is reported that a significant number of adolescents do not successfully achieve identity formation and as a result, may experience negative outcomes for their future plans and mental health (Marcia, 1976; Kroger, Martinessen and Marcia, 2010). Nevertheless, for young people who do not successfully develop identity during their adolescent years, there may be opportunities in adulthood for commitments to be revised (Schwartz, Luyckx and Vignoles, 2011)

For those who do not experience identity achievement, Marcia (1989) proposed that educational professionals and mental-health providers, which may include educational psychologists, should provide intervention to facilitate identity achievement in order to improve outcomes. It is recommended that this intervention would typically involve professionals creating the optimal conditions for successful identity formation; for example, by providing young people with opportunities for success, autonomy and exploration (Erikson, 1968; Marcia, 1989; Sokol, 2009). As theorists have moved on from the age-defined psychosocial stages and now consider identity formation to be a life-long process, this intervention may take place beyond the adolescent period (Marcia, 1989; Kroger, 2004).

2.5.5 Implications for this Study

Part of this study is concerned with identity formation in school-leavers with DS and so the theories summarised in this section of the chapter were significant in guiding later data analysis. However, I have demonstrated how each model has built upon the limitations of preceding models and so, instead of adopting one model to inform part of the analysis employed in this study, I decided to employ my own formulation of identity formation which has been based on the most successful elements of each theory.

It should be noted that the models I chose to use for the analysis are not wholly congruent with the social constructivist narrative methodology I outline in the next chapter. In that the constructivist epistemology and methodology explore the way in which the participants speak about their lives and their subjective understanding of how key life experiences and significant relationships may have shaped their identity development (Cohen, Manion and Morrison, 2018), whereas the

staged models outlined in this chapter have been harnessed to position the participants' accounts against widely used approaches to understanding the process of identity development (Kroger, 2004).

I acknowledge this discrepancy; however, my rationale for choosing to position the accounts using these models is that the authors of these models have provided a context for understanding development and have identified potential contributory factors which may have influenced the identity development of the participants (Kroger, 2004). Furthermore, they are also aligned with literature which has explored identity development in those with 'disabilities' such as DS which I have considered valuable for informing this study (Smart, 2012). The conceptualisation of identity formation I have, therefore, employed for analysis is summarised in the following section.

Identity and Identity Formation

I understand identity to refer to the commitments an individual has made about him/herself and who he/she would like to become (McLean and Syed, 2015). Identity formation may begin in childhood but continues to develop and change throughout someone's life (Kroger, 2004). Rather than stages, there are thought to be two phases in identity formation: the identification phase and then the identity formation phase (Kroger, 2004).

Contributing Factors

It would appear that there are many contributing factors to the formation of an individual's identity. Embedded within a sociocultural context, this includes both social and experiential factors (Farenga and Ness, 2005). Factors inherent to an

individual, including cognitive ability, may also mediate the experience of identity formation (Grotevant, 1987). For successful development of an identity an individual requires the following factors:

- A secure base (Marcia, 1966; Erikson, 1968)
- Social Interaction (Marcia, 1966; Erikson, 1968; Grotevant, 1987; Bosma and Kunnen, 2001; Luyckx et al., 2006)
- Opportunities for exploration (Marcia, 1966; Erikson, 1968; Grotevant, 1987; Bosma and Kunnen, 2001; Luyckx et al., 2006)
- Opportunities for autonomy (Marcia, 1966; Erikson, 1968;)
- Opportunities for success (Erikson, 1968; Grotevant, 1987)

Mechanisms

Through these experiences and relationships the individual is exposed to information about the self (Grotevant, 1987). The individual then evaluates this information against existing identity conclusions and decides whether the information is consistent with this information and so either *assimilates* or *accommodates the* information into existing identity structures (Grotevant, 1987; Bosma and Kunnen, 2001; Luyckx et al., 2016).

Outcomes

Identity can be expressed in different ways but through the commitments an individual has made about him/herself and his/her future (McLean and Syed, 2015). As this research is being conducted in the field of educational psychology, for the purpose of this research I conceptualise identity as: who the school-leaver is in the present and how he/she has committed to vocational, living and/or community–

based aspirations for his/her future, and so I considered the participants' identities and identity formation according to this understanding (Department for Education, 2015).

Moreover, depending on the way in which factors may have contributed to identity formation, the outcome of this process can either be successful (identity achievement) or unsuccessful (identity diffusion, identity foreclosure and identity moratorium) (Marcia, 1966). Unsuccessful identity formation can have a negative impact on mental health and future life trajectories (Georgios and Bosma, 2005). However as identity development is a life-long process there is capacity for individuals to re-evaluate previous conclusions at any point in life (Marcia, 1989).

2.6 Identity Development and 'Disability'

As this research is concerned with identity formation in young people with DS, the following section will consider how identity may develop in those with 'disabilities'. Smart (2012) argues that the theories described in section 2.4 are applicable for understanding identity formation in those with DS, as like their peers, they have to navigate psychosocial development and generate aspirations for future adulthood. However, it may be contended that due to unique circumstances, having impairment to the body and/or mind may disrupt, change or delay the process of identity formation (Marini, Graf and Millington, 2018).

Due to physical restrictions associated with impairments, children may be less able to explore their environment and rely on parents for support (Marini, Graf and Millington, 2018). Culturally, if society holds lower expectations of those with impairments, it may be conceivable that individuals may not be provided with adequate opportunities to develop autonomy (Marini, Graf and Millington, 2018). In

addition, evidence would suggest that children with impairments can experience social rejection which may obstruct their ability to develop secure bases for identity formation (Marini, Graf and Millington, 2018). Finally, those with learning difficulties may not develop the cognitive skills required to overcome and resolve identity crises (Shaffer, 2009). Additional challenges are illustrated in Table 5.

Table 5: Challenges at each Stage of Life for those with ‘Disabilities’ (Smart, 2012; Marini, Graf and Millington, 2018)

Stage of life	Challenges associated with impairment
Infancy To develop relationships with parents and to begin to explore the environment.	• Individuals with impairments may not be able to develop a trusting relationship with caregivers due to hospitalisation and other restrictions. • Children with impairments may not develop the language to begin to explore their environment and gain autonomy with skills • Caregivers may not allow their children to explore their environment due to overprotection. • Impairments may also place physical limitations on exploration in the early years, for example limited development of physical gross motor skills.
Pre-school and school years To develop social relationships and to learn new skills.	• Young children with impairments may have difficulty with or may not be able to develop peer relationships. • They may lack the cognitive development to learn new skills. • Impairments can disrupt school attendance or interfere with academic performance. • Impairments can also negatively affect self-confidence and psychological well-being.
Adolescence To begin to explore sexuality and form identity.	• Physical characteristics of impairment can cause problems with body image, self-concept and sexual expression during the adolescent years. • Parents can be over-protective, at this stage and can limit experiences where individuals explore beliefs separate from their families. • Adolescents may deny their impairments. Goffman (1990) wrote that people with stigmatized identities such as those with impairments engage in identity management in social situations where they control what they disclose about themselves to appear a ‘normal’ people.
Early Adulthood	• People with impairments may experience a delay in gaining independence from their family.

To make choices for vocation, develop intimate and social relationships.	• Individuals with disabilities may experience restrictions from families when setting their life goals. • Impairments may delay intimate relationships or make procreation difficult or impossible.
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In contrast to the ways in which impairment can negatively influence identity development, having a 'disability' is judged by Dunn (2016) to be an important element of a person's identity. Dunn (2016) calls this 'Disability Identity' and it characterises an understanding of the self, providing a guide for the 'disabled' person on how to act, who to be and what they should value (Dunn and Burcaw, 2013). It also refers to the connections a person may have with other members of a community of 'disabled' people and provides a base for which disabled people can understand their individual experiences (Dunn and Burcaw, 2013). It would seem, therefore, that 'disability' can both negatively affect and facilitate identity formation.

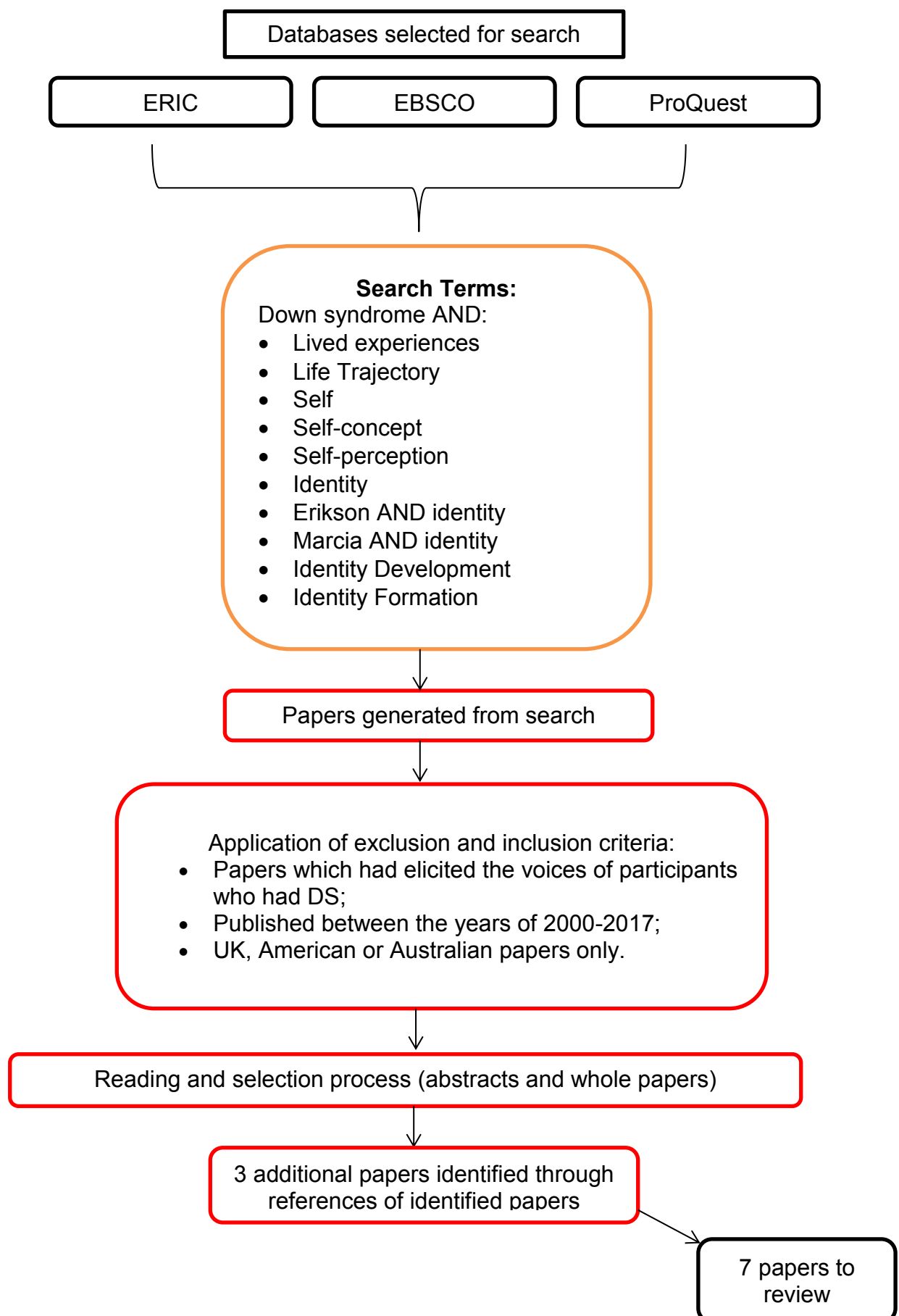
2.7 Life, Identity and Down syndrome

As this research is specifically exploring school-leavers with DS, it is imperative that I consider existing literature specific to DS. As is the case with their peers, adolescence is judged to be a significant period for those with DS to develop personal identities (Buckley and Sacks, 2002). During this phase, young people develop similar self-awareness and have the same physical and emotional experiences as those without DS (Buckley and Sacks, 2002). Adolescents with DS may, therefore, go through a similar process when forming an identity; experiencing the same transition out of school settings where they have to determine their own interests and trajectories for the future (Buckley and Sacks, 2002; Smart, 2012).

However, like other 'disabilities' young people with DS may experience factors which alter lived experiences and consequently influence the process of identity development (Buckley and Sacks, 2002). For instance, due to recognisable physical characteristics of 'disability' significant others may have low expectations of children with DS and so restrict their opportunities for exploration and autonomy (Bhattacharya and Sidebotham, 2000). Due to negative societal attitudes those with DS may experience restricted community involvement (Carr, 2008). Alternatively, by recognising the vulnerabilities associated with the syndrome, significant others (including parents) may restrict levels of autonomy to protect young people with DS from harm (Scott et al., 2014). Additionally, those with DS may lack the cognitive skills required to evaluate, assimilate and accommodate identity alternatives into a unified whole (McLean and Syed, 2015).

These conclusions should be considered as 'working hypotheses', formulated from the general literature on DS and identity formation in those with 'disabilities'. In order to identify whether there has been any similar research to the present study, which has explored the lived experiences and identity formation in those with DS I conducted a literature research in October 2016, July 2017 and repeated it in March 2018. Figure 2 illustrates the process I went through to identify papers to review.

Figure 2: Search Process to Identify Papers to Review



2.8 Existing Research into the Lived Experiences and Identity in those with Down Syndrome

From the search, I identified that there has been limited direct research which has elicited the voices of people with DS to explore their lived experiences and identity formation (Brown, Dodd and Vetere, 2009). However, from reviewing the papers identified from the search I have identified a number of relevant points for providing further context for the present study. Table 6 provides an overview of the papers I considered most applicable. It offers information regarding the paper's relevance, the participants, aims, methodology and findings. I then discuss the conclusions drawn from the papers regarding the lived experiences, the self and identity in young people with DS.

Table 6: Overview of the Papers I Selected from the Search

Study	Relevance	Participants	Aims	Methodology	Findings
Brown, Dodd and Vetere (2009)	Identity formation	6 participants (1 female, 5 males) all aged between 50-53, who had lived in institutionalised settings.	The aim was to find out how older adults with DS talked about identity in relation to their experience in institutionalised settings.	• Semi-structured interview • Narrative analysis	Participants were able to reflect upon life events. Narrative themes included: loss, transition, health, attachment figures, resilience and identity. No one spoke about themselves as having DS. The participants had a range of social roles.
Cunningham and Glenn (2004)	Self-awareness and cognitive ability	Parents and children with DS (78 parents and 77 young people aged from 17-24).	The aim was to explore the awareness of DS and disability in young people with DS.	• Interviews with parents and young people • Cognitive measures • Sorting activity (people with and without DS)	Young people with DS followed a typical developmental trajectory in terms of becoming aware of themselves and their disabilities. However, some did not talk about DS and it was believed this was because it was not important to them at this stage in their lives.
Glenn and Cunningham (2004)	Self-understanding and social comparison	Parents and children with DS (78 parents and 77 young people aged from 17-24).	The aim was to determine whether self-understanding followed a typical developmental pathway in young people with DS.	• Interviews with parents and young people • Cognitive testing	The development of self-representation in people with DS followed a typical developmental path. A qualitative change in self-representation appeared when cognitive and language development were around developmental ages 6-7 years. Around this age young people started comparing themselves with others through mostly upward comparisons.

Barter et al. (2017)	Sociocultural change on experiences of having DS	8 people with DS aged from 24-49	The aim was to reveal what people with DS think of genetic screening procedures for DS.	- Interviews - IPA and Foucauldian discourse analysis	Their experience of DS was viewed as something negative in terms of devalued difference. All the participants spoke about their DS being abnormal. They referred to a lack of autonomy in their life choices and indicated how they were often controlled by others.
Alderson (2001)	Lived experiences	40 adults with DS	The aim was to consider the quality of life when living with DS.	- Interviews - Focus groups	Some people with DS live positive and independent lives. However, participants gave specific negative examples of being physically pushed by others on the street or excluded from mainstream education. The interviewees described that this frustrated them and how it was because they had DS and people have negative attitudes towards DS.
Scott et al. (2014)	Lived experiences	12 young adults with DS aged between 18-29	The aim was to investigate what makes a 'good life' from perspectives of young adults with DS.	- Individual interviews; - Focus groups; - Poster data collection	A good life involved: autonomy, independence, employment, meaningful relationship, continued education, leisure activities and achieving aspirations. The authors recommend how parents should encourage their children to be self-determined and autonomous.
Skotko, Levine and Goldstein (2011)	Lived experiences	284 people with DS	Aimed to explore the perceptions of people with DS when thinking about their life experiences.	- Survey design - Questionnaire	99% of people said they were happy with their lives. 97% liked who they were. 96% liked how they physically looked. A small percentage shared sadness. During the transition to adulthood times can be difficult for them; they may realise that their future may be different to peers.

2.8.1 Self-Awareness and Down Syndrome

A couple of the papers explored the contribution of factors including physical characteristics and cognitive impairment on levels of self-awareness in young people with DS (Cunningham and Glenn, 2004). Cunningham and Glenn (2004) identified that children with DS develop self-awareness and begin to socially categorise at around five to six years. Due to awareness of physical characteristics, through parents explaining to them and/or from placements in special schools, young people become aware that they have something called DS by age 11 (Cunningham, Glenn and Fitzpatrick, 2000; Cunningham and Glenn, 2004). Perhaps by gaining self-awareness children contemplate the significance of DS and this could give meaning to their lived experiences (Buckley and Sacks, 2002; Dunn, 2016).

However, there were participants in the papers who may have been aware that they had DS but chose not to speak about it as a defining feature of their identity. For these people they perceived other aspects more significant, for example, their physical beauty (Brown, Dodd and Vetere, 2009). There were different interpretations for this. Cunningham and Glenn (2004) proposed that participants may not have considered DS as prominent at the time of the research. Alternatively, perhaps as Goffman (1990) suggested, the participants may have denied their 'stigmatized' identities in order to present themselves as 'normal' to researchers. For example, participants in one study spoke about wanting to be 'normal' (Glenn and Cunningham, 2004).

Alternatively it may be presumed, that due to learning difficulties, participants may have lacked the skills to reflect upon their disability (Cunningham and Glenn, 2004). Although the existing literature implies that children with DS follow a typical developmental trajectory (Cunningham and Glenn, 2004), it has been established

that DS causes impairment to cognitive functioning which may limit reflective capabilities (Selikowitz, 2008). Cunningham and Glenn (2004) concluded that only when individuals had acquired a developmental age of eight would they have acquired the cognitive skills to make comparisons between themselves and others. For young people with DS it is possible that identity formation will be delayed, as they may take longer to reach this developmental stage (Selikowitz, 2008). It is conceivable; therefore, that the cognitive impairment may also negatively influence the identity formation process, particularly impacting upon the ability to reflect upon lived experiences and formulating conclusions during identity formation (Boyes and Chandler, 1992).

To summarise, the studies have considered the influence of personal factors such as the awareness of physical differences and cognitive functioning on the processes significant in the formation of identity, including: making social comparisons and reflecting upon personal circumstances, and have implied that identity formation may be mediated by factors associated with DS.

2.8.2 Lived Experiences

The reviewed studies have also gone some way to explore the lived experiences of young people with DS within a sociocultural context. Specifically these studies have considered how lived experiences can be mediated by sociocultural attitudes. Barter et al. (2017) demonstrated that young people with DS can be aware of negative attitudes in society. When asked their opinions on genetic screening, participants questioned their worth and used adjectives of damage and abnormality. Furthermore, Alderson (2001) illustrated examples where individuals with DS had been pushed on the street or excluded from mainstream education and

how the participants attributed these episodes to sociocultural attitudes rather than to their impairment. Dunn (2016) writes that an individual's identity can be influenced or biased by other people's attitudes. The participants in Alderson (2001) were frustrated by not having the same employment opportunities as their peers. Perhaps this was due to societal barriers or alternatively sociocultural attitudes negatively shaping the identity formation which might determine future outcomes.

In order to find opportunities for employment, housing and mainstream education the existing literature revealed how young people with DS typically rely on family and friends to enable such opportunities (Alderson, 2001). This finding is consistent with my earlier assertion that young people with DS may find it more difficult to consider options for their future life trajectories and so may require additional support (Down's Syndrome Association, 2011). Scott et al. (2014) illustrated the importance of meaningful relationships to provide a secure environment for young people with DS, perhaps reflecting the secure base required for positive identity formation.

However, in addition to supporting young people with DS they require autonomy to develop identity successfully. The existing evidence implies that young people with DS may not experience the autonomy they require to develop successful identities due to restricted peer groups, impaired relationship building and viewing themselves as vulnerable (Scott et al., 2014; Barter et al., 2017). The authors of these studies have called on future research to be undertaken, such as the present study, to explore the role of significant relationships in more detail to consider how such relationships may facilitate or hinder opportunities for autonomy, identity formation and future life trajectories (Scott et al., 2014).

2.8.3 Identity, Future Life Trajectories and Down Syndrome

Although the reviewed studies may have implications for considering identity formation in those with DS, only two studies made specific reference to identity. One study explored the identity of older adults with DS and so may not be so applicable to this study (Brown, Dodd and Vetere, 2009). However, the Australian study from Scott et al. (2014) explored what constitutes a 'good life' for young people with DS and from this, drew conclusions regarding the optimal conditions for identity formation. Like the theories of identity discussed previously, the findings emphasised the importance of parents encouraging their children to be autonomous, independent and self-determined (Scott et al., 2014). These conditions were not only important for facilitating identity formation but also reflected the aspirations of participants to become employed and independent (Scott et al., 2014). The researchers suggested that achieving these aspirations was important for the participants' life satisfaction.

It has been established that identity formation may direct future life trajectories and be reflected in vocational aspirations (Dunn and Burcaw, 2013). Such aspirations formed an element of several of the studies. In the UK-based study by Glenn and Cunningham (2004) the participants spoke about their aspirations to have relationships, be employed, live independently and get married. Only a minority of participants wanted to have children of their own and those that did not made realistic appraisals of the challenges of raising a child as a person with DS.

In contrast, there were some participants in this study who had developmentally immature aspirations, for example, aspiring to be a superhero or marry a TV personality (Cunningham and Glenn, 2004). Holding developmentally immature aspirations for the future may be difficult to achieve within an individual's sociocultural context. It may be presumed that a future life trajectory which diverges

from an individual's expectations may have negative consequences for the person's sense of well-being (Scott et al., 2014).

