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Experiences of, and attitudes, towards growing up and adulthood: A comparative study of young people with and without mild intellectual disabilities

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Abstract

To some extent, 'adulthood' and 'adult identity' can be thought of as socially constructed phenomena, capable of evolving in response to societal consensus. For many typically developing young adults, the period that encompasses the transition to adulthood is thought to be elongating. In many ways, the traditional pathways to adulthood have eroded, leaving many young people feeling ambivalent about the process of growing up. Due to a combination of social and economic pressures and ideological shifts, young people are becoming increasingly likely to delay certain social role transitions, most notably marriage and parenthood, until their mid to late twenties and early thirties. Subjective adult identity, or *feeling* like an adult, is also thought to be taking longer to develop.

For young adults with mild intellectual disabilities and their families, however, the transition to adulthood stands to be even more complicated. Developmental delay and difficulties adapting to change can have the potential to make service transitions harder to adjust to. These experiences might also be exacerbated by the fact that options for purposeful daytime activity can be limited for members of this population. Moreover, pervasive narratives of risk and vulnerability necessarily compete with a number of the normative outcomes of transition, most notably the development of self-determination and independence. Concerns about safety and security may therefore prevent parents and service providers from providing opportunities for positive risk-taking and experimentation. This is even though such experiences can make vital contributions to personal development and maturation.

Through strategies such as *Keys to Life* and *More Choice, More Chances*, the Scottish Government has committed itself to help all young people to achieve positive transition outcomes. However, to date, there has been very little research undertaken to find out how young people with and without mild intellectual disabilities think and feel about the transition to adulthood, including their attitudes towards self-determination, independence, and autonomy. This thesis aimed to address this gap in the research by investigating young Scots' and their parents' experiences of, and attitudes towards growing up and adulthood.

Using a mixed-methods approach, including semi-structured interviews, interactive flashcard activities, a vignette, and a questionnaire, data from over 100 participants have been collected and analysed. Our findings suggest that, despite high variation in the levels of autonomy experienced by the participants, young people with and without mild

intellectual disabilities share complicated feelings towards the prospect of increased independence. Both groups, for example, hoped to work towards independence, albeit over different time frames, yet also voiced a degree of reluctance to adopt additional responsibility at home. The desire for an 'easy life', for example, appeared to be present in both groups, though genuine concerns about coping without support were more prevalent in the group with mild intellectual disabilities. Similarly, while attitudes towards parental support and interference were mostly positive in both groups, the majority of participants suggested that they would resist interference in personal, or private domains. However, there was some evidence to suggest that the young people with intellectual disabilities perceived the balance of power within their own families as more skewed towards their parents.

With regards to the nature of adulthood and adult identity, our findings corroborate previous claims that individuals conceptualise adulthood in ways that are relevant and achievable to themselves. We found tentative evidence, for example, that the young adults with intellectual disabilities may prioritise interpersonal dimensions of 'responsibility' - such as looking after other people and fulfilling one's familial obligations - as being the most salient criteria for adulthood. In contrast, the typically developing participants appeared to focus on more individualistic expressions of responsibility, such as self-sufficiency, personal responsibility, and independent decision-making.

Though speculative, our findings demonstrate that individuals with intellectual disabilities can have unique perspectives on universal phenomena that are not only interesting in their own right but may also have consequences for the broader literature. The implications of these findings for policy and practice are also outlined, as well as opportunities for future research.

Table of Contents

List of Tables

List of Figures

Appendices

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Author's Declaration

"I hereby declare that I am the sole author of this thesis, except where the assistance of others has been acknowledged. It has not been submitted in any form for another degree or professional qualification."

Emily Salt
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Chapter 1   Background; Adulthood and Adult Identity

1.1   Introduction

This thesis aims to provide greater insight into how young adults with borderline to moderate intellectual disabilities perceive and experience the transition to adulthood in comparison to their peers without disabilities. The research utilised a mixed-methods approach and included a range of data collection measures, including semi-structured interviews, interactive card-sorting tasks, a vignette, and a brief questionnaire. In total, over 100 young adults with and without disabilities and family members participated in the studies.

The purpose of this chapter is to provide an overview of the literature on adult identity and the transition to adulthood for young adults both with and without intellectual disabilities. The chapter will begin with a brief discussion about how intellectual disabilities are conceived and defined, which will be followed by a discussion of the nature 'identity'. As part of this, competing notions of disability will be critically examined, with particular reference to the strengths and weaknesses of the social model of disability. Sections 1.4.1 and 1.4.2 concern the key societal and subjective definitions of adulthood and adult identity. Section 1.4.3 will outline the salient implications of research into adult identity and the transition process. The chapter will conclude with an overview of research on the experiences and challenges of transitioning to adulthood for young people with and without intellectual disabilities and their families.

1.2   Defining 'Intellectual Disabilities'

Individuals with intellectual disabilities are defined as those whose levels of intellectual and adaptive functioning are considered low in comparison to the general population, and whose difficulties arise during childhood (AAIDD, 2010; The British Psychological Society, 2000). Intellectual functioning is typically used to refer to the capacity to reason, learn, problem-solve, and other such cognitive processes. In contrast, adaptive capacity refers to "the collection of conceptual, social, and practical skills that are learned and performed by people in their everyday lives" (AAIDD, 2010). Adaptive capacity therefore includes linguistic and numerical abilities, interpersonal skills, self-management, risk-awareness, and personal care, among others. Intellectual disabilities can be diagnosed

when an individual's IQ and adaptive behaviour scores, as measured by standardised diagnostic tests, are two or more standard deviations below the population mean (Boat & Wu, 2015). However, as adaptive capacity and IQ scores are both scale variables, intellectual disability represents a spectrum of ability. Furthermore, intellectual disabilities can be categorized using standard scores as 'mild' (69 – 50), 'moderate' (49 - 35), 'severe' (34 - 20), and 'profound' (20>) to help differentiate potential support needs (Whitaker, 2013).

The term 'intellectual disability' was introduced at the beginning of the 21st Century in the United States to replace 'mental retardation', which had come to develop highly hurtful and stigmatising connotations (Stavrakantonaki & Johnson, 2018). In the UK, the term 'learning disabilities' is most commonly used to refer to intellectual disabilities (E. Emerson & Heslop, 2010); however, practitioners and academics in the UK are increasingly likely to adopt 'intellectual disabilities' to conform with the internationally accepted nomenclature. In Scotland, individuals with intellectual disabilities account for approximately 0.5% of the total population (Hughes-McCormack et al., 2017), and 0.6% of school pupil children (Cooper, Henderson, Jacobs, & Smiley, 2016). Possible reasons for the reduction in prevalence between childhood and adulthood include attrition from specialist services, adults choosing not to identify as having an intellectual disability, as well as premature death (E. Emerson et al., 2012).

The aetiology of intellectual disability is varied. Causes may include chromosomal abnormalities, maternal factors (diet, some infections, etc.), metabolic disorders, and brain damage (Simonoff, 2015). Moreover, socio-ecological factors, such as childhood neglect (Strathearn, Gray, & Wood, 2001), poverty and deprivation are also thought to impact psychobiological development (Dickerson & Popli, 2016). However, for many individuals with intellectual disabilities, particularly those who experience milder levels of difficulty, no specific cause can be identified. It has been posited that in some cases, educational, racial, and ethnic bias in cognitive testing may explain why some individuals receive an intellectual diagnosis without the presence of a 'cause' (Boat & Wu, 2015). It is also possible that many individuals with diagnosed borderline to mild intellectual disabilities sit within the spectrum of normal human diversity.

1.3   Disability Identity

1.3.1 Overview of the identity construct

The term 'identity' is typically used to refer to a 'label' that has social and personal significance. An identity can be both self-ascribed and prescribed by other people and can carry both positive and negative connotations. 'Identity' has come to be used within a variety of academic and non-academic contexts and is often assumed not to require explanation, even though the word can be difficult to define (Fearon, 1999). The origin of the term as typically used today is attributed to Erik Erikson, who adopted 'identity' to refer to the beliefs, values, and ideals that motivate and shape an individual's behavioural tendencies. This 'personal identity' is an individual's enduring sense of self that develops during adolescence in response to their experiences and interactions, and lasts throughout their lifetime (Erikson & Erikson, 1998).

The concept of identity has since grown to include different types of identities, such as impermanent adopted identities ("I'm a Gryffindor!") and socially prescribed identities ("You are such an X"). For this reason, identity may now refer to two distinct, yet related concepts: 1) how an individual defines themselves, and 2) how an individual is defined by others (Deng, 1995). Referring to these as personal and social categories of identity respectively, Fearon (1999) has suggested that social categories are applied to individuals who exhibit certain behaviours or characteristics, and in so doing, meet the criteria for membership to a particular social group or community. In contrast, personal categories are labels that are either unchangeable and socially consequential, or chosen by the individual as an expression of an aspect of themselves that is a source of pride, dignity, or self-respect.

The relationship between these two classes of identities can be complex. Social categories may be incongruous with an individual's internal sense of self, for example (Goffman, 1963). In such cases, the social identity (e.g. 'woman', 'homosexual', 'doctor'), or its connotations ('girly', 'camp', 'upright citizen') may influence how individuals are perceived and treated by others, even when the individuals themselves reject those labels and/or connotations. Similarly, an individual may identify with a social group despite failing to exhibit the characteristics typically considered to be necessary for group membership, such as those who identify as transgendered, transracial, or trans-abled (Baril, 2015; Brubaker, 2016). Moreover, traditionally stigmatising social identities can in some

cases become 'reclaimed' by members of the relevant group and adopted as positive personal categories (Bagatell, 2010). Examples include the Lesbian, Gay, Bisexual and Trans (LGBT) and Afro-American communities in America, as well as certain disability communities, who take pride in their identities despite facing continued social marginalisation.

1.3.2 Disability as a Social Identity: Varying Models of Disability

In many ways, 'disability' represents a useful lens through which to understand the inherent complexities of social and personal identity formation. Prima facie, the criteria for 'group membership' are straightforward. Under the Equality Act (2010), an individual is considered to have a disability if they have a "physical or mental impairment that has a substantial and long-term negative effect on their ability to do normal daily activities". However, beliefs differ as to what constitutes the 'origin' of disability, which in turn stands to affect how the label is applied and to whom.

The 'social model of disability', for example, postulates that 'disability' is a product of social infrastructure, rather than the result of an individual's impairment or difference (Oliver, 1996). Advocates of the social model reject the notions that impairment either *is* the disability, or *results* in the disability by preventing individuals from participating in society. Rather, the social model suggests that it is society that *disables* individuals by erecting barriers to their participation (C. Thomas, 1999). In line with this perspective, a number of disabled activists, unions, and organisations have opted to redefine 'impairment' and 'disability' to clarify the distinction between the two concepts:

> *Impairment*: 'The functional limitation within the individual caused by physical, mental, or sensory impairment.'
>
> *Disability:* 'The loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers' (DPI, 1982, cited in Thomas 1999).

The argument that intellectual disability is a social construction is evidenced not only in theory but also in practice. Before the industrial revolution, the majority of the population were unable to read or write and found social and economic participation through industries (farming, fishing etc.) that did not typically require high levels of cognitive ability. However, the intellectual and adaptive abilities required for participation today, both in employment and leisure, are becoming more demanding (Whitaker, 2013). Some

argue that these societal changes have resulted in some individuals becoming classified as having an intellectual disability who would historically have been considered 'able' (Goodey, 2011; Whitaker, 2013).

Additionally, proponents of the social model of disability have suggested that while some barriers have naturally arisen as a result of industrialization and social evolution, others have been deliberately created to prevent people with low intellectual functioning from social participation. Psychologists such as Henry Goddard, for example, perpetuated the view that 'the subnormal' were morally deviant and responsible for many of society's ills (Goddard, 1919), and ought to be institutionalised to prevent reproduction and protect society (Goddard, 1912, p. 101). In the UK, these views are no longer considered acceptable; however, evidence suggests that both social attitudes and behaviour towards individuals with low intellectual functioning have remained negative (Mencap, 2016a). Both in Britain and across the globe, stigma, alienation, and disability-specific discrimination continue to affect individuals with intellectual disability and act as barriers to participation in many areas of life (Diez, 2010; Gilmore & Cuskelly, 2014; K Scior, Potts, & Furnham, 2013; Wolfensberger, 2000).

However, the social model has been criticised for overlooking or over-simplifying a number of the hardships experienced by many individuals with disabilities. The subjective experience of impairment, for example, cannot easily be accounted for by the social model of disability (Morris, 1991). As suggested by medical sociologist Michael Bury, the social model "can easily gloss over social realities and reduce complexities" of the difficulties that "the vast majority of disabled people" face (Bury, 1997, p. 138). Though the medical model of disability to which Bury subscribes can be criticized for assuming that 'impairment' is the antecedent of disability, its proponents argue that it offers a more sympathetic view from which more supportive policies can be derived.

Proponents of the social model, for example, may find it challenging to justify disability and carer welfare payments if the obstacles to employment are considered to be exclusively manufactured by society (C. Thomas, 1999). Furthermore, the suggestion that all impairments can be "solve[d] by social manipulation" (French, 1993, p. 17) does not easily account for the experiences of individuals with profound disabilities, who are unable eat, move, or communicate without trained assistance. Therefore, while the social model of disability has a vital role to play in raising awareness of the social oppression experienced

by individuals with disabilities, it fails to account for a number of the hardships experienced by those same individuals.

1.3.3 Disability as a Social Identity: Attitudes within society

In many ways, the social status of 'disability identity' is difficult to ascertain. One reason for this is that public attitudes have been shown to differ between different disability types, with physical disabilities viewed more favourably than mental disabilities (A. Thomas, 2000; Tringo, 1970). Evidence suggests that 'intellectual disability' in particular remains highly socially stigmatised (Diez, 2010; Gilmore & Cuskelly, 2014; K Scior et al., 2013; Wolfensberger, 2000). Several explanations for this have been posited. As social animals, human beings may have evolved to stigmatise individuals who are perceived as failing to make a sufficient contribution to the good of 'the group' (i.e. society) (Neuberg, Smith, & Asher, 2000). With the shift towards mechanisation and the rise of the service economy, the most valued contributions to society are increasingly likely to require cognitive, rather than manual abilities. This shift may explain why intellectual disabilities are viewed less favourably than physical disabilities (Katrina Scior, 2016). Another possible explanation for the stigma towards individuals with observable characteristics (Down's syndrome, cerebral palsy etc.) may stem from the primal fear of disease (Park, Faulkner, & Schaller, 2003). Although intellectual disabilities are known not to be infectious or transmissible, evolutionary instincts of this nature may be particularly difficult to overcome.

Regardless of the underlying justification, the stigma surrounding intellectual disability can have profoundly adverse effects for individuals and their families. Members of this population are at higher risk of abuse, victimisation and bullying than typically developing individuals, for example (Christensen, Fraynt, Neece, & Baker, 2012; Thornberry & Olson, 2005). Results from a focus group study suggest that negative attitudes within the community were a significant barrier to social inclusion as perceived by a group of adults with intellectual disabilities (Abbott & McConkey, 2006). Moreover, in a qualitative study involving 28 individuals with mild to moderate intellectual disabilities, Jahoda and Markova (2004) found that the participants were acutely aware of having faced stigma and discrimination. Therefore, several of the participants chose to distance themselves from their disability identity, such as by presenting themselves as 'superior' to their peers, adopting a typically developing public persona, and only mixing with non-disabled individuals.

The prescribed social narrative surrounding intellectual disability has nevertheless become more positive than it once was. In opposition to the 'moral deviancy' view propounded by Goddard and others, perspectives have shifted towards highlighting individuals' need for help and support (Katrina Scior, 2003). While too great an emphasis on help and support has the potential to become patronising or paternalistic, the change may nevertheless be considered well-meaning (Gallagher, 2002; S. Young, 2013). Promoting tolerance and acceptance of difference, for example, have become enshrined in Government policies such as *Valuing People* in England and Wales, and *Keys to Life* and *The Same as You?'* in Scotland.

It should also be noted that individuals with disabilities are becoming increasingly visible in the media for positive reasons. Events such as the 2012 London Paralympic games and the 2014 Commonwealth Para-Sport games, television programmes such as 'The Last Leg', and the increasing number of actors with disabilities cast in films have been attributed with making significant contributions to positive disability identity (Giuffre, 2014). Moreover, the rise of disability rights advocacy has resulted in a backlash against many common forms of disability-specific prejudice ('ableism'). Pejorative terms for both physical and intellectual disabilities, for example, have become socially unacceptable within most strata of UK society.

Despite such positive strides, there are grounds for thinking that some individuals with disabilities may be unable to benefit from these changes. The general public appears to have relatively low confidence about how to interact with individuals with disabilities, for example. In a recent poll, Scope found that the majority of UK citizens felt 'uncomfortable' talking to individuals with disabilities for fear of saying something patronising or offensive, with 1/5 of young adults having deliberately avoided encounters with disabled people as a result (Aiden & McCarthy, 2014). As individuals with disabilities are already at increased risk of loneliness (Department of Health, 2009; Gilmore & Cuskelly, 2014), factors that exacerbate the risk of social isolation are of particular concern.

There is also some evidence that individuals with 'invisible disabilities', including many people with milder intellectual disabilities, are viewed less favourably and are at greater risk of maltreatment than people with clearly observable characteristics (Dorozenko, Roberts, & Bishop, 2015; Mcmanus, 2010). One possible explanation for this is that the label of 'disability' alters the social narrative around the perceived blameworthiness of an

individual's actions. People who have undiagnosed emotional, social, or behavioural difficulties, for example, may be treated as being 'weird' or 'rude' because their behaviours are assumed to be deliberately antisocial. In contrast, individuals with a diagnosis (e.g. autism), or who have observable characteristics of 'disability' (e.g. Down's Syndrome) may to some extent be considered 'faultless' in their actions (i.e. "it isn't *her*, it's her *condition*"), and thus deserving of forgiveness, sympathy, and tolerance.

Yet, it is also possible that in some cases, public displays of tolerance towards people with disabilities may be motivated by either the fear of appearing prejudiced or the desire to appear compassionate, rather than by the genuine acceptance of diversity. Anecdotal reports suggest that 'behind closed doors', people with disabilities are more likely to be the victims of bullying, cruel humour, and exclusion, even though these behaviours have been labelled 'socially unacceptable'. Moreover, critics have suggested that the comparably limited global response to the 2016 'Sagamihara Stabbings'[1] in Japan could be explained by widespread indifference towards people with intellectual disabilities (Findlay, 2016; Roberts, 2016). Consequently, while the societal narrative around intellectual disability may be improving, it remains possible that a significant proportion of the population continues to harbour less positive beliefs in private.

1.3.4 Disability as a Personal Identity

Despite the stigma, strides have been made in helping many individuals with disabilities take ownership of their status and reclaim 'disability' as a positive and empowering identity. The Deaf community, for example, has a unique language, identity, and culture, and many of its members wish for to see it receive the same rights and status as any other socio-linguistic minority group (McIlroy & Storbeck, 2011). Consequently, there are factions within the Deaf community who consider aural interventional surgeries, most notably cochlear implants, to be a form of 'cultural genocide' (Balkany, Hodges, & Goodman, 1996). While this position remains controversial (Mack, 2002), it nevertheless serves to illustrate how powerful disability identities can become.

In a review of the literature, Dunn and Burcaw (2013) identified six overarching themes present within the narratives surrounding positive personal disability identity:

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[1] Forty-four adults with intellectual disabilities were violently attacked at a facility in Sagamihara, Japan, 19 of whom lost their lives.

1. Communal attachment (feeling part of a community)

2. Affirmation of disability (believing in the right to be treated equally with individuals without disabilities)

3. Self-worth (believing oneself to have the same worth as people without disabilities)

4. Pride (claiming one's disability identity rather than hiding it)

5. Awareness of discrimination (accepting that prejudice exists in society)

6. Personal meaning (finding the benefits of disability)

While it may be possible to experience some of these positive aspects of disability identity independently of one another, in practice, they typically overlap and reinforce one-another to protect individuals from the adverse effects of social marginalisation (Tajfel & Turner, 2001). Moreover, helping individuals with disabilities to form a positive disability identity may also play a role in combatting the stigma itself. Evidence from within other historically marginalized groups suggests that stigmatised identities can be reclaimed and reframed in a positive light (Galinsky et al., 2013; Rand, 2014). Movements such as Gay Pride, tactical use of social marketing, and the manipulation of other social forces have facilitated the LGBT+ community to re-appropriate their image, which has contributed to a striking shift in social attitudes towards queer issues (Fetner, 2016; Witeck, 2014).

A similar trend can also be found within some regions of the Autism community. Awareness of autism and its associated characteristics has increased substantially over the past couple of decades (Dillenburger, Jordan, McKerr, Devine, & Keenan, 2013). Though misconceptions about autism persist (Ambitiousaboutautism.com, 2017), the diagnostic label of 'autism' has arguably become more socially salient, and individuals with known autism are increasingly finding a sense of identity and belonging through participation in online communities (Bagatell, 2010; Davidson, 2008). Efforts to 'de-medicalise' autism are also gaining traction. The neurodiversity movement aims to challenge the assumption that autism spectrum disorders require 'treatment', and instead promotes and celebrates autism as a valued identity (Kapp, Gillespie-Lynch, Sherman, & Hutman, 2013). Particularly amongst high-functioning individuals, proud self-identification as an 'Aspie'

is becoming increasingly common, and several celebrities, including Chris Packham, Dan Ackroyd and Daryl Hannah have recently 'come out' of the Autism 'closet'.

Importantly, stigma continues to prevent many individuals with disabilities from achieving a positive disability identity. According to Social Identity Theory, members of stigmatised groups have a range of strategies available for coping with their marginalised position, which include choosing to embrace their status as a 'badge of honour' (A.K.A 'the Aspies'), or, if possible, to conceal it and attempt to 'pass off' as a member of the dominant group (Tajfel & Turner, 2001). For many people with disabilities, repeated exposure to negativity and rejection have been posited as equally if not more disabling than structural barriers (C. Thomas, 1999). Consequently, it is unsurprising that a recent report by Scope found that 38% of individuals with disabilities interviewed felt compelled to hide, rather than reveal their disability status (Scope, 2016). Similarly, as suggested, some individuals with intellectual disabilities have been shown to attempt to evade the effects of stigma by creating a typically developing public persona (Jahoda & Markova, 2004). However, this strategy may be much harder to employ for individuals who are, for whatever reason, unable to conceal their impairments.

Particularly for individuals with intellectual disabilities, positive disability identity may be difficult to achieve. As suggested, intellectual disabilities appear to be viewed less favourably by society than other forms of disability (A. Thomas, 2000). There are also anecdotal reports that individuals with intellectual disabilities may even feel excluded from certain aspects of disability culture (Mencap, 2016b, 2018). It is important to acknowledge, for example, that while autism can become a protective identity, reactions to receiving an autism diagnosis are often negative (G. Jones, 2001; Macleod & Johnston, 2007). In part, this may be explained by differences in the social status of individuals with high and low functioning autism. Reports suggest that many self-proclaimed 'Aspies', for example, have resisted the new diagnostic category of 'Autism Spectrum Disorders', as they do not wish to be associated with the intellectual and communication difficulties associated with classical Autism (Linton, Krcek, Sensui, & Spillers, 2014). Consequently, positive disability identity may in some cases be harder for individuals with intellectual, rather than physical or social disabilities, to attain.

1.4   Adult Identity

Much like disability identity, adult identity also can be thought of as having social and personal dimensions. Questions such as 'am I an adult?' may be answered by assessing oneself against certain socially accepted criteria for 'adulthood' as well as by determining the extent to which that individual feels like, or considers themselves to be, an adult. However, there is a surprising lack of literature about how they relate to one-another (Benson & Elder Jr., 2011; Eliason, Mortimer, & Vuolo, 2015). The following section will provide an overview of the different categories of criteria that can be used to determine adult status.

1.4.1 Criteria for Adulthood

1.4.1.1 Adulthood as Sexual Maturity

Within the biological sciences, 'adulthood' is typically used to refer to an organism having reached sexual maturity, as evidenced through reproductive capacity (e.g. menarche and ejaculation) and the development of secondary sex characteristics. In humans, these include but are not limited to: the growth of body hair; facial and bodily shape changes; voice deepening (in males), and genital enlargement. From the biological perspective, the 'transition to adulthood' is equivalent to the period known as 'puberty', which typically begins between the ages of 10 and 13. However, the onset and duration of puberty is not fixed, and it is believed that nutritional, environmental, and genetic factors can influence this process (Parent et al., 2003).

There is evidence, for example, that precocious (early-onset) puberty is becoming increasingly prevalent. Researchers have posited that the rise of childhood obesity may be a contributing factor, as having a higher percentage of body-fat is associated with elevated oestrogen levels (Burt Solorzano & McCartney, 2010). There is also some evidence to suggest that high levels of emotional stress in childhood may be associated with precocious puberty, particularly in girls (Živka & Irena, 2000). As will be discussed in Section 1.4.1.3, these trends are particularly interesting in light of the fact that young people appear to be taking longer to self-identify as adults (Arnett, 2000). Consequently, it appears that the divide between the biological and social definitions of adulthood may be widening at both ends.

1.4.1.2 Adulthood as the 'Age of Majority'

Legal adulthood, or the 'age of majority', is conceptualised as the time at which parents relinquish their legal rights and responsibilities for their children. The age of majority differs between countries, ranging from as young as 15 (Saudi Arabia) to as old as 21 in the United States and several African, Middle Eastern, and East Asian countries. Importantly, the age of majority should not be conflated with the age at which legal permissions, such as the rights to vote, drink alcohol, or marry, are granted to a young person. In Scotland, for example, young people become legal adults at the age of 16 and are therefore considered to be sufficiently mature to give consent, as well as to be tried as an 'adult' within the criminal justice system. However, while 16-year-olds are free to vote in Scottish elections, many other legal permissions and rights are delayed until 17 (driving), 18 (drinking alcohol, smoking, voting in national elections), and even 25 (right to receive full minimum wage).

In specific contexts, the legal application of adult status can differ from these age norms. Capacity and maturity form integral parts of how, and to whom, specific laws are applied. In the UK, children younger than 16 can consent to some medical procedures without parental knowledge or interference if they can demonstrate sufficient maturity, competence, and understanding ('Gillick competence') (Griffith, 2016). Moreover, legal adults who are deemed to lack capacity, either through incompetence, intoxication, or loss of consciousness, can have their wishes and decisions overridden by power of attorney, or by medical professionals involved in their care.

1.4.1.3 Adulthood as Social-Role Change

In his seminal work on psychosocial life-stage development, Erik Erikson (1950) conceptualised the transition to adulthood ('adolescence') as the period from the start of puberty until the late teenage years. This developmental stage was characterised by identity 'crisis', throughout which young people explore themselves and attempt to determine their place in the wider world. The period was thought to conclude with the resolution of this internal conflict through the crystallisation of identity and the adoption of 'adult' social roles: leaving education, gaining employment, marriage, and parenthood. This work has been highly influential on how adulthood is commonly conceived, and many sociologists and social psychologists continue to consider social role changes (sometimes referred to as 'life-stage markers') to be the most salient indicators of an adult identity (Brzezinska & Piotrowski, 2013).

However, it is essential to acknowledge that the socio-demographic context within which Erikson developed his model has changed considerably. In the 1950s, age norms (the socially-prescribed order and timing of life-stage markers) were relatively strict, with the majority of individuals leaving education, getting married, and having children by their late teens and early twenties (Arnett, 2007). Those who failed to achieve these social role changes within the accepted time frame, or in the appropriate order, were to some extent socially marginalised. Both the 'spinster' and the 'unmarried mother' were historically stigmatised statuses, for example, and were "used as warnings to women who might be tempted to challenge social norms" (Fink & Holden, 1999, p. 233). Similarly, fatherhood and employment have traditionally been inexorably linked to notions of masculinity, such that men who failed to find work or father children may have been denied the status attributed to "real men" (Willott & Griffin, 1997).

Over the past few decades, however, notable changes have been observed in how young adults lead their lives. Globally, young men and women are staying in full-time education longer, delaying or rejecting marriage and parenthood, and choosing non-traditional structures of employment (Arnett & Padilla-Walker, 2015; Billari, 2004; Bynner, 2005). Consequently, the traditional pathways that used to characterise the transition to adulthood have, in many ways, eroded (Benson & Elder Jr., 2011; Mortimer, Oesterle, & Kruger, 2005). Numerous explanations have been put forward to explain these changing trends, including generational attitude changes towards work and family life (Arnett, 2000, 2007; Nelson & Luster, 2016), changing social expectations (Mortimer et al., 2005), and the rise of unfavourable economic and infrastructural pressures (Bynner, 2005; Côté & Bynner, 2008; Furstenburg, Kennedy, McCloyd, Rumbaut, & Settersen, 2003). However, regardless of the reasons motivating these changes, there is some evidence to suggest that this may be contributing to a paradigm shift in how adulthood is defined and understood, particularly in English-speaking countries.