Whilst forming aspirations for their future young people with DS also have to navigate the transition from school settings (Scott et al., 2014). The literature suggests that transitions can be stressful and this is exacerbated for those with differences such as DS (Foley et al., 2013). Skotko, Levine and Goldstein (2011) identified that transition is challenging as young people with DS may realise that their future may be different to siblings or typically developing peers and/or their friends may move away. To support young people with transition it may be argued that they require successful identity formation. Existing researchers have claimed that this may involve intervention that facilitate self-awareness and determination, both important conditions for identity development (Cunningham and Glenn, 2004; Scott et al., 2014)

2.8.4 A Critique of the Existing Research

Dunn (2016) makes the distinction between individuals who have a disability, (the insiders), and those who do not (the outsiders), who can only imagine what it is like to have a disability. As part of the inclusion criteria applied in this review I only chose to examine studies which elicited the voices of people with DS, the insiders. These studies can be commended, for providing an authentic insight into the lived experiences of those with DS (Alderson, 2001). By involving young people with DS in the research and giving them an active person-centred 'voice' the studies have attempted to reduce marginalisation and empower participants (Cuskelly, Jobling and Buckley, 2002).

Nonetheless, those studies that elicited parental voice in addition to the voice of the young person may be criticised for underestimating the abilities of people with DS to speak for themselves (Cunningham and Glenn, 2004). In contrast, there were more successful researchers who attempted to overcome the challenges of working with a participant group who have communication and learning difficulties by making adjustments to the research process. For instance, Brown, Dodd and Vetere (2009), adopted a narrative methodology and made use of photographs and objects to facilitate communication and prompt narratives. Furthermore, the approach adopted by Barter et al. (2017) made use of non-verbal gesture in addition to language when interpreting the participants' responses.

However, all researchers can be criticised for drawing conclusions across samples. Brown, Dodd and Vetere (2009) failed to acknowledge the individual differences of participants, who had lived in institutionalised settings, by grouping themes to consider the impact of adversity. Similarly, Scott et al. (2014) called their conclusions the 'collective experiences' of the participants who took part in this research thereby failing to acknowledge unique circumstances. Skotko, Levine and Goldstein (2011) employed a survey design and like Cunningham and Glenn (2004) employed statistical analyses to draw conclusions regarding their sample e.g. 99% of the participants were happy with their lives.

The dangers of drawing conclusions across samples, rather than respecting each case as unique, is that the diversity in experiences is often overlooked (Gilmore, Campbell and Cuskelly, 2003). Due to the shared characteristics associated with the genetic profile of DS, there is a risk that people with DS are treated as a homogenous group and, therefore by drawing generalised conclusions,

researchers may be criticised for reinforcing homogenous attitudes (Gilmore, Campbell and Cuskelly, 2003).

As well as the dangers of homogeneity, several of the studies may be criticised on ethical grounds. Cunningham and Glenn (2004) who investigated self-awareness may have contributed to a participant's sense of stigma by requesting that he/she categorise differences between people, like those with DS and those without. Furthermore, Cunningham and Glenn (2004) probed participants to draw comparisons between themselves and others. Although it was reported that 20% of the participants in this study developed an awareness of DS as a result, this was distressing in some cases and there is no evidence of support to address the harm caused. Similarly, some participants in Barter et al. (2017) became aware that they had DS as a result of taking part in the research. This may also have caused confusion and distress. As indeed Scott et al.'s (2014) research may have. It asked participants what constituted a 'good life' and then to consider their own lives. In doing so they were at-risk of causing upset by demonstrating to the participants the discrepancy between their ideal lives and their realities: for example, participants expressed that they wanted to drive but in reality they were not able to have a driving licence.

In addition to ethical considerations, I have judged the methods adopted by some authors as inappropriate for a sample of people with DS. Scott et al. (2014) chose to use focus groups to elicit 'collective experiences' of participants. However, people with DS can demonstrate strengths in social skills and so may comply or agree in group situations in order to please others (Down Syndrome Association, 2011). Perhaps by employing focus groups, Scott et al. (2014) may have elicited responses based on compliance rather than unique perspectives. Furthermore,

Cunningham and Glenn (2004) chose not to record their interviews with participants due to the participants' articulation difficulties and so instead took notes which were then analysed. In doing so they ran the risk of their hypotheses biasing the process by only attending to and noting the information which reinforced those initial assumptions. I judge Brown, Dodd and Vetere (2009) more successful than the other researchers in that these authors conducted audio-recorded interviews with participants and then analysed the transcripts.

2.9 Conclusion and Implications for the Present Study

In conclusion, during an individual's lifetime it is likely that he/she will ask themselves 'Who am I?' It has been established that a conceptual tool for understanding a sense of self is identity (McLean and Syed, 2015). Identity development is a process which occurs across the lifespan. It involves the evaluation, assimilation and accommodation of information about the self into a coherent whole (Grotevant, 1987). The process is influenced by a number of factors including sociocultural context, experiential, social and personal factors. Successful identity formation is reflected in Marcia's identity achievement status where the individual has questioned previous identifications, explored different identity resolutions and committed to a future life trajectory (Marcia, 1966). Identity development is thought to occur in people with 'disabilities' but the presence of an impairment to the body and/or mind may mediate the identity formation process (Smart, 2012).

The existing literature on lived experiences, the self and identity in those with DS has considered how sociocultural discourses can mediate people's lived experiences (Alderson, 2001). Knowing the contribution of factors on identity

formation, it is likely that the lived experiences of those DS will contribute to the formation of their identities. From existing research I have identified that children with DS appear to develop self-awareness in a similar way to their non-‘disabled’ peers, as long as they have prerequisite cognitive skills (developmental age 8) to undertake social comparisons (Cunningham and Glenn, 2004). It is conceivable; therefore, that identity formation may also occur in a typical sequence as long as the young person has the prerequisite cognitive abilities, experiences and relationships to establish identity achievement.

The present UK-based study aimed to go further than existing research to consider the contribution of lived experiences have to the formation of the identity and future life trajectories of school-leavers with DS. Although the existing research from Scott et al. (2014) may have made several suggestions about the ideal conditions for experiencing a ‘good life’ and identity formation of a person with DS in an Australian context, this study will explore in greater detail the *reality* of lived experiences and identity formation in a *British* sociocultural context. The overall intention was for findings to be used to inform recommendations to improve the life trajectories of young adults with DS after they transition out of school settings.

The research also intended to overcome the methodological challenges associated with the existing literature. The participants who took part were already aware that they had something called DS and so I did not induce disability awareness. By only eliciting the narratives of young people and not parents, I did not underestimate the abilities of the young people to speak for themselves but rather adjusted the methodology to suit their requirements. Recognising the potential distress caused by sharing lived experiences, I employed a methodological approach which had therapeutic qualities: Narrative Inquiry (Block and Weatherford, 2013).

Finally, to avoid reinforcing homogenous attitudes towards those with DS, I have maintained each of the young people's involvement as a unique case study (Gilmore, Campbell and Cuskelly, 2003).

CHAPTER THREE: METHODOLOGY

3.1 Chapter Overview

The following chapter presents the chosen methodology for the study. It commences with the aims, research questions and research design. Following on, it provides information concerning the participants; illustrating recruitment procedures, pen portraits and ethical considerations. It then explores the narrative research approach used, the rationale for this and how the research was grounded in a constructivist epistemology. Subsequently, it outlines the data collection method and then explains how and why parental involvement, visual prompts, a life story timeline and film were employed. Finally, it describes the chosen data analysis process.

3.2 Research Aims, Research Questions and Design

The aim of this research was to explore the (retrospective) narratives of school leavers with DS firstly to consider how individuals with DS speak about their past, present and future lives; secondly to consider how their key life experiences and significant relationships may have contributed to identity formation; and thirdly to consider what these identities could mean for their future life trajectories. The overall purpose of this study was to employ a narrative methodology to 'give voice' to respondents with DS, providing them with a forum to share their own story and with a means to capture their lived experiences (Wertz et al., 2011).

As the research elicited data in a spoken form it was qualitative in nature (Thomas, 2013). The design chosen was a retrospective multiple case study design as it involved a detailed exploration of four individual cases (Thomas, 2013). By only focusing on a small number of cases I was able to gain rich data which respected the complexity and uniqueness of each participant (Richie et al., 2014). The design is

retrospective as the research process involved looking back at respondents' lives and capturing their narratives regarding significant times in their life (Thomas, 2013).

The specific research questions are provided below:

Empirical Research Questions:

1. How do school-leavers with Down syndrome talk about their past, present and future lives?
2. What are the contributions of key life experiences and significant relationships on the formation of identity in school-leavers with Down syndrome?

Broad research question:

3. What is the implication of identity formation on the future life trajectory for school-leavers with DS?

3.3. Participants

3.3.1 Selection and Recruitment

Studies that employ a narrative methodology typically involve a small number of participants due to time-consuming transcription and analysis procedures (Goodson, 2017). Guided by this I recruited a small sample of four participants (three male and one female) aged from 19-25 years. Participants were identified indirectly through a third party organisation to whom they were known, for example, a local division of the Down Syndrome Association. A member of the third party organisation was provided with information on the recruitment criteria (see Table 7) and initial sheets to pass onto prospective participants (see Appendix 2). Following this, if a young person (and their parent) were interested in becoming involved in the study

contact with me was mediated through the member of the organisation who had identified them.

Table 7: Recruitment Criteria

Inclusion Criteria	Rationale
• Aged between 18-25 years	I was interested in asking participants to look back over their lives at a time where they may be transitioning into adulthood in order to consider how key life experiences and significant relationships may have influenced identity formation and future life trajectories.
• Male or female	I was interested in eliciting narratives from both male and female participants.
• Have a parent or carer accessible and willing to support their participation in the project	I wanted the young people to have a parent who could support them with filling in a life story timeline and collecting visual prompts for the interview (see <i>section 3.6.3</i>).
• Be aware that they have Down syndrome and some understanding of what this means	I did not want to deceive my participants in anyway. I wanted them to have a clear understanding what my aim was, why I was interested in carrying out the study and why I was interested in speaking with them as individuals and so I felt knowledge of having DS was significant for this.
• Expressive and receptive language and communication skills to engage in an interview	In order to engage with a verbal interview I required the participants to have language skills to be able to produce narratives which I could then analyse to answer the research questions.
• Considered as having the mental capacity to give informed consent to take part	To meet ethical standards I needed to ensure that the participants were able to give informed consent and did not require a proxy to provide informed consent for them.

3.3.2 *Pen Portraits*

To introduce participants, Hollway and Jefferson (2013) recommend the use of ‘pen portraits’ to provide information about each participant which aids understanding of later interpretations and makes findings and discussions more meaningful. I have provided pen portraits of each of the school-leavers who took part in this research (real names are replaced with pseudonyms) below, making

reference to demographic information, age, family origin, current living situation, educational history and current education or employment status.

Tommy

Tommy is 19 years old. He lives at home with his mother and father; he has an older sister who lives away. Tommy previously lived outside of the UK but has recently returned to England. He went to a mainstream primary school and then to a mainstream secondary school. During his time in secondary school Tommy was taught in a unit for young people with special educational needs. He currently attends a specialist residential college which specialises in hospitality.

Mike

Mike is 25 years old. He lives at home with his mother and father. He is currently going through a process through which he may be granted a house to live independently. Mike went to a mainstream primary school and then to a specialist secondary school for students with learning difficulties. After finishing school he attended a specialist residential college where he received training in hospitality and horticulture. He is currently employed part-time in a shop.

Antony

Antony is 19 years old. He currently lives at home with his mother and grandmother. His parents divorced when he was nine years old and his older sister is currently studying away from home. Born outside of the UK, he began his education in a mainstream primary school and then transitioned to a mainstream secondary school. At age 15, he moved to England and started attending a secondary school for

students with special educational needs and disabilities. He recently started studying at a specialist residential college.

Emma

Emma is 19 years old. She lives at home with her mother. Her mother and father are separated but she still sees her father regularly. She has a brother and a sister. Emma went to mainstream school throughout her education. She then went onto undertake foundation course for people with special educational needs; however, she left this course. She is currently in the process of looking for employment opportunities.

3.4 Ethical Considerations

When considering how to overcome potential ethical issues which may arise from conducting this research I employed the British Psychological Society's Code of Human Research Ethics (BPS, 2014) and guidance from other researchers (Lewis and Porter, 2004). Prior to commencing data collection ethical approval was granted from the University of Birmingham's Research Ethics Committee (See Appendix 4).

As I was working with a vulnerable group I paid careful attention to how I would ensure the school-leavers were giving genuine informed consent to participate (addressed in Table 8). On reflection, I have judged the measures I undertook as sufficient and feel confident that the participants did give informed consent for taking part. For example, in the consent form one of the statements read 'I am happy to tell Annie stories from my life', two of the participants initially questioned what I meant by this statement. As a result I provided further clarification on what I meant by 'story' and the participants were then happy to consent.

Table 8: Ethical Considerations

Ethical Issue	Steps Taken to address this issue
Reducing Risk	Participants • The risks of participation were outlined in the information sheet provided to participants. • If participants became emotionally distressed at any point in the interview I stopped the recording, fortunately this was not necessary. • If the interview evoked some emotional distress for the participant which was deemed to cause impact after the research finished I would provide the participant with a list of services from which s/he would be able to seek support following my involvement. Fortunately this was not necessary. • If any safeguarding concerns were raised during the interview I would pass on this information to the safeguarding officer within the educational or employment setting the individual is attending. Fortunately this was not necessary. • I ensured that regularly during and after every interview I asked how participants were finding the interview and whether they needed a break. • Narrative approaches have been identified as having therapeutic benefits for participants (Murray, 2015). Researcher • To minimise risk to myself I ensured that a supporting adult was within the home or alternative research setting (in close proximity) during the interview. • I made a designated colleague aware of the address I was visiting, an approximation of the time the interview would take and made contact once I had left the interview.
Consent	• All participants were deemed to have the mental capacity to give informed consent by the recruiters (Mental Capacity Act, 2005). • Participants received an accessible information sheet outlining detail of the study. • The information sheet was accessible in that it used easy-to-read language and complicated information was broken down into smaller points. • I then met with participants to verbally talk through the information sheet. • I used an accessible consent form with participants to provide written informed consent (Bold, 2012) • The consent form had two spaces for participants to indicate whether they understood each statement they were consenting too and then whether they gave their consent. • Prior to the interview I established each participant's oral consent to take part in the interview (Bold, 2012). • Information sheets and consent forms were also given to the participants' chosen parent for their involvement in the study.
Withdrawal	• It was explicitly stated in the consent forms and the information

	sheets that participants have the right to withdraw at any point during the project. • Participants would be free to withdraw at any time up to a month after their interview. • I regularly reminded participants of their right to withdraw throughout the process or to withdraw their data from the research following the final session.
Confidentiality	• Pseudonyms were chosen by participants which ensured that the participants' real names were not used at any point during the data collection, analysis or write up of the research (Elliott, 2005) • Participants knew their pseudonyms and so were able to identify and withdraw their data on request; • Names of places and other people e.g. family members and school settings were also omitted from the transcripts.
Protecting data	• Any written notes including my research diary were kept in a locked draw. • Following transcription the video footage was deleted from the video camera and stored on a university BEAR data storage system. • To facilitate feelings of ownership participants were given a copy of their life story film on a password protected memory stick (Elliott, 2005). • To overcome issues with participants giving genuinely informed consent for their data to be kept for 10 years post data collection it was decided (and agreed by the University of Birmingham's Research Ethics Committee) that the video footage would be destroyed post examination of the thesis.

3.5 Research Methodology: Narrative Inquiry

3.5.1 Philosophical Underpinnings

Before introducing the narrative approach it is important to outline the epistemological position adopted in this study (Bailey, 2007). This is because a researcher is never fully neutral and so it is vital to clearly articulate any epistemological beliefs which may permeate the findings prior to commencing data collection (Ritchie et al., 2014). My position is in line with an Interpretivist tradition. I accept that multiple realities exist and I can only understand these realities through exploring human interpretation of lived experiences (Ritchie et al., 2014). To understand the social world, therefore, I did not judge it suitable to employ methods

adopted for a positivist position, such as experimentation, but rather to utilise methods which would support the exploration of human interpretation (Ritchie et al., 2014).

Consequently, I grounded the methodological decisions for this study in a constructivist paradigm (Ritchie, 2014). With this, instead of perceiving that the participants in the study received knowledge about a 'reality' passively, I considered how they were actively involved in constructing their understanding and perspectives (Ritchie et al., 2014). In a sense, I have rejected objectivity in the favour of exploring the subjective perspectives of the school-leavers with DS (Cohen, Manion and Morrison, 2018). I was interested in the individuals at the centre of the study, how the respondents perceived reality and what their narratives revealed about their constructions (Ritchie et al., 2014). Furthermore, I was intrigued by the meaning that respondent's gave to their lived experiences as means to explore what contribution those experiences may have on identity formation and future trajectories for life (Bailey, 2007).

Accordingly, the methods adopted in the present study have been influenced by my position. For example, employing a narrative approach I was able to elicit respondent's constructions regarding their lived experiences and the meaning they made from these experiences (Moen, 2006; McAdams and McLean, 2013). Furthermore, by adopting a case study design I did not intend to draw conclusions across the sample group to reveal information about an external reality, but rather by respecting each individual case, I acknowledged how multiple realities may exist and are revealed through the interpretations of individuals (Ritchie et al., 2014). In addition to the methodological decisions, it is also reasonable to assume that my

position as a researcher may have mediated the findings of this study. This will be discussed in section 3.8 *Reflexivity* (Bailey, 2007).

3.5.2 A Narrative Approach

With this epistemological position, I chose to adopt a narrative approach for this research which involved eliciting stories from participants (Murray, 2015). Bruner (1986) proposed that eliciting stories is an effective method for learning about the world. When people are born they are thought to enter a narrative world and live their lives through stories they share (Murray, 2015). People become 'narrators' and make meaning of their unique realities through the way they tell stories (Andrews, Squire and Tamboukou, 2013). It is presumed that individuals reveal how they represent themselves and their lives through story-telling (Elliot, 2005). Individuals organise their lived experiences into a temporal unit conceptualised as a 'plot' and through analysing these plots, researchers are able to gain access to these representations (Polkinghorne, 1995; Grant et al., 2010).

There are varied ways in which scholars can adopt the narrative approach in their research, for example, as the focus of the study, as the method of investigation or during analysis (Andrews, Squire and Tamboukou, 2013). For the present study, I chose to employ a narrative approach for both the method of investigation (asking respondents to share stories from their lives) and to frame the analysis (to analyse the stories/narratives through a restorying procedure and a narrative thematic analysis process) (Elliott, 2005).

3.5.3 Identity and Narratives

One element of the study explored identity formation in school-leavers with DS. A narrative approach is commonly used to investigate identity (McAdams, 1993). When people share stories, it is believed that they define themselves and reveal what is termed their 'narrative identity' (Murray, 2015). McAdams (1993) likened the construct of identity to a book with different chapters focusing on distinct self-defining episodes. Each chapter is believed to have a psychological implication for the individual's formation of identity (McAdams, 1993). Through asking respondents to share stories (relating to episodic memories) it is believed that they will reveal who they are (identity), how they came to be that way (identity formation) and who they may become in the future (future life trajectories) (McAdams and McLean, 2013).

Within narratives, therefore, are said to be descriptors of their identity formation (Murray, 2015). McAdams' (1993) theory of narrative identity suggests that when people tell their life story, individuals organise elements of themselves (attributions, ambitions and personality traits) in a temporal sequence or a 'plot' which has different situations (experiences) and characters (significant people) (Kroger, 2007). When people share their life stories they represent their construction of how they became who they are (taking account of the contribution of significant experiences and relationships they have had in their lifetime) (Kroger, 2007). With this, I expected that by eliciting narratives, I would be able to explore the identity formation of the school-leavers with DS and consider the contribution of experiences and relationships on their development (Block and Weatherford, 2013).

3.5.4 Rationale for Employing a Narrative Approach

In addition to its suitability for identity research, I also judged the narrative approach as an appropriate method to employ for the chosen sample. It was revealed in the introductory chapter that individuals with DS once experienced historical social exclusion (Oliver, Woodcock and Adams, 2010, p.135) and how people with DS have not had strong voice in existing research (Skotko, Levine and Golstein, 2011). Acknowledging this, narrative methods have been identified as ethical approaches which can be used to strengthen self-advocacy and empower those who may have been previously socially excluded by providing them with a forum to share their perspectives in research (Atkinson, 2004; Squire et al., 2014).

I also judged the narrative approach to be applicable for answering the proposed research questions. The first question explores how young adults with DS talk about their past, present and future lives. Eliciting narratives appeared advantageous for addressing this question as narratives could be summarised into a life story and analysed for tone. Narrative tone refers to the way in which an individual tells their story which may hold information on how he/she feels about his/her life (Crossley, 2000). For example, if an individual talks only negatively about their life whilst sharing their narrative, this may be likened to a depressive narrative tone and may reveal that the individual has a negative view of his/her life (McAdams, 1993). More information regarding narrative tone can be found in section 3.7.4 *Identifying Narrative Tone*.

The second research question is concerned with the contribution of key life experiences and significant relationships on the formation of identity. It has already been established that eliciting narratives is an effective means of studying identity formation (McAdams, 1993). In the narratives people share there are thought to be

causal relationships between the elements of the plot (key experiences) (Labov, 1972). Additionally, they illustrate how their experiences are influenced by their significant relationships through referencing to the important people in their lives, (Clandinin and Connelly 2000). Through eliciting narratives, therefore, I was able to explore the contribution of key experiences and significant relationships to the formation of identity (research question two) (Elliot, 2005).

The third broad research question considers the implications of identity formation on the future life trajectories. Clandinin and Connelly (2000) propose that the narratives exist within a temporal history and can be viewed from past, present and future perspectives. Through eliciting narratives, therefore, researchers are able to consider implications of participants' past experiences and relationships on their present and future life trajectories (Clandinin and Connelly, 2000). Employing a narrative approach, therefore, seemed applicable for the exploration of the school-leavers' lived experiences, identity formation and future life trajectories (Polkinghorne, 1995).

3.6 Method of Data Collection: Narrative Interviews

When deciding on a method of data collection I found that the literature offered varied suggestions, however, the most frequently cited method, and so that which I chose to employ, was narrative interviewing (Murray, 2015; Goodson, 2017). Narrative interviews vary in their level of structure, from completely prescribed (structured interviews) to open-ended (unstructured interviews) (Denzin and Lincoln, 2018). I chose to employ a semi-structured interview as my intention was to guide the interviewees to share narratives which were applicable for the research

questions whilst maintaining flexibility in order to expand upon interesting strands of inquiry (Bold, 2012).

3.6.1 The Life Story Interview

McAdams' (1993) theory regarding using narratives to elicit information about identity suggests that people reveal their identity through sharing their life story. Accordingly I sought to develop an interview schedule which would elicit narratives from across the respondents' whole lives. After examining approaches employed in life history research, I identified the 'Life History Interview', a schedule for collecting narratives from across the entirety of a person's life (Atkinson, 1998). This schedule is advocated by McAdams (1993) for investigating the formation of identity. Atkinson's interview schedule consists of 200 questions and its implementation takes place in three stages: preparation, implementation and transcription (Atkinson, 1998). Its therapeutic benefits include: increasing respondents' self-esteem and supporting them to establish a clearer perspective on their future life trajectories (Atkinson, 1998).

I considered the direct implementation of Atkinson's schedule inappropriate for this study; for example, because of communication difficulties I decided that the interview I employed in the present study would have to incorporate more prompt questions than Atkinson recommended (Atkinson, 1998). However, I used his schedule as a template to develop my own interview called the 'life story interview'. Like Atkinson, I separated the interview questions into 'phases' which include: birth and understanding the family unit, early childhood (0-5 years), school and education (5-15 years), up to the present day (15- present day) and the future. The questions can be found in Appendix 6.

Although I was interested in experiences (research question 2), I understood that it was likely that participants would categorize their experiences and share narratives relating to specific events in their lives. I acknowledged this and developed open questions to elicit narratives regarding such events, for example, ‘Can you tell me a time when...?’ I attempted where possible to formulate the questions with reference to the literature identified in Chapter Two. For example, “What did you find easy/difficult as a child?” may elicit narratives which reveal times the participant may have succeeded or failed as a child and which may have contributed to his/her psychosocial development (Shaffer, 2009). Furthermore, I did not ask participants specifically about having DS as I was interested in exploring whether they spoke about this as being salient in their lives.

Unlike Atkinson (1998), the schedule had significantly fewer questions. Furthermore, due to the flexibility associated with a semi-structured interview I decided I would adapt the questions depending on the participant’s dialogue and needs. For example, one participant requested that I did not ask him any questions which could elicit negative experiences and so I was able to omit any negative questions from the interview schedule prior to the interview.

3.6.2 Using a Narrative Approaches with Respondents who have Down syndrome

Previous authors have stipulated that the cognitive, linguistic and social demands of a narrative methodology may be too challenging for participants who have learning difficulties, like those with DS (Grove, 2015). Although I acknowledged the potential barriers with narrative interviewing I sought to overcome those obstacles by following the recommendations of authors who had previously conducted research with participants with learning difficulties.

In addition to adding prompt questions to the schedule, I also adopted a more direct style of questioning to reduce linguistic demands (Booth and Booth, 1996). Furthermore, I acknowledged that if a respondent did not answer a question then their silence should not be interpreted only as a lack of understanding but also as possibly expressing an emotional response such as sadness (Booth and Booth, 1996). Finally, I followed recommendations that participants should be provided with tangible prompts to aid their participation: for example, objects, photographs and written/visual cues (Lewis, 2004; Murphy and Cameron, 2008).

3.6.3 The Life Story Timeline

Whilst developing these resources I explored the provision employed in similar life history research which included life history grids (Abbas, Ashwin and McLean, 2013). A life history grid is a visual resource which maps out different stages of life and provides physical spaces for participants to make notes regarding experiences they may want to share during the interview (Lalanda Nico, 2016). To ensure this resource would be accessible for the respondents in this study, I developed an adapted version of a life history grid which I called a 'life story timeline' (see Figure 3). Relating to the life story interview, the timeline separated the participant's life into phases, and had spaces where the participants were able to make written notes to aid their memory of specific experiences they wanted to share prior to the interview taking place.

I reflected that the participants may have difficulty with remembering experiences to add to their timelines (Grant et al., 2010). To overcome this I judged it necessary for the respondents to have parental support prior to the interview taking place. I ensured the participants were agreeable to this by including this as part of

the consent process. Moreover, to overcome any bias I ensured that the parents were only involved in supporting their children to remember and write down objective facts on their life story timeline, for example, that the child went to 'XXX School in 1996', rather than asking the parents to actively contribute to the interviews. In addition to the life story timeline I also asked participants to collect photographs and objects which may help them to remember their experiences prior to the interview (Aldridge, 2007).

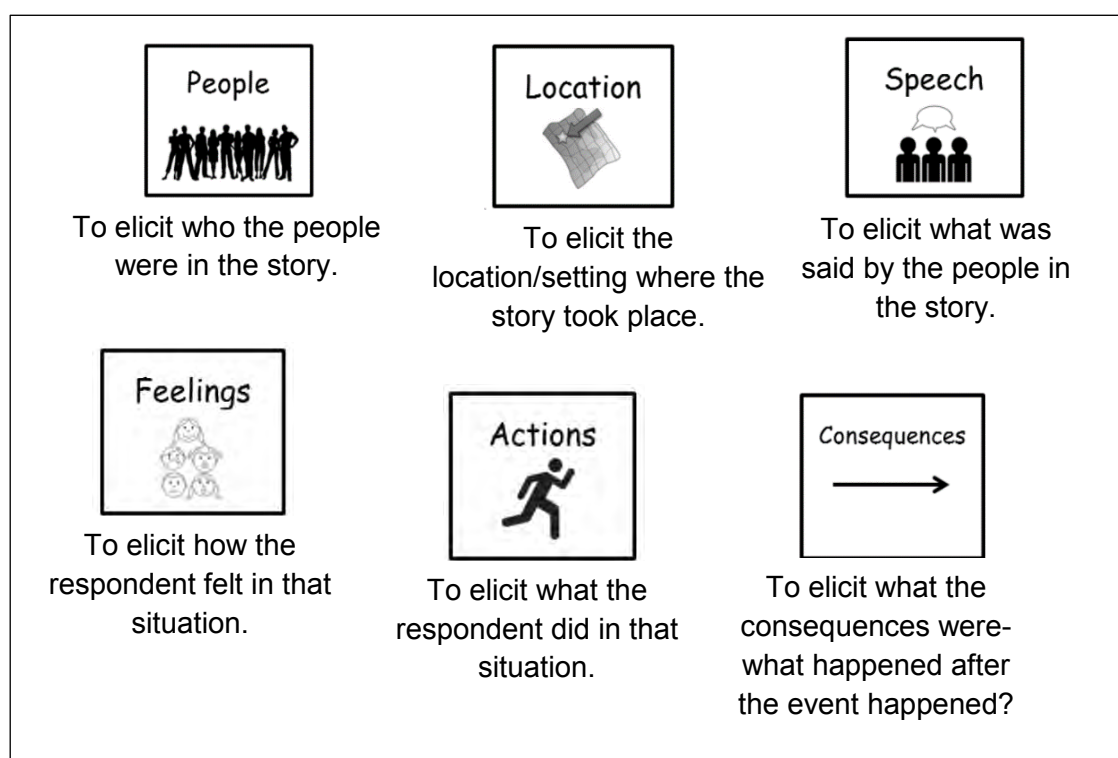
Figure 3: Life Story Timeline

The Timeline of my life							
	Birth	0-5 years	5-10 years	10-15 years	15-20 years	20-25 years	My future
Important experiences (events)							
Photographs from this time							
Objects from this time							

Although I prepared these resources I was concerned that the respondents may have difficulty with responding to the questions in the interview schedule. Lewis (2002) recommends that researchers use visual cue cards to support people with learning difficulties to remember scripts for past events in their lives. Following Lewis' (2002) advice, I created cue cards which had images for prompting elements of a narrative, these included: the people in the story (people), where the story took place (location), what was said (speech), how the participant felt (feelings), what they did (actions) and what the consequences were (consequences) (see Figure 4).

The purpose of these cards was to facilitate the telling of the narratives with limited verbal interference (Lewis, 2002). During an initial meeting with the participants I explained what each card referred to; two respondents rejected the use of these cards. However, I still used these features to structure my questioning (see Appendix 6).

Figure 4: Visual Cue Cards



3.6.4 Life Story Films

To aid transcription and analysis, narrative interviews should be audio-recorded (Elliott, 2005). I elected for video recording to capture the interviews in this study. The rationale for this was three-fold. Firstly, due to the participants' spoken utterances lacking clarity I judged that video recordings would aid the accuracy of the subsequent transcriptions. Secondly, it has been established that non-verbal cues should be included in transcription, to support the narrative tone analysis and video

was able to capture these non-verbal cues (Booth and Booth, 1996) Thirdly, as the participants may have had difficulty in recalling what they had shared during the interview, I deemed it more ethical for them to keep a memento of their participation in the project following the data collection. By filming the participants I was able to create a 'life story film' for each respondent to keep.

3.6.5 Field Testing

According to Kirk and Miller (1986) there are four stages of conducting a qualitative research project: planning, data collection, analysis and reporting. During the planning phase I decided to carry out field testing. Field testing is used to clarify the focus of the study and to illustrate any potential issues with the data collection methods, for example, if adjustments should be made to the interview schedule (Shkedi, 2005). Consequently, I field tested my interview schedule on someone I knew, a young adult with DS.

From the field-testing, I identified that the structure of the interview worked well, however as anticipated, it was better to carry out the interview over two sessions due to the participant becoming fatigued. The participant was able to share narratives, however, struggled with understanding the word 'story' and preferred me to use 'tell me a time when' when eliciting his narratives. The field test also revealed that the language for questioning required some adjustment (see Appendix 6 for the updated schedule). Following the field-test I judged the interview to have elicited a rich data source. Additionally, I did not deem it ethical to deny the voice of this young person in the research process and so I decided to include the field-test interview in the findings.

3.6.6 *The Interview Process*

During the data collection phase I felt it necessary to have an initial session with the respondents to develop a rapport and clarify my purposes (Atkinson, 1998). During this session I outlined the aims of the study and the process of data collection. I also explained the use of the visual cue cards and the life story timeline. I provided participants with a prompt sheet exemplifying some questions (see Appendix 5). The purpose of the sample questions was to reduce participants' anxiety regarding what they may be asked during the interview process (Atkinson, 1998). Finally, the participants were asked where they would wish the interviews to take place. Three of the participants chose the home setting and one chose a neutral location, a cafeteria.

From the field-testing I initially intended to meet with the participants on two occasions with each interview lasting on average one to one and a half hours (Elliott, 2005) (see Table 9 for a chronology). However, two of the respondents decided in the initial meeting that they would like to complete the interview in one session, which I respected. Prior to each interview I reminded the participants of their rights (see section 3.4 *Ethical Considerations*). I then asked questions from the life story interview (using the visual cue cards if requested), making reference to their completed life story timeline (and photographs and/or objects) and filming the interaction with a video camera.

I did not take any notes during the interview as I felt it would interrupt the flow of the conversation, however, I did make reflective notes in a research journal following each interview (Elliott, 2005). These contemporaneous reflective notes helped me to improve following interviews. After the interviews each participant was debriefed: I asked how they felt the interview had gone, if they had found any of the

questions difficult and whether they would consent to being interviewed for a second time.

It is recommended that following data collection, researchers should have a feedback session with participants (Hamilton and Atkinson, 2009). As advised, following the formal data collection sessions, I invited the participants to have a final session with me (it should be noted that one of the participants has yet to agree to meet for this final session). For those who did agree, I used the session to check whether the restoried narratives were representative of the participants' original stories (Reissmann, 2008), to establish if the participants were content with what they had told me during the interview; and to check whether they wanted to change or omit anything (see Table 9).

I also presented the life story films during this session, however, did not use these films to check the narratives as, according to self-perception theory, individuals come to know their own thoughts by inferring them from observations of their own behaviour and so it was likely that by watching themselves speak on film the participants would not want to change what they had said (Bem, 1972). Instead, through hearing their restoried narrative the participants demonstrated genuine reflection, for example, one respondent asked to add a story to his transcript.

Table 9: Chronology of the Interview Process

	Meeting 1	Prior to meeting 2	Meeting 2	Meeting 3 (Optional up to a week later)	Meeting 4 (Optional up to 4 weeks later)
Respondent (Young person with DS)	Initial conversation to explain the remit of the project in more detail.	Preparation of a life story timeline. (1-2 weeks)	Life story interview part 1	Life story interview part 2	A sharing of the restored life story (for checking) and the hand-over the of the life story film
Parent			Not required for interview but close by.	Not required for interview but close by.	May be present for the sharing of the life story film depending on the respondent's preferences

3.7 Data Analysis

After data collection I interpreted the transcripts to offer meanings for what participants have said (Bold, 2012). There is little prescription within the literature for how researchers should analyse narratives (Murray, 2015; Goodson, 2017). Some researchers choose to analyse their transcripts based on content and others analyse for the structure of language usage. With such limited advice to follow I went through a process of reviewing different methods of narrative analysis in order to identify which would be most suitable in answering the empirical research questions (see table 10).

Table 10: The Techniques for Data Analysis I Reviewed

Research Question	Components required from an analysis technique	Method of data analysis for consideration	Description of technique	Excluded or Included	Justification
1. How do school-leavers with DS speak about their past, present and future lives?	- A technique to explore how they speak and what they say. - A technique to combine all elements of the life story interview into a coherent whole in order to consider the past, present and future lives. - A technique that allows specific rather than broad analysis of across the life story in order to consider how they speak	Genre Taxonomy (Frye, 1957)	This analysis technique identifies the broad type of narrative across the interview schedule e.g. comedy, romance, tragedy etc.	Excluded	This technique is too broad, generalising the type of narrative across the life story. The way in which the participant speaks about their life may change with time and I need a technique to account for this temporal influence.
		Narrative Tone Analysis (Crossley, 2000)	This technique comments on the narrative tone which can be derived from the content of the story and the way in which the story is told.	Included	This technique is less broad than the previous one. It allows for cases to be kept as unique. It then explores what and how the young people speaks about. It also accounts for differences in the way that people speak which may change with time, thereby addressing the the challenges with the previous approach.
		The Three-Dimensional Approach (Clandinin and Connelly,	This analysis method breaks the narrative down to consider interaction, temporality and situation and then	Included	This technique provides a method for combining all elements of the narrative into a coherent whole through a restorying process. It keeps the stories as unique cases and accounts for the consideration of the past, present and future elements of

	about the past, present and future.	2000)	restories the narrative into a coherent whole.		the story.
2. What are the contributions of key life experiences and significant relationships on the formation of identity in school-leavers with DS?	- An analysis technique which would explore the meaning of different experiences and relationships as told through the narrative; - Inductive analysis technique to explore meaning; - To draw conclusions which could be related to theories of identity formation	The Problem Solving Approach (Ollerenshaw and Creswell, 2002)	The technique takes the raw data or transcription and analyses the data for 5 elements (characters, setting, problem, actions and resolution). The stories are then graphically organised.	Excluded	This method pays little attention to the context of the narration and I am interested in how contributory factors influence identity formation as told through the narratives.
		Labov's Structural Analysis (Labov, 1972)	This method highlights the narrative structure of each story. The approach breaks the narrative down into clauses and then categorises them into 6 interconnected components: abstract, orientation, complicating action, result, evaluation and coda.	Excluded	This method pays little attention to the context of the narration and I am interested in how contributory factors influence identity formation as told through the narratives.
			This is a strategy	Excluded	It does not emphasise the context in

identified in the literature review.

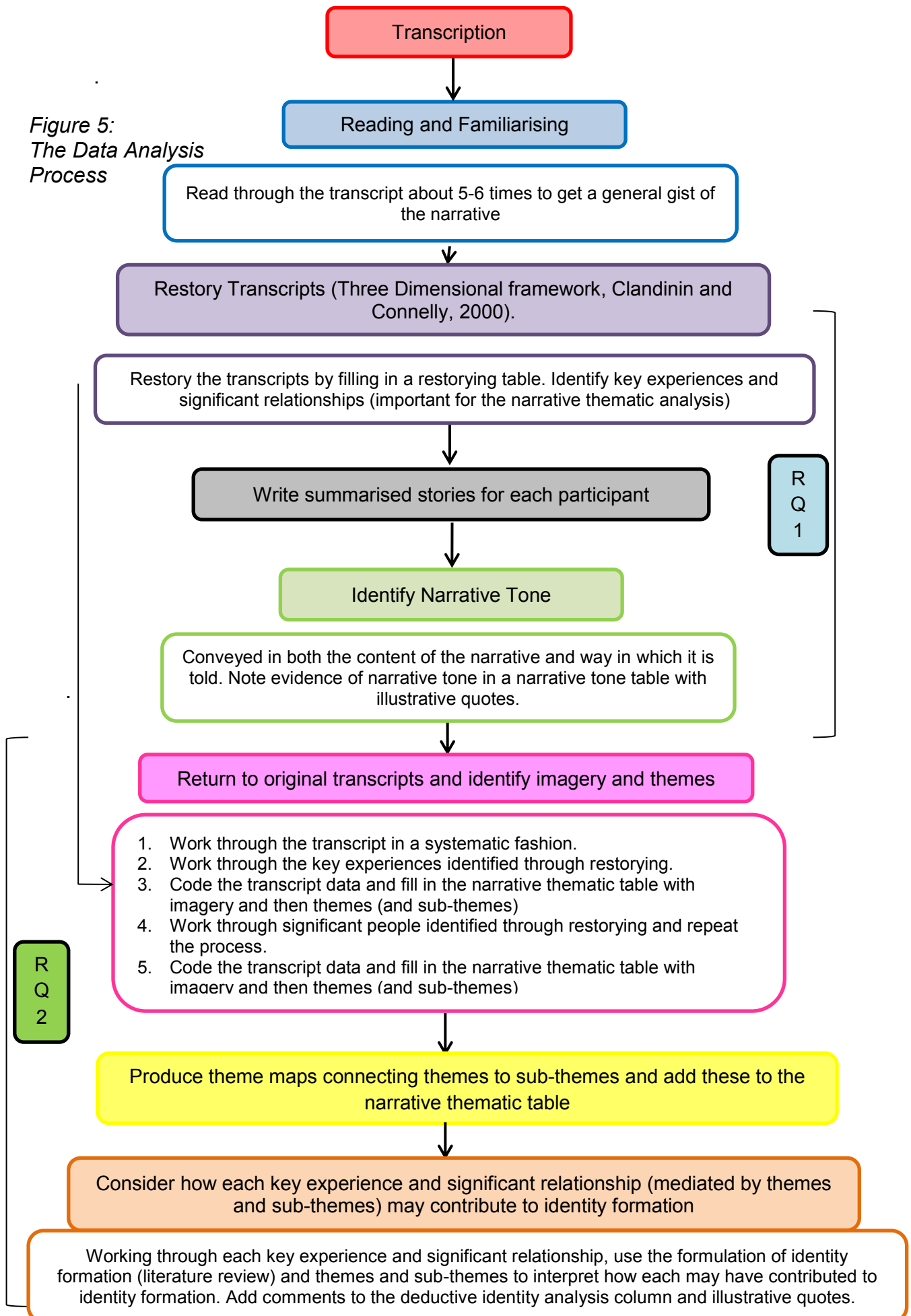
Gergen and Gergen's Model of Narrative Analysis (Gergen and Gergen, 1987).	for the holistic analysis in the form of life stories. It views life stories as a series of chapters each of which can be characterised by the direction of the plot. It involves understanding the course of development of a plot rather than the context in which the development takes place.		which the development of a plot takes place. I am interested in contributory factors and see the experiences as holistic. This requires a technique for considering the influence of context.
Narrative Thematic Analysis (Crossley, 2000)	This technique explores elements of the personal narrative relevant in answering the research question. It is an inductive technique which explores imagery to create meaning denoted through themes which can then be interpreted. The technique can involve analysing the narrative for key	Included	This technique is inductive; it provides a means of exploring the meaning participants make from the different experiences and relationships they speak about in their narratives. It can be analysed for experiences and relationships and then interpreted alongside identity theory.

			life experiences or relationships.		
		Paradigmatic Data Analysis (Polkinghorne, 1995)	This technique locates common themes across stories by combining stories. This creates general knowledge about all respondents life story.	Excluded	I analyse the experiences and significant relationships separately rather than look for themes across the whole life story in order to consider each in turn (relating to research question 2).

3.7.1 *The Process*

From considering different methods of analysis I decided to employ a narrative tone analysis and restorying procedure to elicit findings for research question one (Clandinin and Connelly, 2000; Crossley, 2000) and a narrative thematic and identity analyses for research question two (Crossley, 2000). The general third broad research question could not be answered by the data but rather was addressed through an analysis of the issues arising from both empirical questions informed by the findings from the literature review. The process of employing these methods is illustrated in figure 5, I now provide a rationale and description of each stage of analysis.

Figure 5:
The Data Analysis
Process



3.7.2 Transcription

As illustrated, the first step in the process of data analysis was to transcribe life story interviews; this involved converting the spoken words into written text (Clandinin and Connelly 2000). In order to become familiar with the interviews I transcribed the interviews myself. Furthermore, to determine my influence in the co-construction of narratives I chose not to omit my utterances from the transcripts (Reissman, 1993). As I was transcribing films I was able to add in non-verbal gestures and facial expressions into my transcripts. Through transcribing I was able to begin to make initial interpretations of the data (Murray, 2015) (see Appendix 8 for a full example of a transcript).

3.7.3 Restorying the Life Story Interview

Following transcription I familiarised myself with the narratives through several readings. My initial perceptions were important for the next stage in the process, restorying. Due to the semi-structured nature of the interview the participants did not tend to tell their narratives in a chronological order. Restorying involved gathering the narratives told through the interview into a chronological and coherent whole life story (Lyons and Coyle, 2016). The purpose of restorying was firstly to gain a summarised life story for the participants to check in the feedback session; secondly, to identify key experiences and significant relationships as told through the life story (central to research question 2); thirdly, to restructure the story, in order to consider how they spoke about their past, present and future lives (central to research question 1).