1.4.1.4 Adulthood as Psychosocial Maturity

More recent research into Western conceptions of adulthood has revealed that social role changes may no longer be considered as necessary for the attainment of adult status as they once were. Marriage and parenthood, in particular, appear to have lost their status as fundamental criteria for adulthood, potentially having been replaced by psychosocial indicators of maturity and independence (Arnett, 1997, 2001; Nelson & Barry, 2005; Nelson & Luster, 2016).

To some extent, psychosocial maturation has always played a vital role in the attribution of adult status. The move from being dependent children to independent, autonomous adults formed a critical part of Erikson's model of adolescent identity formation, for example (Erikson, 1950). Moreover, American psychologist Ellen Greenberger cited the development of autonomy (self-reliance, work orientation, identity) and social responsibility (social commitment, openness to socio-political change, tolerance of individual and cultural differences) as critical normative outcomes of the transition process (Greenberger, 1984). However, the possibility that independence and maturity have become *more* important criteria for adulthood than social-role changes is a more recent development. In a very influential paper on the social definitions of adulthood, Arnett (1997) found that American college students considered independent decision-making, accepting responsibility for oneself, and financial independence (hereafter "The Big Three") to be the three most important criteria for adulthood. Subsequent research in similar populations has substantiated these findings, with individual characteristics of maturity seemingly taking precedence over social role transitions or life-stage markers (Arnett, 2001; Arnett & Padilla-Walker, 2015; Lowe, Dillon, Rhodes, & Zwiebach, 2013; Nelson & Barry, 2005; Nelson & Luster, 2016).

It is, however, important to acknowledge that these findings are not universal. In a study on attitudes towards adulthood amongst migrant women in China, for example, the most salient criterion was 'learning to care for parents' (Zhong & Arnett, 2014), while young adults in India prioritised emotional self-control, fulfilment of gender roles, and abiding by social norms (Seiter & Nelson, 2010). Moreover, social role transitions do not appear to have been neglected completely. In Arnett's original study, 486 participants aged between 18 and 28 from a range of were given 40 transition criteria and asked to indicate whether or not they thought that each criterion was necessary for adulthood, or unnecessary. Despite individual characteristics taking precedence, marriage was still considered to be a necessary criterion of adulthood by about 16% of participants, and parenthood by 13% (Arnett, 1997). Moreover, it should be noted that this was a predominantly Caucasian sample and that individuals from Latino, African American, and Asian American backgrounds have been found to place even greater emphasis on social role transitions (Arnett, 2003).

Similarly, there is some evidence that definitions of adulthood may change as individuals age, with social role transitions taking greater precedence amongst those who have experienced them (Arnett, 2001; Lowe et al., 2013). It should also be noted that questions

have been raised concerning the validity of the measures used in studies concerning the definitions of adulthood (Lowe et al., 2013). Studies utilising qualitative methods, for example, have found that individuals sometimes break-down the roles and responsibilities of adulthood differently from how they are presented in many of the established check-lists (Molgat, 2007). Nevertheless, within America and Western Europe, the evidence still suggests that independence and psychosocial maturity are making increasingly significant contributions to how, and to whom, adult status is ascribed.

1.4.1.5 Parallels with Functional Self-Determination

In many ways, the construct of self-determination is mirrored in these psychosocial characteristics of adulthood. Individual-level self-determination is generally accepted to be the embodiment of causal agency, such that an individual may be considered the author of his or her actions (Bandura, 2001). Self-determination does not require that an individual must 'go it alone,' or become entirely self-sufficient, but instead that they exert significant influence over their life trajectory (Wehmeyer, Kelchner, & Richards, 1996). A self-determined individual makes choices and decisions regarding their quality of life without undue external influence or interference (Wehmeyer & Bolding, 2001), and as such, is assumed to possess the "combination of skills, knowledge, and beliefs that enable [that] person to engage in goal-directed, self-regulated, autonomous behaviour" (S. Field, Martin, Miller, Ward, & Wehmeyer, 1998a, p. 2).

According to the functional model of self-determination, in particular, self-determined behaviour is identified by four characteristics: behavioural autonomy, self-regulation, psychological empowerment, and self-realisation (Wehmeyer, 1999). The parallels between these aspects of self-determination and the qualitative characteristics of psychosocial maturity are notable. Behavioural autonomy, for example, is conceptualized by Wehmeyer as "the outcome of the process of individuation" and encompasses "actions in which people act a) according to their preferences, interests, and/or abilities; and b) independently, free from undue external influence or interference" (1999, p57). It is a proactive quality that can only be inferred from an individual's behaviour, rather than from their attitude alone. Psychological empowerment refers to an individual's perceived control over cognitive (personal efficacy), personality (locus of control), and motivational domains (Wehmeyer, 1999; Zimmerman, 1990). As belief in one's own autonomy is underpinned by the corresponding belief that one can exert control over one's life, the relationship between psychological empowerment and maturity may be considered self-evident.

Self-regulation refers to a collection of specific behaviours and skills associated with mature self-management (Wehmeyer, 1999). Examples include self-monitoring, self-instruction, self-evaluation, and self-reinforcement, as well as problem-solving, decision-making, goal setting, and observational learning skills (Agran, 1997). These behaviours also provide substantial justification for the belief in one's own efficacy and autonomy (Wehmeyer & Palmer, 2003). Finally, self-realisation concerns the capacity to know and accept one's own strengths and limitations and to choose to act accordingly (Wehmeyer, 1999). As self-realized individuals know themselves and are capable of mature self-reflection, it is likely that they will also be effective independent decision-makers (Wehmeyer & Schwartz, 1997), drawing another link between self-determination and maturity.

Consequently, while the two constructs remain distinct, self-determination can be used as a useful shorthand to capture much of what successful transition amounts to in 21st-century western cultures. As such, it is unsurprising that self-determination - and its associated constructs - are frequently cited as important and desirable outcomes of the transition process, particularly for individuals with intellectual disabilities (Clark, Olympia, Jensen, Heathfield, & Jenson, 2004; Dyke, Bourke, Llewellyn, & Leonard, 2013; S. Field et al., 1998a; Kilcommons, Withers, & Moreno-Lopez, 2012; Mill, Mayes, & McConnell, 2010; Mitchell, 2012).

1.4.1.6 Summary of the Research on the Criteria for Adulthood

'Adulthood' is a complex and multifaceted construct that remains hard to define categorically. For many individuals, intuitions about adult identity and adult status are likely to be mixed, based on a combination of psychosocial, biological, legal, and experiential factors (Kirkpatrick Johnson, Berg, & Sirotzki, 2007; Lowe et al., 2013; Molgat, 2007; Shanahan, Porfeli, Mortimer, & Erickson, 2005). Arguably, functional self-determination has value as a descriptor of adulthood and may also predict several desirable outcomes independently associated with the transition process. However, as suggested, individuals may exhibit the characteristics required for membership to a particular social group without personally identifying as such. Evidence suggests that mature, independent individuals in their twenties, for example, can continue to reject their adult status, even after the achievement of life-stage markers (Nelson & Luster, 2016). Therefore, subjective adult identity represents a distinct aspect of the transition process that will be discussed in the following section.

1.4.2 Subjective Adult Identity

Much of the work on adult identity development is said to have been influenced by neo-Eriksonian psychologist James Marcia. Marcia's Identity Status Theory suggests that specific elements of an individual's experience, such as their occupation, political and religious beliefs, and general world-view interact to form the basis of their unique personal identity (Marcia, 1966). As with Erikson, Marcia maintained that adult identity only develops in response to a 'crisis' (a period of intense self-exploration) that occurs during the mid-teenage years, and that, once formed, personal identity remains fixed and stable throughout the life-course. However, subsequent research has since revealed that personal identity is a highly complex and dynamic phenomenon that depends upon a range of internal and external processes (Kroger, 2007).

Failure to develop a subjective adult identity by the late teens or early twenties is no longer considered to be indicative of delayed or problematic development (Nelson & Luster, 2016). There is mounting evidence that, while 'child' identity is still most likely to end during the mid-teenage years, subjective adult identity is now more likely to develop during the mid-to-late 20s and early 30s, mirroring the delays to marriage, employment and parenthood discussed in Section 1.4.1.3 (Arnett, 2007, 2016; Benson, Kirkpatrick Johnson, & Elder Jr., 2012; Côté & Bynner, 2008; Kirkpatrick Johnson et al., 2007; Kroger, 2007; Nelson & Barry, 2005; Nelson & Luster, 2016; Shanahan et al., 2005). Consequently, the majority of people in their late teens and early 20s consider themselves to fall somewhere in between a 'child' and an 'adult.'

Importantly, the correlation between delayed social role transitions and delayed subjective adult identity may appear to undermine the argument that 'adulthood' is increasingly defined using psychosocial criteria. However, as will be explained across the following sections, the relationship between adulthood criteria and subjective adult identity appears to be highly complex.

1.4.2.1 Emerging Adulthood

In response to the aforementioned changing demographic trends, it has been suggested that traditional life-course models may no longer reflect the most commonly experienced developmental pathways. Jeffrey Arnett, for example, recommends reframing this period as a new and distinct life-stage called 'Emerging Adulthood' that is characterised by having the freedom of adulthood without the accompanying responsibilities (Arnett, 2000,

2007, 2016). According to Arnett, young people are increasingly likely to *choose* to delay role transitions such as marriage, parenthood, and full-time employment in order to explore themselves and to develop the personal qualities associated with psychosocial maturity. Consequently, it is suggested that subjective adult identity is only likely to develop once the Big Three criteria for adulthood (independent decision-making, accepting responsibility for oneself, financial independence) have been achieved, which is said to occur during this emerging adulthood period.

The theory of emerging adulthood has, however, been subjected to a range of criticisms. The possible existence of an interim period between childhood and adulthood, for example, is not a new idea. Stanley Hall suggested that 'adolescence' could be extended to individuals as old as 25 (S. Hall, 1904), and European sociologists were discussing the possibility of a 'post-adolescence' phase in the 1980s (Bynner, 2005). Furthermore, theories of discontinuous development (life-stages) are to some extent designed to be *prescriptive* as well as descriptive, such that the failure to achieve each stage at the right age may be thought of as abnormal or problematic. If emerging adulthood represents a new and distinct stage on the life-course model, young people who never experience the period of 'freedom-without-responsibility' may be thought of as developmentally atypical.

Evidence also suggests that the experiences associated with emerging adulthood are much more prevalent amongst white, middle-class individuals than those with non-white ethnic heritages or lower socio-economic statuses (Côté & Bynner, 2008; Kirkpatrick Johnson et al., 2007). In Europe, for example, the timing of transition appears to be influenced by institutional factors (how the school to post-school transition is handled) as well as structural factors (class, gender, ethnicity, locality etc.). As suggested by Bynner, "those who have the most to start with extend their transition the longest" (2005, p. 372). Consequently, it would arguably be inappropriate to conclude that emerging adulthood should be considered a *normative* part of the development process if only the most affluent members of society can only experience it..

It has also been suggested that the trend towards delaying transition may reflect younger generations' means of coping with increasingly unfavourable economic conditions. Poor youth labour market activity, stagnant wage inflation, and the rise of unaffordable housing, for example, are all factors that encourage young people to live at home and remain financially dependent on their parents for longer (Côté & Bynner, 2008). Similarly, Mortimer et al. (2005), have suggested that the inherent reward-punishment nature of

society's institutional structures force young people to delay or reject some life-tasks (i.e. parenthood interrupts career progression) and elongate others (i.e. staying in education = better job). From this perspective, the observed changes to how adult identity is perceived and experienced may be better explained as temporary adaptations to unusually challenging social and economic circumstances, rather than permanent changes to the developmental life-course.

1.4.2.2 Social context and subjective age identity

Arguably, the most significant criticism of the 'emerging adulthood' literature is that the impact of social context, norms, and values on the development of age identity has largely been overlooked in favour of establishing when the period of transition begins and ends (Bynner, 2005). Subjective age identity is thought to develop through social interactions and comparisons with significant others, regulated by an individual's social context and cultural norms. As a result, subjective age identities appear to be influenced by how well an individual keeps pace with the determined 'schedule', rather than their chronological age (Benson & Elder Jr., 2011).

Support for this can be found in the fact that different social groups have been shown to develop subjective adult age identity at different rates. Kirkpatrick-Johnson (2007), for example, found that Afro-Americans were significantly more likely feel adult all of the time in comparison to individuals from other racial backgrounds, and that lower levels of economic privilege were also associated with feeling older. One explanation is that life-stage markers have been shown to act as catalysts for the development of a subjective adult identity in some cases. Evidence suggests that children and adolescents growing up with higher levels of economic deprivation are both more likely to take on greater levels of financial and household responsibility (Elder Jr., 1999), for example, which may explain why they typically feel older at an earlier age (Benson & Furstenburg, 2007).

Importantly, an individual's social and personal context may also *moderate* the relationship between life-experiences and subjective age identity. Finishing school, for example, was shown to be comparatively more significant to women from working-class backgrounds than middle-class backgrounds because of the different social expectations regarding the education (Aronson, 2008). Similarly, Kirkpatrick-Johnson et al. (2007) found that getting married and having children were associated with feeling older amongst individuals from more privileged backgrounds, possibly because those who did so were

'ahead of the curve' relative to their peers. Age is also thought to impact the relative importance of social role transitions. Leaving school, getting married, and entering employment, for example, have been shown to make more significant contributions to younger individuals' age identities than to older individuals (Kirkpatrick Johnson et al., 2007). Interestingly, this may be explained by the fact that the relationship between transition experiences and subjective age identity appears to be affected by how many other social role transitions have been experienced (Eliason et al., 2015).

Furthermore, in contrast to the view propounded by Arnett, there is some evidence to suggest that life markers can impact subjective age identity even when the individuals in question do not consider those experiences to be essential criteria for adulthood (Kirkpatrick Johnson et al., 2007; Shanahan, Porfeli, Mortimer, & Erickson, 2005). As suggested, there is evidence to suggest that young people no longer consider marriage and parenthood to be necessary for the attainment of adult status (Arnett, 2001; Nelson & Luster, 2016). Yet, individuals who get married and have children self-identify as adults more often than those who have not yet done so (Kirkpatrick Johnson et al., 2007). Nevertheless, parental support often reduces once a young person marries (Swartz, Kim, Uno, Mortimer, & O'Brien, 2011); therefore, it is likely that the relationship between social role changes and subjective adult identity is even more complicated and multifactorial than this.

The confluence model of age identity, for example, posits that psychosocial maturity and social role transitions interact with one another and with each individual's life experience to form the basis of their subjective adult identity (Shanahan et al., 2005). From this perspective, research that focuses on only one of the two dimensions, such as Arnett's focus on personal qualities only, will inevitably paint an incomplete picture of an individual's development. Instead, it is important to acknowledge that social role changes may spur on the development of maturity and vice-versa (Brzezinska & Piotrowski, 2013; Kirkpatrick Johnson et al., 2007; Lowe et al., 2013). Consequently, the development of age identity is, arguably, better understood as a transactional process that occurs between these factors, moderated by the personal and social context of the individual.

1.4.3 Implications of Adult Identity Research

It is well established that personal and social identities have the potential to make significant contributions – both positive and negative – to mental health and wellbeing

(Quinn & Earnshaw, 2013; Thoits, 1999). However, the relationship between mental health and *age* identity has, to some extent, been neglected in the literature (Kirkpatrick Johnson et al., 2007). There is some evidence that age-identity can influence health outcomes (Logan, Ward, & Spitze, 1992; Mortimer & Aronson, 2000), although the majority of this research has focussed on age-perceptions in older populations (Keyes & Westerhof, 2012; Westerhof & Barrett, 2005).

Of the research undertaken to date, the relationship between age identity and wellbeing amongst younger adults appears to be complex. Research on the positivity or negativity of having an age identity that is older or younger than one's actual age, for example, is mixed. Benson, Kirkpatrick Johnson, and Elder (2012) used data from the longitudinal Add Health study to investigate how age identity and maturity during adolescence impact work and educational outcomes by the mid to late 20s. The results suggested that inappropriate age identity (either feeling older or younger than one's chronological age) may predict lower levels of work and educational attainment in later life, but only when coupled with poor psychosocial maturity (Benson et al., 2012).

There is also some evidence to suggest that feeling older may have a positive impact on quality of life in this age group. Montepare and Lachman (1989), for example, undertook a questionnaire study with 188 participants aged between 14 and 83. The findings suggest that, amongst younger participants, having a subjective age older than their chronological age was associated with having a higher level of life-satisfaction. Similarly, Montepare (1988) found that young adults with older age identities reported higher levels of self-esteem and more positive self-concept than their peers with younger age identities. As young adults who achieve normative transition milestones are more likely to feel older (Lowe et al., 2013; Shanahan et al., 2005), it is also possible that they also feel more positively about themselves and their developmental progress.

Also worth noting is that in some cases, the 'adultification' of children resulting from temporary economic hardship can quicken the maturation process, resulting in positive behavioural and psychological outcomes. Elder Jr. and Conger (2000), for example, followed 451 families in rural Iowa from 7th grade until High School Graduation. Throughout the study, it was found that working on a farm from a young age increased familial cooperation, developed maturity, and fostered positive working habits early. However, young people who 'age' faster than their peers as a result of more sustained adversity, such as accelerated puberty or the early adoption of 'adult' responsibilities (e.g.

young carers) are not always supported to develop the psychological maturity required to cope with their newfound adult status (Burton, 2016). This disparity can induce stress and is associated with a range of poor mental and physical health outcomes (Dorn, 2007; Pakenham, Bursnall, Chiu, Cannon, & Okochi, 2006; Tremblay & Frigon, 2005).

Being 'off-schedule' by failing to achieve transition milestones may also be a risk factor for experiencing negative mental health and social outcomes. Young adults who are forced to remain within, or return to the parental home may struggle to accept their circumstances (Warner, Henderson-Wilson, & Andrews, 2017). Moreover, Copp, Giordano, Longmore, and Manning (2013) found that young adults may be at greater risk of experiencing depression when parental co-residence is combined with employment problems (Copp, Giordano, Longmore, & Manning, 2013). However, the study also found that the participants who had 'boomeranged' (i.e. moved back into their parents' house after a period of independence) demonstrated significantly higher levels of depressive symptoms than those who had always lived at home. Similarly, high levels of parental closeness appeared to have a protective effect. Therefore, it appears that the type of living arrangement and the underlying rationale for living at home are highly salient to questions of wellbeing in this population.

There is also evidence to suggest that relationships between parents and their adult children may suffer when the transition to adulthood becomes protracted. Birditt, Fingerman, and Zarit (2010), for example, asked 633 randomly selected middle-aged parents to rate their children on measures of success, failure, and ambivalence. The results suggested that parents of both sexes exhibited higher ambivalence towards children whom they perceived as having struggled to adopt adult social roles, supporting previous findings (Pillemer et al., 2007). However, it is important to note that this association holds only for parents' *subjective* appraisals of their offspring's development, which appear to be influenced by personal expectations and social group norms (Fingerman, Cheng, Tighe, Birditt, & Zarit, 2012).

Nevertheless, concerns have been raised that the erosion of traditional pathways to adulthood can make the transition experience cognitively and emotionally harder for young adults (Benson & Elder Jr., 2011; Mortimer & Aronson, 2000). Adult identity development, for example, is harder when the criteria for adulthood are becoming increasingly difficult to ascertain. It is possible that this may leave young people feeling

insecure about their developmental progress, or unclear about the trajectory they ought to follow (Eliason et al., 2015).

It is also important to acknowledge that certain obstacles to the development of an adult identity have the potential to impact well-being independently. Overprotective parenting, for example, can increase the risk of anxiety developing in children (Spokas & Heimberg, 2008), and may result in young people failing to develop the risk-assessment skills needed to cope with independence in later life (Markova, Phillips, & Forbes, 1984). The infantilisation of non-children, which individuals with intellectual disabilities are at increased risk of experiencing, can also be associated with internalised vulnerability (Wilkinson, Theodore, & Raczka, 2014), poorer educational outcomes (Garber, 2011), and may also be considered a form of psychological violence in peer relationships (Montminy, 2005). Yet, it is worth noting that adult children who continue to receive intensive support from their parents have been found to report higher life satisfaction and better psychological adjustment than those receiving lower levels of support (Fingerman, Cheng, Wesselmann, et al., 2012). Therefore, high levels of parental involvement during and after the transition to adulthood may have a range of both positive and negative outcomes.

1.5 Experiencing the Transition: Typically Developing Young People and their Families

1.5.1 Overview

The move from childhood to adulthood represents one of the most dynamic periods in the life course, one that can be characterised by increased exposure to a range of internal and external pressures (Coleman, 1993). During this period, young adults are typically expected to seek greater independence, to take risks, and to experiment. As suggested, new social roles are adopted, leading to an increase in opportunity and responsibility, as well as a decrease in protection. The combination of new liberties and responsibilities, greater independence and experimentation, and reduced protections inflates the number of opportunities young adults have to make 'serious' mistakes with criminal ramifications. Moreover, across much of the world, adolescence is the time in which individuals are expected to choose, and take steps towards, their future trajectories. Significant decisions concerning education, careers, residence, and to a lesser extent, relationships are often expected to be made during this period.

1.5.2 Transition Stressors and Mental Health

Importantly, many of these social and environmental transitions can act as stressors that threaten mental health and wellbeing (Schulenberg, Sameroff, & Cicchetti, 2004), particularly as they often coincide with the time when physiological changes are at their most turbulent. Hormone fluctuations have been shown to alter cognition and to destabilise emotional regulation (Steinberg, 2005), which can lead to shifts in self-concept, self-esteem, and confidence (Gable, Scott, & Laughlin, 2000). The emotional instability resulting from these physiological changes may make coping with environmental stressors more difficult. As a consequence, the risk of experiencing stress and anxiety has been shown to rise significantly from childhood to adolescence (Baum & Singer, 1982; Norris, Carroll, & Cochrane, 1992).

Furthermore, the stressors faced by today's young people are arguably more acute than they have been for previous generations. As stated above, evidence suggests that economic pressures such as rising housing costs and low wage inflation have likely hindered many young people in their attempts to gain independence (Bessant, Farthing, & Watts, 2017; ONS, 2016, 2017a). According to a report published by the Centre for Economic Performance, between 2007 and 2015, real-terms wages in the UK fell by more than every other OECD country bar Greece, with young people being the worst affected age-group (Costa & Machin, 2017). Moreover, rising competition for jobs has increased the pressure on young people to perform academically (Newton, 2017), such that 49% of young people in the UK now pursue higher education (ONS, 2017b). The combination of weak labour market prospects and the mass expansion of higher education has led to the UK having one of the highest rates of graduate unemployment in the world (Newton, 2017). One report suggests that current 16 – 25-year-olds are feeling increasingly disempowered and anxious about their prospects and that levels of wellbeing have continued to decline as a result (TPT, 2017).

1.5.3 Social Transitions

Importantly, for the majority of young people, the transition to adulthood is not accomplished in isolation, but instead emerges in response to a negotiation that happens between themselves and those around them (Shumaker, Deutsch, & Brenninkmeyer, 2009). Family systems theories suggest that social roles within the family typically change during this period, with parents moving from protecting and providing for their children to

facilitating their independence (Bowen, 1978; Skowron, Stanley, & Shapiro, 2009). Adolescence is also the period during which young people typically develop closer relationships with peers, and often begin the process of sexual and romantic experimentation (Morgan, 2013).

The move from relying on one's parents to one's friends as the primary source of social support is commonly considered to be a critical psychosocial transition of the period (Skowron et al., 2009). Technological advancement and the rise of online social networking have to some extent changed how, when, and with whom young people socialise (Ellison, Steinfield, & Lampe, 2007; Oh, Ozkaya, & LaRose, 2014). Importantly, online harassment and cyberbullying are estimated to affect around a quarter of young people (Hamm, Newton, & Chisholm, 2015). However, online social networks have become so dominant that young people who fail to engage with sites such as 'Facebook' may find that their social lives become adversely affected (Boyd, 2015). Therefore, research into the potential benefits and harms of social networking on young people's social development have yielded mixed findings (Best, Manktelow, & Taylor, 2014).

The popularity of online social networking has been attributed, at least in part, to the potential it gives young people to interact without adult supervision or interference (Carbonell & Panova, 2017). However, young people should not be thought of as 'cutting ties' entirely with their parents during this period. Instead, the reduction of emotional dependence upon parents may be part of the broader renegotiation of power within the family (Parker, Rubin, Erath, Wojslawowicz, & Buskirk, 2015). Relationships between parents and their adolescent children are often thought to be characterised by a marked increase in conflict (Paikoff & Brooks-Gunn, 1991). In contrast, evidence suggests that the majority of young people hold relatively favourable views of their parents' authority (Levy, 2001).

In a similar vein, one study from the US suggests that young people may continue to retain very close emotional ties with their parents well into adulthood (Fingerman, Cheng, Tighe, et al., 2012). Parents reported high levels of both phone and face-to-face contact with their young adult children and were much more likely to provide regular emotional support than previous generations of parents. These trends have arguably led the media to label the current generation of young people as being "hyper-stressed", overly anxious, and unable to cope with the demands and responsibilities of adulthood without parental support (Barr, 2016; Twenge, 2017).

Despite this, there are grounds for believing that increased parent-adult child interdependency can sometimes be beneficial to both parties. In a mixed-methods study on mother-daughter relationships, Fingerman (2000) found that younger daughters and older mothers took pleasure from receiving help and support, while middle-aged women were more likely to report taking pleasure from *giving* support. Moreover, mothers reportedly remain highly invested in supporting their adult daughters, even if the level of care they provide is never fully reciprocated. The study was cross-sectional and involved a relatively homogenous group of women, and therefore cannot account for longitudinal changes in parent-child relationships in general. Nevertheless, similar findings have been found elsewhere (Byers, Levy, Allore, Bruce, & Kasl, 2008; Fingerman, Cheng, Wesselmann, et al., 2012).

For parents, the process of negotiating this period of change can also be demanding. On a practical level, finding the balance between facilitating autonomy and maintaining appropriate discipline can be difficult to gauge. Furthermore, the emotional experiences of transition and 'letting go' can be turbulent. "Empty nest syndrome" is a much-discussed phenomenon amongst parents whose children have recently left home (Bart, 1971), and the 'run up' to a child moving out can be an acutely stressful period (Karp, Holmstrom, & Gray, 2004). Moreover, continuing to feel 'needed' may also protect parents against depressive symptoms in later life (Byers et al., 2008). Yet, being 'off-schedule' may also be equally, if not more detrimental to parent well-being. Evidence suggests that parents whose children fail to achieve the normative milestones of adulthood in the expected timeframe report higher levels of ambivalence towards their children, and poorer health outcomes than those whose do (Fingerman, Cheng, Tighe, et al., 2012). The social transitions that occur during late adolescence and into adulthood are therefore highly complex and may predict a range of both positive and negative outcomes for all parties.

1.5.4 Laying Foundations for the Future

Throughout adolescence and young adulthood, young people are expected to develop the skills, behaviours, and attitudes required for independence, self-sufficiency, and responsible citizenship. In an attempt to support young people in achieving such outcomes, the Scottish Government has specifically included transition competencies in its Curriculum for Excellence (Government, 2006). Similarly, schools, colleges and universities across the UK are increasingly expected to demonstrate how their curricula

support the development of transferable skills necessary for employment in later life. However, positive risk-taking, experimentation, and self-exploration are generally accepted to be equally if not more important than formal training to achieving these ends.

To some extent, these behaviours can be considered a natural part of development. Evidence from within neurodevelopmental science, for example, suggests that risk-taking and thrill-seeking behaviours increase during the teenage years in response to the hormonal changes of puberty (Steinberg, 2007). Moreover, as discussed at length in Section 1.4.1.4, developmental psychologists have long held that exploration and experimentation with personal identity are fundamental for developmental progression (Erikson, 1950; Erikson & Erikson, 1998; Marcia, 1966). Also worth noting is that, according to Deci and Ryan's Self-Determination Theory, autonomy is a basic human need that motivates other behaviours (Deci & Ryan, 1985; R. M. Ryan & Deci, 2017). From this perspective, individuals who fail to develop the will to self-determine, either through lack of support or having their efforts thwarted, are at risk of experiencing significant detrimental effects to their wellbeing and development.

There is some evidence to support this theoretical position. Yap, Pilkington, Ryan and Jorm (2014), for example, undertook a systematic literature review of the research on the relationship between parent factors and the mental health and wellbeing of their young adult children. Results from across 181 articles suggest that young people whose parents fail to support the development of their autonomy, either through over-involvement or authoritarian parenting, may be more likely to suffer mental health and relationship problems in the future. However, aversive parenting and low levels of warmth were similarly associated with poorer health and wellbeing outcomes, suggesting that when it comes to facilitating autonomy, the appropriate balance between hands-on and hands-off parenting might be hard to draw.