When reviewing potential methods for restorying I identified a model from Clandinin and Connelly (2000) entitled the 'Three Dimensional Approach'. Use of the model involved considering and summarising the transcripts according to different dimensions (illustrated by Figure 6). The dimensions are also illustrated in Table 11

The model helped me to consider the narratives in terms of experiences in the past, present and future. Furthermore, as I was interested in significant relationships the participants had experienced in their lives (research question 2) I added a dimension to the model 'relationships' and this is indicated in Table 11

The restorying process, therefore, involved considering the transcripts according to the different dimensions, filling in restorying tables (see Appendix 9) and then summarising stories for each participant to produce a restoried narrative.

Figure 6: The Three Dimensional Model revised from Clandinin and Connelly (2000)

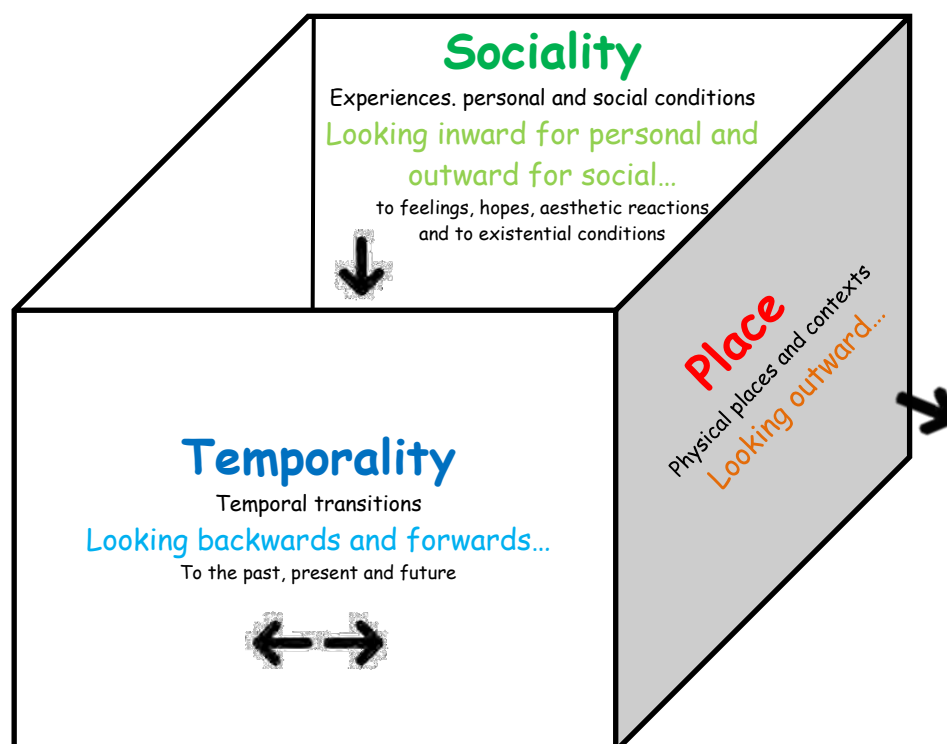


Table 11: Elements of the Three Dimensional Model (Clandinin and Connelly, 2000)

	Dimension of the Three Dimension model	Considering the transcript according to this dimension.	Relation to identity formation
Continuity (time)	Past	Consider and summarise experiences the individual has had in the past.	Past experiences which may have contributed to identity formation.
	Present	Consider and summarise the individual is experiencing currently.	Present experiences which may have contributed to identity formation.
	Future	Consider and summarise the experiences the individual may experiences in the future.	Commitments regarding the future (outcomes of identity formation)
	Settings/places	Consider and summarise physical locations the individual has experienced in their lives.	Settings identity formation takes place.
	Relationships	Consider and summarise the significant relationships the individual has experienced.	Contribution of significant relationships on identity formation.
Interaction	Personal	Consider and summarise the individual's feelings towards the experiences and relationships they have had in their lives.	The meaning an individual makes of his/her experiences.
	Social	Consider and summarise the interactions and involvement of other people in these experiences.	Social interaction and contribution on identity formation.

3.7.4 Identifying Narrative Tone

Although the restorying process was useful in restructuring the life story I required a supplementary procedure to further explore how the participants talked about their past, present and future to fully address research question 1. I triangulated the restorying process, therefore, with an analysis of narrative tone (Crossley, 2000). In section 3.5.4 *Rationale for Employing a Narrative Approach*, I

established that narrative tone was useful for considering how individuals with DS speak about their lives. Lyons and Coyle (2016) write that narrative tone is the most obvious feature of a personal narrative; it refers to both the content of the narrative and the way in which the story is told. Consequently, to analyse for narrative tone, I read through the transcripts whilst watching the life story films to get an impression of the tone of the participants and made notes in a narrative tone table documenting a description of the tone, the rationale and evidence (see Appendix 10).

3.7.5 The Narrative Thematic Analysis

Having restoried the transcripts and analysed them for tone, which elicited findings for research question one, I then undertook an inductive narrative thematic analysis (Crossley, 2000). The purpose of the thematic analysis was to explore the meaning of the key life experiences and significant relationships participants had encountered in their lives (Wertz et al., 2011) which formed part of research question two. To achieve this I followed the guidelines in Crossley (2000). The process involved working through the original transcripts in a systematic way and coding the script (see Appendix 8 for an example coded transcript). Instead of analysing the restructured narrative, I returned to the narratives in their original form as a means of maintaining the authentic voice of the participant during this inductive process (Reissmann, 2008)

Initially I was considering the transcript for imagery, which refers to the images respondents create through the language they use, for example the phrase 'behind my back' created an image of betrayal (Crossley, 2000). Imagery is thought to help reveal themes from the data and so I employed this element of analysis to support the development of themes and sub-themes. I also decided to employ

imagery rather than an analysis of the structure of the participants' language, as other narrative researchers have used, as it was likely that the language difficulties the respondents experienced may implicate the way in which they structured their language (Segal and Pesco, 2015).

Subsequently, using the initial images and codes, I developed the themes and sub-themes. Riessmann (1993) defines themes as the grouping of codes into a framework related to the research. I inferred a theme/sub-theme as a word, group or words or sentence which relates to something about the content of the data source. Firstly, I analysed the codes I had produced in terms of the key experiences and then significant relationships (identified through restorying) (see Appendix 8 for an example of the thematic analysis). I then produced theme maps for each experience and relationship, which related the themes and sub-themes together (see Appendix 11 for the narrative theme tables).

3.7.6 Themes and Identity Formation

The second empirical research question involves exploring the contribution of key life experiences and significant relationships to the formation of identity. Samra (2016) asserts that merely doing a thematic analysis for research which is interested in identity is not sufficient. This furnished me with another element of the thematic analysis process: to consider each experience/relationship in terms of its contribution to the individual's identity formation, mediated through the generation of themes and sub-themes. As I was considering the data in terms of identity formation this aspect of the data analysis process can be considered to be more deductive (Ritchie et al., 2014).

In order to achieve this process and to reduce bias, I employed the formulation of identity formation I had developed from existing theories and which is presented in the literature review (see Section 2.5.5 *Implications for this Study*). I then systematically worked through the thematic analysis tables and considered how each experience and relationship may have contributed to identity formation, considering the meaning of each experience/relationship provided by the themes and sub-themes. Following this I wrote comments regarding the contribution to identity formation alongside each theme map in the narrative thematic tables (see Appendix 11).

3.8 Reflexivity

Undertaking data collection and analysis is an active process which can be influenced by the researcher (King and Horrocks, 2010). 'Reflexivity' is the process where the researcher reflects upon the way in which his/her individual beliefs, interests and experiences may influence the research process (King and Horrocks, 2010). By being reflexive the transparency and sincerity of the research is thought to increase (Tracy, 2010). It was a necessity that I was reflexive as part of the research process to ensure that my own interests and beliefs did not overpower those of the participants (Grant et al., 2010). To be reflexive I endeavoured to engage in continual self-monitoring and reflection in a research journal (Grant et al., 2010).

Whilst reflecting I identified how prior experience of having a friendship with a person with DS may have positively shaped my approach as an interviewer during the data collection. When conducting a life history interview a researcher should adopt a warm and friendly persona (Atkinson, 1998). It may be presumed that due to my experience of befriending a person with DS that I would have been more inclined

to adopt a friendly persona with the respondents during the interview. In addition, having prior experience of DS may have ensured that I was more empathetic and knowledgeable regarding possible difficulties and provision I might need to make to ensure the participants could access the interview.

Furthermore, my friendship may have shaped how much control I gave to the participants during the study. In addition to societal exclusion, individuals with learning difficulties can face power imbalances during the research process and lack control under an authoritative researcher (Tarleton et al., 2004, p.75). Through perceiving my friend as my equal I wanted to ensure the respondents did not experience a power imbalance during our interactions. I aimed to achieve this through shaping my interviews as a conversation. I also monitored how the participants were finding the interview at several times during the process and checked the restoried transcripts during the session following data collection.

In addition to influencing the process of data collection the researcher also has the potential to influence data analysis and interpretation. During the analysis I acknowledged the assumptions derived from my own interest in DS and the conclusions drawn from the literature review (Murray, 2015). My assumptions came as a consequence of observations of those with DS being treated differently to those with non-specific learning disabilities. When reflecting on this I hypothesised that the physical characteristics that those with DS share may be influencing how individuals interacted with them and I was intrigued by what influence this could have on identity formation.

Implicitly, I may have been looking for negative experiences which may have negativity affected identity formation like those I had previously observed. To overcome any bias which may result from this prior assumption, I attempted to adopt

a neutral stance when analysing my data, being initially inductive. Consequently I analysed the data to identify what themes emerged rather than working from a top down approach (Gubrium and Holstein, 2001). This provides the rationale for the initial inductive thematic analysis, where I explored the meaning the participants made of their experiences and relationships rather than inferring that they may be negative due to my past experiences. As the analysis for identity formation was more deductive, I attempted to overcome any bias by developing a formulation of identity formation derived from established theory, on which to base it.

3.9 Decisions and Dilemmas

Throughout the process of data collection and analysis I faced several dilemmas that I had to consider carefully. The following section outlines three examples of such dilemmas and the decisions I made regarding each are outlined below.

3.9.1 Establishing Narrative Tone

Firstly, the narrative tone analysis was completely dependent on my subjective interpretation, creating the challenge of how best to reduce risks of personal bias. In an attempt to contain such risks, I developed a systematic process for eliciting the narrative tone of each interview (Crossley, 2000). This involved watching and re-watching the videos, reading and re-reading the transcripts, making notes and providing evidence for why I had made a claim in my interpretation of a participant's tone. Through this process the tone for each phase of each participant's narrative evolved, changing over time suggesting that the interpretation was not biased by my initial impressions.

3.9.2 Parental Considerations

From conducting the research, typically in each participant's home, I was able to meet different members of Tommy's, Antony's, Mike's and Emma's families. Moreover, I worked closely with each participant's parents when organising the logistics of data collection. As I was only eliciting the young people's voices in this work, my second dilemma was that I wanted to illustrate the true voice of the young person, including any negative experiences they may share with me. However, this presented the dilemma that a parent might find some of the negative findings distressing and difficult to read about. I had to weigh carefully the balance to be drawn between maintaining the authenticity of the participants' stories, whilst respecting and showing sensitivity toward their parents' feelings, in my reporting the participants' accounts.

Through careful consideration I decided that as the participants were adults with the mental capacity to give informed consent to take part in this project, I needed to provide an accurate reflection of the stories they shared and to include more negative or challenging findings. A poignant moment during one of the rapport-building sessions led me to make this decision. When I asked the participant an exemplar question he turned to his mother and said "Mum" and she said "you are an adult now, say what you want to say". This moment made me reflect that to respect the integrity of the participants and to avoid any well-intentioned censorship of their stories should be my primary objective in this project.

Initially I was not sure of what the findings may reveal and how challenging the findings would be for the parents to read. To be respectful I consider it important to take a moment to emphasise here that from my time spent with the participants' families I believe that each young person had a caring, supportive and loving family.

Moreover, my impression was that the parents with whom I worked closely strove to do their best to provide the young people who had vulnerabilities associated with DS with positive life experiences. Moreover, I considered that the young people appeared to lead positive and happy lives. From this I judged that the parents' care and commitment would act as a 'buffer' against any distress evoked by learning of adversities in the participants' past lives or any disappointment they shared regarding their present and future aspirations.

3.9.3 Personal Values and Judgement

A final dilemma arose in relation to the final research question (What is the implication of identity formation on the future life trajectory for school-leavers with DS?). This question sought to explore the participants' aspirations and how their identity development to date may have contributed to their future plans. This process involved my judgements as to whether I considered aspirations to be achievable within the current sociocultural context. I faced a dilemma here in that mediating the risk that I assimilated cultural beliefs that what is possible for adults with learning difficulties and/or disabilities is 'less than' what can be achieved by their non-disabled peers. From this I considered my language usage carefully and in an attempt to overcome this, instead of describing the aspirations as 'unachievable' I employed a developmental perspective and the term used by Cunningham and Glenn (2004) in their study which was 'developmentally immature'. The challenges with using this inherently norm-referenced term are discussed in *section 6.2.1 Theory Development*.

3.10 Evaluation

When considering how the study can be evaluated, typically, research is judged to be credible according to validity and reliability criteria (Elliott, 2005). Reliability refers to how replicable the findings are and validity refers to the ability to the researcher to measure the concept of interest (Elliott, 2005). Reliable and valid studies are considered to be more generalizable (Elliott, 2005). For narrative research studies one of the primary concerns is that due to the data being subjective the analysis may not be reliable, valid or generalizable (Bold, 2012). However, my intention was never to generalise but rather to illuminate and raise theoretical awareness in this area (Thomas, 2013). Moreover, the findings may still be considered valid in that they are purposeful in one context which is similar to other contexts (Bold, 2012). Furthermore, I employed measures through the data collection and analysis to address the potential criticisms of this research which are illustrated in Table 12.

Table 12: Measures to Address Potential Criticisms of the Research (Tracy, 2010)

Criteria	What does this mean?	How I addressed this...
Worthy topic	The research topic is relevant, timely, significant and interesting.	• Research sparked from debates around DS following the introduction of the NIPT; • Research around what they think about themselves in relation to screening procedures • SEN code of practice which has intended to raise aspirations of school-leavers with DS.
Rich rigour	• The researcher elicits data to support claims • The researcher spends time collecting data • The sample is appropriate for the	• Narrative studies use small samples of participants; I undertook four interviews; • Participants all met the inclusion criteria for the study; • Transparent methodology and data

	aims of the study • The researcher employs appropriate data collection and analysis measures.	analysis procedures; • Clear rationale for choice of methods and data analysis procedures; • I adapted interview from an established method (Atkinson, 1998); • Analysis procedures were adapted from known methods and grounded in a substantive literature review (Crossley, 2000; Clandinin and Connelly 2000)
Sincerity	• The researcher is self-reflexive on her strengths and limitations. • The researcher is transparent about the research process.	• Epistemological position has been established (see section 3.3 <i>Philosophical Underpinnings</i>) • I have been reflexive (see section 3.8). • Transparent and detailed write up. • The research process is stated clearly.
Credibility	This refers to the trustworthiness of the research.	• I employed multiple methods of data analysis. • The participants were able to check and make changes to their narratives in the final session.
Resonance	The researcher's ability to communicate findings to an audience.	• High quality of presentation; • Research findings may be transferable to other contexts.
Significant contribution	The research is theoretically, heuristically and methodologically significant	• See Chapter 4 and 5.
Ethical	The study is ethical	• See Ethical Considerations section 3.4
Meaningful coherence	The study achieved its stated purpose and use established methods.	• Achieved aims of eliciting narratives • Methods are adapted from established methods (Atkinson, 1998; Lewis, 2004).

3.11 Summary

The present research adopted a retrospective multiple case study design. It used a narrative approach to elicit stories from respondents which were then analysed to reveal how school-leavers with DS spoke about their lives, the contribution of key life experiences and significant relationships on the formation of their identity and what

implications this identity may have on their future life trajectories. Restorying, narrative tone analysis and narrative thematic analyses were employed as the data analysis procedures. The following section illustrates the findings and discussion.

CHAPTER FOUR: HOW DO SCHOOL-LEAVERS WITH DOWN SYNDROME TALK ABOUT THEIR PAST, PRESENT AND FUTURE LIVES?

4.1 Chapter Overview

The following chapter presents and discusses findings for the first empirical research question: How do school-leavers with Down syndrome talk about their past, present and future lives? Obtained through the restorying procedure, a summary of each restoried narrative is provided (see Appendix 9 for restorying tables and Appendix 10 for narrative tone tables). Subsequently, I discuss how each participant talks about their lives with reference to the narrative tone analysis and literature.

4.2 Tommy

Table 13: Tommy's Restored Life Story Interview

Phase	Restored Life Story Interview according to each phase
Past	- Tommy was born into a family, which consisted of his mother, father, and older sister. His mother looked after him as a baby; she made sure he was dressed and clean. As a child Tommy enjoyed dressing up and pretending to be different characters, including spider man and a dinosaur. For his 6th birthday party Tommy dressed up as Tigger from 'Winnie the Pooh' and his friends thought he was really cool. - As well as dressing up, Tommy loved playing with his friends when he was a young boy and would often go to his friends' houses to play football, board games, like monopoly, or go on the trampoline. At school Tommy's favourite experience was when he walked with his friend to take his class register to the reception office. He also liked doing arts and crafts at school where he was able to use paints and different colours to make pictures. - As a teenager Tommy has enjoyed many holidays with his mother and father, like the time he went to Lake District and enjoyed eating fish and chips. When Tommy went to Italy he saw many statues and enjoyed the local cuisine: pizza. Whilst on a cruise Tommy attempted to put together a gingerbread house; it was really difficult at first, but he achieved it and enjoyed eating it after! - Tommy also had a special holiday to watch his older sister get married. His mother asked him to do an important job during the ceremony which was to be a ring bearer and carry the ring up the aisle to his sister on a white cushion. Tommy was very pleased to be asked and excited to do this job for his special sister. After the ceremony Tommy got to dance at the disco to Queen, dancing is something he loves.
Present	- Currently, at 19 years old, Tommy is studying food preparation at a residential college. He has enjoyed going to college, he has developed friendships and loves his bedroom there. Tommy does not have help at college but his mother and father continue to care for him at home by helping him to complete his morning routines. - Tommy continues to enjoy dressing up as different characters and dancing at discos. He has passion for dance and has attempted and accomplished learning dance moves including handstands, cartwheels and the splits. Tommy practises dance every day. When the music comes on and Tommy dances it gives him energy and makes him feel proud.
Future	In the future Tommy aspires to return to where his parents live. He would like to be employed to work in the kitchen of the local pub and live in a house with his friends. He would also like to continue learning about performing arts and drama and possibly commence another college course.

4.2.1 How does Tommy Speak about his Past, Present and Future Life?

Past

Through analysing Tommy's narrative I concluded that, like the majority of participants in Skotko, Levine and Goldstein (2011) he spoke with overall positivity.

He requested that all negative questions be omitted from the interview schedule prior to filming take place. From this, it is conceivable that either Tommy had not faced adversity or he was hiding any negativity from me in order to maintain a positive self-image (Glenn and Cunningham, 2004). Alternatively, due to the negative attitudes continuing to shape sociocultural acceptance of those with DS, it is possible that Tommy may have been protected from negative situations in his past life (Marini, Graf and Millington, 2018).

Although it is not clear which interpretation is accurate, any protection Tommy might have experienced, may have had a positive impact on his overall well-being and tone but it equally may have prevented his meaningful inclusion in society (Shakespeare, 2006). This shows how although inclusion is the ultimate aim for improving outcomes for those with 'disabilities', it can be challenging to achieve (Alderson, 2001)

Inclusion is often associated with empowerment (Cuskelly, Jobling and Buckley, 2002). Tommy shared narratives from times he had felt empowered in his past life, for example, being the ring bearer at his sister's wedding (Cuskelly, Jobling and Buckley, 2002). Furthermore, I got the sense that Tommy believed he had accomplished goals in his life, for example learning to dance which may have made him feel empowered.

I: Tell me about the time you went there

T: It was very hot for my sister's wedding. I was a ring bearer.

I: How did you feel about that?

T: I was feeling excited

T: This is me on the sand doing handstands

I: When did you start doing handstands?

T: I learnt it in dance class

These experiences may have contributed to his positivity and may reflect how there are people within society who celebrate those with differences to foster wider positive attitudes (Cuskelly, Jobling and Buckley, 2008).

Present

In terms of his present life, Tommy was positive about attending a residential college where he was being trained in food preparation.

I: Where do you go to college now?

T: X College

I: Can you tell me about that?

T: Good, I like it there.

I: And why?

T: Because I love it I like lot of space, a better place for me and I like my room in the hotel I do food prep.

However, the tone of Tommy's present life narratives could appear conflicted at times. For example, there was a discrepancy between Tommy speaking about requiring support at home and stating that he did not have help at college.

I: Who is important in your life?

T: Mum and dad.

I: Why are they important in your life?

T: They support me doing hygiene routines and morning jobs as well.

I: And is there anything you find more difficult at X college?

T: Cleaning

I: Does anyone help you at X college?

T: No.

This discrepancy may be interpreted in different ways. Perhaps Tommy attends a college which encourages autonomy and independence (Atherton and Crickmore, 2011). The tone in which Tommy dismissed this idea, however, suggested that he was denying the possibility of needing help at college. Such denial may well be related to him maintaining a positive self-image and intended to present an image of him as a competent and autonomous young person (Goffman, 1990).

Future

Although the transitions have been identified as a potentially worrying and stressful period for young adults with DS, Tommy spoke optimistically regarding his plans for when he leaves residential college (Ryan and Deci, 2017). These plans reflect the aspirations of policy makers and include: to become employed, live partially independently and further his education (Department for Education, 2015).

I: Thinking about the future, what would you like to do?

T: I like a house with my friends um I like to work Weatherspoon in X doing food service, serving guests and my course at X college performing arts, crafts acting and drama course.

It is not clear from Tommy's narrative whether these aspirations are person-centred or whether they have been given to him (Atherton and Crickmore, 2011). However, as Tommy presented with positivity when speaking about his aspirations it may be interpreted that he is satisfied with his future life trajectory.

Additional Information

The overall tone of Tommy's interview was restrained and concerned, in that he waited for a question to be asked after which he would offer a single word answer. Initially I wondered if Tommy had found the interview difficult due to problems with receptive understanding (Laws, Byrne and Buckley, 2000). However, as the interview progressed his tone became pensive. Perhaps as previous literature has indicated, Tommy may have had others speak for him in the past and so has had limited experiences of being asked to share his perspectives; this may have contributed to his concerned tone (Skotko, Levine and Godstein, 2011).

4.3 Mike

Table 14: Mike's Restoried Life Story Interview

Phase	Restoried Life Story Interview according to each phase of life
Past	- As a young child Mike found it difficult to learn to walk, so had special shoes to help him. His mother looked after him and made sure he ate and drank enough. Mike had a lot of fun with his father and brother. They would often tease each other and Mike loved this: he found it hilarious when his brother rode his tricycle and fell into the bush! - As a young child Mike went to primary school and developed relationships with both the staff and other pupils. Mike liked the teachers and other children because they looked after him. He also played with them, like the time they told him to hide in a dust bin during a game of hide and seek and all the teachers were worried. Mike enjoyed primary school. He had lots of experiences and opportunities to learn new skills like English, maths, African dancing and fishing. When he left the school he did a dance and everyone stood up and clapped. He thought they were cheering him because he has Down syndrome. - Outside school Mike went to Beavers and Cubs and enjoyed all the experiences he had there like watching a fireworks display, singing silly songs and eating sausages. One of his best experiences was when he had to be brave and slide down a hill really fast. - After Mike left primary school he went to secondary school. He was given responsibilities in this school which he enjoyed, such as being in charge of putting the tables and chairs out and being in the school council. Whilst at secondary school Mike had to do work experience in a charity shop. He enjoyed walking independently to the shop and did lots of hard work whilst he was there, like polishing and sorting out dusty clothes. - Mike also attended a special needs charity group where he did lots of things like trips out, holidays and discos. As Mike helped other children in this group he was asked whether he wanted to support the others on an official basis by becoming a support worker. Mike has been recognised for his achievements many times in his past. He has received several cups and trophies, including one for 'best pupil'. - After Mike left secondary school he went away to a residential college. College was exciting as he got to do his own thing and stay up very late. Mike's achievements were recognised at residential college, where he was awarded the 'Independence Award'. He continued to help his friends at college, like the time his friend had a fit and called on Mike to help him. He developed many friendships and loved social occasions like the discos. - He also continued to do work experience whilst at college: he had opportunities to practise working in a shop and a café. Serving customers could be stressful and hard work at times but Mike enjoyed it. After leaving residential college Mike continued to develop his skills in catering by attending a new college. He also went on holiday to visit his favourite animal, the elephant.
Present	Mike is currently employed and works in a shop. He loves working and embraces the new challenge. Mike felt really proud when he got a job and enjoys spending his wages on his girlfriend. Mike has a support worker who helps him to learn the skills he will need to become more independent.
Future	In the future Mike hopes to live in his own house with his girlfriend. He is a bit nervous that this won't happen, but hopes to be independent. He recognises that his parents will miss him and may be sad when he moves out, but this is something he wants to do.

4.3.1 How does Mike speak about his past, present and future life?

Past

Mike's narrative demonstrated that he was able to reflect thoughtfully upon past lived experiences, thereby challenging the assertions of some researchers regarding the cognitive limitations of young people with DS (Selikowitz, 2008). For example, he explained the audience's reaction to a dance performance as motivated by respect for his DS rather than in response to the quality of the performance.

M: Yeah well it was interesting doing dancing it is good fun and ye again I am very happy.

I: When you did the dance what happened after?

M: I can't remember, at the end of the dance everybody stand up, since I have Down syndrome, and everyone stand one and someone shout one more one more one more dance, and I did some more dance and everyone cheered and clapped.

This experience also reflects how there are groups within society who seek to celebrate those with differences (Cuskelly, Jobling and Buckley, 2002). This celebration was a positive experience for Mike and may have been intended to encourage his inclusion. However, by explaining it in terms of DS, it could be interpreted as demeaning. Instead of being treated as an equal, it appeared that Mike was being celebrated for his 'differences'. Mike experienced many occasions during his past life where he was the subject of celebration, such as receiving many awards. Once more these incidences may be perceived as positive (Cuskelly, Jobling and Buckley, 2002).

I: Do you remember what the award was for?

M: I think it was swimming, I can't remember I have too many cups.

However, Mike spoke with indifference when talking about this particular award. This may reflect how, as a consequence of excessive celebration, these episodes have become somewhat meaningless. Perhaps the authenticity of celebrating those with DS can be lost if excessive (Cuskelly, Jobling and Buckley, 2002).

Mike was explicit about DS and used it to give meaning to his lived experiences (Dunn, 2016). Although he acknowledged the physical restrictions associated with DS, such as difficulties with learning to walk, he was joyful and upbeat. This may be because Mike viewed DS positively and not with any reference to societal adversity. It is conceivable that he has developed a 'disability identity' or may have been protected from any negativity (Marini, Graf and Millington, 2018).

Present

Another aspect of Mike's positivity was his sense of pride. He viewed securing employment as a culmination of his past successes and he talked about his enjoyable participation in social groups.

I: Can you tell me about other things you do for fun now, now you are 25?

M: Oh lots of things for fun. Having fun with my girlfriend of course um especially having fun at X (special needs group), last weekend just gone we have market stalls, you can have the moneys and you can have the change, like jewellery and making stuff to raise moneys and then all the Christmas serving.

Currently Mike has achieved the goals set out by educational policy as he has secured employment (Department for Education, 2015). Furthermore, he is having meaningful participation in the community and his circumstances illustrate the optimal conditions set out in Scott et al. (2014) for what makes a 'good life' as a person with DS. It is likely, therefore, that Mike's present circumstances may be positively contributing to his overall well-being and positive tone (Skotko, Levine and Goldstein, 2011).

Future

For his future life, Mike has aspirations to live independently. He demonstrated pride when speaking about this but also pragmatism when reflecting on the physical challenges of living alone (Buckley and Sacks, 2002)

M: I just worry about the panel, before I move house I worry about the money, settle in and stuff, whether it will come through, I am settled now so I don't worry about that.

Mike's future ambition may be considered positive in how it shows that a young person with DS is motivated to live independently (Department for Education, 2015). However, his caution when speaking about the future may reflect that there are continued challenges associated with the transition to independent living which may be a product of Mike previously relying on others for support (Buckley and Sacks, 2002).

4.4 Antony

Table 15: Antony's Restoried Life Story Interview

Phase	Restoried Life Story Interview according to each phase of life
Past	- Antony was born into a family which consisted of his mother, his father, and his sister. He spent the first few years of his life living outside of England. During this time he liked to look after his pet chickens. He also copied his sister and took up gymnastics and Irish dancing. With his family's support he enjoyed learning these new skills and performing. - It was a sad and emotional time for Antony when his parents decided to separate and he moved back to England with his mother, leaving his father. Antony found it very difficult not living with his father but viewed the move back to England as a positive opportunity to better his education and to look after his grandmother following his grandfather's death. - Antony had both positive and negative experiences whilst in mainstream school. He enjoyed the relationships he built with his teachers who looked after him and helped him when he needed it. He also had opportunities to pursue his interests in music and art, inspired by his parents. Antony particularly enjoyed times in school when he got positive reactions from his peers, such as when he pretended to be a dog and his classmates stroked him and called him a 'good boy'. - He did not enjoy times when he was bullied by his peers as this made him feel hurt inside. Antony experienced some negative times at school where other pupils pushed him and made him bleed. He also behaved at times in a way which made him seem like a troublemaker, for example, when he entered the principal's office and spoke on the microphone or when he used inappropriate language. The teachers were not impressed with Antony on these occasions and he got into trouble, which he believes he deserved. Antony also got into trouble at special school too because he copied some other young people and said a swear word. - Outside school Antony enjoyed and continues to enjoy acting and performing in plays. As a teenager he played Romeo in 'Romeo and Juliet', and a 'jock' in 'High School Musical'. Antony was so pleased to be acting in 'High School Musical', as his role model Zac Efron had played a starring role in the film. Antony likes Zac Efron because he believes he is cool and good looking.
Present	Presently, at age 19, Antony likes being grown up and able to do adult things such as drinking cider. Antony does miss his childhood years and especially living with his father in Australia. He recently made the transition from secondary school to residential college and found this challenging. Antony experienced a conflict between wanting to stay with his mother at home and going off to live his own life. He wanted to go away and get qualifications because that is what his sister had done, but going to college made him feel scared and nervous.
Future	Following the death of his grandfather Antony has become the man of the house. In the future he wants to get a job so he is able to look after his mother and grandmother. He aspires to work in Asda, where he completed some work experience. Antony also wants to be just like his father.

4.4.1 How does Antony speak about his past, present and future life?

Past

Although Antony spoke about a number of positive life experiences, I judged that he spoke with sadness when referring to his time in mainstream school, particularly when describing occasions when he had been socially rejected and bullied by his peers.

A: Being bullied isn't fun.

I: What happened?

A: Somebody pushed me and then I was bleeding.

It is not clear if this incident reflects literature which has concluded that those with DS can be rejected in mainstream schools due to characteristics of disability (Schwab, Huber and Gebhardt, 2016). However, Antony's struggles represent the challenges a young person with DS can experience in mainstream education and how efforts for inclusion can ultimately result in segregation (Frederickson and Cline, 2009).

When sharing his past narratives, Antony was both sentimental and nostalgic. He seemed to be mourning the separation from his father following his parents' divorce. At times he could appear conflicted and ambivalent regarding this experience. He did not want to lose his father but felt a sense of duty to move away and care for his grandmother.

A: Sad, leaving my dad it was a really really hard choice to leave my dad (sad facial expression)

I: What do you think about being here in England?

A: Good because my grandpa passed away and I couldn't leave my grandma, she couldn't be on her own, that's why at the time we had to stay.

Divorce causes disruption in a family and is an experience which can affect children long into their future (Watson and Skinner, 2004; Everett, 2013). Perhaps this disruption may have caused Antony to experience a state of disequilibrium which is

reflected in his conflicted narratives. Conflict was also evident in how Antony spoke about wanting to be a “good boy” but yet participated in more challenging acts of behaviour whilst in school.

A: Sometimes I am a bit of a troublemaker.

A: Sometimes I am a good boy.

A: I was in trouble all the time. I said the f word (says with sadness).

I: Do you remember why you used to say that word?

A: Because I hear other people say it.

It is conceivable that experiences of segregation may have contributed to Antony engaging in this undesirable behaviour. By copying peers Antony may have gained their social approval. Perhaps these acts were Antony attempts to feel more included in a mainstream environment (Frederickson and Cline, 2009).

Present

Currently, Antony speaks with happiness when talking about participating in adult activities, such as drinking cider. However, he spoke with anxiety when considering the prospect of growing up and moving away from childhood sources of enjoyment. Antony’s recent transition from school marked a period of apprehension for him and he spoke with unease about his current attendance at residential college.

A: This is my first time being in college and I feel kind of nervous, scared

Perhaps Antony shows here how transition from secondary school can be a challenging life event for young people with DS, as was the case for the participants in Skotko, Levine and Goldstein’s study (2011). Alternatively, Antony may be experiencing fear as he has based expectations of the college on his previous segregating experiences in school and has moved away from his family who provide him a sense of security (Frederickson and Cline, 2009).

Future

When speaking about his future Antony shared his aspirations to be employed but also to be like significant others including, his mother, father and his role model (an actor).

A: Yes I did I worked at Asda because I really really want to get a job when I am older, so that I can look after mum and my Grandma.

A: I want to become an actor one day

A: Because I want to be like my dad, or be myself maybe mum

As educational policy intended Antony has a goal of future employment (Department for Education, 2015). When he speaks about this, he does with pragmatism and he clearly has a realistic trajectory for his future vocational aspirations (Down's Syndrome Association, 2011). His other aspiration, to become an actor reflects how he has identified with and imitated a role model in his life. This will be discussed in more detail in Chapter Five.

4.5 Emma

Table 16: Emma's Restoried Life Story Interview

Phase	Restoried Life Story Interview according to each phase of life
Past	• Emma was born into a family which consists of her mother, father, brother and her sister. Emma doesn't remember times from when she was a young child. • She does remember the time when she went to mainstream primary school. When Emma started school she really wanted to make friends, but this was difficult for her as the other children used to leave her alone at lunch. She moved schools and was much happier at her new mainstream school because she made friends there. • Emma enjoyed learning at school, particularly about homosexuality in RE lessons and doing experiments in Science. One of her favourite times was when she got to play Juliet in 'Romeo and Juliet' during an English lesson, and the experience was magical. • After finishing school Emma spent some time doing a foundation course at a college but didn't like the course because she felt as though she didn't learn anything and was treated like an infant. The other people on the course, who had disabilities, were not what she expected and she didn't like them. • After that experience Emma has learnt lots of new skills, including pole dancing. She also did a nail art course where she was trained in how to paint nails. She practised a lot on her mother, but found this difficult as her mother complained to her about the colours she chose. • Emma has always enjoyed spending time with her friends. When she was 17 she invited them over to her house for a brunch. When she opened the fridge to get some alcohol, her friends said to her mum, "Is she allowed to do that?" and her mum replied, "Yes, she is 17", so she drank the alcohol. • A couple of years ago Emma became an auntie as her older sister gave birth to a baby. Emma had always had a positive relationship with her sister as she had always "been there for her". The sibling relationship changed when Emma's nephew was born. Emma felt betrayed that she did not know her sister was pregnant and felt her sister could be mean to her mum. She wanted the relationship to go back to the way it was before the baby was born.
Present	• At 19 Emma enjoys going to nightclubs with her friends. She has a passion for make-up and fashion and so views going to a night club as an opportunity to 'make a statement' and 'look the part'. Her role model is Jessie J. Like Emma, this singer has an interest in fashion and make-up and has an individual style. Emma values her talent with music and how she has travelled to different places whilst on tour. • Travel is important to Emma and she has had many opportunities to travel by going on holidays with her family in the past to different countries, including Turkey and Singapore. Emma desires to travel and see the world; this is something she wants to continue doing in the future. • Emma currently has a passion for photography. Her father helped her to pursue this interest by buying her a red camera for Christmas. With support from a tutor, Emma visits different places like the parks around her local area to take photographs. Emma demonstrates confidence and considers herself to be very capable at taking photographs. Her pictures have been displayed in a photography exhibition. At almost 20, she feels ecstatic about entering adulthood, and boys have become really important in her life.
Future	• Emma would like to continue her passion for photography by aspiring to be a photographer. She would also like to be a catwalk model in the future.

4.5.1 How does Emma speak about her past, present and future life?

Past

Emma did not share many narratives from her past. She may have had difficulty with recalling experiences. However, it would appear Emma was monitoring our interaction during the interview: for example, she chose to use the pronoun 'she' rather than 'I' when talking about herself. Perhaps, in addition to self-monitoring, Emma may have censored the image she presented of her life and as a result chose not to focus on her past (Goffman, 1990)

The past experiences that Emma did share revealed that she too had experienced social rejection in a mainstream school, like those in Alderson's study (2001).

E: I was really not happy at X school in X and I really didn't like it there. And I didn't make some new friends they left me alone at lunch and at break and we didn't go to the canteen because we ate lunch at the class.

It is not clear what this experience can be attributed to and whether it echoes previous research which suggests that characteristics of disability may be responsible for rejection (Schwab, Huber and Gebhardt, 2016). However, Emma did not overtly attribute the rejection to DS. She dismissed any association with the term 'Down syndrome'.

E: I am not Down syndrome.

She also described time she had spent in a college where she had learnt alongside other young people with 'disabilities' and found this to be a negative and alienating experience.

E: Well I went to, I have been to college but I didn't learn anything in Maths we do games I did CBeebies and it feels like being a going to infant school and being acting like babies and um and I didn't like the foundation people

I: Why didn't you like them?

E: I think there are not the type of people I've been expected.

This past experience would appear to demonstrate that Emma views DS negatively. It is not clear why Emma has this perception, perhaps it is due to her experiences of social rejection. Alternatively it may be a result of her awareness of negative sociocultural discourse arising from DS, from which she wanted to disassociate herself (Haegele and Hodge, 2016; Schwab, Huber and Gebhardt, 2016; Barter et al., 2017).

Despite the more negative experiences she recounted, Emma was predominantly positive about her past. Although she had experienced adversity, similar to that described in Begley (1999), she demonstrated confidence when speaking about her competencies in mainstream school. This may represent the benefit that mainstream education had for Emma in facilitating her skills (Buckley et al., 2006)

(Of herself) E: She is really clever and she is really good at focus"

Although Emma spoke about her competence she demonstrated ambivalence when speaking about her past experiences with friends who had questioned her ability to make an autonomous decision.

E: Okay (laughs) that was really years ago I was about 17 and um mum made up really good brunch with all my friends coming over and um when my friends are there and she opens the fridge and my own friends just said to mum is she allowed that and um my mum yes and um yes she's 17.

Emma's friends have reflected here how people have previously held low expectations of young people with DS (Bhattacharya and Sidebotham, 2000). It may also reflect the conflict between the effort to raise the expectations of young people with DS to be autonomous and the challenges to this; namely how such young people's abilities may be underestimated and how as a consequence they may be

denied opportunities for autonomy to protect them from potential harm (Bhattacharya and Sidebotham, 2000; Department of Education, 2015).

Present

Emma continued to overlook DS as being part of her present life. Moreover, image appeared to have been an important concept for her; she spoke about how she sought to create a positive image when going to nightclubs.

E: She is really into fashion and beauty because she's want to look the part and make a statement put slap on ye she's been to a nightclub so when I go out to show my assets, she's got a cleavage.

It is conceivable that Emma wanted to maintain a positive self-image and continues to deny any form of disability as a means of portraying a 'normalised' image to her peers (Goffman, 1990). Furthermore, it reflects how Emma judges her self based on her physical appearance rather than on her inner qualities (Shaffer, 2009).

Emma spoke with vibrancy and passion when speaking about her present interests. She also appeared to be boastful about her abilities in fashion, make-up, pole dancing, nail art and her current "passion" for photography.

E: She is really capable at taking photographs

Such confidence and competence may reveal that Emma has high self-esteem (Begely, 1999). Perhaps experiences where she has received validation may have contributed to this high self-esteem and this implies that she is satisfied with her present life (Scott et al., 2014).

Future

Emma spoke with enthusiasm about her plans to become a photographer and catwalk model in the future. Due to the passion she spoke with I judged her to be committed to achieving these goals.

E: Photos are my thing and I really is my passion and she loves taking photos” (Emma’s tone of voice changed when expressing her passion for photography, she appeared to move from conversational to more serious)

*E: I want to be a photographer and I want to be a model on someday
I: What would you like to model?*

E: Catwalks

Like those in Glenn and Cunningham (2004) Emma’s aspiration to become a catwalk model may appear ‘developmentally immature’. However, unlike those in this research her aspirations are related to her key interests and sources of satisfaction in her life, photography, fashion and make-up. It may be concluded from this that Emma has engaged with a person-centred process where her wishes are positioned at the centre of decision making (Byrnes, 2012).

4.6 Research Question 1 Summary

This chapter has addressed: How do school-leavers with DS speak about their past, present and future lives. To summarise, participants did speak with positivity and this was derived from different experiences such as winning awards (Mike), developing passions (Emma), spending time with friends (Tommy) and family (Antony).

However, the narratives have also revealed that although there has been an effort to improve the inclusion of young people with DS in mainstream schools, it would appear that by listening to Antony and Emma speak about school that this can be problematic. Furthermore, Mike illustrated how the efforts to empower those with disabilities, by celebrating their achievements can lose authenticity if excessive.

Although Antony and Mike referred to DS, they did not refer to any negative sociocultural discourse. Perhaps this may reflect how discourse around DS may be

more positive than previously reflected or perhaps these individuals have been protected from adversity. I have discussed how, although protection may have positive consequences for the way in which young people speak about their lives, it is a factor which might ultimately prevent the equal participation of young people with DS in society.

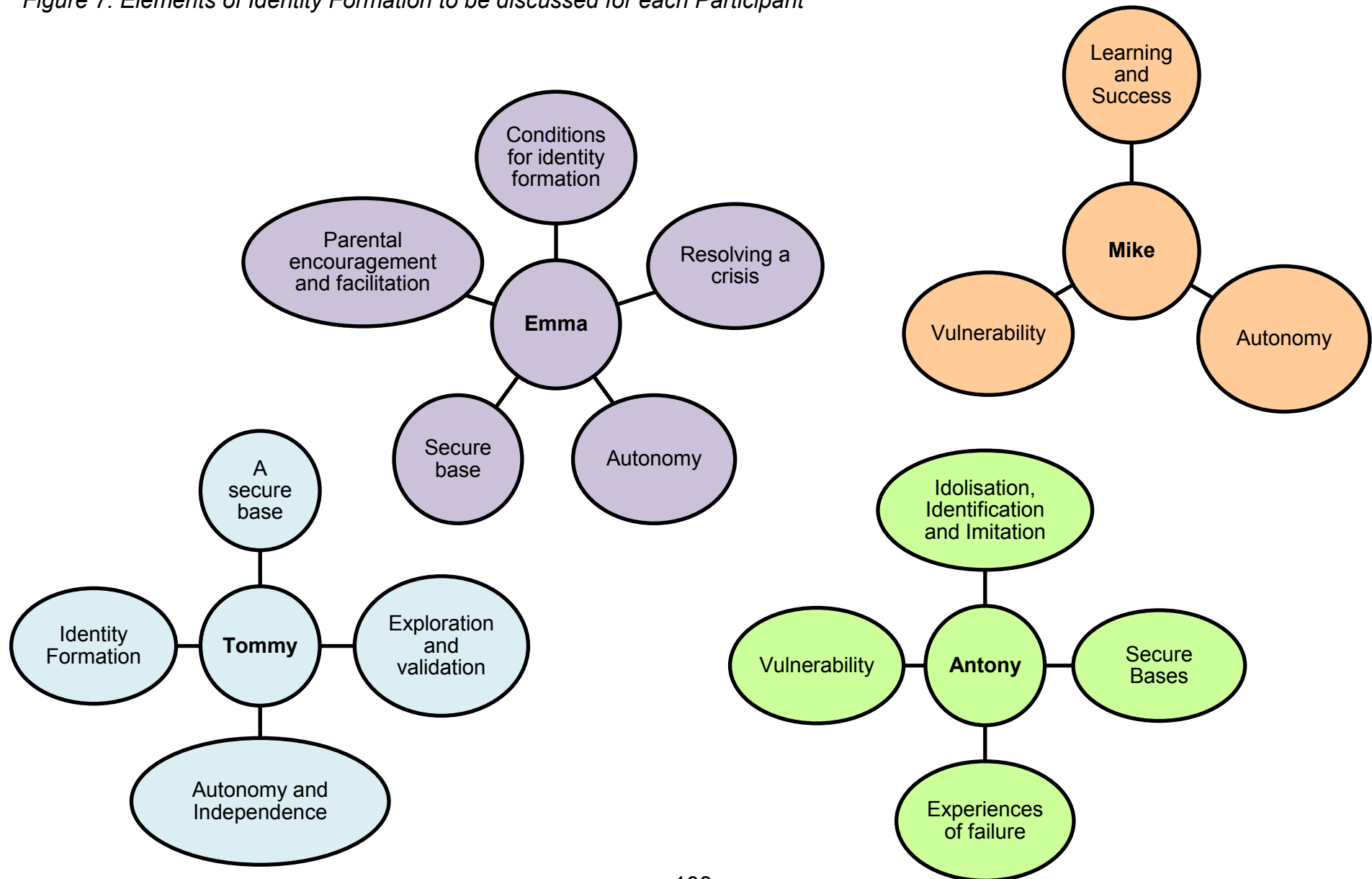
Finally this section has outlined the school-leavers' aspirations for their future lives. Ambitions varied from pragmatic goals (Tommy, Mike and Antony) to aspirations which may reflect 'developmental immaturity' (Emma). As established it is likely that the formation of identity may have directed these hopes for the future. The contribution of key experiences and significant relationships on the formation of identity is explored in the next chapter.