Moreover, as suggested, young adults who fail to meet the milestones of independence (moving out of their parents' house, becoming financially self-sufficient etc.) risk negatively impacting both their own and their families' wellbeing (Copp et al., 2013; Fingerman, Cheng, Tighe, et al., 2012). Yet, as will be discussed in Section 12.1.3, the experiences of many young adults with intellectual disabilities may throw the universality of Deci and Ryan's Self-Determination Theory into doubt.

1.6 Experiencing the Transition: Young People With Mild to Moderate Intellectual Disabilities and their Families

1.6.1 Overview

The transition to adulthood can be a particularly difficult time for young adults with mild to moderate intellectual disabilities and their families. For individuals with developmental delay, psychological and emotional maturation typically occurs at a slower rate than in the general population, and may not keep pace with their rates of physical and sexual development. As a result, adolescents with intellectual disabilities may experience the urges and impulses of puberty before developing the psychosocial maturity to manage them effectively (Read, 2000). Moreover, the cognitive and adaptive deficits central to a diagnosis of intellectual disability can make a number of the competencies required for independence and self-determination harder to achieve (Khemka, Hickson, Casella, Accetturi, & Rooney, 2009; Mitchell, 2012). Everyday skills such as money-management and independent travel may never be fully mastered, increasing the need for parents and families to provide long-term support. Similarly, difficulties evaluating risk, anticipating the consequences of one's actions, and adapting to circumstances as they change can dramatically increase young peoples' vulnerability to harm. Consequently, care-providers of young people with intellectual disabilities may choose to prioritise safety and security over providing them with opportunities to take risks and make mistakes (Seale, Nind, & Simmons, 2013).

Additionally, increased dependence upon parents and obstacles to developing friendships with peers can make social transitions harder to achieve, particularly with regards to experiencing romantic and sexual relationships (Evans, McGuire, Healy, & Carley, 2009; Healy, McGuire, Evans, & Carley, 2009). Moreover, disability services designed to guide and support the transition to adulthood can vary in both accessibility and quality. Post-school options can be limited for young people with intellectual disabilities, particularly with regards to paid employment, and community participation can be difficult to facilitate (Verdonschot, de Witte, Reichrath, Buntinx, & Curfs, 2009). Finally, the combination of these factors with long-standing social preconceptions about intellectual disability can negatively impact young peoples' ability to develop an adult identity (Wilkinson et al., 2014).

However, despite these challenges, it is essential to acknowledge that many people with intellectual disabilities do grow up to lead happy and fulfilled adult lives. The following sections will address some of the above issues in greater detail by exploring the similarities and differences between how young adults with and without mild intellectual disabilities experience the transition process.

1.6.2 Balancing Self-determination and Risk

As suggested in Section 1.4.1.5, the construct of self-determination embodies a number of the normative psychosocial outcomes of the transition process. Moreover, individuals with intellectual disabilities have historically been denied self-determination, even though self-determination is widely considered to be a fundamental human right (Araujo, 2000; Wolfensberger, 1970, 2000). Consequently, autonomy and independence represent priority issues for many individuals with intellectual disabilities and their advocates (Conder, Mirfin-Veitch, & Gates, 2015; B. F. Cooney, 2002; Mannino, 2015).

However, research suggests that levels of functional self-determination are low amongst young adults with intellectual disabilities when compared to their peers without disabilities (Chambers et al., 2007). Several factors may contribute to this disparity. Importantly, self-determination is a complex outcome, one that is likely to arise in response to an on-going negotiation that occurs between young people and those around them. A variety of factors may influence this negotiation, including the young person's capabilities and behavioural tendencies, social expectations, parents' attitudes towards risk, and the young person's desires and expectations.

1.6.2.1 Young Peoples' Capabilities and Behaviours

Discussions about self-determination in young adults with mild to moderate intellectual disabilities often hinge upon questions of competence and capability. Yet, the majority of young people, including those with and without intellectual disabilities, can be considered cognitively 'immature' at the beginning of the transition process. Under 14-year olds, for example, are often "less able to create options, identify a wide range of risks and benefits, foresee the consequences of alternatives, and gauge the credibility of information from sources with vested interests" (Mann, Harmoni, & Power, 1989). There is also evidence to suggest that risk-seeking behaviours often increase, and inhibitions decrease, in response to the hormonal changes of adolescence (Peper & Dahl, 2013). Questions of capacity and responsibility are therefore not unique to young people with intellectual disabilities.

However, this is not to suggest that the maturation process is the same between both groups. One of the most significant differences between young adults with and without mild intellectual disabilities concerns the speed at which competence develops. The developmental delay associated with mild intellectual disabilities, for example, can elongate the process of psychosocial maturation. In turn, this may create a disparity between the young person's physical and psychological development. The consequences of such a disparity can be challenging to navigate. As suggested in the overview, young people with mild intellectual disabilities may sometimes develop the sexual urges of adolescence before developing the self-management skills or emotional maturity required to act upon them safely (Read, 2000). Moreover, individuals who look 'older', yet whose behaviour may be considered 'inappropriate' or 'juvenile' are more likely to face intolerance and derision, which can be difficult for both themselves and their families.

It is also worth noting that legal permissions relate to age, rather than maturity. As a result, young people with mild intellectual disabilities may start to encounter restricted activities (sex, alcohol, and smoking etc.) before having developed the level of maturity typically thought necessary to engage in such behaviours responsibly. Evidence from 'Next Steps' (previously referred to as the Longitudinal Survey of Young People in England), for example, suggests that the majority of individuals with mild to moderate intellectual disabilities in England have had sexual intercourse by the age of 19/20. Moreover, the same study found that members of this group were significantly more likely to have unsafe sex 50% or more of the time and to have experienced an unplanned pregnancy (Baines, Emerson, Robertson, & Hatton, 2018). Similarly, though on the whole, individuals with intellectual disabilities typically smoke and drink less than the general population (Robertson et al., 2000; Whitaker & Hughes, 2003), young people with *milder* intellectual disabilities may be *more* likely to drink excessively and smoke than their typically developing peers (Chapman & Wu, 2012).

Still, in order to mature, young people both with and without intellectual disabilities require opportunities to gain life experience. While life experience may be attained through the simple passage of time, taking risks and making mistakes can also make significant contributions to personal development. Similarly, cognitive skills, such as decision-making, risk-evaluation, and problem-solving, require practice if they are to improve. Importantly, evidence suggests that individuals with intellectual disabilities are less likely to receive such opportunities (Chambers et al., 2007; Curryer, Stancliffe, Dew, & Wiese, 2018). Thus, it is possible that environmental barriers *exacerbate* developmental delay.

1.6.2.2 Attitudes towards Risk

Self-determination is frequently considered to be a normative outcome of the transition process (Dyke et.al 2013). For young people with disabilities, in particular, increasing self-determination has become a key focus of government disability policy within many Western countries. Through initiatives such as *The Keys to Life* (2013) and *Improving Lives* (2017), both the Scottish and UK governments have expressed a commitment to respecting the dignity and autonomy of individuals with intellectual disabilities by facilitating choice and community participation wherever possible (May & Simpson, 2003).

Yet, for young adults with intellectual disabilities, there is an additional competing narrative at play – one of 'inherent vulnerability' (Wilkinson et al., 2014). This narrative - sometimes referred to as 'guardianship discourse' - promotes the idea that individuals with intellectual disabilities are, by definition, vulnerable and in need of protection (Katrina Scior, 2003). From this perspective, any decision *not* to protect young people with intellectual disabilities from threats of harm should be viewed as neglectful and represents a failure in the duty of care.

Despite the aforementioned similarities between young adults with and without mild intellectual disabilities, the effects of guardianship discourse are pervasive. In some cases, protectionism and paternalism can become such strong forces that individuals with intellectual disabilities sometimes struggle to achieve alternative identities, and may even internalise beliefs about their own vulnerability (Wilkinson et al., 2014). There are also grounds for believing that the fear of litigation, motivated by this narrative of vulnerability, has led many service providers to prioritise safeguarding over all other outcomes (Seale et al., 2013). Jingree and Finlay (2013), for example, interviewed 11 individuals with mild intellectual disabilities about their experiences engaging with social care services in England. Several of the participants positioned staff as being controlling and interfering and voiced frustration at having restrictions placed on their activities. These frustrations were particularly acute amongst individuals who considered themselves to be competent and mature.

Moreover, evidence suggests that the power imbalance between parents and young people with intellectual disabilities may remain for longer (Hamilton, Mazzucchelli, & Sanders, 2015). In such cases, autonomy may be more likely to become compromised when the

young person's views or desires are at odds with those of their parents. Results from an interview study undertaken with professionals suggest that despite the emphasis on self-determination for service users with disabilities, parents and carers typically retain the ultimate decision-making power when such conflicts occur (Pilnick, Clegg, Murphy, & Almack, 2011). This paternalism may thus persist despite the emphasis on self-determination at the level of Governmental policy, as well as the fact that a degree of positive risk-taking is considered necessary for functional development.

However, it is prudent to recognise that decision-makers are often reluctant to restrict risk-taking opportunities for young adults with intellectual disabilities. Parents, carers and teachers reportedly struggle to reconcile their wishes to promote self-determination with the realities of their dependents' support needs (Almack, Clegg, & Murphy, 2009; Carter, Lane, Cooney, Weir, Moss, & Machalicek, 2013; van Hooren, Widdershoven, van der Bruggen, van den Borne, & Curfs, 2005). As suggested, competence, responsibility, and maturity often develop more slowly in individuals with mild intellectual disabilities; therefore, concerns about risk may often be justified. Moreover, conditions such as epilepsy are common amongst individuals with intellectual disabilities (Allerton, Welch, & Emerson, 2011), and may independently account for higher levels of supervision (Affdal et al., 2015; van Hooren et al., 2005).

The tension between empowering and protecting people with intellectual disabilities is therefore well documented (Dorozenko et al., 2015; Seale et al., 2013). Striking a balance between positive and negative risk-taking opportunities can be very difficult. Families may find themselves in a 'Catch-22', caught between the knowledge that opportunity and experience are fundamental for each young person's development, yet unable to trust their young people to cope with additional risk. Negative interactions with professionals may also exacerbate these difficulties. Evidence suggests that parents and professionals frequently have competing priorities, and yet this conflict is rarely acknowledged by either party, leading to frustration on both sides (B. F. Cooney, 2002). Moreover, when such tensions arise, professionals may criticise parents – mothers in particular - for inhibiting their child's path to independence (Hillyer, 1993). Such criticisms may arise even though efforts to promote self-determination can be difficult to implement effectively.

Importantly, concerns about risk and the desire to retain control are not unique to parents of young people with intellectual disabilities. The term 'helicopter parenting,' for example, has been used to describe parents who remain overly involved in the lives of their young

adult children - a phenomenon that anecdotal reports suggest may be on the rise (Gabriel, 2010). Moreover, overprotective parenting, motivated by the growing social pressure on young people to excel – is also thought to be increasingly widespread (Michael Ungar, 2009). Nevertheless, as it stands, the road to independence for young adults with mild intellectual disabilities tends to be more complex, and paved with a more significant number of obstacles, than the path taken by the majority of young people.

1.6.3 Practical Transitions

As suggested in Section 1.5.2, the risk of mental ill-health rises throughout adolescence, which may in part be motivated or exacerbated by stressors such as leaving school and moving out. However, for young people with mild to moderate intellectual disabilities and their families, in particular, leaving school can be particularly daunting (Cheak-Zamora, Teti, & First, 2015). In part, transition anxieties arise when the options for post-school daytime activity are thought to be limited, as they are often perceived to be for members of this population (Cheak-Zamora et al., 2015). Any young person who fails to find purposeful daily activity is likely to be at increased risk of becoming bored and socially isolated, which can have profound negative implications for both mental and physical health and wellbeing (Matthews et al., 2016; Vodanovich, Verner, & Gilbride, 1991). The following sections outline some of the practical considerations faced by young people with mild intellectual disabilities and their families during the transition period.

1.6.3.1 College

In Scotland, 52% of school-leavers with an intellectual disability attend a Further Education College (Mctier, Macdougall, & Mcgregor, 2016). For the most part, specialised college curricula have been designed to help members of this population transition from school into employment by focussing on transferable skills development, and providing plentiful opportunities for work experience. Courses can range from providing basic training in literacy and numeracy, to working towards industry-recognised vocational qualifications. Moreover, varying routes are often available to support students to progress at the appropriate pace.

However, further education in Scotland has seen a significant drop in funding over the past decade, the consequences of which are believed to have directly impacted students with intellectual disabilities (The Scottish Consortium for Learning Disability, 2011). A number of more general courses, such as those designed to teach life-skills, have been discontinued

(The Scottish Government, 2000b). This is although many young people with intellectual disabilities go to college to gain additional life experience, make friends, and develop general life-skills, rather than to pursue a vocational education (McMurray, 2017). Moreover, according to a report published by the Scottish Consortium for Learning Disabilities, approximately 1/3rd of applicants with intellectual disabilities missed out on college places in 2011, the year the report was released (The Scottish Consortium for Learning Disability, 2011). Suggestions have been made that this may have directly contributed to an increased demand for day services reported by social workers (The Scottish Consortium for Learning Disability, 2017).

1.6.3.2 Employment

In Scotland, only 10% of 16 to 24-year-olds with intellectual disabilities are in paid employment compared to 52% of their age-matched peers without disabilities (Scottish Learning Disabilities Observatory, 2018a). To some extent, there are good reasons for attempting to increase employment levels in this population. While definitions of adulthood may be changing (Nelson & Luster, 2016), employment continues to make significant contributions to the attribution of adult status, both by facilitating financial independence and by providing a sense of direction and meaning in a person's life (B. F. Cooney, 2002). Employment is associated with higher subjective well-being than joblessness (C. Thomas, Benzeval, & Stansfeld, 2005), and may imply successful coping with everyday responsibilities and stressors. Moreover, individuals in steady employment have better opportunities for social inclusion within employment communities, and to extend their social capital as a result (A. C. Hall & Kramer, 2009). As community inclusion can be harder to achieve for individuals with intellectual disabilities (L. Hall & Hewson, 2006), the opportunities for social interaction and friendship-building provided by employment may be particularly beneficial.

Employment is often considered to be an *inherent* good. However, according to a systematic review on community participation, the vast majority of employed individuals with intellectual disabilities are engaged in low-skilled, low-paid jobs in sectors, such as domestic services and industrial production, that frequently have unsociable working hours (Verdonschot et al., 2009). Employment of this nature may be contrary to an individual's ambitions (B. F. Cooney, 2002), and may adversely affect their quality of life as a result. Moreover, results from a qualitative investigation found that work placements can also be tokenistic in nature and that employees with intellectual disabilities are often neglected or

left with insufficient support (Dyke et al., 2013). Therefore, while employment has the *potential* to increase social capital, this potential is not always realised.

Furthermore, issues with transport (inadequate provision of public transport, complicated changes, etc.) can make commuting more challenging (Friedman & Rizzolo, 2016). Employment may therefore also place a greater burden on families to provide transport to and from work. Consequently, while employment can be a positive outcome for young people with intellectual disabilities, there are also some social and practical drawbacks to pursuing work that must also be acknowledged.

1.6.3.3 Moving out of the parental home

Moving out of the parental home, or 'launching,' is another important transition marker used in the attribution of adult status. Campaigns such as the Independent Living in Scotland (ILiS) project advocate that all people with disabilities should receive "the same **freedom, choice, dignity** and **control** as other citizens" by being provided with the support and assistance needed to lead ordinary, independent lives (ILIS, 2018). However, 'launching' can be a difficult outcome to achieve for individuals with greater than average needs for support. In Scotland, for example, the number of 21 – 34-year-olds with intellectual disabilities living with a family carer ranges from between 65.2% and 78.6% (The Scottish Consortium for Learning Disability, 2017) compared to only 25% of their age-matched peers without disabilities (ONS, 2017a).

In the UK, many residential services are provided through local councils and allocated according to each's particular support needs (Care Info Scotland, 2018). Options can include full-time specialist residential services, supported living and sheltered housing, and home-based respite care. However, despite the centrality of independent living within the Scottish Government's current strategy for people with intellectual disabilities, *The Keys to Life,* waiting lists are reportedly long, and funding limited (Ormston, Eunson, & McAteer, 2017). Suggestions have been made that the UK Government's welfare reforms and austerity measures have also exacerbated, rather than alleviated the growing gap between the demand and supply of social care services (Ormston et al., 2017). As a result, individuals with the most significant support needs typically receive priority (Welfare Reform Act 2012). Concerns have been raised that individuals with only mild to moderate intellectual disabilities are finding it increasingly difficult to gain access to appropriate housing, and that independence is being affected as a result (Mencap, 2012).

It is important to acknowledge that housing represents a broader issue within contemporary UK society (Kay, 2017). According to the ONS, housing affordability worsened significantly in England between 2012 and 2017 (Office of National Statistics, 2018). Moreover, in Scotland, the average Local Authority rent increase by 65% between 2005 and 2015, a rise that far exceeds the rate of wage inflation (Shelter Scotland, 2018). As discussed in Section 1.4.1, reasons such as these may in part explain why young people are increasingly likely to live with their parents for longer (ONS, 2016). Nevertheless, for young people with support needs, the barriers to independent living are even more significant in number.

1.6.3.4 Transition Planning and Services

In Scotland, transition planning has become an integral part of the school-leaving process for young adults both with and without intellectual disabilities. Frameworks such as *More Choices, More Chances* and the *Curriculum for Excellence* have been introduced to minimise the numbers of 16 to 19-year-olds outwith education, employment, or training (The Scottish Government, 2012). For young adults with intellectual disabilities, in particular, the transition process is designed to facilitate information sharing between key stakeholders, including young people and their families, schools, social workers, and voluntary agencies, to achieve the best post-school outcomes (The Scottish Government, 2005). However, critics have accused the framework of failing to provide the guidance necessary to ensure that this process is carried out effectively (Conlon, 2014). Moreover, as transition planning typically falls under the remit of local education authorities, and as local voluntary organisations often provide a lot of the available transition services, both quality and consistency are likely to differ across the country.

Very little research has been undertaken to evaluate transition experiences in Scotland. Results from one longitudinal study suggest that collaboration between professionals may be improving and that young people may be starting to take a more active role in developing their own transition plans since the policies were introduced (Richardson, Jindal-Snape, & Hannah, 2017). However, only one education authority was involved in the study, and views from families and young people were not collected. The authors acknowledge that there may be a gap between the professionals' perceptions of the changes and the reality of what happens. Therefore, the findings should be treated with caution, and cannot be generalised to the whole of Scotland.

Evidence from across the rest of the UK suggests that negative experiences often characterise the transition process (Grant & Ramcharan, 2001; Heslop, Mallett, Simons, & Ward, 2002). As part of a study on the continuity of care, Hudson (2006) interviewed managers, professionals, parents, and service-users about their transition experiences, and found that insufficient resourcing, competing priorities, and organisational complexity frequently mar the process. Budgeting limitations across the whole care-sector, for example, may generate disagreements about which agencies should take responsibility for managing the process. This lack of clarity can lead to reactive management and delayed or last-minute decision-making, which increases the risk that some young people fall through the cracks in the system.

Moreover, the transition process can be an acutely stressful period for parents in particular, who not only have responsibility for guiding their child through their adolescent development, but also have to negotiate and overcome barriers in the environment (Foley, Dyke, Girdler, Bourke, & Leonard, 2012). Both in the UK and across the globe, parents frequently report that information about services can be hard to come by, and that formal support is rarely made available in the way that it is advertised to be (Dyke et al., 2013; Gillan, 2010; Griffith, 2016; Hudson, 2006; Leonard et al., 2016). As a result, many parents feel that they have no choice but to act as their child's advocate, and fight for the support that they are nominally entitled to receive (Cheak-Zamora et al., 2015; Rapanaro, Bartu, H., & Lee, 2007).

1.6.4 Social Transitions

As explained throughout Section 1.4, part of the process of transitioning to adulthood typically involves replacing one's family with one's peers as the primary source of comfort, advice, knowledge, and general social support (Bowen, 1978). Friendships with one's peers can also serve as the motivation behind wanting greater autonomy, as young adults may be more likely to wish to undertake activities without supervision if they have friends with whom to do those activities.

However, young adults with intellectual disabilities tend to have significantly less social capital than their typically developing peers (A. C. Hall & Kramer, 2009). Evidence suggests that people with intellectual disabilities experience far fewer opportunities to both visit and be visited by friends (E. Emerson & McVilly, 2004; L. Hall & Hewson, 2006), and it is estimated that up to half of the population is chronically lonely as a result

(Stancliffe et al., 2010). Both practical and social obstacles exist that can make friendship-building harder for members of this population. Abbot and McConkey (2006), for example, undertook a focus group study with 68 Northern Irish individuals with intellectual disabilities about perceived barriers to social inclusion. Within that sample, negative attitudes within the community, insufficient numbers of activities, and lack of confidence in social skills were said to be the biggest obstacles. Problems concerning travel and transport, which affect many individuals with intellectual disabilities, can also make community participation harder to achieve (Friedman & Rizzolo, 2016). Importantly, the majority of these barriers are environmental and are not unique to individuals with intellectual disabilities. Nevertheless, issues of this variety disproportionately affect populations with higher support needs.

Opportunities for romantic relationships and sexual experimentation are also less likely to be available to young adults with intellectual disabilities (Healy et al., 2009). This lack of opportunity persists despite calls for greater autonomy regarding sex and relationships by advocates (Department of Health, 2009), and even though many young people with intellectual disabilities have ambitions to fall in love and get married at some point (Healy et al., 2009). Unlike their peers without disabilities, members of this group typically have low levels of privacy and may be more reliant upon supervising adults to facilitate social meet-ups (Fulford & Cobigo, 2016). Without the active support and approval of carers and parents, opportunities for sexual and romantic experimentation are likely to be very limited (McVilly, Stancliffe, Parmenter, & Burton-Smith, 2006). Furthermore, marriage rates amongst Caucasian British adults with intellectual disabilities remain low in comparison to the general population (Beber & Biswas, 2009).

Attitudes towards the sexuality of members of this group are often negative (R. Young, Gore, & McCarthy, 2012). For parents, in particular, the fears of risk, vulnerability, and coping felt about their young person's transition to adulthood are often magnified in discussions about sexuality (Pownall, Jahoda, Hastings, & Kerr, 2011). Several studies, for example, have found that parents may be more inclined towards holding conservative views about intimacy than paid carers and members of staff (Aunos & Feldman, 2002; Cuskelly & Bryde, 2004; Evans et al., 2009). This disparity may be because parents are more likely to bear the responsibility of any unplanned pregnancies or contracted sexually-transmitted diseases. It may also mark an ideological shift in the care sector regarding the rights of persons with disabilities to engage in intimate relationships (Evans et al., 2009). However, as the parents involved in these studies are typically older than the carers, these

differences may also be a function of age (Cuskelly & Bryde, 2004; Evans et al., 2009). If so, these findings could suggest that attitudes towards the sexuality of individuals with intellectual disabilities are becoming more liberal with time.

1.7 Summary

Identity has at least two distinct but related dimensions: a personal dimension (how the individual defines themselves), and a social dimension (how the individual is defined by others). An identity may be adopted by the individual but rejected by the group, and vice-versa. As such, identities can be a source of pride or shame, as well as being protective or stigmatising, and may even be both simultaneously. 'Disability,' as a traditionally stigmatised identity, can be a useful lens through which to understand the complexity of identity issues. Arguments abound as to whether or not 'disability' is a product of individual deficit, or whether society *disables* physically and cognitively diverse individuals by preventing them from achieving full participation at home, at work, and in the community. In either case, a disability identity may be protective in some, but not all circumstances, and has the potential to become a source of pride and belonging – mainly when individuals feel that they are part of a specific disability community.

Similarly, the development of an adult identity is a highly complex process that appears to be influenced by a variety of social, cultural, and personal factors. The relationships between 1) how an individual conceptualises adulthood, 2) the number of adulthood criteria they have achieved and 3) how adult they feel likely make significant contributions to that individual's overall age identity. Moreover, there is some evidence to suggest that definitions of adulthood may be changing in specific western contexts. However, research suggests that both the character qualities of psychosocial maturity and social role transitions influence subjective adult identity, moderated by social and personal context (Shanahan et al., 2005).

The transition to adulthood is a uniquely challenging stage in the life course, one that is characterised by both internal and external pressures, and perpetual change. For young adults without disabilities, there are grounds for thinking that this period is becoming increasingly stressful. Economic and social pressures, for example, appear to be elongating the transition process, and the erosion of the traditional pathways to adulthood may be increasing levels of ambivalence towards growing up. For young people with intellectual disabilities and their families, the transition to adulthood presents an additional range of

challenges. Social narratives surrounding intellectual disability, for example, have the potential to be infantilising, and may serve to inhibit young people from developing a socially salient adult status. Moreover, both the social role transitions and characteristics of psychosocial maturity associated with adulthood may be harder to achieve for this population. However, evidence suggests that, in spite of the barriers, many individuals with intellectual disabilities go on to lead self-determined, independent lives. Furthermore, those who do have been shown to be more likely to achieve other normative outcomes associated with adulthood. In order to gain an insight into how and why these outcomes are achieved, a systematic literature review was conducted concerning the predictors of self-determination in young adults with mild to moderate intellectual disabilities. Results from this process are presented in Chapter 2.

Chapter 2   Systematic Literature Review

2.1 Introduction

The purpose of the following chapter is to present findings from a systematic literature review undertaken to investigate the predictors of self-determination in young adults with intellectual disabilities. The chapter will begin with an explanation of the search methodology, including the specific inclusion and exclusion criteria used to guide this process. Findings will be presented in Section 2.6 and will be discussed in relation to the wider literature concerning predictors of self-determination in individuals with intellectual disabilities. Sections 2.8 and 2.9 will present a critique of the self-determination literature, including common limitations of the studies, and problems with the model itself. The chapter will conclude with a discussion of the potential benefits of drawing links between self-determination the theory of Social Information Processing.

2.2 Methodology

Prior to the start of the process, a multiple-database search for systematic reviews concerning self-determination in young adults with disabilities was undertaken to establish whether or not the research question had already been addressed. This search rendered 11 English Language results; however, none focused on factors that *predict* self-determination, and none were specific to young adults with mild intellectual disabilities. The following study aimed to fill this gap by investigating the factors that predict enhanced self-determination in transition-age individuals with mild to moderate intellectual disabilities.

MOOSE guidelines have been adhered to throughout the review process to maintain consistency across reporting (Pettigrew & Roberts, 2006). Critical aspects of the review, including the screening process and quality assessment, were undertaken jointly with colleagues within the department. After the completion of the scoping review to help identify the areas of self-determination research most apt for systematic analysis, the author and her supervisors agreed the study design (PICOS). The author designed the search strategy after consultation with the department's librarian. To maximise the sensitivity of the search, key concepts and demographic criteria were input into the PsycInfo Thesaurus function to identify related terms for inclusion in the search. This list was expanded further through discussions with colleagues, data mining related articles, and

a priori consideration. As a result, "locus of control" and "autonomy" were included to widen the self-determination search, as were terms historically used to describe intellectual disability. The final search strategy is presented in Table 1.

Combinations of different searches were trialled in five databases - Medline (1947 – Nov Week 3 2015), Embase (1947 - Present), Web of Science, PsycINFO, and Google Scholar – from which the three authors jointly agreed upon the final search criteria. Search were not restricted by date; however, an English Language limitation was used in all databases that had such a function available. The final search was conducted on 30th November 2015 within the databases listed above, from which references were downloaded to Endnote X7.

Search Terms
Exp developmental disorder/ or intellectual impairment/ or exp mental deficiency/ or exp learning disorder/
Exp developmental disabilities/ or exp intellectual disability/ or exp learning disorders/ or mentally disabled persons/
Exp developmental disabilities/ or exp intellectual development disorder/ or "intellectual development disorder (attitudes toward)"/ or exp learning disabilities
((intellect$ adj3 (deficien$ or difficult$ ordisab$ or disorder$ or impair$ or handicap$ orincapacit$ or handicap$ orsub?averageorsub?norm$)) or (low$2 adj2 intellect$)).tw.
(learningadj3 (deficien$ or difficult$ ordisab$ or disorder$ or handicap$ or impair$ orincapacit$ or handicap$ orsub?averageorsub?norm$)).tw.
(mental$ adj3 (deficien$ or disab$ or handicap$ or impair$ or handicap$ or incapacit$ or retard$ or sub?averageorsub?norm$)).tw.
((subaverage or sub$1 average or subnormal or sub$1 normal$) adj3 (cognit$ orintel$)).tw.
((development$ or neurodevelopment$)adj disab$).tw.
(education$ adj5su?bnorm$).tw.
(cretin$ or feeble minded$ orimbecil$ or moron$).tw.
Or/ 1-10
Teen* or Youth* or Adolesc*
Young adj3 Adult*
Emerg* adj3 Adult*
Or/ 12-14
Self-determin* OR "selfdetermin*"
Autonom*.mp.
"internal locus of control".mp.
Or/ 16-18
AND/ 11, 15,19
FILTER: English Language and Human

Table 1: Search strategy used in Embase (1947 – Present) and Medline (1947 – Nov Week 3)

A total 1169 papers were returned, 395 of which were duplicates and therefore removed.