CHAPTER FIVE: THE FORMATION OF IDENTITY AND FUTURE LIFE TRAJECTORIES IN SCHOOL-LEAVERS WITH DOWN SYNDROME

5.1 Chapter Overview

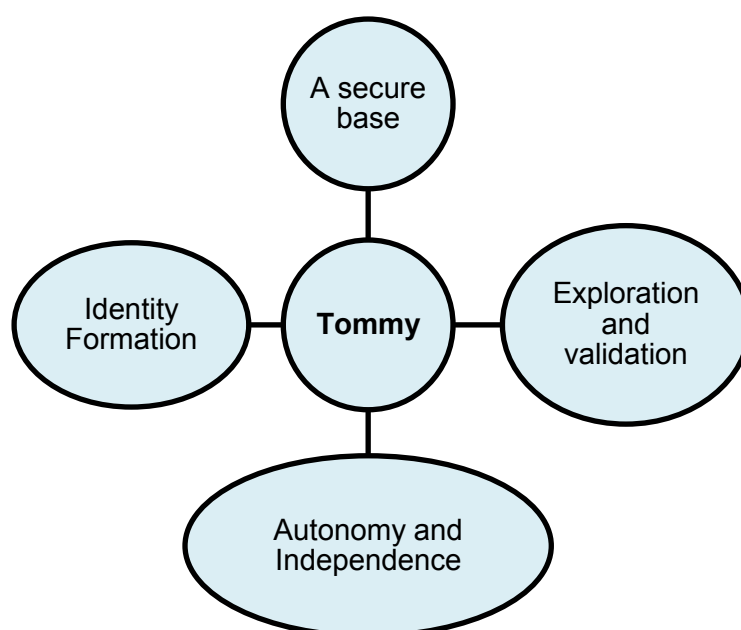
In this chapter I address the second empirical research question: What are the contributions of key life experiences and significant relationships on the formation of identity in school-leavers with DS? To ease reading, I initially provide a figure to illustrate the elements of identity formation that I will be discussing for each participant. I then discuss how these elements were derived, making reference to the narrative thematic analysis (for more information see Appendix 11). Following this, I provide a response to address the third research question: What is the implication of this identity formation on the future life trajectory for school-leavers with DS?

Figure 7: Elements of Identity Formation to be discussed for each Participant



5.2 Tommy

Figure 8: Elements of Identity Formation: Tommy



5.2.1 A Secure Base

The analysis would indicate that Tommy established stable relationships which may have acted as a secure base to provide support during the process of identity formation (Marcia, 1966; Underwood and Rosen, 2011). Moreover, he spoke about a range of experiences where he had explored his environment such as travelling to new countries which may have contributed positively to his development (Erikson, 1995)

Table 17: A Secure Base Themes and Quotes 1

Experience/relationship	Theme	Sub-theme	Illustrative Quote
Going on Holidays	Food	-	<i>I: Can you tell me about when you went to Italy?</i> <i>T: It was a good place</i> <i>I: What did you like about it?</i> <i>T: Food</i>
	Exploration	Active	<i>T: Walking with my parents, I saw a statue.</i>
Parents	Facilitation	Enjoyment	<i>I: Was there anything else you saw there?</i> <i>T: A flag, buildings.</i>

It would appear that Tommy's exploratory experiences have been facilitated for him by his parents. As a result, it is possible that Tommy may be at-risk for relying on his parents to try new things and consequently lacks independent exploration (Marini, Graf and Millington, 2018). Over-reliance on others has the potential to restrict an individual from exploring their own alternatives for who he/she is and who he/she wants to become (Marcia, 1966).

However, Tommy appears to follow a typical trajectory in that as he progresses through adolescence his friendships become more central in his life; this was illustrated in his experiences at residential college (Shaffer, 2009).

Table 18: A Secure Base: Themes and Quotes 2

Experience/relationship	Theme	Sub-theme	Illustrative Quote
Residential College	Friendships	-	<i>I: What are the people like?</i> <i>T: Good, I make friends at college.</i> <i>I: What do you like doing with your friends?</i> <i>T: Having a disco.</i>

College may have signified a challenging transition in Tommy's life, living away from his parents (Skotko, Levine and Goldstein, 2011). However, it appears that this experience was viewed positively due to the friendships he formed. These secure bonds may have provided Tommy with stability during an uncertain time (Underwood and Rosen, 2011). Friendships, therefore, may have made a positive contribution to his identity formation by providing him with stability to try new experiences (Underwood and Rosen, 2011).

5.2.3 Exploration and Validation

Tommy appeared to explore alternatives for his identity through dressing up during his childhood and adolescence.

Table 19: Exploration and Validation Themes and Quotes 1

Experience/relationship	Theme	Sub-theme	Illustrative Quote
Dressing up as Tigger for his 6th Birthday party	Dressing Up	Characterisation	<i>I: Can you tell me about your party?" T: This is me as Tigger.</i>
	Friendship	Social Validation	<i>I: What do other people say when you dress up? T: They say 'that's really cool.</i>
Friends	Shared interests	Social validation	<i>I: This is a letter from your school saying you performed in 'Grease the musical' can you tell me about this time? T: I was in, I was in, I was fixing a car.</i>
		Interaction	
Performing in 'Grease the Musical'	Pretending	-	

As his parents appeared to facilitate Tommy's exploration, dressing up may represent how he attempted to explore identity alternatives independently (Marcia, 1966). As an adolescent he dressed up as different characters and received social feedback from friends, for example, hearing that he is "cool". This feedback may have been evaluated, assimilated and/or accommodated into his identity (Grotevant, 1987).

There is also evidence that Tommy may have had exploratory opportunities whilst in educational settings. As Underwood and Rosen (2011) propose, these settings have afforded him opportunities for self-discovery and provided opportunities to explore new interests, including art, dance and food preparation.

Table 20: Exploration and Validation Themes and Quotes 2

Experience/relationship	Theme	Sub-theme	Illustrative Quote
School Experiences	Exploration of new skills	-	<i>T: I do arts and crafts. I: Can you tell me about that time, what kinds of things did you like doing? T: I like to make a tree house.</i>
Learning to dance	Performance	Achievement	<i>T: I always like to dance. I: How do you feel when you dance? T: I feel proud.</i>
Residential College	Learning new skills	Food	<i>T: I do food prep. I: What kinds of things do you have to prepare? T: I prepare puddings.</i>

Tommy felt successful when participating in these activities and success is an important contributing factor to increasing self-esteem (Grotevant, 1987). This self-esteem may have motivated Tommy to explore more new interests and so may have had a positive contribution to the process of identity formation (Grotevant, 1987).

5.2.4 Autonomy and Independence

In addition to exploration, experiences of autonomy are required for identity formation (Scott et al., 2014). Tommy may have felt autonomous during experiences where he was given responsibility.

Table 21: Autonomy and Independence Themes and Quotes

Experience/relationship	Theme	Sub-theme	Illustrative Quote
School Experiences	Responsibility	Pride	<i>I: What was your favourite thing to do at school? T: My favourite thing at school was going to reception; I was with my friend, taking the register.</i>
Being ring bearer at his sister's wedding	Responsibility	Pride	<i>T: It was very hot for my sister's wedding. I was a</i>

			<i>ring bearer</i> <i>I: Do you remember what you had to do?</i> <i>T: I carefully hold the ring give it to my special sister.</i>
Sister	Relationship	Responsibility Pride	<i>I: Do you remember how you felt when you were asked?</i> <i>T: I feel pleased.</i>

Although these autonomous experiences were positive and made Tommy feel proud, these experiences have been determined and potentially limited by other people (Marini, Graf and Millington, 2018). It is unclear as to why Tommy may have had restricted autonomy, one explanation is he was perceived to be vulnerable and so need protection and/or supervision (Marini, Graf and Millington, 2018).

5.2.5 Crisis

Perhaps the most autonomy Antony experienced was his transition to residential college. During this time it appeared that Antony may have experienced what theorists describe as a 'crisis' (Marcia, 1966; Erikson, 1968).

Table 22: Crisis Themes and Quotes 1

Experience/relationship	Theme	Sub-theme	Illustrative Quote
Residential college	Vulnerability	Support	<i>I: Is there anything you find more difficult at X college?</i> <i>T: Cleaning.</i> <i>I: Does anyone help you at college?</i> <i>T: No.</i>

With increased autonomy, Tommy may have questioned and evaluated previous conclusions that he was vulnerable and dependent on others for his care (Marcia, 1966). He spoke about not requiring help or did not demonstrate any awareness than he had help at college. It would appear that Tommy may not have resolved this

conflict, continuing to perceive himself as someone who requires parental support at home.

Table 23: Crisis Themes and Quotes 2

Experience/relationship	Theme	Sub-theme	Illustrative Quote
Parents (mother)	Practical support	-	<i>I: Who is important in your life?</i> <i>T: Mum and dad.</i> <i>I: Why are they important in your life?</i> <i>T: They support me doing hygiene routines and morning jobs as well.</i>

It may be proposed that Tommy is at-risk of being overly reliant on his parents by viewing himself as vulnerable and continuing to require their support (Scott et al., 2014; Barter et al., 2017). However, what is not clear from his narrative is why Tommy perceives himself this way, for instance has he had experiences where other people have perceived him as vulnerable which may have reinforced his view?

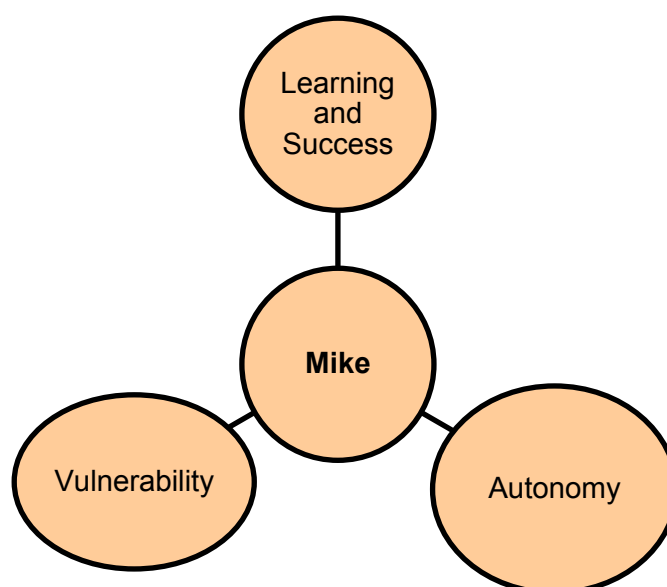
5.2.6 Identity Formation

Although the analysis indicated Tommy had experienced factors which may have contributed positively to his identity formation, a lack of autonomy may put him at-risk of relying on others to determine who he is and who he wants to become in the future (Marcia, 1966). When considering Tommy's goals for the future there is a lack of evidence in Tommy's narrative that he has explored alternative plans for his future before making a commitment.

It is conceivable that, when reflecting on previous exploratory experiences, that Tommy has been guided to make decisions regarding his future by significant others (Marcia, 1966). Existing literature suggests young people with DS can have difficulty with engaging in decision making processes and so require guidance from parents and educational professionals (Down's syndrome Association, 2011). The impact of this guidance on Tommy's future life trajectory will be addressed by research question 3.

5.3 Mike

Figure 9: Elements of Identity Formation: Mike



5.3.1 Learning and Success

It would appear that Mike has experienced factors imperative for healthy psychosocial development. In and out of education, for example, Mike has had the opportunity to learn new skills and to develop competence in several areas (Shaffer, 2009).

Table 24: Learning and Success Themes and Quotes 1

Experience/relationship	Theme	Sub-theme	Illustrative Quote
Experiences in primary school	Learning new skills	Competence	<i>M: We did some lessons like English, maths, science technology that's helped me to learn.</i>
Beavers and Cubs	Exploration	Bravery	<i>M: Sometimes we watch the fireworks display and we do remembrance day like marching to the church and marching back we do birthday celebrations, party stuff, ye quite good we went to pioneer centre years ago we did some silly songs and all that stuff.</i>
Special needs	Exploration	-	<i>M: Is called X (special needs charity)</i>

charity			<i>it is all about charity, we do lots of things, we do out and about trips, holidays you can stay the night, most of things like day trips, special events in the evenings like pubs and meals, sometimes a disco, it is quite really good because it gets busy.</i>
Catering college	Learning new skills	-	<i>I: Okay tell me about X college. What did you do there? M: I do catering and housekeeping.</i>
Activity weekend	Challenge	Bravery	<i>M: I am just like a monkey climbing, I was bit shaky, first when I start climbing, my hands get shakes, my legs get shakes because I am a bit nervous to climb but I just keep going, all the way to the top.</i>

By accessing a wide range of experiences, Mike may have been able explore alternatives for his identity and engage in self-discovery (Underwood and Rosen, 2011). From the transcripts it would appear that Mike's parents and teachers have enabled these opportunities and so may have directed what he subsequently explored (Scott et al., 2014).

Table 25: Learning and Success Themes and Quotes 2

Experience/relationship	Theme	Sub-theme	Illustrative Quote
Mother	Care	Enabling opportunities	<i>M: Mum took me in the car to the station.</i>

Although this direction is typical in childhood, Mike continues to rely on his parents to facilitate his involvement in activities at 25 years old (Marcia, 1966; Bjorklund and Blasi, 2012). Perhaps Mike reflects the literature here which suggests that young people with DS can have difficulty with making decisions for themselves and so require guidance and for significant others to enable their opportunities (Down's Syndrome Association, 2011).

Nevertheless, these opportunities have caused Mike to feel successful and productive; two factors Erikson (1995) deemed important for development. For example, whilst attending the special needs group Mike was recognised for being helpful and was asked to support other young people. Furthermore, as already established he has previously won several awards.

Table 26: Learning and Success Themes and Quotes 3

Experience/ relationship	Theme	Sub-theme	Illustrative Quote
Special needs charity	Vulnerability	Recognition	<i>M: I've got loads of friends in X and now because I am a good helper and stuff the X charity manager called X he runs all of X he told me I want you to help because lots of people need help, I've got the, he give me the X jumper because you were part of the people to help any help or activities always someone kicking, out in the mood or doing stuff inappropriately I in there sort everyone out.</i>
Winning the award for 'best pupil'	Validation	Being awarded	<i>I: Do you remember what you got this for? (pointing to an award) M:... being the best pupil, the whole lot. I: Why do you think you got that? What made you the best pupil? M:The best pupil like me. I: What was good about you? M: Making happy. I: How do you make people happy? M: Being helpful, helping everybody, got it in assembly, Mrs X, cup on the table, Mrs X handed the cups and say who's the best pupil here, who's the best friend in here its Mike. I: How did you feel when she read out your name? M:I thought oh my god what's Mrs X going to say about this (smiling) this is fantastic cup there, I went up, everyone was clapping, all my friends say come on Mike, come on Mike, go on Mike. I was happy after that, very proud of that cup. This is a very important cup, at college.</i>

These experiences may have made a positive contribution to identity formation. The validation he received may have been assimilated into his sense of identity (Grotevant, 1987). Furthermore, his sense of accomplishment may have contributed to feelings of competency, increasing his self-esteem and motivation to try new experiences (Grotevant, 1987).

Increased motivation may have encouraged Mike to secure employment. He viewed this experience with pride.

Table 27: Learning and Success Themes and Quotes 4

Experience/ relationship	Theme	Sub-theme	Illustrative Quote
Being employed	Autonomy	Achievement	<i>I: What did you want to do for a job do you remember?</i> <i>M: To get interviewed at the farm shop. The farm shop manager X and I talked to there and I took all my qualifications and show her I and said oh okay show how you do well and introduce to the farm shop staff and then you start work and so if you like it then you get paid every month.</i> <i>I: What do you think of your qualifications?</i> <i>M: I am really proud and everybody happy including my parents as well.</i>
		Pride	

As a result of Mike's diverse experiences it may be concluded that he has had adequate opportunities to explore alternatives for his identity before making commitments to his vocation (Marcia, 1966).

When asked about his success with employment, Mike made reference to making his parents "happy". This may indicate that Mike has stable relationships with his parents, important for identity formation but may also suggest some dependence (Marcia; 1966). If Mike was over-reliant on his parents this may put him at-risk of

relying on their guidance and foreclosing on commitments without a period of exploration (Marcia, 1966).

5.3.2 Autonomy

However, prior to committing to his vocation, it would appear Mike's time in special school and residential college provided him with opportunities to consider a range of vocational choices, through work experience in both retail and hospitality settings (Underwood and Rosen, 2011). These opportunities also enabled Mike to feel autonomous.

Table 28: Autonomy Themes and Quotes 1

Experience/relationship	Theme	Sub-theme	Illustrative Quote
Work experience in a shop	Autonomy	Independence	<i>I: Did you like your work experience? M: Yes very good, we walk independent...</i>
Work experience in a café	Learning new skills	-	<i>M: It is good really, it helped me to learn.</i>

Within Mike's narrative it would appear that these opportunities have been enabled by other people (Underwood and Rosen, 2011). There is no evidence of a 'crisis' in Mike's narrative, where he has questioned alternatives for his vocation before making a commitment to work in a shop (Marcia, 1966). It may be interpreted that Mike has relied on significant others to offer him opportunities to explore alternatives for his career (Scott et al., 2014).

He appears to be compliant: for example, when describing his experiences in school he recalled a time where he got into a dustbin because someone had told him to.

Table 29: Autonomy Themes and Quotes 2

Experience/ relationship	Theme	Sub-theme	Illustrative Quote
Experiences in primary school	Learning new skills	Compliance	<i>M: Someone tell me you can hide in the dust bin and say you can fit in... okay I will go in the bin, my friends put the lid down, all the staff were worried, didn't know where I am, I didn't hear the bell go, party group all keep searching around, and found me by the bin.</i> <i>M: My friends starting laugh so I started laugh.</i>

Compliance may have had a negative contribution on identity formation. For example, he may resist autonomy in favour of complying with what others have facilitated or chosen for him (Marcia, 1966).

5.3.3 Vulnerability

However, there is evidence that Mike has embraced experiences for autonomy, for example, accepting responsibility at school and living with limited support whilst at residential college.

Table 30: Vulnerability Themes and Quotes 1

Experience/ relationship	Theme	Sub-theme	Illustrative Quote
Secondary school	Responsibility	-	<i>I: Can you tell me what you did at secondary school?</i> <i>M: I am in charge of tables and chairs, I am charge everything, I in school council.</i>
Residential college	Autonomy	Independence	<i>M: Ye to get my own bungalow, do my own thing, in the bungalow we watch the tele a lot in the evenings, lots of programmes, we watch football on a Friday night, we stay up very late, about 1 o clock in the morning, I was tired the next day.</i>

Autonomous experiences may have contributed positively to Mike's identity formation (Schwartz, Luyckx and Vignoles, 2011). However, Mike appears to perceive himself as vulnerable which may counteract the contribution of autonomy (Barter et al., 2017). Mike's relationships with significant others may have contributed to this sense of vulnerability.