2.3 Inclusion and Exclusion Criteria and Justification

Included in the review were peer-reviewed studies involving 16 to 30-year-olds with mild or moderate intellectual disabilities. Moreover, self-determination (or an associated concept) was required to be a dependent variable in the study, quantitatively measured in relation to one or more independent variables. Articles were excluded for the following reasons:

- Less than 50% of the target population was aged between 16 and 30.
- Any of the study participants were aged below 14, or over 35.
- Less than 80% of the target population had mild or moderate intellectual disabilities.
- Self-determination outcomes cannot be differentiated from other outcomes.
- The sample had been institutionalised at some point.
- The study only reports pre-post intervention data

An age group of 18 to 25 had initially been chosen to reflect the conceptual parameters of the child-to-adult transition process, as informed by Arnett's work on Emerging Adulthood (2000). However, results from the scoping review revealed that this age range would exclude several relevant papers. Furthermore, intellectual disability is characterised by developmental delay; therefore, the authors believed that a wider age range might better reflect the transition period for this group. Consequently, the decision was taken to extend the parameters to include participants aged between 16 and 30. Samples involving under 14-year-olds or over 35-year-olds, however, were considered too far removed from the transition period to be included in the study.

Searches were limited to those focussing on mild to moderate intellectual disabilities, as the manifestation of self-determination can be different across the spectrum. Furthermore, studies of this population are most likely to implement self-report measures, which are often considered to be more reliable than proxy-reports when used in similar contexts (Claes et al., 2012). In addition, studies involving participants from residential facilities have been excluded, as the life experiences of individuals within this population are likely to be non-comparable to those raised in the community.

'Locus of control' and 'autonomy' were included in the search, as these constructs were judged to reflect causal agency. However, the term 'independence', though often used interchangeably with 'autonomy', carries connotations associated with acting alone or without assistance. As such, studies of independence in the fields of health and social care

primarily concern aspects of practical self-sufficiency, such as mobility and communication. While self-sufficiency may be associated with self-determination, the two are considered to reflect separate phenomena. It is for this reason that the term "independence" was not included in the search.

Finally, all but one intervention study were omitted for failing to run analyses on the possible predictive relationship between self-determination and other non-intervention variables. As will be elaborated upon in the following section, this exclusion criterion was added after the preliminary search had been completed.

2.4 Screening Process

Article screening occurred in two phases (see fig. 1). During the initial phase, the researcher and her first supervisor conducted a title and abstract search of the 774 articles that remained after duplicates had been removed, from which 731 were screened for failing to meet the inclusion criteria. Forty-three papers were then subject to a second, full-article screening by the researcher, from which eight studies emerged as appropriate for analysis. Google Scholar's 'cited-by' function was used on each of these to determine if any relevant papers had since been published. One additional paper was found through this process. The bibliographies of these were then hand-searched; however, no papers of relevance were found through this process. Finally, two papers were added to the list from the initial scoping review, raising the total number of studies to 11.

However, only 3 of the 11 studies included data that met the original research aim to find factors that *predict* self-determination in transition-age individuals with mild to moderate intellectual disabilities. Specifically, this aim regarded the inclusion of correlational analyses between self-determination and one or more additional variable. Though interventions themselves have the potential to fit this definition, 8 of the 11 studies reported pre-to-post intervention changes only, and as such, were retrospectively judged by the authors to fall outwith the scope of the study. Consequently, the final number of studies included in this review was reduced to three.

2.4.1 Search Methodology
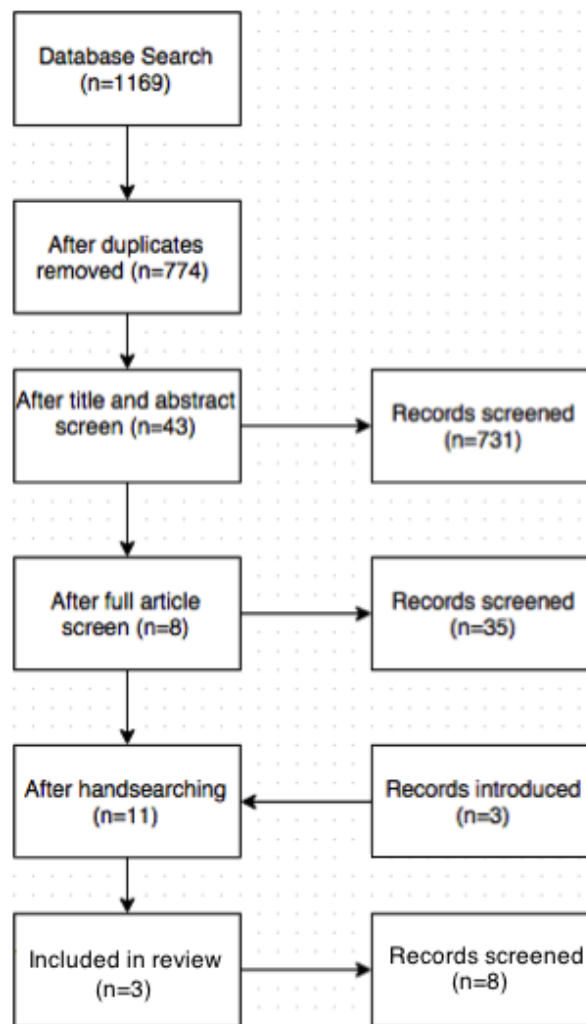
Figure 1. Flowchart showing systematic literature review search methodology

2.5 Data Extraction and Quality Assessment

A data extraction form was designed for the analysis of the studies, an example of which can be found in Appendix A. The Standard Quality Assessment Criteria for Evaluating Primary Research Papers From a Variety of Fields (Kmet et al., 2004) was used to assess the quality of the papers. This framework was designed to be applicable within a wide variety of contexts, providing evaluation systems for both quantitative and qualitative methodologies. However, as this review is limited to quantitative studies, only the first system was utilised. Fourteen questions concerning the study were asked, with objective criteria provided to indicate whether the answer ought to be scored as 'yes' (2 points), 'partially' (1 point), 'no' (0 points), or 'not applicable.' After answering the fourteen questions, the number of questions scored 'not applicable' is tallied and deducted from the maximum of 28 points. All other points are summed and then divided by the new

maximum number to provide a fraction or percentage score. The questions themselves concern the following areas of evaluation:

- Question/objective sufficiently described?
- Study design evident and appropriate?
- Method of subject/comparison group selection or source of information/input variables described and appropriate?
- Subject (and comparison group, if applicable) characteristics sufficiently described?
- If interventional and random allocation was possible, was it described?
- If blinding of investigators was possible, was it reported?
- If blinding of subjects was possible, was it reported?
- Outcome and (if possible) exposure measure(s) well defined and robust to measurement/misclassification bias? Means of assessment reported?
- Sample size appropriate?
- Analytic methods described/justified and appropriate?
- Some estimate of variance is reported for the main results?
- Controlled for confounding?
- Results reported in sufficient detail?
- Conclusions supported by the results?

An example framework can be found in Appendix B.

Data extraction and quality assessment were completed separately by the researcher and her primary supervisor. A consensus was reached with an initial inter-rater reliability of 83.7%.

2.6 Results

All of the studies utilized the ARC Self-Determination Scale, a 72 item questionnaire based on the four criteria of Functional Self-Determination: behavioural autonomy; self-regulation; psychological empowerment; and self-realisation (Wehmeyer, 1999). Scores can be analysed separately by subscale, as well as amalgamated to form a total score of global self-determination.

2.6.1 McGuire and McDonnel (2008)

McGuire and McDonnel's 2008 study aimed to determine whether or not "active involvement in recreation predict[s] the level of self-determination for adolescents and young adults with intellectual disabilities" (p155). Participants included forty-seven 15 to 21-year-olds with IQs ranging from 40 to 75, all from northern Utah. Levels of self-

determination were analysed against several recreation variables, including the total time spent in recreation outside the home, length of individual activities, and intensity of the activity (measured in METs[2]). Data for these variables were collected using a recreation log, completed by participants for a two-week period. The analysis also included age, sex, family socioeconomic status, level of school inclusion, and IQ score.

Using the Pearson product-momentum correlation, McGuire and McDonnell found a positive correlation between the physical intensity of an individual's leisure activities and both their global self-determination ($r = .320$, $p = .03$) and self-regulation ($r = .291$, $p = .05$). Moreover, duration of recreation activities showed a positive correlation with global self-determination ($r = .319$, $p = .03$), while the total amount of time in recreation predicted both global self-determination ($r = .358$, $p = .014$) and self-regulation ($r = .407$, $p = .005$). IQ scores were also shown to share a significant correlation with global self-determination ($r = .571$, $p = .00$), as well as self-regulation ($r = .449$, $p = .000$), autonomous functioning ($r = .477$, $p = .01$), and psychological empowerment ($r = .565$, $p = .000$). No variables correlated significantly with the self-realization subdomain. Furthermore, using a multiple regression analysis, 36% of total variance in self-determination scores was shown to be attributable to both IQ ($t = 4.67$, $p = .00$) and time spent in recreation ($t = 2.29$, $p = .03$).

The authors acknowledge that both the duration of data collection and its place in the calendar year (overlapping some schools' spring break) may have artificially inflated the number of leisure hours typically undertaken by some participants. Moreover, such a homogenous group has the potential to make results harder to generalise. These particular limitations are unlikely to have distorted the study's findings in any significant way, as the significant variables are likely to remain relatively stable across time. While the sample size is notably small for a descriptive study of this nature, analytic methods were judged to be appropriate and well reported. However, despite the study's statistical findings, the theoretical relationship between self-determination and leisure is unclear. As such, the study was considered to have a moderate value of 65% according to Kmet et al.'s assessment.

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[2] METs, or Metabolic Equialvalents, refer to the amount of oxygen consumed per unit of body weight over a minute. Watching a film, as a physically passive activity, has a MET intensity of level 1 (Ainsworth et al., 1993; McGuire & McDonnell, 2008).

2.6.2 Gaumer Erickson et al (2015)

Gaumer Erickson et al. (2015) used secondary data from the National Longitudinal Transition Study-2 (NLTS2) to determine the relationship between Functional Self-Determination and academic achievement. The NLTS2 was a study designed to determine the school and home life, academic performance, and post-school outcomes of disabled adolescents across the US over a ten-year period. Data on self-determination and academic performance (reading and mathematical ability) were available for 480 16 to 18-year-olds with intellectual disabilities.

Results from the Woodcock-Johnson III Research Edition tests of mathematical and reading ability were converted to Z-scores, which were used to generate total academic achievement scores. The number of ARC questionnaire items was reduced from 72 to 26 items, including the removal of the entire 'self-regulation' domain. Loadings from the factor analysis suggest significant, albeit weak positive correlations between academic achievement and autonomy (r=.208, p=.01>) and psychological empowerment (r=.553, p=.01>). The correlation between academic achievement and self-realization lost significance after accounting for demographic variables. Moreover, as the self-regulation domain was missing from the original data, global self-determination could not be measured.

It should also be noted that specific IQ data was missing from the final report, as was information regarding the participants' ethnicity. As both of these variables are likely to have affected results, the study was evaluated as being of only moderate value, scoring 68% on Kmet et al.'s assessment.

2.6.3 Palmer et al (2012)

Palmer et al.'s 2012 study aimed to evaluate the impact of the *Beyond High School* curriculum using pre-to-post intervention arc self-determination scores. A total of 109 young adults with mild to moderate intellectual disabilities (of between 17.2 to 21.8 years of age) participated in the study, which lasted a total of two years. While the majority of analyses concerned the pre-to-post intervention changes, and therefore fall beyond the remit of this review, intellectual impairment level and gender were included as between-participant factors in a mixed-factor ANOVA. Though gender did not produce a significant main effect, intellectual impairment did ($F(1, 69) = 14.83$, p <.001). While the pattern of

change was the same for both the mild and moderate groups, mildly disabled participants both began and ended the study with significantly higher scores.

It should be noted that intellectual impairment levels were determined by proxy reports (specifically by teacher assessment), as formal IQ scores were unavailable. As the direction of effect between intellectual ability and self-determination is unknown, it is possible that the participants' teachers perceived their more self-determined students to be of higher ability, thus potentially undermining the findings. However, it should also be noted that the relationship between intellectual ability and self-determination is supported both by McGuire and McDonnel's findings, as well as by studies involving demographically broader samples (Chambers et al., 2007; Wehmeyer & Abery, 2013). For this reason, the study scored 65% on Kmet et al.'s assessment and is therefore judged to be of moderate value.

2.7 Discussion

The purpose of this review was to identify all papers presenting findings that include possible predictors of self-determination in 16 – 30-year-olds with mild to moderate intellectual disabilities. Several papers examining the antecedents of self-determination were found; however, only three were judged to meet the designated inclusion and exclusion criteria. Moreover, the three that were found were only deemed to be of moderate value using Kmet et al.'s quality assessment measure. From these papers, possible predictors of self-determination include the nature and duration of leisure activities, IQ/level of intellectual impairment, and academic achievement.

Research on broader populations does to some extent support some of these findings. There is consistent evidence that self-determination correlates with a number of measures of cognitive ability, including IQ score, learning capacity, and intellectual impairment level, for example (Wehmeyer 1996; Stancliffe et al. 2000; Wehmeyer & Garner 2003; Nota et al. 2007; Shogren et al. 2007). However, Wehmeyer et al. (2011) contend that the relationship is relatively weak. Wehmeyer and Garner (2003), for example, found that an adult's opportunity to make choices was the only factor that predicted membership in the high self-determination group, despite IQ score being one of the variables of analysis. Moreover, as IQ was the only significant predictor of outcomes associated with self-determination in Wehmeyer and Garner's study, specifically residential and employment outcomes, the relationship was reported to be a complicated one. Stancliffe et al. (2000)

also found that adaptive capacity, rather than IQ score, was the more significant predictor of self-determination, suggesting that the manner in which intellectual ability is defined and measured within the studies could account for these discrepancies. This relationship is made all the more complicated when considering how academic achievement, as studied by Gaumer Erickson et al., relates to both. Unfortunately, there seems to be "lack of focus on academic skills in the self-determination literature for students with mental retardation/developmental delays" (Fowler, Konrad, Walker, Test, & Wood, 2007, p. 281) from which to draw any further conclusions about the work presented by Gaumer Erickson et al.

Similarly, no other studies regarding the correlative relationship between functional self-determination and the nature and intensity of leisure activities could be found. The theoretical relationship between functional self-determination and recreation, however, is unclear. Self-determination describes individuals who are causal agents within their own lives. Yet, the manner in which self-determined individuals choose to lead their lives is not prescribed. A young person who chooses to spend their time playing video games may have the potential to be equally as self-determined as someone who play football for several hours a per day, for example. Consequently, while McGuire and McDonnel's study found a significant association between self-determination and greater intensity and duration of leisure activities, the reliability of this finding may be called into question.

Looking beyond the factors discussed in this review, a number of additional predictors of self-determination have been investigated in different populations. With regards to intrapersonal factors, Nota et al. (2007) undertook a study to find the relationship between self-determination and social ability. Healthcare professionals and social workers acted as proxy respondents on behalf of 141 adults (16 to 65 years old) with mild to severe intellectual disabilities. Self-determination was assessed using the Evaluation of Self-Determination Instrument (Soresi, Nota, & Ferrari, 2006), a 24-item measure covering four domains: 1) self-determination in daily activities, 2) self-determination in expressing opinions, ideas, and emotions, 3) self-determination in activities and commitments, and 4) self-determination in choices and desires. Social ability was measured using the Social Ability Evaluation Scale for Adults with Mental Retardation. Results from a regression analysis suggest that both social abilities and IQ score significantly predict self-determination levels. Social acceptance and parental support have also been shown to correlate with the psychological empowerment and self-realization levels as determined by the ARC self-determination scale in younger children (J. L. Jones, 2012).

Age may also predict levels of self-determination in young adults, with older individuals scoring more highly than their younger peers. During the ARC validation process, self-determination scores increased in line with chronological age for a group of mixed-disability adolescents (Wehmeyer, 1996). However, according to Wehmeyer and Garner (2003), age fails to retain any predictive significance once adulthood has been reached.

Evidence for the relationship between self-determination and gender is mixed. Neither Wehmeyer (1996) nor Wehmeyer and Garner (2003) found any significant differences in self-determination scores between genders, though Wehmeyer (1996) did find that women's scores were marginally higher. This trend was supported in Nota et al. (2007), who found women's self-determination scores to be higher by a significant margin. Soresi et al. (2004), in contrast, found that men's scores were slightly higher. While this may reflect natural variation across samples, it should also be noted that both Soresi et al. (2004) and Nota et al. (2007) undertook studies in Italy, whereas Wehmeyer's work is based in the USA.

There is a small amount of evidence that cultural differences can account for significant disparities in self-determination. Part of this may stem from differing conceptualisations of the self-determination construct across the globe (Turnbull & Turnbull, 2001). Frankland et al. (2004), for example, provide a commentary on self-determination as it relates to the values and beliefs of the Diné (Navajo) people. As a clan-based culture, social interactions, status, and personal responsibilities are determined by the community in a way that they might not in a more individualistic culture. Self-determination is therefore conceived as the development of self-knowledge regarding one's place in the universe, rather than as an expression of personal autonomy. Though as of yet untested, there is reason to hypothesise that individuals of Diné origin, along with other tribal peoples, may score less highly than their Anglo-European peers on some of the more common self-determination measures.

Leake and Boone (2007) undertook a qualitative investigation of the influence of culture on self-determination. Participants were recruited in both Hawaii and Washington DC and represented seven separate ethnic backgrounds: Black, White, East Asian, Hawaiian, Hispanic, and Pacific Islanders. Within Samoan culture, for example, children are afforded far fewer opportunities to make choices or exert influence than in American culture, where such opportunities are encouraged (Kusserow, 2004). Some East Asian families also take a more strict approach to parenting than families of Caucasian heritage, particularly in relation to post-school outcomes. While there is currently a paucity of research

investigating the direct impact these differing cultural attitudes have on individual self-determination levels (Wehmeyer & Abery, 2013), environmental factors have been shown to have a very significant impact. Choice opportunity, for example, is one of the single-most significant predictors of overall self-determination; particularly in relation to the size and restrictiveness of individuals' living and working environments (Duvdevany, Ben-Zur, & Ambar, 2002; Stancliffe, 2001; Tossebro, 1995; Wehmeyer & Bolding, 1999, 2001; Wehmeyer & Garner, 2003; Wehmeyer & Metzler, 1995). Similarly, studies by Zhang (2001) Shogren et al. (2007), and Williams-Diehm et al. (2008) found that greater inclusion and involvement also predict higher levels of self-determination for disabled populations.

2.8 Critique of research across the field

Young adults with mild to moderate intellectual disabilities are commonly believed to be the most researched population within the field self-determination research, not least because of the number of interventions that have been designed with them in mind. Contrary to expectations, only three studies could be found that exclusively recruited from this population, suggesting that there is a significant paucity of research in this area. One of the reasons this may have gone unnoticed is that factors that predict self-determination are frequently referenced in papers regarding this population. However, this evidence stems almost exclusively from a small number of studies involving either broader cohorts or entirely separate populations.

Moreover, there are grounds for arguing that the quality of the research in these papers should be treated with more caution than they typically receive. As different populations are likely to produce significantly different results, studies that fail to differentiate their results between different age or disability groups are at risk of conflating data and distorting findings. The factors that predict self-determination in elderly or physically disabled individuals, for example, may not be generalizable to young adults with intellectual disabilities, as the participants' life experiences are unlikely to be comparable.

Furthermore, the transition to adulthood is a uniquely important life-stage with regards to the development of self-determination. The research itself has shown that different age groups report significantly different levels of self-determination (Wehmeyer, 1996), and that intellectual disability cannot be collapsed with other disability groups (Shogren, Kennedy, Dowsett, & Little, 2014). Even within the same disability type, differences

between mildly and severely disabled individuals are likely to be significant (Bouck 2014). As a result, conclusions from studies that treat these samples as homogenous, or that attempt to generalise conclusions from separate studies on different populations, must be interpreted with caution.

It is also worth noting that many of the studies on the predictors of self-determination utilise relatively small sample sizes. Studies such as Stancliffe et al. (2000), Wehmeyer and Bolding (2001), Zhang (2001), Duvdevany et al. (2002), and McGuire and McDonnel (2008) involve fewer than 100 participants, with four involving fewer than 50. While studies with small sample sizes do not inherently lack value, the weight of their evidence may not justify the strength of the conclusions being drawn from them in the broader literature. Even some of the larger frequently cited studies, such as Wehmeyer and Bolding (1999), Wehmeyer and Garner (2003), Shogren et al. (2007), Nota et al (2007), and Williams-Diehm (2008) include fewer than 350 recruits of mixed ages or disability types, and are mostly collected across limited geographical areas. Importantly, this is not a criticism of the studies per se, but instead of the way in which their results have been accepted without question within the field. In reality, more research must be undertaken before conclusions regarding these predictor variables can be drawn with any confidence.

However, the most salient criticisms of the self-determination literature stem from the lack of clarity about the meaning and use of the term 'self-determination,' and the methodological problems that have arisen as a result of these ambiguities.

2.9 Critique of the self-determination construct

According to the functional model, an individual may be considered self-determin*ed* if they consistently demonstrate self-determin*ed* behaviours, i.e. those that embody behavioural autonomy, psychological empowerment, self-regulation, and self-realisation (Wehmeyer et al., 1996). Being self-determin*ed* is, therefore, a **dispositional trait** that remains reliably and predictably stable across both time and different situations (Wehmeyer et al., 1996). In contrast, 'self-determination' is defined as follows:

> *"Being the primary actor in one's life, having the capacity for making choices and decisions regarding one's quality of life, free from undue external influence or interference"* (Wehmeyer, 1992, 1996; Wehmeyer & Abery, 2013).

Consequently, 'self-determination' may be thought of as a **transactional outcome** that emerges in response to a power negotiation *between persons*. The differences between these two constructs are notable. The criteria for dispositional self-determination, for example, are far more stringent than the criteria for transactional self-determination. Where the former requires that every action be autonomous, psychologically empowered, self-regulated, and self-realised, the latter requires that an individual is the primary decision-maker in their own life. Moreover, dispositional self-determined behaviours are neither necessary nor sufficient for transactional self-determination, which can only ever be reached collaboratively. To live a life 'free from undue external influence or interference' necessarily requires that an individual live within a socio-ecological system that grants such freedom.

It should also be noted that self-determination theorists are unified in suggesting that dispositional self-determination is only possible if people have the "combination of skills, knowledge, and beliefs that enable a person to engage in goal-directed, self-regulated, autonomous behaviour" (S. Field, Martin, Miller, Ward, & Wehmeyer, 1998b, p. 2). According to Wehmeyer (1999), these competencies include:

> Choice-making skills
> Decision-making skills
> Problem-solving skills
> Goal-setting and attainment skills
> Self-observation, self-evaluation and Self-reinforcement skills
> Self-instruction skills
> Self-advocacy and leadership skills
> Internal locus of control
> Positive attributions of efficacy and outcome expectancy
> Self-awareness
> Self-knowledge

Consequently, self-determination competencies, dispositional self-determination, and transactional self-determination represent three distinct, but interrelated dimensions of functional self-determination. Other theorists have highlighted the fact that such distinctions exist (Stancliffe et al., 2000); however, the self-determination literature is replete with examples of conceptual conflation. Despite being designed to measure individual levels of dispositional self-determination, the ARC self-determination scale has been used in studies on self-determination competencies as well as transactional outcomes. Even if researchers themselves understand the nuanced distinctions between these different dimensions of self-determination, these distinctions are rarely made explicit to their

readers. The following description of the ARC self-determination scale taken from Wehmeyer and Garner's 2003 paper serves as an example of this:

> *"The Arc's self-determination scale (Wehmeyer and Kelchner 1995) is a 72-item self-report scale that provides data on overall self-determination by measuring individual performance in the four 'essential characteristics' of self-determination identified by Wehmeyer et al. (1996). The first section measures autonomy, including the individual's independence, and the degree to which he or she acts on the basis of personal beliefs, values, interests, and abilities."³*

Arguably, this description misrepresents the instrument as one that measures transactional self-determination outcomes as well as dispositional behaviours. The term 'independence', for example, carries transactional connotations and may be mistakenly interpreted as suggesting that the first section concerns *opportunity* for autonomy. In contrast, every question in the 32-item autonomy section necessarily removes the transactional element required for an individual to be considered 'independent':

Question: I make my own meals or snacks:
Answer 1: I do not *even if I have the chance*
Answer 2: I do sometimes *when I have the chance*
Answer 3: I do most of the time *I have a chance*
Answer 4: I do every time *I have the chance*.⁴

Thus, while the scale proves to be a useful indicator of an individual's *volition* to behave autonomously, it is directly misleading to suggest that it has the potential to measure *actual* autonomy or independence. Importantly, this is not a criticism of either the ARC or the functional model, but instead of the way in which they are described and used. Moreover, this example is far from anomalous. Numerous papers, including Wehmeyer and Bolding (1999), Cross et al. (1999), Lachappelle et al. (2005), Wehmeyer et al. (2006), Wehmeyer et al. (2011), Jones et al. (2014) either describe their constructs in an unclear or misleading fashion, or fail to provide definitions of their terms. The resulting lack of transparency makes each study harder to engage with and arguably has the potential to undermine the value of such papers' findings.

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³ Bold added by author for emphasis.

⁴ Italics added for emphasis

2.10 How do the transactional, dispositional, and competency dimensions of self-determination interact?

As suggested, transactional self-determination can be thought of as the product of power negotiations between an agent and the people around them. As a result, transactional self-determination is only likely to occur when a) an individual demonstrates self-determined behaviours and b) their environment supports self-determination as an outcome:
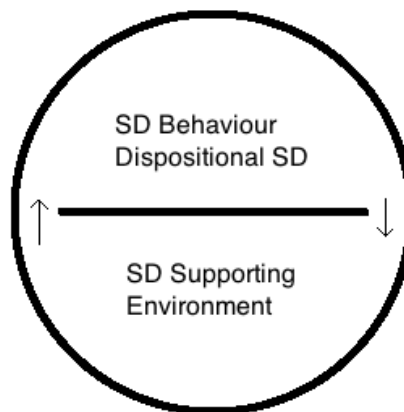
Figure 2: Transactional Self-Determination

The significant association between environmental features and levels of dispositional self-determination supports this conceptual relationship (Chambers et al., 2007; Shogren et al., 2007; Wehmeyer & Abery, 2013). Factors such a residence-size and choice opportunity, for example, are positively correlated with ARC scores (Shogren et al., 2007; Wehmeyer & Bolding, 1999). Yet, as discussed at length in Section 1.6.2, parents and carers are often caught between the desire to promote self-determination, and the need to protect and support their dependents (E. W. Carter, Lane, Cooney, Weir, Moss, & MacHalicek, 2013; G. H. Murphy & O'Callaghan, 2004; Pilnick et al., 2010; Seale et al., 2013). This dilemma creates a catch-22. On the one hand, environments are unlikely to support self-determination for individuals who are unable to demonstrate the capacity for self-determined behaviour. On the other, self-determined behaviours are less likely to be exhibited in a non-conducive environment.

Arguably, it is for these reasons that capability plays such a significant role in debates about self-determination. Without the right skills and competencies, it is reasonable to assume that an individual's behaviour is unlikely to become self-determined, from which

they will almost never be in a position to negotiate a more autonomous, self-determining lifestyle. Consequently, the diagram could be expanded as follows:

TRANSACTIONAL SELF-DETERMINATION
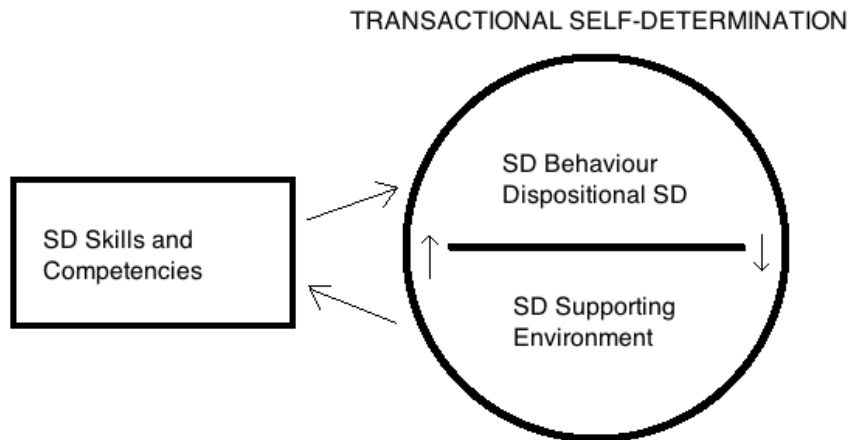
Figure 3: The Relationship Between SD Skills, Dispositional SD, and Transactional SD

Importantly, the conceptual relationship depicted in Figure 3 is insufficient to predict self-determination outcomes. While dispositional self-determination most likely depends upon an individual having both the right skills and opportunities, having the skills and the opportunities does not guarantee that an individual will develop a self-determined disposition. One of the most notable findings from the systematic review was how few variables had been investigated as potential predictors of self-determined behaviour. Human beings are complex social creatures, whose behaviour is influenced by beliefs and perceptions, social goals, and emotions. As proposed by Noom, Dekovic and Meeus (2001), autonomous behaviour has three dimensions: functional, attitudinal, and emotional. However, bar one study on learned hopelessness (Wehmeyer & Palmer, 1998), there is currently a paucity of research into the relationships between self-determination and emotional states and social cognition processes.

2.11 Bridging self-determination and social information processing theory

As an intrinsically social phenomenon, social cognitions may influence the extent to which an individual exhibits self-determined behaviours. Social cognition theories attempt to explain how human beings make sense of social encounters, and how these cognitive processes underlie interaction behaviour. The Social Information Processing theory developed by Crick and Dodge (1994) provides a model for how "children process and interpret cues in social situations and arrive at a behavioural or emotional decision

regarding those cues" (Bauminger & Kimhi-Kind, 2008, p. 315). Specifically, Crick and Dodge posit that a self-reinforcing set of dynamic, non-linear socio-cognitive processes underpin human social interaction. Social cues are encoded and interpreted, from which personal goals are developed, and a range of possible responses generated. These responses are then chosen and enacted by the individual, from which new social cues emerge that indicate whether the chosen strategy was effective or not. All such experiences are stored in long-term memory as social knowledge, including things such as social rules and heuristics/social schema, helping individuals to refine their behaviour as they develop. Importantly, these processes are mostly automated, rather than controlled - individuals are not perpetually engaging in deliberate self-reflective thinking. Moreover, though primarily a cognitive theory, Social Information Processing Theory is believed to both influence, and be influenced by, an individual's emotional state (Crick & Dodge, 1994; Lemerise & Arsenio, 2000).

In line with other social cognitive theories, Social Information Processing Theory emphasises the transactional nature of human interaction by suggesting that behaviours emerge as a result of complex negotiations that occur between individuals (Bandura, 1971, 2001). Behavioural responses are elicited when a subject's social knowledge – their beliefs, expectations, goals, and values (as determined by prior social experiences) combines with their current affective state (Crick & Dodge, 1994). Social Information Processing Theory can thus be understood as the set of processes underpinning social problem-solving (Embregts & van Nieuwenhuijzen, 2009).

The potential application of this theoretical model to functional self-determination is notable, as factors such as providing emotional support, facilitating dialogue between stakeholders, improving expectations, developing confidence, and inspiring motivational changes may well increase levels of self-determined behaviour. Yet, as suggested, of the intra-personal factors studies to date, learned hopelessness is the only one that fits into this framework (Wehmeyer & Palmer, 1998). Until we have a better understanding of how social goals and expectation beliefs relate to dispositional self-determination, and what the emotional implications of self-determined behaviour are, improvements to self-determination outcomes may remain limited.

2.12 Limitations of the review and future research

Despite efforts to design an effective search strategy, the initial criteria may have been too narrow to locate studies focussed on specific aspects of the self-determination construct, such as choice-making and goal attainment. Had the skills domains associated with self-determination been included as separate search items, it is possible that more studies of relevance would have been found. It should be noted that less stringent exclusion criteria would have resulted in a greater number of studies being considered for review, such as those involving mixed disability/severity groups and broader age ranges. However, as argued in the discussion, the authors contend that these studies potentially conflate heteronomous factors that are unique to distinct populations within these samples. As the objective of the review was to establish the factors that predict self-determination in transition-age individuals with mild to moderate intellectual disabilities, studies that did not isolate results for this particular population were considered inappropriate for inclusion.

It should also be mentioned that several qualitative studies were excluded that may to some extent enlighten the research question. As the purpose of this review was to find studies from which findings could be generalised, the decision not to include qualitative studies remains justified. However, the authors recommend that a qualitative systematic review be conducted, to help expand or explain any subsequent correlative or experimental research that may be undertaken on this topic.

Moreover, the review has highlighted how little research has been undertaken on the socio-cognitive and emotional processes that stand to facilitate and impede the development of self-determination. Knowledge about these factors may have implications for the effectiveness of interventions to increase self-determination. How comfortable an individual feels about asserting themselves against authority figures may make a significant difference to the self-determination of their behaviour, for example. Similarly, it is reasonable to hypothesise that without positive outcome expectations, self-determined behaviours are less likely to be exhibited. Until we have a better understanding of how these other psychological mechanisms relate to self-determination, it is unlikely that the efficacy of these interventions will be maximised. As such, there is a strong argument for expanding research in this area.

2.13 Key Findings

- Only three papers could be found that included possible predictors of self-determination in young adults with mild intellectual disabilities that passed our inclusion and exclusion criteria.

- From these studies, factors possibly associated with self-determination include nature and duration of leisure activities, IQ/level of intellectual impairment, and academic achievement.

- Studies of self-determination are not always clear about the outcomes of interest and often have either small or mixed samples. These factors may impact the quality of their findings.

- There is a deficit of research on the possible relationships between self-determination and emotional and socio-cognitive factors.

2.14 Summary

The purpose of this review was to determine which factors are evidenced to predict self-determination in transition-age individuals with mild to moderate intellectual disabilities. Hand searching, plus a systematic search of five databases (PsycInfo, Medline, Embase, Web of Science, and Google Scholar) returned 1172 references, of which three papers were considered appropriate to the research question. Two correlational studies revealed three main predictors of self-determination: IQ score, recreational activity, and academic achievement. Furthermore, a paper by Palmer et al. (2012) provided additional evidence that disability severity also shares a correlative relationship with self-determination. Additional non-intervention studies in broader populations provide evidence that age, gender, social ability, and environmental factors also predict self-determination. However, as only three studies were found that exclusively reported findings for the target population, it is suggested that there is currently a deficit of research from which to draw any firm conclusions.

Moreover, though described in seemingly straightforward and specific terms, the functional model of self-determination embodies three distinct dimensions - dispositional self-determination, transactional self-determination, and self-determination competencies – that are rarely distinguished and often appear to be conflated in the literature. The

relationships between these three dimensions are likely to be complex and interdependent. Environments are more likely to facilitate self-determination for individuals who exhibit self-determined behaviour, and individuals are more likely to exhibit those behaviours when the environment is favourable. However, from a developmental perspective, dispositional self-determination is likely to depend upon a far more complex interplay between socio-cognitive and emotional mechanisms than discussed in the literature to date. Factors such as outcome expectancy, social goals, and the emotional impact of pursuing greater autonomy are likely to be highly influential on an individual's behaviour, regardless of how skilled they are, or how many opportunities they have to express those behaviours. Consequently, additional research in this area may help to improve the efficacy of self-determination interventions.

Chapter 3   Development and Implementation of the Qualitative Phase (Study 1)

3.1 Introduction

Factors such as low hopefulness and negative self-perceptions have been posited as direct obstacles to the development of self-determination (Wehmeyer & Palmer, 1998). However, very little additional research has been undertaken to investigate how personal and environmental factors interact to affect young peoples' attitudes towards their own transition, or how these cognitive and affective processes impact their adult identity and self-determined behaviour. The purpose of the following chapter is to outline the methods used for undertaking three qualitative studies designed to explore the emotional and socio-cognitive dimensions of transitioning to adulthood as experienced by young adults with and without intellectual disabilities. The chapter begins by discussing the overall aims of the qualitative phase of the project, before discussing its design and rationale. Participants and recruitment are outlined in Section 3.3.2, followed by explanations of the procedure, data analysis, and question development in Sections 3.3.3, 3.3.4, and 3.3.5 respectively. The chapter concludes with a description of the pilot studies undertaken to help improve the content and structure of the final studies.

3.2 Aims

As growing up is a complex and multifactorial outcome, it was decided that a mixed-methods approach would add more value to the project than the adoption of a single method. Moreover, mixed-methods is appropriate to the pragmatist paradigm, according to which this thesis has been conducted (Rorty, 1999). The main study (Study 2), details of which are presented in Chapter 7, involved a series of unique tasks to investigate experiences of, and attitudes towards autonomy, social goals, and adulthood. However, the development of ecologically valid novel measures requires sufficient knowledge and understanding of the life contexts of the target populations. For this reason, a sequential-exploratory study design was chosen to guide the thesis, according to which qualitative data is collected to develop quantitative measures (Creswell, Plano Clark, Gutmann, & Hanson, 2003).

A series of interviews were therefore undertaken to gain a deeper insight into the attitudes, aspirations, and experiences of young adults with and without disabilities, and their

parents, during the transition process. Particular focus was paid to 1) how the participants' experiences of parental involvement relate to their expectations, and 2) how the participants' social goals and outcome expectancies influence their transition. Topics included perspectives on autonomy, responsibility, trust, independence, the parent experience of transition, and adult identity. However, while descriptive data was collected to inform the design of the second study, interpretative analysis of the interviews revealed valuable findings in and of their own right. The design, procedure, and analysis process involved in these interview studies are outlined below.

3.3 Methods

3.3.1 Design and Rationale

The study was designed to gain an in-depth understanding of young peoples' experiences of, and thoughts and feelings towards decision-making, autonomy, independence, and growing up. Semi-structured interviews were undertaken with young people in years S5 and S6 both with borderline to mild intellectual disabilities (n=8), and without (n=8). Furthermore, as families are known to contribute significantly to these outcomes, five parents of adolescents with learning disabilities were also interviewed to explore their perspectives on their young person's transition to adulthood.

Interpretive phenomenological analysis (IPA) was initially chosen to underpin the study, as this approach was explicitly designed to explore participants' lived experiences and personal perspectives (J. A. Smith, 1996; J. A. Smith & Osborn, 2015). The hermeneutic emphasis of IPA was considered to be in keeping with the study's aims and focus. However, the phenomenon under investigation – transition to adulthood – was judged to be too nebulous, and the associated experiences too heterogeneous to be subjected to an idiographic mode of enquiry (J. A. Smith, Flowers, & Larkin, 2009). As a result, thematic analysis was chosen for providing the flexibility required for undertaking a broader, more exploratory study of this type.

Importantly, unlike other forms of qualitative analysis, thematic analysis "is not wed to any pre-existing theoretical framework [ ] and can be used to do different things within them" (Clarke, Braun, & Hayfield, 2015, p. 9). While the pragmatist research epistemology allows for the use of any method appropriate to the research topic and question (Rorty, 1999), thematic analysis was deemed to be particularly suitable for handling both

descriptive and more interpretative themes (Boyatzis, 1998). As with IPA, thematic analysis can be used to develop an insight beyond the semantic content of the data (Patton, 1990). The process of interpretation is active, with the researcher acknowledging their role in both identifying patterns and selecting the final themes (Ely, Vinz, Downing, & Anzul, 1997). While each transcript was analysed in isolation, attention was given to patterns occurring across each group's data set. However, salience, rather than prevalence, served as the defining justification for the themes' inclusion in the final write-up.

The adoption of thematic analysis for an interpretative study may be criticised for attempting to 'cherry-pick' from IPA without adhering to the restrictions of either methodology. Justification has been provided for why a full IPA approach was not taken for this study. Nevertheless, the author acknowledges that a larger sample, as often expected from a standard thematic analysis, may have broadened the scope of the findings. The study's sample size was too small to achieve thematic saturation, for example. Yet, due to the scope of the research topic, thematic saturation was not an intended outcome of the study. Instead, the researchers adopted an interpretative strategy to facilitate a more in-depth analysis of the participants' unique perspectives. Consequently, the themes presented are not exhaustive, but rather reflect a snapshot of our participants' perspectives on, experiences of, and aspirations for the transition to adulthood.

3.3.2 Participants and Recruitment

A non-random sample of borderline to mildly learning-disabled young adults (n=8), typically developing young adults (n=8), and parents of learning disabled individuals (n=4) were recruited through schools in Edinburgh. Schools were initially invited to participate by the Head of ASL at Edinburgh Council on the researcher's behalf. Contact details of schools wishing to be involved were then passed to the researcher directly. Two special schools and two mainstream schools responded to follow-up contact. Meetings were arranged with Support for Learning Leaders, Heads of Year, and one Head Teacher, during which the project was explained in further detail, and potential students were identified. The schools then contacted parents as a courtesy, as well as to extend invitations for participation in the parent interviews. With permission, schools passed parent contact details to the researcher to arrange interview times.

School ID	School Type	No. Pupils Interviewed	No. Interviews Included	Reason for exclusion	No. Parents Interviews
A	Mainstream	2 with IDs 7 Typically Developing	2 with IDs 5 Typically Developing	IQ scores fell within borderline range	2 Parents
B	Catholic Mainstream	3 with IDs	1 with an ID	IQ scores fell within normal range	1 Parent
C	Special School	6 with IDs	5 with IDs	IQ score fell within normal range	2 Parents

Table 2: Participating institutions for Study 1

3.3.2.1 Young Adults with Intellectual Disabilities

The participants' demographic details are presented in Table 3. All participants were aged between 15.9 and 17.7 years (M =16.9 years, SD = 0.58). Students were eligible for participation according to the following criteria:

    a. Aged 16 – 18 years old

    b. Living at home with one or more parents

    c. IQ scores within the mild intellectual disability range

    d. Capable of providing their own consent to participate

    e. No known emotional or behavioural difficulties

    f. Willing to chat at length and in detail about their thoughts and feelings about transition and adulthood

Participants were recruited from one special school and two ASN departments in mainstream schools. Eleven young people were initially identified by their schools and invited to participate. As part of the screening process, IQ scores were collected using the WASI-II. Three young people were excluded from the study for attaining IQ-scores within the normal range. Though the study aimed to investigate individuals with mild intellectual disabilities, three participants with borderline IQ-scores were included, as their schools had identified them as having sufficiently limited adaptive capacity to be considered to have a mild intellectual disability. These young adults were considered borderline because their scores on the WASI-II had a 95% confidence interval range that included IQ scores between 65 and 80. This decision was taken as the 2-scale WASI-II is an abbreviated measure and has a greater potential for error than the more comprehensive 4-scale version.

Furthermore, one 15-year-old participant was included in the sample after parental consent had been obtained, as she was only one week away from her 16th birthday at the time of the interview. Eight participants (4 male) were therefore included in the final study, as sample sizes of between six and eight are typically considered to be appropriate for interpretative methods (Turpin, Barley, & Scaife, 1997). Neighbourhood deprivation details were established using the Scottish Index of Multiple Deprivation (SIMD), based on the participants' postcodes. For simplicity, overall scores have been converted to quintiles, from the highest level of deprivation (1) to the lowest (5). All participants were living at home at the point of the interview.

3.3.2.2 Young Adults without Intellectual Disabilities

Participant characteristics are presented in Table 4. All participants were aged between 16.16 and 18.16 years (M=17.0, SD =0.54) and were recruited from the same school. Students were eligible for participation according to the following criteria:

g. Aged 16 – 18 years old

h. Living at home with one or more parents

i. IQ scores within the 'normal' range

j. No recorded disabilities

k. No known emotional or behavioural difficulties

l. Willing to chat at length and in detail about their thoughts and feelings about transition and adulthood

Eight eligible students (four male, four female) were identified by the school and invited to participate. Participants' neighbourhood deprivation status was assessed using the Scottish Index of Multiple Deprivation. The WASI-II was used to screen participants by IQ score, after which two pupils were excluded for scoring in the borderline range. Two replacement participants were identified by the school and invited to participate.

3.3.2.3 Parents of Young Adults with Intellectual Disabilities

Parents of every young participant with an intellectual disability were invited to interview. Of these, five volunteered to take part in the study (three mothers and two fathers). No additional inclusion or exclusion criteria were considered necessary. Participant characteristics can be found in Table 5.

3.3.3 Procedure

3.3.3.1 Ethical Approval

Ethics approval was initially sought and granted from the MVLS Research Ethics Committee at the University of Glasgow. Furthermore, as the planned research was to be undertaken in schools, additional ethical approval was requested from Glasgow Council's Education Authority. However, Glasgow Council's Education Research Committee rejected the application as questions relating to sex and relationships were said to be inappropriate in the school context. Glasgow Council also raised concerns about the use of the terms 'intellectual disability' and 'learning disability,' as they felt that these could be offensive to individuals with additional support needs. The committee also felt that IQ testing was a poor indicator of educational difficulties, and could not be justified. As no appeals process was available, all research relating to the project was prohibited from being undertaken in schools within the remit of Glasgow council. Ethical approval was later sought from Edinburgh council, who granted the application without amendments.

Information sheets about the study were sent home to every participant prior to the commencement of the study, copies of which can be found in Appendix C. Schools contacted the parents of each young participant with an intellectual disability to seek permission for the study as well as to extend invitations to the parent interviews. All participants signed consent forms before the start of each interview session. Examples can be found in Appendix D. Furthermore, the right to withdraw was reiterated each time, and the session did not begin until the researcher was confident that each young person was happy to take part. One female participant asked to leave at this point but returned of her own volition later during the school day. A copy of the ethical approval can be found in Appendix E.

3.3.3.2 Interview Procedure

Semi-structured interview schedules, examples of which are presented in Appendices F and G, were developed to help guide the discussions; however, the sessions were not restricted to these predetermined items or topics. Young person interviews were conducted on school grounds during the school day and arranged per the participants' timetables. Parent interviews occurred at a time and location decided by the participant, most frequently at their home, though in one case, at the school. All interviews lasted between 30 minutes and 1hr 30 and were transcribed verbatim after each session. Demographic

information was collected as part of the induction process before the beginning of the interview. However, the WASI-II test was administered at the end of the session, as it was felt that sitting an IQ test beforehand had the potential to put participants in the wrong frame of mind for the interview.

For the pilot study, three adolescents with intellectual disabilities and one parent were recruited through organisations in the West of Scotland with which the lead researcher was affiliated. Three typically developing adolescents were recruited through personal networks. Interviews were held in private locations chosen for the convenience of the participant and lasted between 40 minutes and an hour and a half.

3.3.4 Data Analysis

Each transcript was read repeatedly to maximise familiarity with the data, before being subjected to several rounds of analysis. An initial list of themes was by compiled by undertaking a line-by-line analysis of the text. This process was repeated to create more latent themes, which were then clustered, paired with appropriate quotes from the text, and named to form meta-themes. However, because of the complex, overlapping nature of the transcripts, this process was fluid, with the meta-themes changing and evolving throughout the process.

After the process had been repeated for each transcript, all meta-themes and their associated quotes were printed, cut out, and re-grouped according to the similarity of the themes, from which new meta-themes were created for the group. Much like the initial analysis, this was an active process that continued to evolve throughout the write-up. As a result, the results reflect the researcher's interpretation of the data, which is itself highly contextual. However, to ensure that the process was as rigorous as possible, each transcript was considered in isolation, to prevent previous themes from influencing the analysis. Furthermore, aspects of each stage of the analysis process were undertaken separately by the lead supervisor to establish reliability. The themes presented were agreed upon jointly as a result of this process. A research diary and participant summaries were also written to prevent the themes from becoming too abstracted from the original interview.

Descriptive data from the interviews was also analysed informally to help develop the subsequent quantitative phase of the project. Details regarding this process are presented in Chapter 7.

3.3.5 Question Development

The initial topics of conversation were based on Stancliffe and Parmenter's *Choice Questionnaire* (1999) as a valid measure relating to everyday choice-making. However, a number of domains were updated to better reflect the target populations' lifestyles. Topics concerning living in a residential facility, for example, were replaced with questions about technology and entertainment. Furthermore, in order to elicit the more nuanced responses required for an interpretative thematic analysis study (Clarke et al., 2015), all main questions were written in an open-ended fashion, designed to be as non-leading as possible. However, several additional prompts were included to help scaffold the discussion as required.

Following advice from experienced researchers in the field, an 'opener' question was included to begin the discussion, as it has been shown that participants often need to 'warm into' the interview (J. A. Smith & Osborn, 2015). 'Can you tell me a bit about a typical day' was chosen, as it was believed that this would not only provide a simple overview of the individual's life, but also that it would help to contextualise the rest of the questions. Furthermore, questions relating to the process of transition and perspectives on adulthood were introduced at this stage, as it was acknowledged that this was an important dimension of the research aim that was otherwise not being addressed. A vignette-style question was also added to investigate participants' outcome expectancy beliefs regarding making a decision that their parents disapproved of:

> *Imagine that you made a decision that was really against what they wanted for you, how would you feel? How would they feel?*

Finally, rather than risk participants ruminating on any potentially troubling thoughts of the future, a 'Harry Potter' themed closing-question was added to end the interview on a positive note. A set of interview questions for parents was also developed at this stage to complement and contextualise the young people's answers. These directly mirrored the items in the young-person interview but were re-phrased to make the parent the question's subject.

Prior to data collection, a pilot study was undertaken to ensure that the question items were appropriate for all participants.

3.3.6 Young Person Pilot

The young person interview schedule was piloted with six young adults (three male, three female). Three young adults with intellectual disabilities were recruited through organisations familiar to the researcher. Interviews were conducted on site, and lasted between half an hour and 1.5 hours. Three young adults without intellectual disabilities were recruited through personal connections. These sessions were undertaken at the participants' homes and lasted between forty minutes and an hour. During this process, changes were made across four key areas: question content; language and phrasing; item order, and procedure.

3.3.6.1 Question Content

Though the original opener to some extent 'warmed' participants into the interview process, it became clear that individuals from both groups struggled to answer the question. Some had no clear routine, others found it hard to pick a 'typical' day to describe, and there were others still who suggested that the details – waking up, having breakfast, showering, etc. – were too mundane to discuss. The question was therefore changed to "can you tell me a bit about your family?" which not only elicited more confident answers but also gave the researcher a better insight into participant's lives. Similarly, it quickly became apparent that the 'Harry Potter' closing question was not culturally relevant to the target age-group and was therefore replaced with "if you could have a superpower, what would you choose?"

Several specific items were replaced with more general questions about decision-making, responsibility, and transition. This decision was taken once it became clear that the participants with intellectual disabilities were happy and able to engage with more abstract topics. This alteration provided greater freedom to respondents to tell their own stories as "experiential experts," leaving more room for content that the researcher had not pre-empted (J. A. Smith & Osborn, 2015). Additional probes were also developed to ensure that the emotional and cognitive dimensions of decision-making could be recorded, rather than focussing explicitly on how much decision-making opportunity participants do or do not have.

Early analysis also revealed that the process of moving up a year-group at school can make a significant contribution to an individual's subjective adult identity that is distinct from

the contribution made by that individual's birthday. Questions about these and similar objective life-markers were therefore included in the final draft. Finally, it quickly became clear that the 'vignette' question was too abstract and hypothetical for members of either group to respond to with ease. Moreover, none of the respondents could empathise with a situation in which they might deliberately defy their parents. Members of both groups expressed the desire to maintain positive relations with their parents, as well as an appreciation of their parents' best intentions.

For this reason, the scenario was changed to one about leaving home. However, for many young people with intellectual disabilities, permanently moving out of their parents' home is not often considered a realistic option. The scenario was therefore based on a decision to go on holiday without family, as it was judged that this would be sufficiently daunting to both groups to warrant discussion without also being unrealistically ambitious for the participants with disabilities. The questions continued to revolve around the anticipated emotional experience of making the decision, expected parental attitudes, and how these would affect the final decision.

3.3.6.2 Language, Phrasing, and Rapport

Significant care was taken during the piloting process to develop ways of asking questions that were appropriate for both groups. A number of the questions were deemed to be overly linguistically complex and were changed accordingly; for example, references to 'siblings' were changed to 'brothers and sisters' after one participant went on to discuss his parents. In particular, several items relating to sex and relationships were initially worded figuratively to avoid embarrassment. However, referring to sexual intercourse as a 'grown-up sleepover' continued to generate embarrassment from those who understood, confusion from those who did not. As a result, a more direct approach was developed, as it was found that this was the most reliable tactic for eliciting relevant answers. Time was also taken to ensure that questions were in no way leading to avoid influencing the participants' responses.

In addition, the process of transcription revealed that the researcher had some unprofessional conversational habits of which she was unaware. These include complicating a question's wording at the last minute for no gain, showing positive and negative judgement rather than remaining neutral, using an apologetic or defensive tone when discussing intimate matters, and vocalising her own experiences during the

interview. The piloting process not only revealed these behaviours but also provided an opportunity for practice and improvement. As in all qualitative research, interaction style and rapport with the participant are as integral to data collection as the schedule itself. Much care was taken to become as familiar as possible with the questions, to ensure that the discussion could flow as smoothly and as naturally as possible. Furthermore, the piloting sessions provided several opportunities for the researcher to practice adapting her vocabulary and register as appropriate for each participant.

3.3.6.3 Item Order

After the first couple of interviews, a logical progression to the questions emerged. While thematic analysis allows for the interview to evolve in response to the flow of the conversation (Clarke et al., 2015), reordering the question items helped the researcher to guide the discussion in a way that felt natural while feeling confident that no items were being missed. Furthermore, the order of the final section of the interview was rearranged after the question 'how do you feel about the future?' ended one session on a rather negative note. In response to this, the vignette was chosen to guide the final few questions before the official 'closing question', as its hypothetical stance was deemed to make it less emotionally loaded.

3.3.6.4 Procedure

A number of changes were made to the interview procedure. In order to have as much demographic information as possible, the question 'how old are you?' was replaced with 'Can you tell me your date of birth / when is your birthday and what year were you born?' This decision was introduced to help differentiate between older and younger individuals of the same 'age.' Furthermore, the decision to include an IQ measure as part of the session was made after it became clear that the term 'learning disability', used in the UK to refer to intellectual disability, can generate confusion, and that participant screening was required.

One pilot interview had to be discounted because the participant had a learning *difficulty*, rather than a learning *disability*. Although the individual in question was in supported employment and had attended an Additional Support for Learning (ASL) school, the researcher felt that he was too high-functioning to form part of the group with intellectual disabilities. However, having not attended mainstream school, it was not felt that he should

form part of the control group either. By conducting a measure of cognitive ability as part of the interview, participants could be allocated to each group with greater accuracy. However, it was decided that the measure would be undertaken at the end of the session, so as not to distract or upset participants before the interview. Finally, as the piloting process requires a significant amount of time for analysis and reflection, pilot interviews were limited to one per day.

3.3.7 Parent Pilot

The parent schedule was piloted with the mother of a young man with an intellectual disability who had also participated in the young person pilot. The interview was undertaken in the family home and lasted one hour and twenty minutes. In response to this session, questions relating to the challenges of raising children with differing support needs were included in the final schedule.

3.4 Summary

Very little research attention has been given to the expectations and attitudes current young adults with and without intellectual disabilities have towards transitioning to adulthood, particularly in the Scottish context. Three sets of interviews were undertaken with eight young adults with mild to borderline intellectual disabilities, eight young adults without disabilities, and five parents of the young participants with intellectual disabilities to address this gap in the research, three. Semi-structured interviews were developed around the topics of independence, responsibility, trust, the parent experience of transition, and adult identity. Responses were also used to develop the quantitative phase of the research. Results from these groups can be found in Chapters 4, 5, and 6 respectively.