Table 31: Vulnerability Themes and Quotes 2

Experience/r elationship	Theme	Sub-theme	Illustrative Quote
Experiences in primary school	Relationships	Fun Support	<i>M: Sometimes I play with friends, all the time, look after me a lot, other friends play with me loads of times, are you okay, are you alright, if you've got any problems if you're upset or worried you can talk to your friends or staff there is no problems with that.</i>
Year 5 leavers performance	Celebration	Disability	<i>M: At the end of the dance everybody stand up, since I have Down syndrome, and everyone stand one and someone shout one more one more one more dance, and I did some more dance and everyone cheered and clapped.</i>
Work experience in a shop	Autonomy	Vulnerability	<i>I: Did you like your work experience? M: Yes very good, we walk independent, some staff are okay for independence, some staff okay for road safety and make sure you are safe.</i>
Africa	Vulnerability	-	<i>I: Why do you like elephants Mike? M: Because elephants likes me, he knows me because I'm special, a special person.</i>
Mother	Care	-	<i>M: Mum always like let me have healthy living thing and he told me to eat plenty and drink plenty, if I don't drink I get headache, keep me going and he always cook like a meal lunchtimes evening times.</i>
Teachers	Relationship	Support	<i>M: If you've got any problems if you're upset or worried you can talk to your friends or staff there is no problems with that.</i>

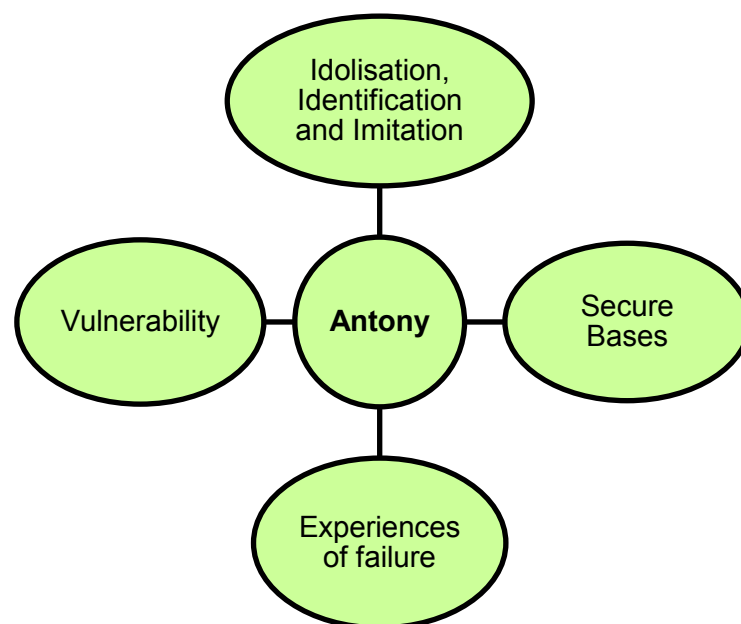
Friends	Relationship	Support	<i>M: Sometimes I play with friends, all the time, look after me a lot, other friends play with me loads of times, are you okay, are you alright, if you've got any problems if you're upset or worried you can talk to your friends.</i>
Girlfriend	Relationship	-	<i>M: My girlfriend helps me as well, that's quite nice.</i>
Residential College	Autonomy	Vulnerability	<i>M: Independently doing the computer, do meals and cooking, I am good at cooking but staff keep an eye on cooking, health and safety, hot pans and sharp knives and stuff we've got to be safe.</i>
	Relationships	Support	<i>M: If you have any problems you can talk to the staff, you do have a problem or if you are upset or cross or worried you can talk to the staff and see what's happened.</i>
Having a support worker	Autonomy	Exploration	<i>M: I am not very good at changing monies, my support friend will teach me which monies to spend then take me to the youth club in X in leisure centre then at 3 o'clock mum and dad take me back.</i>
Moving into his own house	Autonomy	Vulnerability	<i>M: I just worry about the panel, before I move house I worry about the money, settle in and stuff, whether it will come through, I am settled now so I don't worry about that.</i>

Perhaps the significant people in Mike's life have perceived him to be vulnerable and sought to protect him from harm (Marini, Graf and Millington, 2018). It is conceivable that Mike may have assimilated or accommodated this into his identity, that he is a man who is vulnerable and so requires care (Bosma and Kunnen, 2001; Scott et al., 2014). The consequence of this may be that Mike is hesitant to try new experiences and he relies on others to facilitate opportunities for him (Down's Syndrome Association, 2011).

Perceiving oneself as vulnerable may contribute negatively to identity formation. Marcia (1966) writes that those individuals who are at-risk of foreclosing on their identity formation typically over-rely on others which limits their independence to explore identity alternatives. It is conceivable that Mike's apprehension to live independently may reflect how he has relied on significant others previously. Alternatively, this could reflect how Mike demonstrates some critical awareness (Skotko, Levine and Goldstein, 2011).

5.4 Antony

Figure 10: Elements of Identity Formation: Antony



5.4.1 Idolisation, Identification and Imitation

The analysis of Antony's life story interview has revealed a reoccurring theme of idolisation and imitation. In terms of identity formation this could represent the

identification phase (Sokol, 2009). Antony identifies with both his family members and the characters he plays as an actor.

Table 32: Idolisation, Identification and Imitation Themes and Quotes 1

Experience/relationship	Theme	Sub-theme	Illustrative Quote
Mother	Idolisation	Physical appearance	<i>A: I want to be like my dad, or be myself or maybe mum.</i>
		Aspiration	
Father	Idolisation	Aspiration	<i>A: One day I will be in a band like my dad.</i> <i>A: I feel excited about it, maybe I can get into my dad's style (clicking fingers) sometimes when I play guitar I get into my dad's style.</i>
		Imitation	
Sister	Idolisation	Imitation	<i>A: I really want to do the same as my sister.</i> <i>A: I tried to copy my sister.</i>
		Physical characteristics	
Living out of England (including gymnastics and Irish dancing)	Learning new skills	Imitation	<i>A: I was doing my Irish dancing. My sister used to do Irish dancing lessons and I really want to do the same as my sister so we went and did it together.</i>
		Idolisation	
Performing in plays as an actor	Performing	Idolisation	<i>A: I was so excited to be in High School Musical...I was a jock, a jock means I sing in the Chorus...</i> <i>I: What else did you enjoy about being in the show?</i> <i>A: Because my favourite actor was in it Zac Efron.</i>
		Imitation	
School experiences	Learning	Imitation	<i>I: Do you like to do art at primary school?</i> <i>A: Yes sometimes I paint could be rainbows.</i> <i>I: How did you get into art?</i> <i>A: Because my mum loves art.</i>
Leaving High School and transitioning to residential college	Transition	Imitation	<i>I: Why do you think it is important to get qualified?</i> <i>A: Because my sister did all those things because she went to college just like I did and this is my first</i>

			<i>time being in college and I feel nervous, scared.</i>
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Typically identification concludes at the start of adolescence (McLean and Syed, 2015). However, Antony continues to identify with significant people at 19 years old. Consequently, it may be interpreted that Antony has developed his interests through imitating significant others (Sokol, 2009). Furthermore, his identifications have partially shaped his aspirations for the future: to become like his father and mother, or an actor like his role model.

Perhaps this indicates that Antony is still in the identification phase of development (Erikson, 1995). Experiences which may have contributed to this may include his parents' divorce (Watson and Skinner, 2004).

Table 33: Idolisation, Identification and Imitation Themes and Quotes 2

Experience/relationship	Theme	Sub-theme	Illustrative Quote
Living out of England	Happiness	Family Unit	<i>A: I liked to enjoy living with my dad.</i>
Moving to England and the divorce of his parents	Conflict	Emotional Turmoil	<i>A: My parents used to be together but they had to break up. It was really hard when my parents break up because that's why I ended up here.</i> <i>A: Living with my dad, it was a really really hard not being a kid and being with my dad anymore.</i>
		Duty	<i>I: What do you think about being here in England?</i> <i>A: Good because my grandpa passed away and I couldn't leave my grandma, she couldn't be on her own, that's why at the time we had to stay.</i>

Grotevant (1987) highlighted the impact of experiences including divorce on the process of identity formation. Antony experienced conflict between sadness caused

by the divorce and a sense of duty to return to England to look after his grandmother. Perhaps the loss of the family unit he once cherished may have contributed to why he identifies so much with his father: as a means to re-connect (Watson and Skinner, 2004).

5.4.2 Secure Bases

Furthermore, Antony may have lacked friendships whilst at school and this may have contributed to his over-identification (Underwood and Rosen, 2011).

Table 34: Lacking a Secure Friendship Base Themes and Quotes

Experience/relationship	Theme	Sub-theme	Illustrative Quote
School experiences	Support	Vulnerabilities	<i>I: Did you find anything difficult when you were at primary school?</i> <i>A: Making friends</i> <i>I: Is it important to you to have friends?</i> <i>A: Yes because I used to get bullied and I didn't have many friends so that's why I need friends to start again.</i>
Being bullied	Vulnerability	Harm	<i>A: Being bullied isn't fun</i>
		Support	<i>A: somebody pushed me and I was bleeding.</i> <i>I: How did you feel?</i> <i>A: Hurt inside.</i>

Due to the social rejection Antony experienced, it is plausible that if he failed to develop the secure base he required in order to try new experiences (Underwood and Rosen, 2011). Furthermore, if peer acceptance is associated with a positive self-concept, through gaining negative feedback from peers, Antony may have assimilated this into his sense of identity (Bosma and Kunnen, 2001; Huck, Kemp and Carter, 2012).

5.4.3 Experiences of Failure

An analysis of Antony's school experiences shows that he also had difficulty meeting teachers' expectations.

Table 35: Experiences of Failure Themes and Quotes 1

Experience/ relationship	Theme	Sub-theme	Illustrative Quote
School experiences	Conflict	Mis- behaviour	<i>A: Sometimes I went into the principal's office and I was talking to the microphone and one of my teachers tried to stop me</i> <i>I: What did the teachers think when you did that?</i> <i>A: They think I am not allowed.</i> <i>I: What did the teachers think?</i> <i>A: Not impressed.</i> <i>A: I got myself in trouble, I deserve it.</i> <i>A: Sometimes I am a bit of a troublemaker.</i> <i>A: I was in trouble all the time, I said the f word</i> <i>I: why?</i> <i>A: Because I hear other people say it.</i>
		Validation	

Through these experiences Antony may have felt as though he failed. Experiences of failure can contribute to low self-esteem which can decrease an individual's motivation to try new experiences (Grotevant, 1987). Although Antony may have experienced failure in school he had experienced success within his family unit.

Table 36: Experiences of Failure Themes and Quotes 2

Experience/ relationship	Theme	Sub-theme	Illustrative Quote
Grandparents	Vulnerability	Duty	<i>I: Have you got any stories from when you were caring?</i> <i>A: My grandad because my grandad was really old and he had a walking stick and we had to help him a lot, when he wanted to go out he has to walk really slowly, we have to walk slowly.</i>

Living out of England (including Irish dancing)	Learning new skills	Imitation	<i>A: I really want to do the same as my sister.</i> <i>A: I tried to copy my sister.</i> <i>I: So how do you think you are at Irish dancing?</i> <i>A: Um I was really really powerful because I went in there and I knew what I was doing.</i>
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Perhaps if Antony experienced more success at home, he may have been more able to try new experiences with the support of his family (Scott et al., 2014). For example, he experienced success when he imitated his sister at Irish dancing; this may have increased his motivation to continue identifying and imitating his family members (Kroger, 2004).

5.4.4 Vulnerability

It would also appear that Antony may perceive himself as vulnerable through experiences where he relied on significant others to support him.

Table 37: Vulnerability (Antony) Themes and Quotes 1

Experience/relationship	Theme	Sub-theme	Illustrative Quote
School experiences	Support	Vulnerabilities	<i>A: That school was good because they looked after me and they were nice teachers.</i>
Grandfather	Vulnerability	-	<i>A: He was holding me and I imagine he is still there, like when I needed him when I was growing up.</i>

If this is the case, this may have resulted in limiting opportunities to be autonomous and contributed to why he chose to identify with his family members rather than to explore other alternatives also him not wanting to try autonomous experiences (Marcia, 1966). Moreover, Antony demonstrated anxiety when he left his family home to attend residential college.

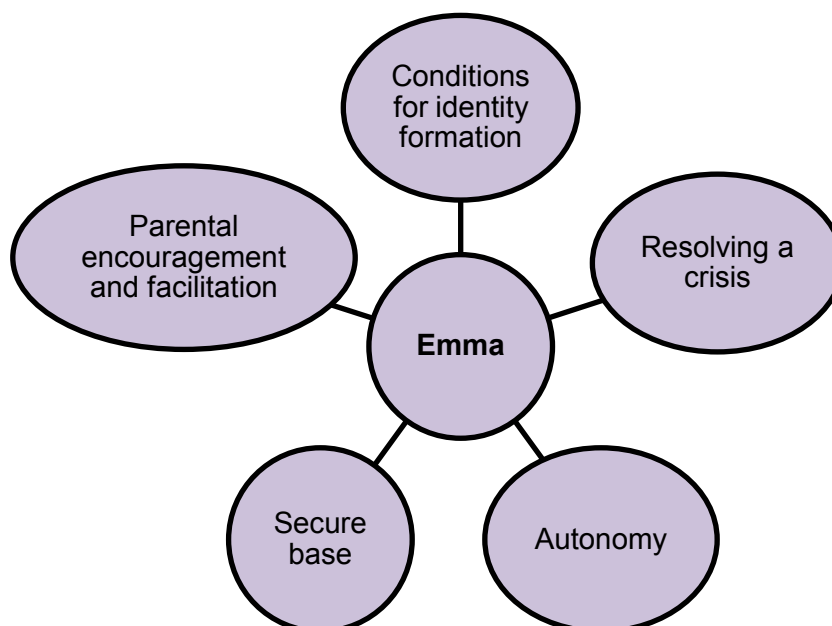
Table 38: Vulnerability (Antony) Themes and Quotes 2

Experience/ relationship	Theme	Sub-theme	Illustrative Quote
Leaving High School and transitioning to residential college	Transition	Anxiety	<i>A: I have to go to college so then I can get qualified. I just really want to stay here but I can't I have to grow up living my own life.</i> <i>A: um I have college parents because I need a parent because if I am living away from mum or dad.</i>
		Anxiety	<i>I: Why do you think it is important to get qualified?</i> <i>A: Because my sister did all those things because she went to college just like I did and this is my first time being in college and I feel nervous, scared</i>
		Imitation	

Antony appears here to rely on others. Moreover, his decision to go to college appears to have been driven by his identification with his sister rather than an autonomous decision based on his own exploration of alternatives. Antony may have over-identified with his family members and as a consequence is at-risk for foreclosing on his commitments for the future (Marcia, 1966).

5.5 Emma

Figure 11: Elements of Identity Formation: Emma



5.5.1 Conditions for Identity Formation

Emma appears to show that she has experienced important conditions for successful identity formation (Scott et al., 2014). She appears to be self-determined and views her transition to adulthood as a positive experience. She embraces the increased independence, autonomy and control over her future vocation and relationships.

Table 39: Optimal Conditions for Identity Formation Themes and Quotes 1

Experience/relationship	Theme	Sub-theme	Illustrative Quote
Becoming 20	Growing up	Employment	<i>I: How do you feel about being 20?</i> <i>E: I don't know just um getting old.</i> <i>I: Is it good or bad to get old? How do you feel about it?</i> <i>E: Yes, I feel like ecstatic.</i> <i>I: Why do you feel like that?</i> <i>E: Well some of my teenage years, um I was getting young when you're baby</i>

			<i>you have to grow up older like get a job, make some new friends, move on.</i>
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Moreover, Emma presents as someone who is satisfied with whom she is, demonstrating high self-esteem which may have motivated her to try new experiences and persevere in the face of adversity, such as when she experienced social rejection (Grotevant, 1987).

Table 40: Optimal Conditions for Identity Formation Themes and Quotes 2

Experience/ relationship	Theme	Sub-theme	Illustrative Quote
School experiences	Friendships	Social rejection	<i>E: I didn't make some new friends they left me alone at lunch and at break and we didn't go to the canteen because we ate lunch at the class.</i> <i>E: When I got out of there and I was really really happy to got my friends there.</i>

Emma demonstrates here how high self-esteem may have increased her motivation to embrace new experiences, for example, her move to a new school (Grotevant, 1987). When considering why Emma might have high self-esteem previous literature would indicate that young people with DS who attend mainstream schools can experience higher self-esteem than those in special schools (Begeley, 1999). Emma may represent this finding, having only attended mainstream schools throughout her childhood and adolescence

5.5.2 Resolving a Crisis

Additionally Emma appears to have experienced crises in her life: for example, the current re-evaluation of her relationship with her sister following the

birth of her nephew and also during her time in college when she questioned and evaluated her identifications with other young people with 'disabilities'.

Table 41: Resolving a Crisis Themes and Quotes

Experience/ relationship	Theme	Sub-theme	Illustrative Quote
The birth of her nephew	Being replaced	Betrayal	<i>E: Well my sad day would be (silence) I just want X to be normal sister and I don't want, she can be monster sometimes but she because she is snaps at my mum and I really really want to stick up for my mum, the way she says things to my mum she does really really mean it when she was pregnant, no no, when she had the baby but she's not the same X because she has been always there, she's been there for me since I was young, when I was little and she's want her back desperately.</i>
Sister	Relationship	Support Rejection	
Going to college	Feeling different	Dissociation	<i>I: Okay when you were at school what did you want to do when you left school? What did you want to do, college a job for example?"</i> <i>E: Well I went to, I have been to college but I didn't learn anything in Maths we do games I did CBebbies and it feels like being a going to infant school and being acting like babies and um and I didn't like the foundation people</i> <i>I: Why didn't you like them?</i> <i>E: I think there are not the type of people I've been expected.</i> <i>E: I am not Down syndrome.</i>

Through these experiences Emma has used reflection to reconcile contradictions about herself (McLean and Syed, 2015). Having previously only attended mainstream schools, Emma may have elicited information about herself when

attending a college with students with ‘disabilities’ (Grotevant, 1987). Consequently, she may have rejected any incoming information that she was similar in some way to the other learners (Grotevant, 1987). Emma appears to have resolved this crisis by leaving the college and maintaining the image she formed whilst at mainstream school.

5.5.3 Autonomy

Furthermore, Emma has had opportunities to engage in autonomous decision-making which may have positively contributed to her identity development (Scott et al., 2014). For example, Emma made the decision to drink alcohol at an event with her friends and she also talked about episodes where she rejects her mother’s authority.

Table 42: Autonomy (Emma) Themes and Quotes

Experience/relationship	Theme	Sub-theme	Illustrative Quote
Having brunch with her friends	Autonomy	Conflict	<i>E: Okay (laughs) that was really years ago I was about 17 and um mum made up really good brunch with all my friends coming over and um when my friends are there and she opens the fridge and my own friends just said to mum is she allowed that and um my mum yes and um yes she’s 17.”</i>
Mother	Relationship	Facilitation	
		Conflict	<i>E: I don’t listen to Mum and um I am the boss.</i>

Although her friends questioned her competency, it would appear that Emma’s mother supported her autonomy, perceiving her as competent to make her own decisions (Buckley and Sacks, 2002). Emma does not appear to be reliant on others to make decisions, therefore, and so may have experienced the autonomy required for successful identity development (Erikson, 1995).

5.5.4 Secure Base

Furthermore, Emma's close friendships may have acted as a secure base for her to explore new interests such as going to nightclubs (Underwood and Rosen, 2011). From these experiences Emma appears to have been seeking social validation.

Table 43: A Secure Base Themes and Quotes 1

Experience/ relationship	Theme	Sub-theme	Illustrative Quote
Going to a nightclub	Physical appearance	Validation	<i>I: Are fashion and makeup things you like?</i> <i>E: She is really into fashion and beauty because she's want to look the part and make a statement put slap on ye she's been to a nightclub so when I go out to show my assets, she's got a cleavage.</i>

This validation may have assimilated into her identity (Underwood and Rosen, 2011). The information she received through interacting with peers may have caused her to question how she fits into her social group (Kroger, 2004).

Table 44: A Secure Base Themes and Quotes 2

Experience/ relationship	Theme	Sub-theme	Illustrative Quote
Friends	Relationship	Connected	<i>E: Well she's not wild but my friends are wild she's sensitive and she is responsible, she's (unclear word) and really sensitive.</i>

This would suggest that Emma, through establishing friendships, has had the social feedback required to stabilise identity formation, revealing to her, how she is similar and different from her peers (Luyckx et al., 2006).

As well as identifying with peers, Emma also has a role model she identifies with.

Table 45: A Secure Base Themes and Quotes 3

Experience/relationship	Theme	Sub-theme	Illustrative Quote
Jessie J	Idolisation	Individuality	<i>I: why do you like Jessie J?</i> <i>E: Well she's really good with music and she's write her own songs and lyrics and she's been on tour. Yep</i> <i>I: Why would you say she is a role model?"</i> <i>E: Yes and it's because she choose her own style and she's really good at her fashion and her makeup.</i>

Emma has reflected on why she identifies with her role model and talks about her 'individuality'. Perhaps this identification illustrates how Emma seeks to be her own unique person and so stabilises her conclusion that she is an individual (Ratele and Duncan, 2003).

5.5.5 Parental Encouragement and Facilitation

In order to develop her own unique identity, Emma has participated in a range of exploratory experiences in and out of educational environments. These experiences may have been facilitated by others (Alderson, 2001).

Table 46: Parental Encouragement and Facilitation Themes and Quotes

Experience/relationship	Theme	Sub-theme	Illustrative Quote
School experience	Learning new skills	Exploration	<i>E: She is into Science and RE.</i> <i>I: Why do you like Science and RE?</i> <i>E: Science is my fave and I love doing all the experiments and writing the stuff down what the experiments I have using and the RE she's really good at homosexuality to</i>

			<i>Christians.</i>
Taking photographs	Competence	Validation	<i>E: She is really capable at taking photographs.</i> <i>E: Photos are my thing and I really is my passion and she loves taking photos.</i> <i>E: I have been a really good job and I have done exhibitions.</i>
Going on holidays	Travel	Exploration	<i>I: What has been the happiest time in your life?</i> <i>E: My happiest day would be to, my happiest day to go on holiday.</i> <i>I: Can you tell me about the holidays you've been on?</i> <i>E: I have been to Singapore when I was little, I have been to Jamaica, I have been to Turkey and I have been to Corfu and I have been to Morocco and I have been to Turkey with my dad.</i> <i>I: Why does going on holiday make you happy?</i> <i>E: Because she wants to see the world and she wants to travel the world so that is happiest day on the universe.</i>
Tutor	Facilitation	-	<i>E: I practice with my tutor</i>
Father	Facilitation	-	<i>I: When did you discover it is your passion?</i> <i>E: Well last year at Christmas dad got me a red canon camera.</i> <i>I: So you got a red canon camera for Christmas, is this when you discovered it was your passion?</i> <i>E: No.</i> <i>I: So did you know before this?</i> <i>E: Yeah.</i>

Although significant others may have supported Emma to access these experiences, it seems that that she has chosen what she has explored based on her interests. For example, her father bought her a camera to facilitate her interest in photography, but he has not determined her interest or restricted her opportunities.

Her interests have then shaped her vocational aspirations, to work in photography and modelling. She appears to have explored different options for her vocation which have included nail art but identifies photography and fashion as her chosen area (Marcia, 1966). If significant others have encouraged her to pursue her interests, it may be concluded that Emma has had experiences which have facilitated her exploration of alternatives for her identity.