Chapter 4   Results from the Young Adults with Intellectual Disabilities (Study 1.1)

4.1 Introduction

The themes have been divided into two broad categories: A: On a Developmental Trajectory, and B: Negotiations in the Environment. Themes within category A focus on the young peoples' attitudes towards themselves and their own relationship to transition. Themes within category B place the young people within their socio-ecological context, and therefore concern interactions with the family, friends, and the external world. Importantly, responses were heterogeneous across a number of the topics. As a result, care has been taken to ensure that each theme accurately accounts for the full scope of the experience discussed across the interviews. Please note that pseudonyms have been used in the reporting of all data to maintain anonymity and the following forms of notation are used with the quotes:

… Pause; [ ] Words omitted; [Text] Added for clarity; **Non-verbal expression**

4.2 Participant Characteristics

Name	Gender	Age (years, months)	School	IQ Score	Living Situation	SIMD Score
Sam	Male	17, 0	A	Borderline	Shared Custody	7
Elliot	Male	16, 10	A	Borderline	Single Mother	3
Emma	Female	17, 8	B	Borderline	Both parents	10
James	Male	16, 0	C	Mild	Single Mother	6
Stuart	Male	16, 11	C	Mild	Both parents	1
Sarah	Female	17, 7	C	Mild	Both parents	1
Amy	Female	17, 1	C	Mild	Both parents	4
Lauren	Female	15, 11	C	Mild	Single Mother	5

Scottish Index of Multiple Deprivation Score: Highest deprivation (1), Lowest deprivation (10)

Table 3: Participant Characteristics for Study 1.1 (Interviews with young adults with IDs)

4.3 Theme A: On A Developmental Trajectory

4.3.1 Old in some ways, young in others

Most of the participants felt that neither the terms 'adult' or 'child' were particularly appropriate, preferring the label 'teen' or 'young adult'. In some cases, participants expressed awareness that their level of maturity differed between contexts, while others felt that their behaviour failed to reflect their chronological age. Exceptions, however, were

Sarah, whose self-perceived level of adulthood was high despite having minimal experience of, or desire for responsibility or independence, and Stuart, who fixated on his own lack of maturity despite being one of the most independent participants:

I'd call myself a baby…. I know! I'm so childish! It's funny…I'm just like a kid (Stuart)

One possible explanation stems from the different notions of adulthood against which the participants compared themselves. Every participant considered 'having responsibilities' to be the cornerstone of adulthood, and several made specific reference to looking after loved ones:

Being a good husband, being a good wife… looking after kids, like, well. (James)

However, Sarah placed the greatest significance on being chronologically older, whereas Stuart attributed more value to financial independence. Furthermore, he chose to compare himself against his parents, rather than his peers:

They're like 'oh, you can do this, you can do that', so it's like… they've got a wee bit more independence than me. (Stuart)

However, while levels of self-perceived maturity differed, all participants acknowledged that they were becoming more mature with time. For some, this recognition was based upon self-observed behavioural change. Stuart and Amy, for example, reflected on having learned the value of honesty:

I've lied a lot in my life about stuff. [ ] I'm building trust up with the school and stuff, and my mum and dad, and my granny and granddad (Amy)

Others cited interpersonal confidence as contributing to their self-perceived maturity, along with learning to speak for themselves. In one case, this was accompanied by the realisation that adults are "just people," and that everyone deserves the same amount of respect:

I've got the confidence to sit down and talk to somebody. It doesn't really bother me, you're just another person. Going through the same stuff. We just talk. You're a person. Two equal peoples, talking like normal. That's what we're doing now. Perfectly fine. Just be civil, that's what I tell myself, just be civil, and that's you – done. (Stuart)

4.3.2 The march of time

Though not every participant attributed the same significance to their age and stage, the abstract notion of 'getting older'' was nevertheless a reoccurring theme. Despite acknowledging their own youth, five participants voiced general unease at the prospect of aging. For Elliot, Amy, and Lauren in particular, the fear death – including their own death and the deaths of their parents - contributed significantly to this unease:

Weepily I just pretend, like, that she's gonna be here forever (Lauren)

Others' reluctance to grow older was framed in terms of increased pressure, both regarding academic performance and the expectation to behave more maturely. In both cases, participants demonstrated an awareness that their social roles were changing with age. For a couple of participants, significant birthdays held only positive associations, built around new liberty and opportunity:

It was like, really happy, turning 16 because it's an important year, sorta thing… it's the age limit to… vote, or have sex, sorta thing (Sam)

Importantly, Sam had no desire to take advantage of these new liberties. Their significance to him appeared to come from the point of principle - the desire for increased trust, rather than new experience. In a similar vein, Emma wished to celebrate her 18th birthday with a glass of wine, despite having no particular interest in either the taste or the prospect of getting drunk. Therefore, for a few of the participants, the new rights afforded with significant birthdays were viewed as intrinsic goods, rather than as means to particular ends.

4.3.3 I don't know how I'll cope without help

While the majority of participants agreed that adult responsibilities seem demanding, the amount of faith they had in themselves to cope with responsibility varied considerably. Regarding household management, Sarah, Elliot, and Lauren demonstrated very low levels of perceived self-efficacy, assuming that they would 'do it wrong,' or even be unsafe:

"I like cooking, I just don't want to do it on my own, for safety, so the kitchen doesn't go on fire, like, 'oh no, it's on fire!!' (Sarah)

The others voiced more confidence in themselves, with some feeling that they only needed to be shown what to do. However, when it came to responsibilities with significant consequences, such as managing finances and making decisions, several participants were more vocal about wanting support. Elliot, for example, aware of his difficulties with maths, felt that he would always require "someone to help [him] pay the bills and that." Similarly, Sam expressed quite low levels of confidence in himself to cope with responsibility, and suggested that he would rather avoid using his newly opened bank account than risk something going wrong. This lack of trust also extended to decision-making. His frequent use of the terms 'right' and 'wrong,' coupled with his expressed assumption that his parents know best, may explain Sam's apparent preference for delegating responsibility:

I like to rely on my parents to help me make a decision or make a decision for me sort of thing… I'd rather rely on my parents than get it wrong (Sam)

The fear of coping experienced by Lauren, however, was felt much more viscerally than by any of the other participants. Lauren discussed her Mum as being the most important person in her life - her sole support, both practically and emotionally. Despite Lauren demonstrating quite high levels of domestic competence, her perceived self-efficacy and confidence were quite low. This, coupled with her mum's recent experience with breast-cancer resulted in much greater levels of anxiety about coping in the future:

I'm just scared that, like, if I do something wrong, if I don't, like, feed myself, but I can like cook and stuff, but I'm I just want my mum to be around, and like, I don't know how to manage and stuff. (Lauren)

However, rather than ignoring the problem, Lauren expressed a commitment to "fac[ing] her fears" and taking on new challenges, including doing things on her own. The knowledge that her Mum will not always be there, though highly worrying, may also be motivating her to develop herself in a way that she otherwise might not.

4.3.4 It's not time for me to do it yet

The majority of participants admitted preferring to avoid responsibility for the sake of a simpler life. Though attitudes towards their current responsibilities were sometimes positive, most of the young people resisted the prospect of doing additional work. At the

extreme, Elliot found the prospect of helping around the house laughable, despite acknowledging that his Mum would appreciate more support. Stuart was equally honest about his preference for being looked after, though was prepared to help around the house as required:

I: How independent would you like to be?
P: Not that independent. I'm happy with the way my mum is helping me just now.

[On doing more chores] Oh, I'd hate it. I don't like it just now, but I have to do it (Stuart)

The only individual who described actively engaging with new responsibilities was James, who had already gained quite a lot of experience in household management. As well as feeling able and willing to engage with responsibility, James seemed to take pride in his initiative. However, part of this independence appeared to stem from a general aversion to being told what to do, both by his Mum and at school:

Instead of mum telling me to do it all the time, that gets annoying, so I just tell myself to do it, and it works. (James)

Interestingly, several participants referred to the fact that more responsibility was neither required nor appropriate for people at their age and stage in life. Sam, for example, found the prospect of learning how to handle bills at the age of 16 to be almost bizarre. Similarly, Emma and Amy implied that their parents *ought* to provide for as long as they remain living at home, as doing so is a parent's "job."

However, responses were not limited to the realm of responsibility. A couple of participants felt that too much freedom would also be inappropriate at their age. Though generally independent, James felt that he was too young and vulnerable to travel the world at his age. Similar beliefs were implied by the participants' strict adherence to legal age limits, particularly concerning alcohol and mature film content.

4.3.5 I'll be independent one day

Importantly, despite their reluctance to adopt the roles and responsibilities of adulthood at the point of the interview, the majority of participants felt that they would end up gaining

independence in the future. Feelings towards this eventuality appeared to be complicated. On some level, Stuart seemed to be resigned to the notion of moving out as being an inevitable step that everyone must take, regardless of how difficult he may find it. Yet, he also implied that moving out was a personal goal, something that only financial barriers were preventing him from undertaking:

When I'm old enough, I'll independently myself. That's… what I hope for.
I wouldn't be able to move out yet, until I've got a good job, then that'll be me. (Stuart)

Similarly, Amy expressed a strong desire for freedom, despite also acknowledging how dependent she currently is on her mum:

My friend, she's put her name on the housing list, and I said I'll move in with you and we'll split the cost
I've got an easy life [ ] I rely a lot on mum right now. (Amy)

Interestingly, where Stuart viewed independence as a necessary, albeit difficult part of the transition to adulthood, Amy perceived independence as the inevitable consequence of parental aging and death. Unlike Lauren, Amy discussed mortality in matter of fact terms:

What happens when they die, they can't protect me then, can they? (Amy)

Therefore, despite being reluctant to increase her domestic responsibilities, Amy acknowledged that she would not be able to delay these changes forever. Time-scale appeared to explain a number of the participants' attitudes towards gaining independence. Sam spoke excitedly about moving out; however, it later became clear that he envisaged waiting until his mid-twenties to do so, practically half of his life into the future. Thus, the majority of participants had an abstract desire for independence *at some point*, rather than concrete plans working towards a specific timeframe.

4.4 Theme B: Negotiations in the environment

4.4.1 My disability makes it harder

Six of the participants specifically referenced their academic difficulties and acknowledged the problems that these may cause them in the future. However, each demonstrated slightly

different attitudes towards these difficulties. For many years, Lauren's confidence suffered as a result of having been told that she would never succeed:

There was this lady [in the school]… she was telling me that I couldn't be a teacher, I couldn't be a carer, because I've got a learning difficulty, like, learning problems and like, I went home and I was crying all the time (Lauren)

In contrast, Sam appeared to accept his limitations, and adjusted his expectations accordingly:

It does seem a little bit hard to try to find a job, sorta thing. Because… like, some application forms [ ] They might ask me a question that's… everybody would understand, but I won't, sort of thing. (Sam)

However, both had learned to view their achievements as more impressive for having a disability and demonstrated a defiant commitment to overcoming other peoples' low expectations. In contrast, James appeared to view himself as falling short of some intangible standard he felt he *ought* to meet. Despite having formal diagnoses of dyslexia and having an intellectual disability, James nevertheless understood his struggles in terms of personal failings that he ought to try to overcome. Though to some extent resigned to his academic difficulties, James voiced frustration at how hard he continues to find concepts that he felt he *should* find easy:

I've got to work more on my English, 'cos I'm dyslexic, so my English really bad. It's not the best of the best as it should be right now. That, and just like normal stuff like time. That frustrates me so much. [ ] It's… slow processing, my mind. (James)

One possible explanation is that, despite having one of the lowest IQ scores of all the participants, James's more advanced adaptive capabilities meant that he did not view himself as being different. As well as socialising with predominantly typically developing friends, he spoke of his schoolmates as being substantively less capable than himself in the "important" aspects of growing up:

There's some people in this school who I think will never get to go by their self, [ ] you can speak to them and that – but I'm like, they don't know the simple stuff… The stuff you need to know [ ] how to… do a washing machine. (James)

Thus, James' perceptions of his academic difficulties appeared to be more pronounced because he compared himself to his mainstream friends. However, the fact that he viewed himself as having better prospects for self-reliance than his classmates with intellectual disabilities seemed to assure him that he would nevertheless be okay in the future. Stuart, in contrast, expressed levels of optimism about his academic potential that may not be justified by his current level of achievement. Similar to James, Stuart also expressed a need to work hard to reach a certain level of academic attainment. However, his academic goals were concrete, targeted explicitly towards achieving the qualifications necessary to apply for Mechanics at college:

I've been trying really hard to get my [ ] maths so I can do that in college, mechanic work at college… It's quite hard, but I'm just gonna have to keep trying with it. (Stuart)

Despite having demonstrated little improvement in the subjects required to pursue his chosen career, Stuart expressed high levels of optimism and perseverance. Rather than feeling doomed to failure, he was committed to the belief that success may be possible with a lot of hard work and dedication.

4.4.2 Separate spheres of decision-making

For the most part, participants described themselves as sharing the responsibility for making decisions about their own lives with their parents. For Stuart, the balance of power appeared to be tipped in his favour - his parents playing more of an advisory role than anything else. However, the majority of participants described having decision-making control in only a limited number of areas. For these individuals, 'shared' appeared to be defined as having distinct decision-making domains, rather than collaborating as equals. While these participants were afforded decision-making autonomy over low-level or routine matters, more significant decisions rested firmly with the parents. In some cases, having separate spheres of decision-making was clearly felt; however, others perceived their contribution to decision-making as being equal if their parents had listened to their preferences. The participants appeared to retain this perception, despite acknowledging that their parents continue to have the final say the majority of situations:

That, like, um… um… it was… well, that was sort of half and half, too. But, like, some… like, for, like, yeah. That was sort of half and half. Like, my mum first of all didn't want me

to go to college, but I think... over the last, sort of, [school year], she sort of got used to me, yeah. (Emma)

Importantly, regardless of how much decision-making autonomy the participants had, *feeling* in control of at least some decisions was seemingly very significant to them.

4.4.3 I deserve trust and respect

Though levels of independence varied significantly between participants, every young person expressed the desire for trust and respect. With Amy as a notable exception, the participants seemed to consider obedience to be an inherent good, and presented themselves as feeling motivated to do the "right thing." Though both prone to 'cheeky' behaviour, James and Stuart acknowledged and appreciated the amount of trust their parents placed in them, and responded by acting sensibly. In particular, James stated that he would never choose to deliberately hurt or disappoint his Mum, even though naughty behaviour is often tempting:

[On being obedient] Not because I'd get told off, just because my mum's not happy with it. (James)

As a result, both participants felt entitled to a minimum level of trust and respect. Much as Stuart had learned to view adults as 'just people,' James perceived himself as having rights on a par with his Mum. Rather than viewing her as having a special parental authority to intrude on his life, he expected to give and receive the same level of respect. Interestingly, lack of parity did not seem to frustrate or annoy James, as it did with other participants. At the prospect of his mum breaching his privacy, James voiced a preference for calmly and rationally explaining his preference, or responding in kind to 'right the injustice':

*[If Mum checked his phone] I'd be fine with it. I'd just check hers **laugh*** (James)

In contrast, half of the participants expressed profound frustration at the prospect of their parents trying to control their lives. For three, this manifested as feeling patronised and underestimated. At the prospect of his mum reading his texts without permission, Elliot anticipated feeling "betrayed," as if such an act represented a significant breach of trust. This feeling was more pronounced for Sam and Amy, who accused their respective

Mothers of regularly checking their phones without permission. Sam's irritation in this matter stemmed from feeling ostensibly 'micromanaged' and unable to take ownership of his affairs:

I'm not really happy with that, because it's my personal own space, sorta thing. So I don't want my parents to do. It's my business and my business alone… it's my private business, sorta thing, it's not your [Mum's] business. (Sam)

Similarly, Amy felt frustrated that her parents denied her the right to make her own mistakes:

I'm like a little girl, so they've got to try and protect me in the most responsible way they can, but then, I need to find these things out for myself. (Amy)

However, these individuals demonstrated a greater sense of resignation to external authority than their more independent peers. Elliot, for example, described an on-going struggle regarding the colour of his room. His mum's decision to paint - and subsequently keep - his room blue, rather than pink as he wished exemplified the sense of disempowerment he felt at home. By repeatedly failing to engage her on the topic, Elliot had developed quite a pessimistic attitude towards his own capacity to influence change:

If I had my way, my room would be pink and purple by now, but instead she always decides on blue, unfortunately [ ] it's my room, and she should put colour I want in it. It's my room, not hers [ ] we've been having this conversation for years. I've always wanted it pink. (Elliot)

As a young man with conventionally feminine interests, it is possible that this argument is symptomatic of his mum's struggle to accept her son's non-conformity. Taking room colour to be emblematic of identity, the rejection of Elliot's wishes carries more significance – as if his mum were dismissing *him*, rather than just his superficial interests. The subsequent frustration and sense of powerlessness are liable to be more profound as a result. However, despite their frustrations, the majority of participants acknowledged that their parents' rules and restrictions came from a place of love, rather than lack of trust:

I know she's trying to look out for me. (Amy)

4.4.4 Taking risks vs seeking protection

The participants' attitudes towards risk and protection were highly diverse. Unsurprisingly, the most independent participants were the least risk-averse, in part because they already trusted in their own capacity to look after themselves. However, while lack of capability explained some of less independent participants' risk-aversion, a number also expressed a distinct set of abstract fears based around the fact that *something bad could happen*. Sam and Sarah, for example, discussed avoiding situations that make them nervous or uncomfortable, rather than just situations that might be dangerous. For them, home represented a secure space removed from the risks of the outside world, while their families were viewed as protectors. Sam, in particular, implied that most of his fears subside when at home or in the company of his parents:

[On never being alone overnight] *I feel happy about that, aye. Just knowing that my parents are home, I feel safe.*
I'd like to… a parent or someone I know to come with me so that I feel safe (Sam

In contrast, Lauren expressed feeling nervous about her home security even with her mum in the house, in part because she views herself as her mum's protector rather than the other way around:

If my mum's still in the house, I just lock the doors cos I'm paranoid that something's gonna happen. (Lauren)

Lauren's attitudes towards her mum's past romantic relationships also appeared to reflect this need to protect her mum from harm:

Mum's always getting hurt with, like, relationships and everything [ ] I tried to fix it, and it didn't help [ ] I talked to him and saying 'why are you doing this' and everything, and he told me to shut up and go away. (Lauren)

Three of the female participants expressed significant levels of distrust towards other people. Lauren and Amy in particular described having been "used by people," and no longer felt able to rely on friends and boyfriends to treat them with respect. Similarly, despite having no direct experience, Sarah felt that social networking sites represent a real risk of "trouble" because people cannot be trusted to behave appropriately:

Cos Facebook, like, people go on it cos its fun, but I say, after a while it causes serious trouble afterwards, cos people are doing texting, like, words they shouldn't've, and that causes trouble. (Sarah)

It is worth noting that the participants' attitudes towards risk appeared to reflect the level of risk-aversion felt by their parents. The more nervous participants were highly cognizant of their parents' fears, particularly in relation to them going out and about:

I started to get trained up for taking the bus myself, but my mum was really quite nervous, and she wouldn't let me. (Emma)

I wanted to apply for a job at [shop] last year, but my mum wouldn't because she was afraid of how I would get back home. (Elliot)

In contrast, James and his Mum did not appear to feel the same level of emotional interdependence. As well as being given relative freedom to come and go as he pleases, James felt actively encouraged to take risks and explore:

She'll phone me and go 'when'll you be back', and I go mm, and that's it. And she'll just tell me what she's making for tea, and she'll just leave it on the counter, and I'll be like 'alright, I'll be back for it'. (James)

It is also worth noting that James was the most willing to take risks and experiment in other areas, particularly in relation to drinking alcohol.

4.5 Discussion

Aside from themes specific to having an intellectual disability, the participants' perspectives were generally very similar to those that one might expect to record amongst typically developing young adults. In many ways, this was surprising, as previous research has suggested that young adults with and without intellectual disabilities have different concerns at this stage in life (Forte, Jahoda, & Dagnan, 2011). Instead, the desire for increased autonomy, coupled with the aversion to responsibility aired by the participants in this study closely mirrors current generational attitudes towards growing up.

4.5.1 Perspectives on self-determination

Furthermore, in contrast to the suggestion that self-determination ought to be considered a holistic phenomenon (S. Field et al., 1998a), our participants' willingness to engage in "goal-directed, self-regulated, autonomous behaviour" instead appeared to be highly domain specific. Several participants expressed frustration at being denied control over particular aspects of their lives, and yet considered it their parents 'job' to continue to protect, provide, and make decisions for them. Part of this inconsistency may be explained by the fact that the participants' emotional relationship to the notion of independence appeared to be complicated. Several participants seemed to feel burdened by the social expectation for independence, simultaneously wanting to meet the transition norms for their age-group while fearing their own inability to cope. Others equated 'doing the right thing' with compliance, and were more concerned with appeasing their parents than pushing for greater autonomy. Emotional factors like low hopefulness and negative perceptions have been posited as direct obstacles to the development of self-determination (Wehmeyer & Palmer, 1998). However, the possibility that more complex emotional and socio-cognitive processes contribute to the lower levels of self-determination in this population warrants further investigation.

4.5.2 Social comparisons and age identity

The participants' criteria for adulthood largely overlapped and included a mix of personal characteristics and social role changes. In line with the majority of adulthood identity research in typically developing young adults, 'responsibility' was considered to be the most significant marker of adulthood. However, in contrast to the work of Arnett (1997, 2000), our participants were more likely to define 'responsibility' as meeting the responsibilities associated with social role transitions. Moreover, in some cases there appeared to be a greater emphasis placed on familial responsibilities and interpersonal maturity (being a *good* husband, *looking after* your kids) than personal responsibilities or self-sufficiency. It should, however, be noted that the amount of importance each participant attributed to these transition criteria varied considerably.

In a study comparing young adults' attitudes towards transition criteria, Nelson and Mcnamara-Barry (2005) found high levels of agreement that personal characteristics are significantly more important to 'adulthood' than social role changes. While this may indicate that young adults with intellectual disabilities adopt a broader range of criteria for

adulthood, higher levels of heterogeneity amongst typically developing young adults have been recorded elsewhere (Arnett, 1997). In addition, differences in participant age, as well as the focus and design of these studies make comparisons with our own hard to draw. Nevertheless, the possibility that young adults with intellectual disabilities adopt broader, or more social-role orientated criteria for adulthood is worth further investigation.

The participants' definitions of adulthood also appeared to influence their subjective age identities. Those who either had or were soon to meet the criteria that they considered to be the most significant markers of adulthood felt older than those who did not. Proponents of the confluence model of age identity (Shanahan et al., 2005) have suggested that social role transitions make individuals feel older, "regardless of whether [those individuals] identify role transitions as necessary for people in general to be considered adults" (Kirkpatrick Johnson et al., 2007, p. 257). In contrast, our findings suggest that for the young adults in our study, the impact a role change has on an individual's age identity is relative to how significant a marker of adulthood that individual considers it to be.

Consistent with previous findings, social comparisons also appear to be linked to the participants' adult identities (Benson & Elder Jr., 2011). The transformation from viewing one's parents as authorities to peers with equal status has been proposed as playing a key role in the development of an adult identity (Smollar & Youniss, 1989). However, while subjective identities are generally thought to be constructed through comparisons with significant others (Stryker & Serpe, 1994), age identities are typically formed in relation to those at the same stage of life (Kaufman & Elder Jr., 2003). No other studies could be found in which adolescents' age identities were formed in comparison with parents, rather than peers.

4.5.3 Social comparisons and disability identity

The participants' social comparisons also appeared to be linked to their perceptions of and attitudes towards their disabilities. Previous studies have suggested that pupils in special schools may feel more positively towards their educational attainment than those in mainstream schools (Kelly & Norwich, 2004). However, in our study, participants with typically developing friends voiced greater levels of frustration towards their academic difficulties than those whose friends also had intellectual disabilities, regardless of the type of school they attended. Social-comparisons with friends have been shown to be more affecting than comparisons with strangers (Tesser, Millar, & Moore, 1988), therefore the

possibility that friendship-group configuration may mediate the relationship between the school-type and self-concept warrants further investigation.

It is also possible that social attitudes towards specific diagnoses affect the way in which these social comparisons manifest. As discussed in Chapter 1, reports suggest that members of the autism community are using the internet to promote autism as a positive identity, one based on difference, rather than deficiency (Bagatell, 2010). These attitudes were to some extent mirrored by the autistic participants in our study, who appeared to embrace and take comfort from their autism diagnoses. However, while previous work has suggested that autism diagnoses can be protective, and even enhance self-esteem (G. Jones, 2001; Willey, 2006), research in this field is limited, and the findings mixed (Macleod & Johnston, 2007). Therefore, it is advised that these findings be interpreted with caution.

4.5.4 Age appropriateness and role changes

The majority of participants voiced reluctance to adopt additional responsibility at home. Much as Amy referred to the housework as 'mum's job,' Midjo and Aune (2016) found that the young male interviewees in particular argued for the 'normality' of being looked after while still living in the parental home. Consistent with previous findings, few of the participants had plans to move out in either the short or mid-term, but rather discussed leaving their parental home as being a non-specific, long-term goal (Pallisera, Fullana, Puyalto, & Vila, 2016). Similarly, the participants' preference for parental involvement in financial matters supports prior research (Isaacson, Cocks, & Netto, 2014). Importantly, while some of the participants held genuine concerns about their capacity to cope, the majority admitted that they simply preferred an easier life. However, as in the Midjo and Aune study, the knowledge that they could do more to support their parents appeared to weigh uneasily on their consciences.

4.5.5 Risks relating to safety and security

Despite not wishing to be treated 'like a baby,' Sam's risk-aversion suggests that the balance between too much and not enough freedom might be hard to strike. In contrast, Amy's acute awareness of risk was inexorably linked to her desire for autonomy, preferring to learn from her mistakes than be shielded from harm. The tension between the desire for independence and the desire for safety and protection has been discussed elsewhere. In a study undertaken by Condor, Mirfin and Veitch (2014) participants' attitudes towards sacrificing their autonomy for safety were equally as diverse.

Furthermore, while young adults with intellectual disabilities have been shown to fear death significantly more than their typically developing peers (Forte et al., 2011), the impact of these worries on the desire for freedom is unknown. As a result, while carers are much more likely to favour protection over independence (Seale et al., 2013), the attitudes of disabled individuals themselves warrants further investigation.

4.5.6 Risks relating to 'doing the wrong thing'

Consistent with previous findings (Ziegler and Balla, 1982; Wehmeyer and Palmer, 1998), a number of the participants demonstrated low self-perceived efficacy, resulting in a fear of 'getting things wrong.' However, in a few of cases, this aversion to doing the *wrong* thing appeared to arise out of the desire to do the *right* thing. Sam, Elliot, and James, in particular, discussed obedience to parents and teachers as being 'right' or 'good,' and *being* obedient as a source of pride. However, while Sam and Elliot appeared to view rule-following as an inherent good, James justified his obedience in relation to not wanting to hurt his Mum. For him, much as for Lauren, the desire to protect Mum from harm played a significant role in his decision-making and resultant behaviour. In many ways, this trend is unsurprising. Previous research has found that young adults with intellectual disabilities worry about their parents' wellbeing more than their typically developing peers (Forte et al., 2011). Moreover, there is preliminary evidence to suggest that they may also place greater significance on their parents' opinions of themselves (Pownall, 2010); therefore, the desire to *protect* their parents from harm or disappointment is a natural extension of these feelings.

4.6 Key Findings

- Most defined adulthood as fulfilling one's familial obligations. Some also used unique criteria that had personal salience, such as maintaining a car.

- Most thought of themselves as in-between a child and an adult. Subjective adult identity appeared to be influenced by social comparisons and the extent to which the participants met their own definitions of adulthood.

- High variation in the participants' levels of independence. The most independent were the least risk-averse.

- Independence viewed as an inevitable outcome of aging, and most presented themselves as working towards independence over the long-term. However, most also expressed anxiety at prospect of having to cope without support.

- Majority did not feel obliged to adopt additional responsibility, and were happy to delegate decisions and chores to their parents.

- Accepted that having an intellectual disability may make life difficult in the future, but some viewed their achievements to date as being more impressive as a result.

- Viewed themselves as mature and deserving of trust and respect. This caused frustration amongst those who felt that their autonomy was being unfairly compromised in personal matters.

- Keen to protect their parents from harm.

- Reoccurring references to death occurred during discussions of aging and the future.

4.7 Summary

Eight semi-structured interviews were undertaken with young adults with borderline to mild intellectual disabilities about their perspectives on transitioning to adulthood. The findings in this study suggest that some young adults with mild intellectual disabilities may have similar hopes and expectations for adulthood as found amongst typically developing adolescents. Furthermore, in contrast to suggestions that self-determination is a holistic phenomenon, our findings suggest that attitudes towards independence are domain specific and likely to be influenced by competing socio-cognitive and emotional processes.

Importantly, optimism and positive self-efficacy beliefs are adaptive traits that have both been found to be negatively associated with depression and anxiety (Conversano et al., 2010; Tahmassian & Jalali Moghadam, 2011). Furthermore, as these traits have been shown to be significantly lower in intellectually disabled populations (Wehmeyer, 1994), it was positive to find that a number of the participants in this study felt confident about their futures. However, it is equally important that young adults with intellectual disabilities develop expectations for themselves that are attainable. Repeated failure has been shown to

lead to feelings of learned hopelessness and low confidence, lowering subsequent performance in this population (Zigler & Balla, 1982). Additional research into the concerns, aspirations, and expectations of young adults with intellectual disabilities will serve to contextualise our understanding of transition for this group, which may, in turn, have implications across a range of practical, social, and health outcomes.

Chapter 5   Results from Young Adults without Intellectual Disabilities (Study 1.2)

5.1 Introduction

Results have been divided into three broad categories: A) negotiating the line between autonomy and support, B) managing the parental transition, and C) it's all relative. Themes in category A focus on the participants' experiences of, and attitudes towards finding the balance between too much and too little parental interference. Themes in category B concern the participants' perceptions of their parents' transition experiences, and the impact that these perceptions are having on the participants' attitudes and behaviours. Themes in category C concern the contextual nature of adult identity. As in Chapter 6, all participants have been given pseudonyms to help protect their anonymity, and the following notation has been used with the quotations.

… Pause; [ ] Words omitted; [Text] Added for clarity; **Non-verbal expression**

5.2 Participant Characteristics

Name	Gender	Age (years, months)	Living Situation	SIMD Score
Charlie	Male	18, 2	Both parents	3
Gemma	Female	16, 8	Single mum	7
Connie	Female	17, 1	Both parents	4
Graham	Male	16, 8	Both parents	8
William	Male	17, 4	Single mum	3
Oliver	Male	16, 11	Both parents	7
Harriet	Female	17, 3	Mum and Stepfather	7
Maisie	Female	16, 8	Single mum	2

Scottish Index of Multiple Deprivation Score: Highest deprivation (1), Lowest deprivation (10)

Table 4: Participant Characteristics for Study 1.2 (Interviews with Young Adults without IDs)

5.3 Theme A: Negotiating the line between autonomy and support

5.3.1 From rules to expectations of conduct

The participants tended to define 'rules' as expectations of appropriate conduct, rather than as specific prohibitions. The majority described their personal goals and their family's wishes as being so closely aligned that conflict was rare. Parents' attitudes towards drinking alcohol, staying out late, and engaging in sexual relationships were largely permissive, provided that the activities were undertaken safely and sensibly. However,

while the lack of necessity meant that actual prohibitions remained unspoken and unenforced, the knowledge that a 'red line' still existed was sufficient to prevent participants from claiming complete autonomy.

I'm allowed to be as a mature adult would act [ ] I'm just not allowed to live the life of an irresponsible adult yet. (Graham)

Unsurprisingly, participants for whom the breaking of rules would likely result in punishment were far more concerned with permission than their less restricted counterparts. In contrast, participants who shared a more balanced power relationship with their parents interpreted 'asking permission' as seeking their parents' blessing. In a couple of cases, parental support was described as a desirable, but non-essential factor in their decision-making.

I: Did you have to ask permission?
P: "Like…. A request for permission. But we'd already planned it so much that we would've gone anyway, I think. (William)

5.3.2 Interference warrants justification

The easing of protective restrictions was generally attributed to increased parental trust. Participants described themselves as sensible and responsible, and viewed their liberty as appropriate as a result. In some cases, freedom was viewed as a privilege 'earned' through their mature and trustworthy behaviour.

If they told me I wasn't allowed to go out and stuff, I just wouldn't go out, but because they did it when they were younger and I've been honest with them, they trust me completely (Harriet)

Others viewed their liberty as a 'right' that should only be interfered with in cases of erratic or irresponsible behaviour.

I'm not crazy or anything like that [ ] you don't need to write rules in my household [ ] I can't imagine them ever saying 'no', there wouldn't really be a reason to (Oliver)

However, all participants claimed that they only accept external interference that they consider to be justified. This position was most strongly felt about privacy. Snooping and spying were considered highly inappropriate, trust-breaching behaviours, mainly because the participants felt that they had given their parents no call for doing so.

I think that'd be too far [ ] I've not shown any reason for them to do that (Graham)

Interestingly, the extent to which spying behaviours were considered to be transgressions appeared to be linked to the nature of the information discovered. Four participants claimed that they "have nothing to hide", and were much more likely to forgive their parents' behaviour than those who preferred to control the information their parents received. Similar attitudes were held towards rules and restrictions, with the majority of participants claiming to challenge attempts at unwarranted parental interference. However, it should be noted that a few participants acknowledged that even unwelcome interference can be beneficial.

I'd prefer it if they had a bit more control, to a certain extent. Because as free as I am, and I'm able to do what I want, if that was limited a little bit, I'd be able to manage things a bit better (Charlie)

5.3.3 It's my life (but two heads are better than one)

While the right to complete autonomy appeared to be contested by some participants, the right to decide one's future was universally agreed. Every participant claimed to have ultimate power in decisions regarding their own lives and futures, and were committed to the right of self-determination.

Other people can influence me and give me their opinions, but really it's about what I want to do, and its about what I think's best for myself, rather than listening to what everyone else wants me to do. (Maisie)

However, this commitment was not mirrored in the desire to make decisions in complete isolation. In contrast, all participants sought external influence of some kind or another. Key individuals were used not merely as sources of information, but as active *guides,* capable of providing informed advice based on experience. In some cases, family members appeared to be attributed with so much respect they became the decision-maker by proxy, despite the participants claiming to have accountability. The power dynamic between Gemma and her Mum, for example, looked to be complex, with Gemma feeling the need to assert herself as 'decision-maker,' despite feeling uncomfortable in the role.

It's my choice, so I would decide. But she would advise, like what she thinks – she would tell me her opinion, but like, I would decide.[ ] She like obviously came with me and helps me decide [ ] she asks questions that, like, I wouldn't have like thought of [ ] We'll discuss it, and then make a decision. So it'd be more a joint decision if it's something to do with…

cos I'm quite involved in it as well. [ ] I don't mind somebody helping me to make decisions. Cos like, I don't always want to make them myself. (Gemma)

All four female participants showed a preference for delegating decision-making responsibility and sharing accountability, and reported much higher levels of worry, rumination, and catastrophisation than their male counterparts. However, participants of both sexes described using their friends and family as sources of reassurance Charlie, William, and Maisie, for example, took comfort in the idea that they were not "doing it alone," preferring company – or the knowledge that company was available - during the decision-making process.

I would always go to my mum, but I mean, she's never very decisive. We always have a discussion about what are the benefits or… the pros and cons of every decision (William)

5.3.4 They're just people

Despite appreciating advice and support, four of the participants no longer attributed 'special' significance to their parents' guidance. Two participants, for example, felt that their parents' advice was equal to that provided by other people, while others described their parents as being "out of touch," and less able to provide useful guidance as a result. In a couple of cases, siblings adopted the role of mentor not only as a result of being more informed but also because of their superior capacity to empathise. However, both participants suggested that their reliance on their respective siblings, rather than on their parents, might be considered unusual.

I know maybe some brother-sister relationships, it's maybe not like that [ ], but er, I really use my sister as like a really good inspiration, and I just… trying to ask her for advice and stuff. She's really helped me through school and through general work and stuff like that [ ] [Mum and Dad] still listen, but they maybe don't have as helpful advice as my sister does, 'cos she's been through it. (Oliver)

Interestingly, the move away from viewing parents as having a special, uniquely elevated level of influence appeared to reflect the participants' beliefs that adults are "just people." Charlie, for example, recounted his realisation that adults – particularly those in positions of authority - are not only imperfect but are often "winging it." The revelation that authority figures can be equally as insecure and unprepared for life's challenges as children was described as a significant moment in his maturation process.

5.4 Theme B: Managing the parent transition

The majority of participants demonstrated sensitivity to the impact that their growing-up was having on their parents. The negotiations that occurred as a result were both complicated and diverse.

5.4.1 The lingering need to protect

Despite feeling trusted by their parents, every participant was acutely aware of their parents persisting safety fears. In almost every case, participants implied that their parents' feelings were complex, torn between wanting to protect their child from harm while being cognitively aware of the need to let them go. However, even the most liberated participants described their parents as requiring reassurance. In every case, keeping in contact when out and about was firmly stipulated to appease their parents' safety fears. Furthermore, despite not being formally restricted, several participants were aware that pursuing a sexual relationship would make their parents uncomfortable.

Friends of someone have found out their children are having sex, and [Mum]'s been, like, "strange." (William)

Three participants suggested that their parents might be struggling to reconcile their transition with the development of a sexual identity. Harriet, for example, explained that her stepfather had not yet come to terms with her having a boyfriend, whom she believed may represent both a rival to her stepfather's affections and a threat to his image of her as his child.

My stepdad's more, like, 'I don't want him taking you away from me', because I'm, like, his little girl (Harriet)

Unsurprisingly, several participants felt patronised by their parent's concerns.
This feeling was particularly evident amongst participants whose parents felt compelled to vocalise clichéd platitudes without justification. Yet, as unnecessary or overprotective as these concerns were felt to be, the majority of participants nevertheless described feeling obligated to protect their parents from unwarranted distress. Maisie, for example, described forgoing late nights to protect her Mum from poor sleep, while others chose to withhold information likely to cause unwarranted anxiety.

[Mum] likes to stay up until I'm home [ ] so I kind of take it upon myself to go home at a reasonable time (Maisie)

Attitudes to causing distress appeared to depend on how justified the young people judged their parents' concerns to be, as well as to the size of the sacrifice they would have to make to avoid that distress. Maisie, for example, claimed to feel "guilty" after forgetting to keep in contact, not only because of the worry she causes but also because sending a text is such a small and reasonable act. In a similar vein, Charlie made it clear that, while he would disregard his parents' concerns in some cases, very few risks would actually be worth the distress they may cause.

If they really didn't want me to go to Japan[ ], I wouldn't really care, just because there's so many things that you can visit in Japan… I'd find that to be a lot more valuable than their piece of mind [ ] If it's somewhere like the middle east [ ] what I'd get out of visiting those places wouldn't be as valuable as, like, making sure that my parents are okay with me going places, and they aren't, like, stressed out by me going somewhere. (Charlie)

5.4.2 The lingering need to provide

5.4.2.1 Housework

While some participants described being aware that their parents wanted more help around the house, several suggested that their parents preferred to take responsibility for cooking and cleaning as a means of prolonging their status as 'caregiver.' However, participants' attitudes towards being 'looked after' in this manner varied enormously. Charlie, for example, described his family as having transitioned beyond the roles of caregivers and care-receivers and viewed his uptake of responsibility as a normative prerogative.

I should take on a lot more responsibilities, and should do all these things, and I know that I should, and I know that I can…(Charlie)

This view was shared by some of the less domestically active participants, who admitted to taking advantage of their parents' generosity. While some appeared to feel guilty at this arrangement, a couple were open about wanting to make the most having a more comfortable life while they still can, or even resented the prospect of having to self-sustain.

"I still get loads of stuff done for me [ ] I quite like still getting stuff done for me" (Gemma)

5.4.2.2 Finances

Several participants also referred to their parents' desire to retain financial responsibility for their children. In the majority of cases, this was viewed as a purely practical arrangement until the point of financial independence. However, in a couple of cases, the act of providing was attributed with special, almost ritualistic significance. Although not necessarily typical of most adolescents, Harriet described her parents as committed to buying her a car once she has passed her driving test. While the majority considered themselves to be "lucky" or even "privileged" to be funded in this manner, three participants described feeling uncomfortable receiving money or items from their parents, preferring instead to take financial responsibility for themselves. In one case, this differing perspective had even been a cause of conflict within the family.

I paid £200 for that, all by myself, all off my own money, even though they wanted to pay for that for me [ ] and my parents are annoyed at that because they don't want me to spend my own money. (Charlie)

5.4.3 Staying involved

Several participants made reference to the fact that their mums' wish to remain involved in their children's private lives. However, reports differed regarding parents' attitudes towards being excluded. Charlie, for example, suggested that his parents respected his right to withhold information.

If they ask and I don't want to answer, they don't really pursue that at all, so they just kind of respect my privacy (Charlie)

In contrast, William predicted a much more emotional response from his Mum, suggesting that on some level, she felt entitled to the information.

[On informing her about a new relationship] I think she'd probably feel happy that I confided in her, that I told her, but erm… she maybe wouldn't want to wait… to know earlier… I think she'd be annoyed that I didn't share my feelings for the other person (William)

Participants' attitudes towards being pressed for information were equally as varied. Amongst the more empowered participants, "nosiness" was viewed as a natural, albeit frustrating, parental trait. For others, parental knowledge was viewed as inevitable, and attempts to withhold information were viewed as futile as a result. For Connie, however,

concealing information served as one of the few ways in which she could assert control in her otherwise heavily regulated life:

I don't particularly want to share everything with them, cos like, if I shared everything with them, it'd mean that had total reign over my life (Connie)

5.4.4 Wanting space not distance

All participants valued having time to themselves and a place to which to retreat. However, only two young people claimed to enjoy being left alone in the house. In the majority of cases, participants claimed to feel indifferent towards solitude or actively wished to avoid it. Attitudes towards spending time away from family were equally muted. In response to questions about going on holiday without family, five participants either had been or were about to go away without their parents. However, the prospect of a trip lasting three weeks or more was less attractive to all but two of the young people. The potential for loss of novelty, boredom and friendship problems accounted for some of this low enthusiasm; however, a few participants described themselves as insufficiently equipped to cope with the level of responsibility required for an extended vacation.

Being a month [ ] that's a lot more like almost independent living… I think they'd definitely need to inform me a lot more about how to actually, you know, keep my finances for a month. Cos I ended up running out of money when I was on holiday (Graham)

Moreover, several participants made reference to the impact that leaving family behind can have on parents. Charlie, for example, anticipated that his parents would respond more positively to a more extended holiday than a shorter one, which would contribute to his decision-making. In contrast, Maisie felt that spending more than a week or two away from home would be too emotionally taxing for both herself and her family. The desire to protect both herself and her parents from the hardship of separation also translated to her attitude towards moving out. Both she and Harriet demonstrated an acute awareness of the impact that leaving home could have on their parents, despite neither leading to an 'empty nest.'

I don't think she'd want me to move too far away from home [ ] It's, like, her first time doing it, so I think it'd be really hard for her (Maisie)

Interestingly, every participant wished to remain in Edinburgh for higher education, and most planned to continue living at home throughout this period. Charlie, for example, initially justified his decision in cost-benefit terms, suggesting that the advantages of moving out were outweighed by the practical and financial benefits of staying with his parents. However, he later admitted that staying at home brought emotional benefits as well.

If I ever have any problems, I'll always have my parents there for any kind of support, so. Remaining positive (Charlie)

While only two participants made explicit reference to the emotional consequences of moving out, the desire to stay close to the comfort and familiarity of home was heavily implied. The fear of 'going it alone' and carving out a new life in a new location was very much present in half of the group. For others, the stress of self-sufficiency simply outweighed the benefits that increased freedom might bring.

If I moved out, I'd get, like, a shock. [I don't want to be] that much more independent than I already am. (Gemma)

5.5 Theme C: It's all relative

5.5.1 Adult identity changes with context

No participant felt entirely comfortable identifying as either an adult or a child. In most cases, 'adulthood' was viewed as the end point of the linear developmental trajectory that they were currently working towards. William, for example, referred to himself as sufficiently mature to recognise when a course of action is ill-advised but immature enough to carry on regardless:

"I've got to a point where um, if I'm into something, and it's, like a typical teenager thing, and it's like trying to be rebellious, I often think, like, at some point in the future, I'm probably going to look back and [ ] think that was a bad decision or something, but still carry on doing it, so... it's kind of like, I'm not fully adult, but I'm getting closer." (William)

However, a few participants suggested that the development of an adult identity is non-linear and context-specific. Harriet, for example, described her behaviour changing in line

with the expectations and connotations of each situation she finds herself in. For her, *feeling* like an adult in response to a situation's connotations, and subsequently *behaving* like an adult appeared to make two distinct contributions to her subjective adult identity, causing it to fluctuate with each change of context:

"Depends on what situation I'm in, like, at work I feel more like an adult because I'm higher up than some people who are a lot older than me, and sometimes if I go out on the town I feel more adultish, but then when I'm at school I feel a bit childish, like I... I get to act more like a child when I'm in school, I get to be a bit more immature and silly with my friends that are younger." (Harriet)

In contrast, Charlie suggested that his subjective adult identity when considering the different aspects of adult life. As a confident, physically imposing, and highly independent individual, Charlie in many ways felt as adult as it is possible to feel. Yet, he nevertheless acknowledged that lack of responsibility and insufficient life-experience prevented him from adopting an adult identity in full:

"In some aspects of life, pretty much as adult as it gets. Um.. I feel like if I view my opinions or anything like that, or discuss anything with someone, I'm a lot more, like, adulty about it [ ] I kind of look like an adult [ ] but in terms of like things that I have to take responsibility for, I'm still like a kid. I don't really have to take responsibility for anything." (Charlie)

5.5.2 I don't mind being different (as long as I'm not the only one)

While the majority of participants admitted to drinking alcohol, only Harriet described actively seeking to drink on nights out. Having befriended University students predominantly, Harriet described her ability to socialise as dependent on having access to alcohol:

"About 5 or 6 months ago I got into the group of friends that I'm into now with my work. They're all 19 20, so they're all going to the pub and that, and I was like 'I really want to go as well [] I used fake ID." (Harriet)

However, for the most part, alcohol did not appear to have any special significance to the participants. Importantly, several of the young people made reference to the fact that their

lack of enthusiasm for drinking may be considered unusual or atypical. Maisie, for example, referred to partying as an obvious part of 'teenage life,' despite struggling to name any peers to whom this stereotype applied:

"Obviously it's high school, people tend to go out and stuff. Nobody really comes to mind when I say that, it's just the stereotype of everyone is." (Maisie)

A few participants thought of themselves being different from other teenagers as a positive characteristic, and indicative of having an unusually high level of maturity. Yet, the same participants sought to normalise their attitudes within the cultural context of their specific friendship groups:

"Most of my friends tend to do other things socially [ ] we don't drink that much"(Charlie)

Attitudes towards sex were similar. Only one participant had ever been sexually active at the point of the interview, with all other participants showing very little interest in pursuing an intimate relationship. Much as with alcohol, several participants made reference to the fact that "other people" were having sex, but that none of their friends had, and that pressure was reduced as a result. Oliver, for example, took comfort in the knowledge that, being in the majority, his developmental trajectory could be considered typical:

"You know how in school there's a group that have and there's a group that hasn't, like, there's loads of groups in this school that haven't either, so it's kind of normal" (Oliver)

However, by judging himself against his peers in this fashion, Oliver implied that pressure would likely increase once the majority changes.

5.5.3 Birthdays are only significant if your life actually changes as a result

The impact of chronological age on adult identity varied between participants, having the biggest effect on those whose lives had changed after reaching a particular birthday. Maisie described turning 16 as highly significant because this paved her way to undertake paid employment for the first time. Connie, however, was one of many whose lack of interest in the legal rights associated with turning 16 reduced the birthday's significance:

"16 didn't feel that different, it was just more... people were making a big deal of it, because obviously you can get married, have kids, have sex legally and all that,[but]the thing about getting married and stuff, hardly anyone gets married at 16." (Connie)

In a similar fashion, the impact of turning 17 was almost exclusively based on attitudes towards driving. However, several participants referred to the ceremonial significance of turning 18. This was despite the facts that 16 is the legal age of adulthood in Scotland, and that everyone wishing to engage in activities restricted to over-18s were to some extent already doing so. One explanation was that the 'coming of age' connotations of turning 18 were presumed to carry more social currency than previous birthdays, leading to a status-boost both within and outwith the home. For three participants, chronological age was said to have more salience for their family than for themselves. Connie, for example, anticipated gaining more freedom at 18, having witnessed a similar change in her parents' behaviour towards her older sister:

"I think when I turn 18 it'll change, 'cos it changed with my sister, and it changed quite quickly, because they kind of realised that she's not so small anymore." (Connie)

In a similar vein, Charlie described his 18th birthday as resulting in a swift and dramatic change in status from 'child' to 'adult' in the eyes of his extended family:

"[regarding birthday presents] *This year, 1 litre of vodka – erm, erotic massage oil, and three condoms. They were like, 'you're 18, time to rock and roll, friend.' Sex, drugs, and stuff... Whereas they treated me more like a little kid, or little brother before."* (Charlie)

For Maisie, however, growing older was only said to remind her parents of the passage of time, and the increased risks associated with her stage in life:

"She's freaking out at me turning 16 [ ] Dad was texting her that, 'I cant believe it, already' [ ] I think what they were most scared of is if I end up like my mum was, like, pregnant at 16." (Maisie)

5.5.4 Coming to terms with change

Almost every participant described joining 6th year as a 'weird' or jarring experience. In some cases, this feeling arose as a result of the incongruity between being the oldest in the school while still feeling very young:

"It barely feels like I've even started secondary school" (Graham)

In other cases, the prospect of leaving school acted as the primary source of unease. For participants with a clearly defined plan, leaving school was said to be bittersweet – sad as the close of one chapter, but exciting as the start of the next. While the prospect of changing routine and making new friends was daunting, these individuals nevertheless took comfort in the knowledge that the next steps were laid out for them. However, for those whose post-school goals were less clear or secure, leaving school was a greater source of consternation. For Maisie in particular, graduation was more akin to reaching the end of a book without a sequel, making her less inclined to leave as a result:

"I don't want to leave this year, I'm not ready to leave [ ] it's just the uncertainty of what I'm going to do next… I've got not set aspiration." (Maisie)

Yet, even the most apprehensive participants acknowledged that their trepidation would likely pass, and felt optimistic that they will be ready to leave once the time comes:
"I think by the time you've kind of accepted that you're leaving, you're fine, 'cos I know people that were terrified at the point that I'm at, but then when [ ] it gets to April, they're, like. "GET ME OUT OF HERE!" (Connie)

5.5.5 Adulthood = standing on your own two feet

When asked to conceptualise adulthood, almost every participant referred to the ability to "take care of" or "look after" oneself. However, participants chose to focus on different aspects of the autonomy construct. Gemma, Oliver, Harriet, and Maisie, for example, focussed on the behavioural qualities of autonomy, such as personal responsibility and self-reliance. However, three participants instead chose to focus on the right to determine one's life without interference:

"It's just that you have complete independence over yourself [ ] Just being able to choose your own… what you want to do" (Graham)

Only one participant mentioned life-stage markers. For the most part, participants focussed on the ability to cope with, and adapt to, the challenges and adversities of life:

"I think it means being able to adapt to what life throws at you. Because, at my age, if something happens to you that you don't see coming, you freak out, because you're like 'how can I cope with this?' 'cos you've not got that experience. But once you've have that experience, and life throws things at you, you can adapt to it [ ] being an adult basically means that you can take what life throws at you." (Connie)

5.6 Discussion

5.6.1 Attitudes to interference

While mid-to-late adolescence is often associated with anti-authoritarianism and increased parent-child conflict, the participants in our study described experiencing low levels of conflict at home, and discussed their relationships with their parents in mostly positive terms. Previous work has suggested that the majority of adolescents hold favourable views of parents as authority figures (Levy, 2001), but that attitudes and behaviours differ in response to different styles of parenting (J. G. Smetana, 1995). Interestingly, parenting style, as described by the participants, did not appear to impact attitudes to parental authority. This finding may be explained by the fact that both the highly restricted and unrestricted participants shared their parents' expectations for what does and does not constitute appropriate behaviour. However, in line with previous work (Kakihara & Tilton-Weaver, 2009), the participants' attitudes towards parental jurisdiction were domain specific and dependent upon justification. Interference was accepted only when they considered it to be appropriate and legitimate, such as in response to irresponsible or dangerous behaviour. As a result, parental attempts to impose control over personal matters without adequate justification were unwelcome.

5.6.2 The appearance of self-determination

Interestingly, in contrast to the view that the desire for personal control increases as part of the adolescent development process, the majority of participants voiced a preference for

sharing, or even delegating decision-making responsibility. In some ways, this finding is unsurprising, as the fear of decision-making in adolescents has been reported elsewhere. Forte and colleagues (2011), for example, found that decision-making was one of the highest rated fears amongst Scottish teenagers. Similarly, results from a longitudinal study in the US suggest that High School students experience consistently high levels of stress and difficulty during the transition-planning process (Galotti & Kozberg, 1996). However, a number of our participants also claimed to be committed to the notions of self-determination and autonomy as rights, suggesting that some may desire to *appear* self-determined without necessarily wanting the associated decision-making responsibility.

One possible explanation of this can be found in Erikson's life stages theory (1950), which posits that young adults often feel pressured to decide on a future path before they are ready, resulting in resistance to commitment. However, several participants exhibited reluctance to make even small, comparatively inconsequential decisions without assistance, reducing the theory's explanatory power in this instance. Another possible explanation concerns social desirability. Self-determination is frequently cited as a normative outcome, particularly in cultures that value and promote autonomous thinking and individual success, such as the UK and US (Hofstede, 2001). It is therefore possible that, in these cases, societal pressures may have led some of the participants to want *to want* to be self-determined, even though their true feelings are more mixed. Either way, the tensions exhibited by some of the participants in this study suggest that the desire for autonomy associated with adolescence may not be as straightforward as is often implied.

5.6.3 Attitudes towards reciprocal support

In a similar vein, participants described receiving considerable levels of practical support from their parents, most of which was reportedly unreciprocated. Evidence suggests that in Western countries, parents continue to give more to their children than they receive until the point of death (Fingerman et al. 2011), therefore this finding is unsurprising. However, in contrast to evidence that imbalanced relationships of support can continue to be viewed positively by both parties (Fingerman, 2000), a number of our participants expressed guilt that they may be taking advantage of their parents' generosity. This trend may be indicative of the participants' desire for mutual reciprocity, which describes relationships in which all parties are respected and treated as equals. However, as mutual reciprocity is

considered a normative aspect of positive parent-child relationships (Wintre & Yaffe, 2000), it is equally possible that these responses were influenced by social desirability.

Nevertheless, in the majority of cases, the participants expressed the desire to protect their parents from unnecessary harms during the process of transition. One of the most surprising findings was that a number of the participants voiced reluctance to spend too much time away from the family base, to protect both themselves and their parents from separation anxieties. However, this is supported by evidence that emotional interdependency between young adults and their parents is increasing (Fingerman, Cheng, Tighe, et al., 2012). From certain perspectives, this trend may be a cause for concern. Family systems theories, for example, maintain that poor parent-child differentiation, or "fusion" during adolescence and adulthood risks leading to relationship problems both within and outwith the family unit (Skowron et al., 2009). In addition, parental over-involvement in the lives of their children has been associated with poorer mental health outcomes (Spokas & Heimberg, 2008).

Despite this, there is increasing evidence to suggest that close parent-child relationships into adulthood have a range of health benefits for both parties (S. Cohen & Janicki-Deverts, 2009). Though still relatively young, the participants in our study emphasized the value of their parents' continued emotional support, and most wished to maintain the closeness of those relationships through geographical proximity. It is, therefore, possible that the differentiation-fusion dichotomy may represent an overly simplistic view of the conditions required for the development of healthy familial relationships.

5.6.4 Perspectives on adulthood

In line with much of the recent work on adult identity (Aronson, 2006; Eliason et al., 2015), almost all of the participants conceptualised adulthood in terms associated with self-determination and self-sufficiency. Only one participant mentioned the importance of achieving objective life-stage markers, such as chronological age, and social role transitions like getting married. However, when discussing how adult they themselves felt, the salience of social role transitions to subjective adult identity became more apparent for several of the participants.

Employment, for example, appeared to facilitate feelings of 'adultness,' while those who lacked any formal responsibilities felt more child-like as a result. This was the case even for those who considered themselves to have fully developed the character qualities of

psychosocial maturity, providing additional evidence for the confluence model of age identity (Shanahan et al., 2005). However, it should be noted that not all of the participants held this position. Self-perceived maturity appeared to take precedence over objective life stage-markers, such as significant birthdays. Joining the final year of school even acted to highlight the disparity between the participants' chronological ages and subjective ages, making them feel younger and less prepared as a result.

Furthermore, as suggested elsewhere in the literature (Benson & Elder Jr., 2011; Kaufman & Elder Jr., 2003), social comparisons also appeared to influence the participants' attitudes towards their own developmental progress. All of the participants felt positively towards their own transitions because they were aware that they had not fallen behind their friends. However, several acknowledged the possibility that pressure to experiment might increase with time as more of their friends begin to engage in more adult activities. The importance of hitting adult milestones 'on time' has been addressed in research on parental attitudes towards transition (Fingerman, Cheng, Tighe, et al., 2012); however, 'on time' in a number of these studies tends to be defined around chronological age. In contrast, our findings support those of Panagakis (2015) to suggest that young adults may use more relative transition schedules, influenced more by peer activity than chronological age.

5.7 Key Findings

- Most felt that their parents had moved beyond 'rules' to having 'expectations of conduct'. Participants saw themselves as mature and responsible, and viewed rules as unnecessary.

- Most described having very positive relationships with their parents, but demanded justification if their parents attempted to interfere in their lives. Autonomy within personal domains was viewed as a right. Participants suggested that they would resist unwarranted interference unless they viewed their parents' actions as being inconsequential.

- Presented themselves as self-determined, but still sought advice and support from friends and family. Most suggested that they continue to delegate responsibility wherever possible. This was a source of guilt in some cases.

- Wished to protect their parents from harm during the transition process, but some felt the need to balance this against their own interests.

- Viewed adult identity as relative, changing with context. Most were concerned with keeping pace with their friends' development, rather than achieving adult milestones by a particular age.

- Adulthood viewed in terms of self-sufficiency and independence.

5.8 Summary

Eight semi-structured interviews were undertaken with young adults without intellectual disabilities about their perspectives on growing up and adulthood. The majority of participants voiced a greater degree of reluctance to adopt the freedom and responsibility of adulthood than expected, despite voicing a firm commitment to the idea of self-determination. In some cases, interdependency between young adults and their parents may even be sufficient to impact the young adults' desire for independence. However, unjustified parental interference in personal domains continues to be perceived as a breach of the young persons' rights to self-determination and privacy.