5.6 Research Question Two Summary

This section has illustrated the contributions of key life experiences and significant relationships on the formation of identity. The analysis has suggested that Tommy, Antony, Mike and Emma have all experienced factors which had a positive contribution on their identity formation. However, through varied life circumstances, including restricted autonomous experiences, perceiving oneself as vulnerable and over-identification with significant others, the majority of participants have demonstrated how they may over-rely on others to guide their identity development rather than engage in free exploration of alternatives. I now address the broad research question to consider the implications of identity formation for the participants' future life trajectories.

5.7 What is the implication of this identity formation on the future life trajectory of school-leavers with DS?

If theorists are correct in their assertions that identity formation may direct an individual's life trajectory, it is conceivable that experiences which have contributed to identity formation may have directed Tommy, Mike, Antony and Emma's aspirations (Marcia, 1976; McLean and Syed, 2015). Their aspirations included: additional study, kitchen work in a pub and living partially independently (Tommy); becoming like his role models, supermarket work and returning to the family home (Antony); shop work and living independently (Mike); and work as a photographer and catwalk model (Emma).

The analysis revealed how Tommy, Mike and Antony may have had experiences and relationships through which they have relied on others to guide their identity formation (Marcia, 1966). Emma appeared to have relationships and experiences through which she was encouraged to be autonomous and engage in her own exploration of alternatives for her identity (Marcia, 1966). Although existing literature would suggest that being guided (identity foreclosure) does not prevent an individual from achieving his/her future plans (Marcia, 1976), if theorists are correct in proposing that the development of identity is a component of mental health, then those with at risk of foreclosure might experience mental distress (Erikson, 1968). Different experiences could have implications for mental health.

Although Tommy and Mike currently speak with positivity, it is conceivable that a realisation that the fact that trajectories have been determined or at least guided by others may cause them upset (Buckley and Sacks, 2002). It is perhaps significant that Antony currently uses an anxious tone when speaking about his

future. It is possible that he is already experiencing anguish associated with the potential foreclosure of his identity (Erikson, 1968). In contrast, Emma speaks with passion when describing her future plans as an adult; perhaps this is the result of her establishing her aspirations with less guidance but encouragement.

However, irrespective of their identities statuses, according to the literature, life satisfaction is thought to result from an individual achieving his/her ambitions (Scott et al., 2014). It may be contended that the likelihood of an individual reaching his/her goals is dependent on how achievable his/her aspirations are (Glenn and Cunningham, 2004). Tommy, Mike and Antony all spoke with pragmatism when describing their aspirations which were consistent with the existing expectations regarding adulthood for those with DS from the Down's syndrome Association (2011). On the other hand, Emma's aspirations were interpreted to reflect the 'developmental immaturity' identified by Glenn and Cunningham (2004).

Consequently, Emma could experience a discrepancy between what she hopes for the future and what she experiences in reality. As she spoke with such passion and commitment regarding her aspirations perhaps as a result of this discrepancy she may experience negative consequences for her emotional well-being (Carr, 2008). Buckley and Sacks (2002) advise educational professionals and parents to guide young people with DS to form goals which are reflective of the skills and competencies the individual has. Perhaps this was the case in Tommy, Mike and Antony's lives, where due to their difficulties with making decisions, parents and teachers have guided them to make realistic appraisals (Down's Syndrome Association, 2011). However, the findings have demonstrated that with such guidance individuals can foreclose on their identity and this has the potential to affect well-being (Marcia, 1966).

Furthermore, with the efforts to involve young people with DS as equal partners in decision making, such guidance may be perceived to be oppressive. In promoting person-centred practices, some may question why those with 'differences' such as DS should not generate ambitions for their future which have been chosen exclusively by them, based on their interests and 'passions' in life (Atherton and Crickmore, 2011). As identity formation is thought to be a lifelong process, there appears to be a balance to be had, therefore, between providing school-leavers who have DS with optimal conditions for identity development at all phases of their life whilst supporting them to identify realistic goals based on their interests (Scott et al., 2014). How this may be achieved is addressed in the next chapter.

CHAPTER SIX: CONCLUSION

6.1 Chapter Overview

The following chapter summarises the findings, and discusses the contribution of the study in terms of theory development and methodology. Afterwards it offers implications for practice and to conclude, it critiques the research and proposes recommendations for future inquiry.

6.2 Contribution of the Current Study

6.2.1 Theory Development

The overarching aim of the study was to explore how school-leavers with DS spoke about their lived experiences in order to contribute to the limited literature which has elicited the voices of young adults with DS (Skotko, Levine and Goldstein, 2011). Although inclusion in mainstream education and society is perceived to be the ideal and beneficial for those with DS (Buckley et al., 2006), the narratives from this study have demonstrated the challenges of making inclusion successful, the negative consequences of social adversity and how attempts to celebrate those with 'disabilities' although often contributing to their self-esteem may not reflect true social equality.

The narratives also indicated that the school-leavers view themselves positively. It is possible that, due to the continued existence of negative attitudes towards those with DS in society (Barter et al., 2017), that the participants may have been protected from social adversity. Although this protection has typically benefited self-esteem and well-being, it may become a barrier to the inclusion that educational policy is calling for (Department for Education, 2015). From this, it may be concluded that society's efforts to improve inclusion remain problematic in a society which continues to view DS as a 'deficit' (Barter et al., 2017).

The second aim was to consider the formation of identity. Previous literature has proposed that due to intellectual impairments, those with DS may lack the cognitive ability to engage with the processes involved in identity formation (Cunningham and Glenn, 2004). However, the participants were all able to demonstrate inference skills and reflection. Perhaps this finding should raise awareness that those with DS should not have their abilities to reflect upon their lives underestimated because of a 'learning disability'. This is important when considering person-centred practices in that those with DS should have an active voice in decision making (Department for Education, 2015).

Furthermore, this study has demonstrated how young people with DS navigate psychosocial development and develop goals for their future life trajectories (Smart, 2012). From the analysis I interpreted how all participants had some experiences and relationships which would have had a positive contribution on identity formation. However, experiences which facilitated perceptions of vulnerability, traumatic life events and their protection by parents and teachers have limited life experiences and as a result may have caused three young people to rely on the guidance they received from others when formulating their future plans (Marcia, 1966; Down's Syndrome Association, 2011).

Emma's case has illustrated how, akin to the optimal conditions for successful identity formation set out in Scott et al. (2014), she was able to experience: exploration, autonomy and self-determination. Emma was the only participant to have been fully integrated in mainstream schools throughout her life. Although a causal relationship has not been established, it is conceivable that her time spent with 'typically developing peers' may have contributed to her success with forming her identity which would contrast with existing recommendations that young people

with DS should form friendships with others with DS in order to develop identity (Buckley and Sacks, 2002).

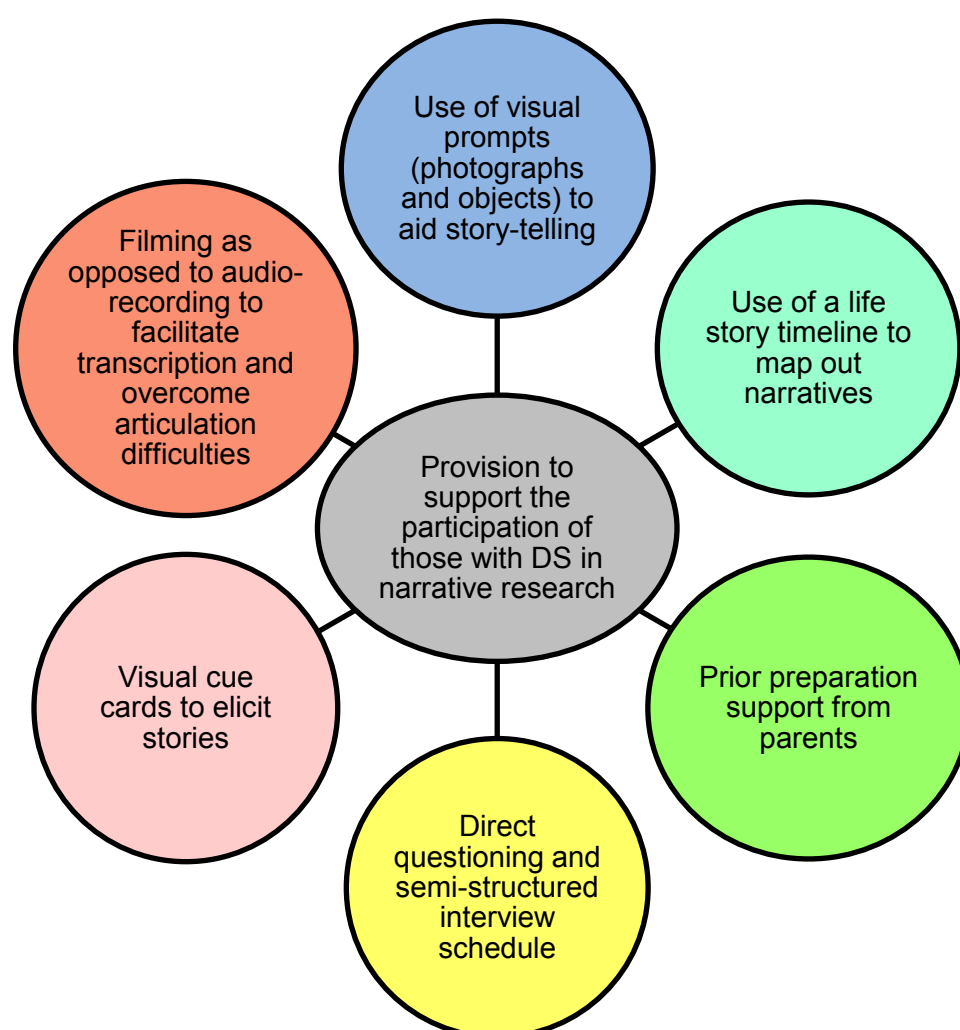
However, the study has also reflected upon the implications of identity formation on future life trajectories and has indicated that although Emma may have based her future aspirations on her exploration of alternatives, her ambition for the future may also reflect 'developmental immaturity' (Glenn and Cunningham, 2004). As Emma appeared to be fully committed to achieving her aspirations, she may be at-risk of becoming less satisfied with her life if she does not achieve her ambitions. However, the other participants, having more pragmatic aspirations, may gain satisfaction through achieving their goals (Scott et al., 2014). This indicates how the current educational policy's efforts to increase the aspirations and autonomy of those with DS may be challenging in the current sociocultural climate (Department for Education, 2015).

It should be noted that the conclusions I have drawn regarding the identity formation of the four participants are tentative in nature and should, therefore, be taken with caution. The conclusions have been drawn from the experiences told through the participants' narratives only and may over-rely on a developmental approach to understanding identity formation (Morss, 1996). Some may criticise this interpretation of identity formation as a regulated developmental process. For example, using the term 'developmentally immature' when referring to Emma's aspirations inherently invokes a normative perspective which is unhelpful, implicitly endorsing the practices of judging a person's worth and the scale of their achievements with reference to others, rather than from an individualistic perspective (Morss, 1996).

6.2.2 Contribution to Methodology

Authors previously stipulated that the demands of a narrative methodology may be too challenging for those who experience difficulties with learning and communication (Grove, 2015). However, this study has demonstrated that with appropriate provision put in place, a narrative approach can be an effective method to elicit the perspectives of young adults with DS (see figure 12 for recommended provision).

Figure 12: Provision to support individuals with DS participating in narrative research



6.2.3 Implications for practice

The initial ambition of this research was to be able to offer recommendations to professionals working for young people with DS. Existing literature advises that in educational settings, teachers should encourage young people to engage in self-discovery (Underwood and Rosen, 2011). Furthermore, families should provide guidance, autonomy and opportunities for young people with DS to interact with other people with DS in order to facilitate identity formation and the establishment of realistic goals for their future life (Buckley and Sacks, 2002; Scott et al., 2014). Furthermore, the literature proposes that those with DS require support throughout their lives to have a happy life (Marshall et al., 2015).

Although I acknowledge the benefit of guidance, this study has demonstrated the complex balance between facilitating identity formation whilst avoiding unsuccessful identity development which may impact on mental health (Georgios and Bosma, 2012). Echoing the ambition of current educational policy, the study has indicated that young people with DS need to experience self-determination, have genuine opportunities to explore alternatives for their identity and to develop their own interests rather than merely being expected to comply with expectations imposed upon them by other people (Department for Education, 2015). Furthermore, Emma may demonstrate the benefit of integration in mainstream education or time spent with 'typically developing peers' as it is probable that her extensive time in mainstream schools has contributed to her successful identity formation.

Furthermore, with the drive for professionals to employ person-centred approaches perhaps it is inappropriate to propose that we should discount young peoples' aspirations because they may appear 'developmentally immature' when the young person has such passion and commitment (Atherton and Crickmore, 2011). In

addition, it is also inappropriate to suggest that physical restrictions caused by genetic conditions such as DS may deem autonomy unachievable (Marini, Graf and Millington, 2018). Perhaps for person-centred approaches to be effective there needs to be a shift in society so that those with DS are not viewed as inferior, but rather their impairment is a difference which becomes disabling due to societal negativity (Shakespeare, 2006).

Although this may be difficult to achieve, a starting point may be to reconceptualise the concept of 'autonomy' by considering how young people with DS can have authentic autonomous experiences in society. Furthermore, it should be considered how professionals can work in partnership with a young person to consider how their achievable plans. For example, for Emma this might involve considering what interests drove her aspiration to become a catwalk model and what employment opportunities may exist for her which incorporate those interests.

Having established that the formation of identity may go on beyond the adolescent period and as a future educational psychologist working with young people up to the age of 25, this work should continue into adulthood. As a school-leaver it may be beneficial for young adults with DS to continue to have opportunities for autonomy, exploration, self-awareness and self-determination into their adulthood. Furthermore, any educational setting they access should employ these person-centred principles (Atherton and Crickmore, 2011).

6.3 Strengths and Trustworthiness

The present study intended to overcome the limitations of previous similar studies (see Chapter 1, *section 2.8.4*). It also can be judged a study which was highly participatory for the young people. However, it may be argued that due to the

methodological approach I employed, that the study may lack validity and reliability. I was explicit in Chapter Two, *section 3.5.1* that narrative approaches are based on interpretation and stated how this study was grounded in a constructivist paradigm and so, it cannot be judged on the same measures of reliability and validity as are other positivist studies are judged on. The study, therefore, requires evaluation according to an alternative dimension: trustworthiness (Elliott, 2005).

Reissmann (2008) also proposes that the validity of narrative research can be assessed by the way in which the researcher maintains the respondents' original stories throughout the research. To achieve this I carried out checks with the participants to guarantee that the restorying procedure had reflected their 'voice' and used illustrative quotations throughout the findings and discussion to reflect the original stories. Table 48 provides further information on the way in which I have maintained trustworthiness throughout the process.

Table 47: How I maintained Trustworthiness

Element	Meaning	How I achieved this in the study
Dependability	The design, data collection and analysis should be constant. The researcher should make it clear what processes he/she went through during each stage of the process.	• I clearly stated the methods of data collection in <i>Chapter Three section 3.6</i>. • The process of data analysis was consistent across participants and is clearly stated in <i>Chapter Three section 3.7</i>. • Additional detail regarding each participant's analysis can be found in Appendices 8, 9, 10 and 11.
Credibility	The extent to which the researcher represents each participant's constructed reality and gives meaning to their experiences.	• The restoried narratives were checked by participants for authenticity. • Direct quotes have been used throughout the study to reflect each participant's construction. • The methods of data analysis were specifically chosen to give meaning to the participant's experiences.
Transferability	The findings are transferable to similar situations and similar	• The study was not intended for generalisation. • Each case was respected as a unique case study. • The studies raise awareness into each case

	participants.	which may be transferable to similar cases.
Confirmability	The findings are not the result of the researcher's assumptions and preconceptions.	• There has been limited research into this area prior to this study which may have biased my assumptions regarding the results. • I employed an inductive thematic analysis. • I clearly stated how my position may influence data collection and findings and the efforts I made to overcome this in Chapter Three section 3.5.1 and section 3.8.

6.4 Limitations

As a reflective researcher I will now provide an overview of the limitations of this research. Initially I experienced difficulty with recruiting a sample. Although the participants did not require parental consent to take part, two young people initially identified were prevented from partaking due to parental disagreement. Perhaps from this it can be inferred that the recruited sample may have been biased in that parents of Tommy, Mike, Antony and Emma may have had a greater belief that their child should have the right share their perspectives. Parents with these traits may have granted their children more opportunities for autonomy during childhood than would have been the case of young people who did not have their parents 'permission' to participate.

Furthermore, I initially criticised previous researchers for interviewing parents rather than young people with DS exclusively (Cunningham and Glenn, 2004). However, I employed parental involvement myself. I might be criticised for asking parents to support their children with preparing the life story timeline in that parents may have influenced what their children did or did not share with me. However, in response to this I would argue that the semi-structured nature of the interview schedule ensured that I retained flexibility throughout the process to elicit stories

which were not defined by what parents may or may not have helped their children to write down on the life story timeline.

Although the narrative methodology was advantageous in many ways I cannot deny how some of the participants struggled to fully access the approach. For example, two participants struggled with comprehending the word 'story' and another struggled with the subtlety of language. For example, she misinterpreted the question 'Tell me a time when you were responsible' and shared a time where she was 'irresponsible'. Additionally, one participant had difficulty with using a wide vocabulary to answer evaluative questions and used the word 'good' consistently. With this it was difficult to know whether the participant thought the experiences were 'good' or whether there was a misunderstanding and this word was a default for him to use in an uncomfortable situation.

Furthermore, previous authors have identified how cognitive skills may mediate identity formation and took account of this in research by assessing the cognitive skills of participants (Cunningham and Glenn, 2004). In this study, I did not carry out any formal testing; I assumed that the participants would have sufficient cognitive and linguistic skills as this was included in the recruitment criteria. However, I did not verify this and so cannot conclude as to the influence of the cognitive ability of the participants on their identity formation.

Finally, it must be noted that the conclusions have been drawn only from what the participants were able to or wanted to share with me during the interviews. The findings were based on my interpretations only and so may lack inter-rater reliability. Furthermore, any conclusions I have made regarding the formation of their identity and regarding how they talk about their life should be taken with caution, therefore, as the narratives were context dependent. Furthermore, in reference to research

question 2, I was unable to identify causation or the direction of causation between experiences, relationships and identity formation but also whether there were other factors which mediated this relationship such as the young person's personality. However, I have raised awareness regarding the possible relationships between certain lived experiences and possible outcomes for identity formation.

6.5 Avenues for Future Research

The present study has explored the lived experiences, identity formation and future life trajectories of school-leavers with DS and has made some recommendations to inform professional practice. It may be beneficial for future research to be carried out to better inform this practice. This may include considering how far educational experiences are preparing young people with DS for adult life. This will include exploration into what is already being done by educational professionals to promote identity formation, for example, whether schools are promoting authentic autonomy, exploration and self-determination in those with DS or whether this could be improved and if so, what this would comprise. The ultimate goal of this future inquiry would be to support the person-centred approaches and to promote greater inclusion of those with DS in society (Department for Education, 2015).

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APPENDICES TO VOLUME 1

**“I AM NOT DOWN SYNDROME”: A NARRATIVE EXPLORATION OF LIFE AND
IDENTITY IN SCHOOL-LEAVERS WITH DOWN SYNDROME.**

By

Annie Kent

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APPENDIX 1: EXISTING LITEATURE ON DOWN SYNDROME

Table A1: Existing Literature on Down Syndrome

Author(s)	Participant	Focus	Methods	Findings
Lalvani, 2008	Mothers of children with DS	Experiences of having a child with DS.	Interview	The mothers had experienced negative attitudes and responses following the birth of their child with DS.
Lalvani, 2013	Mothers of children with DS	Experiences of mothers of children with DS.	Interviews	The mothers expressed concerns regarding acceptance and the difficulties with inclusive education for children with DS.
Starr et al., 2006	Parents of children with DS	This study aimed to identify parental satisfaction with education.	Interviews	Parents felt that teachers did not understand the nature of characteristics associated with specific disabilities.
Takataya, Yamazaki, Mizuno, 2016	Fathers of children with DS	Wanted to find out about the lives of families with children with DS.	Interviews	Fathers demonstrated upset that their child had been born with DS but had accepted their fatherhood.
Bhattacharya and Sidebotham, 2000	- Parents of children with DS - Doctors	This was looking at whether parents of children with DS view their child's level of disability differently from medical professionals.	Interviews	There are some areas of agreement regarding the children's difficulties. However, parents significantly differ from others in the assessment of how the different factors associated with DS impact the child's quality of life. Medical professionals could be patronising and limiting.
Lightfoot and Bond, 2013	Support staff and parents	Explored the factors which influence decisions about transition and what works well for those with DS.	Interview	Parents should be involved in transition planning and should recognise the needs of the individual child.
Cuskelly, Jobling and Buckley, 2002	Trainee Teachers	Looked at the attitudes towards trainee teachers towards education inclusion for children with DS.	Interviews	13% indicated that that they would welcome the opportunity to work in an inclusive environment and teach a child with DS.

Cuskelly, Jobling and Buckley, 2002	• Students • Doctors • Health visitors • Psychologists	Wanted to identify what these professionals knew about DS.	Questionnaire	Children with DS are believed to have some common identities whereas typically developing children are considered to have distinctive individual personalities.
Schwab, Huber and Gebhardt, 2016	Children in mainstream educational settings	They investigated the social acceptance of peers with DS and peers without DS.	Experiment	Those with DS were less socially accepted than those without a disability.
Gannon and McGilloway, 2009;	Children in mainstream educational settings	Wanted to explore children's attitudes towards peers with DS.	Questionnaire	The children's attitudes towards the inclusion of a peer with DS were negative.
Gilmore, Campbell and Cuskelly, 2003	The general public	Wanted to explore knowledge about DS and attitudes towards education.	Questionnaire	They identified significant misconceptions about the factors associated with DS, negative attitudes towards inclusion and unrealistic understanding regarding life expectancy.
Fox, Farrell and Davis, 2004;	School Staff	This study was looking at experiences of inclusion of children with DS in mainstream provision.	Interviews, focus groups and observations	The teacher needs to be fully involved in the child's education to ensure inclusion is successful.
Byrnes, 2012	Educational Psychologists	This looked at the role of the EP in engaging with parents and children with DS special educational needs during times of transition.	Interviews	When educational psychologists and parent groups work together this can have a positive impact on parental confidence.