These findings provide additional support for the suggestion that today's 16 to 18-year-olds are experiencing a generational shift towards greater emotional interdependence with their parents. However, more work is needed to investigate the extent of this phenomenon, as well as the potential impact on young adults' decisions, behaviour, and future wellbeing. It is advised that future research focus on parents' attitudes towards this process, as well as more longitudinal studies to investigate how expectations and perceptions change across the entire transition period.

Chapter 6   Results from the Parent Group (Study 1.3)

6.1 Introduction

Themes have been divided into three overarching categories: A: Maturing in some ways, B: The roles we play, and C: Remaining positive in the face of adversity. Themes within category A focus on the developmental challenges associated with transitioning to adulthood with an intellectual disability. Category B concerns the multiple roles that parents of disabled children have to play and the emotional toll that this can take. Finally, Category C regards themes relating to support, assistance, and thoughts on the future.

… Pause; [ ] Words omitted; [Text] Added for clarity; **Non-verbal expression**

6.2 Participant Characteristics

Name	Child	No. of Additional Children	Employment status	Living Situation	School	SIMD
Mark	Sam	None	Employed	Married	Mainstream	7
Linda	Elliot	One TD son	Employed	Widowed	Mainstream	3
Carol	Emma	One TD daughter	Not currently Employed	Married	Mainstream	10
Helen and Clive	Amy	One TD daughter	Not currently Employed	Married	Special	4

Scottish Index of Multiple Deprivation Score: Highest deprivation (1), Lowest deprivation (10); TD = Typically Developing

Table 5: Participant Characteristics for Study 1.3 (Parents of participants with IDs)

6.3 Theme A: Maturing in some ways

6.3.1 A 13-year-old in a 17-year-old's body

The developmental delay associated with having an intellectual disability was described as manifesting in a variety of ways. Hobbies and interests, for example, such as playing with cuddly toys and dolls or preferring to watch children's TV, were primarily viewed as harmless 'quirks' that would eventually pass. However, for Helen and Clive, and Linda in particular, the discrepancy between their child's physical and sexual development, and their cognitive and emotional development was becoming an increasing cause for concern. Elliot, Sam and Amy were described as not yet having developed the maturity to

appreciate how certain behaviours, such as poor hygiene and childish antics, are perceived by the outside world. For Lynda in particular, these fears were compounded by the invisibility of Elliot's disability, as she felt that the outside world held him to a higher standard of behaviour than they would someone with physical characteristics of disability. Moreover, both young people had unwittingly instigated sexual behaviours in public, without recognising the potentially serious consequences of their actions:

Last time I took them [swimming], he's trying to play about with [his female friends] in the pool as children would [ ] but he doesn't see that as inappropriate behaviour. Where anybody else would. And again, looking from the outside, if you didn't know him, you'd be like, that's a bit strange there, know what I mean? (Linda, Elliot's Mum)

There was a certain wee boy that kept asking her for nude pictures, and she just kept sending them [ ] the kids were sending it around everybody. 'Oh, look at Amy naked, heheehehe' sorta thing [ ] But she never knew the consequences [ ] she just thought it was a fun laugh. Police were all for getting them all in deep trouble. (Helen, Amy's Mum).

For Elliot and Amy's parents, their child's naivety was a cause of worry, upset, and embarrassment, particularly in regards to these inadvertently sexual behaviours. However, for Carol, Emma's lack of shame did not appear to have the same negative connotations, possibly because her body-confidence was viewed as preferable to the physical identity issues experienced by many teenagers.

6.3.2 Resistant to change

Emma, Sam, and Elliot were said to have not yet developed the desire for freedom and independence experienced by most of their peers. For Emma, this was described as a simple lack of interest. For Sam and Elliot, however, social anxiety and peer-relationship difficulties served as the largest obstacle:

He feels excluded at times, but [ ] he does ostracise himself to a big degree. (Lynda, Elliot's Mum)

For the parents, this appeared to result in a Catch-22. On the one hand, all were keen to see their children extend their peer relationships, and were concerned at their unwillingness to take-up the social opportunities that presented themselves. However, the knowledge that

their children were safe at home, rather than getting into trouble or putting themselves in danger, remained a deep source of comfort.

He needs to learn to be out there, [but] I know where he is, he's not out getting stabbed, you know what I mean? He's not pished at the corner, or what have you, you know? So... that side of it is fantastic. (Mark, Sam's Dad)

This was particularly felt amongst the parents who did not trust their children to respond appropriately to the risks of the outside world. Amy, for example, was described as prone to putting herself in unnecessary danger by walking across busy roads without looking and forgetting to phone home when lost and alone. The restrictions put on her independence were described as frustrating for both Amy, who failed to understand her parents' justification, and for Helen and Clive, who could not trust to her the level of freedom that they wanted to:

We've explained it to her, "you can't go, because if [your friends] leave you, you won't know how to get home [ ] and if you did learn to phone us and say "I'm lost, this is what I can see", we would maybe give you a wee bit more [independence], but you don't even do that!" (Helen, Amy's Mum)

In Amy's case, this lack of responsibility extended to the reluctance to take any responsibility for herself at home, a trait shared by all of the participants' children. Mark and Carol admitted to enabling their children's 'laziness' by maintaining the same routine that had always been in place, and described the division of household labour as "something we need to work on," rather than a significant burden. However, having tried and failed to introduce chores, Helen and Lynda appeared to feel unappreciated, and powerless to instigate change:

She comes in and thinks we do nothing all day [ ] "I've had a hard day at school, you haven't done anything in the house!", and we're like "is there washing on your bed? Is there rubbish on the floor?" [and she says] "Aye, but that's easy." (Helen, Amy's Mum)

6.3.3 They're still a teenager

Despite describing their sons and daughers as having childish tendencies, all parents were unified in asserting that their children were nevertheless teenagers, and prone to many of

the same tendencies. Every young person, for example, was described as spending the totality of their free time alone in their rooms on their computers and phones. While all of the parents appreciated the 'typicality' of this behaviour, opinions were divided about its appropriateness, ranging from complete support to the desire to intervene:

That's fair, that's correct, that's absolutely how it should be, 'cos that's his little domain (Mark, Sam's Dad)

She's a bit, kind of, you know, likes to hang out in her bedroom looking at her iPad a fair bit, actually, in the evenings, so we do kind of… we're conscious of that lately, so we are trying to drag her downstairs (Carol, Emma's Mum)

The knowledge that they, as parents, ought to stop being seen as "cool" in the eyes of their children was generally accepted, and all were keen to see their children shift away from using the family as their main social network. However, in a couple of cases, these social role transitions were beginning to cause practical problems within the family. For Helen and Clive, and Mark, even the slightest attempts to mentor their children were now viewed as patronising. Sam and Amy were described as prone to bouts of stroppiness, and keen to assert their individuality and independence from their parents. Though frustrating, the resulting shift in power was viewed as an inevitable part of the transition process that had to be accepted and strategised for rather than resisted:

We'd have to go through the temper stage, and all the 'Oh do I have to do this and all that". It's like with her teeth [ ] We're letting the dentist do all the teaching now [ ] other people teaching her how to do stuff, she'll listen to them rather than us, and then we'll say 'remember how the dentist showed you to do it. (Clive, Amy's Dad)

6.4 Theme B: The Roles We Play

6.4.1 Acting as Judge

All of the parents described the decision-making process as a team-effort; however, the extent to which they retained final control differed considerably. The parenting philosophy described by Helen and Clive placed significant emphasis on the development of autonomy and learning by experience. Amy was said to be encouraged to come to them with ideas, which they could then discuss and implement as a family. As such, Helen and

Clive claimed to only overrule Amy when they considered her safety or security to be under threat.

It's about 50/50 the decision-making. Aye, as I said, she'll come to us with her ideas, and we'll sort of plough them over between us, and we'll either try and find an avenue that we can take [DD] down, or sometimes it is a flat out no, like the disco, can I go to the disco? No. that's adult things, and right now you're not mature enough to do that. [ ] Try and help her into adulthood, rather than hinder her. (Helen, Amy's Mum)

For this reason, parenting Amy was described as a constant negotiation. Decisions tended to be made on a case-by-case basis, as rules were thought to be too rigid and difficult to implement consistently when the limits to their daughter's capacity kept changing. In contrast, Carol appeared to feel more comfortable when in control, but had nevertheless begun to relinquish decision-making power once her daughter began to assert herself. Mark and Lynda, on the other hand, were quick to suggest that they retained final decision-making control. For Lynda, this responsibility was said to be hers by default, as Elliot's indecision and lack of common-sense gave her no alternative:

You can't give Elliot a decision. If I was to say to Elliot, 'do you want mince for you tea tonight, would you like sausages, or would you like steak pie?' 'It's alright, I'm not hungry'. He would do that rather than make a decision because that's too much for him. (Lynda, Elliot's Mum)

Mark, in contrast, saw decision-making control as one of the domains over which his parental authority naturally extended. However, his son's life was said to be so built around routine that there were no longer many decisions left to make, particularly as the whole family supported Sam's post-school plans.

6.4.2 Acting as Researcher

All of the parents reported experiencing difficulties accessing helpful information about suitable services and opportunities, particularly as their children have only borderline or mild intellectual disabilities, and therefore fall down the gap between mainstream and special education. Carol, in particular, described the difficulty of finding a high school that could support Emma's physical and intellectual disabilities, while still allowing her to reach her academic potential. Moreover, several parents noted that the push towards

integration had forced mainstream schools to promote themselves as inclusive, despite being insufficiently equipped to provide the necessary support. Having sent their children to mainstream schools with specialist bases, Mark, Carol, and Lynda each described the curriculum as having "run its course", leaving college as the only option for the next stage. Though speaking very positively about their school's intentions and efforts, Mark and Lynda, in particular, felt that the school had little precedent for handling individuals like Elliot and Sam:

He was to do his [Drama course] this year, but, the way the timetable ran, they couldn't, so they let Elliot join the Higher group, although he was doing [a lower level qualification]*... anyway, as the teacher said, she tried it and she wouldn't do it again. Elliot was an experiment, and it just, again, because of the support he needs, trying to juggle the two, it was like she was taking two classes [ ] ... I think it's been a challenge for the school as well* (Lynda, Elliot's Mum)

Without guidance or a central pool of information available, a couple of the parents described having to use personal networks to seek information. The research process itself was therefore time-consuming, stressful, and frustrating, and also added to the parents' sense of powerlessness and isolation:

[On befriending services]*... but again, I don't know if I've got to go through the social work for that, or… you know, nobody seems to know [ ] I do feel there is a big grey area there that nobody seems to know how to tap into. And it's not… easily accessible, if you know what I mean. But, as I say, I'll need to try and work out how...* (Lynda, Elliot's Mum)

6.4.3 Acting as Advocate

Despite being mostly positive about the schools' efforts to support their children, Helen and Clive, Lynda and Mark each reported having had to overcome prejudice (ableism), ignorance, and bias within the education system. Lynda, for example, described how Elliot's primary school teachers encouraged him to publicly 'snitch' on his classmates, thus turning him into a social pariah. In a similar vein, Helen and Clive explained that Amy's primary school chose to physically segregate her from the rest of the class by building a walled 'cubicle' around her desk. As a result, both her social experience and learning suffered dramatically:

When we arrived down in Edinburgh, and she went into [primary school], we actually realised how far behind she had actually fell. As I said, Amy could only count to 20 when she went to High School [ ] Even in special schools she should have been higher than that. (Helen, Amy's Mum)

As well as being unable to provide appropriate support, certain members of the school staff were said to hold unfair, or unrealistic expectations. General ignorance regarding the traits of Autism, for example, had resulted in Elliot being unfairly reprimanded by teachers. In contrast, Mark explained that teachers and specialists had underestimated Sam on a number of occasions, all of whom saw his disability rather than his potential:

We were told as well that he'd have to leave in 4th year because there's nothing else they can do for him, and we were like 'no no, … he's really doing well', so yeah, they were quite negative. Although we did get… the person who said that was very apologetic last year when he got his 'Persevere Award'. She said 'you go with paperwork'. (Mark, Sam's Dad)

However, these experiences were viewed as symptomatic of the broader failure to adequately prepare schools and teachers for taking on young adults with additional support needs. The parents, therefore, seemed to target their frustrations towards the system rather than at the individuals or institutions themselves.

6.5 Theme C: Remaining optimistic in the face of adversity

6.5.1 Keeping our fingers crossed

Each parent referred to his or her child as "getting there" with regards to the process of growing up. On one level, the developmental delay associated with having an intellectual disability was discussed as *just* a delay, and all were hopeful that their children would eventually "catch-up" with their typically developing peers. Sam, Emma, and Amy, for example, were all said to have exhibited much higher levels of maturity over the past year, which was thought indicate that transition was occurring, just at a slightly slower pace. For this reason, the parents were verbally committed to remaining positive. In Mark's case, this

optimism extended beyond the school's hopes for Sam's future, and may even have been at odds with his own expectations:

If he got 1 more [qualification], he'd be able to chance his luck for Uni, which would be right gun for him to go for, but err, that's not going to happen – we know that's not going to happen [ ] He'll be fine, he says with a nervous laugh. He'll be fine. (Mark, Sam's Dad)

However, despite this positivity, all of the parents voiced concerns about the future. That their children would always need support, for example, appeared to be cognitively accepted by the parents, which raised unanswerable questions about long-term care. Moreover, while all were reportedly happy to fulfil the caring role for as long as required, doing so was nevertheless said to be both emotionally and physically tiring:

With Emma, there were major physical challenges [ ] having epilepsy, and so… you know, it's much more hands on, I think, for longer, having a child with additional needs. (Carol, Emma's Mum)

It can be tiring though, aye. Constant. It's just cos we've got to do everything for another person. (Helen, Amy's Mum)

Parental anxieties also appeared to be compounded by the fact that the most significant challenges most likely still lay ahead. The school was viewed as a safety blanket for all parties, and while college provided an opportunity for the next step, what could follow remained a mystery. With regards to employment, Lynda felt that the types of jobs suitable for Elliot no longer existed in the 21st-century labour market:

The best job for Elliot would have been the old-fashioned mail room, and the mail come in, it got sorted, somebody come round everybody's desk, he'd have it at the same time, same place every day. (Lynda, Elliot's Mum)

In contrast, while Helen and Clive felt that Amy had the potential for employment, prior experience had demonstrated that pursuing work with an intellectual disability can cause both practical and emotional problems for the individual and their family:

My brother – he had development delay – and he went in when it was his formal meeting and said 'oh, I want to work', so they signed him off the [Disability welfare payment]. He

spent years in and out of jobs [ ] we're not really wanting that for Amy [ ] if she's wanting to do something that'll give her money, fair enough, I just don't want her going in and going 'oh I want to work' and then stuck in the same situation as [her Uncle], writing out dole books and going to different jobs… (Helen, Amy's Mum)

There's no doubt about it, she's always going to need help [ ] so if me and Mum are both working and Amy's got a job, that's gonna make it even worse, even more difficult again [ ] if Amy finishes work she's always gonna need picked up or met somewhere, or… it's gonna be… hard again. (Clive, Amy's Dad)

As a consequence, the parents voiced trying not to worry too much about the future, opting instead for an "each day as it comes" mentality.

6.5.2 We support one-another

For Amy and Sam's parents, significant emphasis was placed on the roles that their extended families played in providing support. Despite being divorced from Sam's Mum, Mark explained how both sides made identical contributions to Sam's upbringing, from splitting custody to having equal involvement in decision-making. As well as sharing accountability and responsibility, however, Mark explained that the two-family system provided both sides with the opportunity for respite, and even increased their social opportunities:

We have a very, very close relationship with Sam's mum as well, and Sam's stepdad – we're all very good friends. Erm, to the point where me and [stepdad] escape every year to the cricket! (Mark, Sam's Dad)

In the case of Helen and Clive, family support was one of the driving factors behind their decision to move back to Edinburgh from the Highlands. Helen described her family as not only large and willing to help but also sufficiently experienced with individuals with intellectual disabilities to know how to cope with Amy's needs:

Amy's got a huge network – aunties, uncles, cousins – mum worked as a special needs carer [ ] so she knows how to look after special needs kids as well, so it's a good bit of respite for us as well at weekends and stuff. It helps a lot. (Helen, Amy's Mum)

The combination of practical and emotional support offered by family thus appeared to be fundamental to these parents' health and wellbeing and allowed them to retain greater optimism for the future. Lynda, however, as a widow and single mother, described having little to no family support available. For this reason, Elliot was said to have taken it upon himself to become his Mum's emotional support and 'protector':

Elliot can sometimes hide a lot from me because he feels he's got to be there for me, if you know what I mean. He's trying to support me as much as I'm trying to support him, and it's like taking over the protective role. 'Don't tell her, then it won't upset her or anything like that', because there has been times when I'm like 'why didn't you say?' and he's like 'well, I didn't want to worry you'. (Lynda, Elliot's Mum).

6.6 Discussion

In line with the expected trajectory for young adults with mild developmental delay, every parent gauged their child's maturity level to be equivalent to a typically developing 13-year-old. Elsewhere, parents have reported feeling that their disabled children's development would likely stagnate without constant proactive support (Docherty & Reid, 2009). In contrast, the parents involved in our study described their offspring's transition as occurring naturally, just at a slightly slower rate. This ties in with the generally more forcefully optimistic stance maintained about their children's developmental trajectories. However, it is worth noting that the average age of child in the Docherty and Reid study was 23, and that all had left school at the point at which the interviews were undertaken. Consequently, their perspectives on the post-school stage were based on actual, rather than predicted experiences. The fact that the biggest challenges had yet to arise was very much acknowledged by the parents in our study and contributed to anxiety about the future.

Their life-stage may to some extent explain the mixture of forceful optimism and anxiety expressed by some of the parents in our study. According to Erikson's life-stages theory, mid-life parents feel compelled to pass on life-skills and lessons to their adolescent children (Erikson, 1950). These acts of 'generativity' are motivated by the need to establish one's offspring as autonomous, self-sufficient adults prior to one's own eventual demise. In the typically developing literature, parents whose children fail to meet the normative milestones for independence within the desired timescale are therefore more likely to experience greater ambivalence towards their children and poorer health outcomes (Fingerman, Cheng, Tighe, et al., 2012).

These trends are to some extent mirrored in the experiences of parents of adults with intellectual disabilities. Evidence suggests that individuals in this group whose children move out often report improved quality of life (Dyke et al., 2013). However, as the majority continue to be either partly or entirely responsible for providing life-long care (E. Emerson & Hatton, 2008), most are unable to make the transition to the post-parent stage. The caring role has been described as a form of "hidden work" that increases the number of emotional and financial burdens on parents, while simultaneously preventing them from finding respite and fulfilment through employment (Chou, Wang, Chang, & Fu, 2014). Consequently, the prospect of being denied the right to reduce parenting responsibilities has been shown to cause disappointment and resent in this population (Docherty & Reid, 2009). To some extent, it is therefore unsurprising that the parents in our study had chosen to view the future in abstract hopeful terms while putting the majority of their emotional energy into the here and now.

However, the parents' attitudes towards the prospect of their offspring's independence were seemingly complicated. Despite wanting to support their daughter to get a good job, Helen and Clive expressed concerns about both the practical and emotional impact that doing so could have on Amy and the wider family. In many ways, these concerns are justified. As suggested in 1.6.3.2, adults with intellectual disabilities are more likely to be employed in low-wage jobs with unsociable working hours (Verdonschot et al., 2009), and to be neglected rather than supported by their employers (Dyke et al., 2013). Moreover, individuals who claim to be capable of work are likely to have their disability support payments stopped, putting greater financial pressure on the individuals and their families.

For the other parents, however, attitudes towards independence were primarily complicated for emotional reasons. Mark, Lynda, and Carol, for example, were keen to see their children spend more time out of the house with friends, and yet were thankful that they were never getting into trouble or putting themselves at risk. Historically, parents and carers of disabled individuals have been characterised as perpetuating the parent-child relationship into adulthood (Baron, Riddell, & Wilson, 1999), and parents are still more likely to remain the primary decision-maker in their children's lives (Mitchell, 2012). Over-protection, patronisation, and infantilisation, for example, have frequently been reported in relation to adults with intellectual disabilities (Payne-christiansen & Sitlington, 2016; Seale et al., 2013). However, more recent research suggests that parents feel increasingly torn between wanting their children to become autonomous, and wanting to retain their parental role and protect them from harm (Pownall et al., 2011).

One possible explanation for this can be found in the work of McAdams and De St Aubin (1992), who suggest that both cultural demands for eventual independence and the internal desire to retain a sense of communion (the "need to be needed") motivate the parental drive for generativity. The competing nature of these internal and external motivations may explain why, as in our study, some parents feel the need to force themselves, as well as their children, to push for greater independence (Docherty & Reid, 2009). Arguably, this dilemma has the potential to be exacerbated by justified fears concerning competence and risk. Elliot and Amy, for example, were said to have repeatedly demonstrated that they could not be trusted to behave safely and sensibly when given greater freedom. In these cases, the 'Catch-22' experienced by parents is based on concrete, practical concerns, rather than the abstract or purely emotional concerns felt by parents of typically developing adolescents.

The invisibility of their young peoples' disabilities was also thought to increase the risks, as expectations would likely be the same as they would be for other 17-year-olds. These fears are to some extent substantiated in the literature. Evidence suggests that visible disabilities can be protective, as unusual or antisocial behaviours are viewed more sympathetically when the subject's disability is easily identifiable (Dorozenko et al., 2015). However, the stigmatised position of disability in society increases risks in other areas. All of the parents described encounters with educators and other professionals that demonstrated ignorance and prejudice, specifically within the mainstream sector.

Similarly, problematic encounters with professionals are frequently cited by parents (Rapanaro et al., 2007; Stainton & Besser, 1998; Stoner et al., 2005). The prevalence of the 'innate deficiency' view of young adults with intellectual disabilities is well documented (Carter et al., 2015), and parents of children with intellectual disabilities typically have to advocate much more frequently and forcefully than other parents (S. Ryan & Cole, 2009). Moreover, as concerns have been raised that mainstream schools have been pressured to accept pupils with special needs without being equipped to provide appropriate support (Hodkinson, 2006), the advocacy role may be all the more important for integrated students.

However, while one study found that students with intellectual disabilities educated in mainstream schools experienced significantly higher levels of stigma than those in special schools (G. Cooney, Jahoda, Gumley, & Knott, 2006), the literature on attitudes towards inclusion and integration for young adults with disabilities are generally positive (for

reviews of the literature, see Avramidis & Norwich, 2002; de Boer et al. 2010). Nevertheless, the valence of these attitudes appears to be dependent upon the strength of the support infrastructure available at the school, and the level of experience teachers had working with the population (Avramidis & Norwich, 2002). For the most part, lack of experience and general ignorance accounted for the negative encounters experienced by the parents in our study, and all felt that their schools were doing the best they could under trying circumstances.

Importantly, inadequate resourcing, lack of options, and poor access to information accounted for a number of the parents' anxieties and frustrations during the transition process. Lynda, in particular, felt that no one had the answers she needed and that information was remarkably difficult to come by, problems that are well documented in the literature (Bhaumik et al., 2011; Heslop et al., 2002). In Scotland, reports such as *Changing Childhoods* and *The Same as You* have highlighted the importance of inclusive approaches and partnerships between stakeholders for improving transition planning for young adults with intellectual disabilities (The Scottish Government, 2000; The Scottish Government, 2000). Moreover, the introduction of the Education (Disability Strategies and Pupils' Educational Records) (Scotland) Act 2002, and the *Curriculum for Excellence* were designed to improve the accessibility of information and transition planning. However, the statutory framework has been criticised for its simplicity and lack of specificity, which has led to inconsistent design and delivery of transition practices across the country (Conlon, 2014). It is therefore unsurprising that several of the parents in our study described being forced to rely on friends and family to access information and guidance.

Arguably, these systematic problems further highlight the fundamental role that personal social networks play in supporting parents of children with intellectual disabilities. For Mark, Helen, and Clive, in particular, extended family were said to provide opportunities for both practical respite and emotional support, both of which have been shown to predict parent wellbeing (M. E. Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Skok, Harvey, & Reddihough, 2006). This mirrors suggestions that resilience is a function of the interactive processes that occur between the various levels of an individual's social infrastructure (Michael Ungar, 2012). The strength of the social support available to these participants may go some way to explaining their capacity for optimism in the face of the challenges that lay ahead.

6.7 Key Findings

- In general, parents described their children as making the transition to adulthood, just at a slower pace than their peers without disabilities. However, the discrepancy between physical and psychosocial development was a cause of concern in some cases.

- Parents appeared to feel torn between wanting to encourage their child to develop autonomy and independence, and wanting to protect them from harm. Viewed parenting as a constant negotiation between these two outcomes.

- Parents described having to remain highly proactive to support their children, in part to cope with the lack of institutional support. Information about available options was felt to be hard to access.

- Parents felt that all of the stakeholders involved in their children's transitions were having to make-do with the information and resources available to them. Some felt that no one had any answers.

- Parents attempted to remain as optimistic about the future as possible, and appeared to be highly reliant upon family support.

6.8 Summary

Four semi-structured interviews with five parents of young adults with borderline to mild intellectual disabilities were undertaken about their experiences of, and attitudes towards their child's transition. The parents discussed the unique challenges of raising a son or daughter with developmental delay, including the number of additional roles that they felt compelled to adopt during the process. While post-school uncertainty and the difficulty of balancing autonomy with protection were sources of anxiety, the parents' trust in the strength of their social networks and their commitment to optimism helped them to sustain every-day resilience. These findings provide additional evidence for the fundamental roles that communication and partnership between parents and other key stakeholders play during the transition period.

Chapter 7   Development and Implementation of the Quasi-Experimental Phase (Study 2)

7.1 Introduction

Self-determination and subjective adult identity are often considered to be positive outcomes that young adults with intellectual disabilities are at greater risk of failing to achieve than their typically developing peers. As suggested, 'self-determination' can be used to refer to a situational phenomenon, a dispositional set, and a set of competencies, all of which are interdependent. Furthermore, social information processing theory suggests that behavioural outcomes such as these are dependent upon transactional interactions that promote the right beliefs, expectations, attitudes, and goals (Crick and Dodge, 1994). Consequently, individuals who are frequently reminded of their vulnerabilities through parental rules and restrictions may be less likely to expect or wish to adopt greater freedom and responsibility in adulthood. Similarly, young adults who have learned to associate growing-up with independence and autonomy may be more resistant to parental interference than those who never developed the same expectations for adulthood.

The purpose of the following study was to extend the results from the first phase by exploring how young adults with mild intellectual disabilities experience, perceive, and feel about growing-up and adulthood in comparison to their typically developing peers. In light of this, the following research questions were devised:

Research questions:

1) Which transition activities do young adults with intellectual disabilities undertake in comparison to their typically developing peers, and what are the predominant obstacles to these activities?

2) How do young adults with intellectual disabilities feel about their levels of freedom and responsibility in comparison to their typically developing peers?

3) How do social goals and outcome expectancy beliefs impact the desire for autonomy in young adults with intellectual disabilities compared to their typically developing peers?

4) How do young adults with intellectual disabilities conceptualise adulthood in comparison to their typically developing peers, and how do these conceptualisations relate to their subjective adult identity?

5) How does parental support for autonomy relate to their young peoples' everyday activity levels, outcome expectancies, and how grown-up the young people feel?

7.2 Finding a Method

While the majority of the second study was to be undertaken quantitatively, questions relating to emotions, perceptions, expectations, and identity are necessarily nuanced and unpredictable. Consequently, the design of the study had to allow for qualitative data to be collected simultaneously, in order to account for these subtle variations. Furthermore, it was also necessary to find examples of research methods known to be successful with young adults with mild to moderate intellectual disabilities that could also engage individuals without disabilities. For these reasons, it was decided that the study would be conducted one-to-one, with the researcher playing an active role in the data collection process.

As a group, individuals with mild to moderate intellectual disabilities are more likely to have short-term memory impairments and to have a limited attention span than their typically developing peers (Dekker, Koot, Ende, & Verhulst, 2002; Schuchardt, Gebhardt, & Mäehler, 2010). The researcher was therefore keen to collect data using a series of brief interactive activities, as it was felt that a more dynamic approach would maintain the participants' interest, and reduce reliance on memory. Furthermore, individuals with intellectual disabilities are more likely to have more limited communication abilities and may find abstract topics such as growing up and adulthood difficult to engage with (Flynn, 1986). Therefore, the decision was taken to avoid activities that require high levels of linguistic competence or abstraction.

In addition, as visual aids have been shown to aid comprehension, concentration, and memory (Rao & Gagie, 2006), only activities that could be supported visually were considered. It is for these reasons that established measures, most notably the ARC self-determination scale, formed no part of the study. Despite being a well-validated measure of self-determination frequently used in populations with intellectual disabilities, the ARC is time-consuming, abstract, and cannot easily be supported visually. It was felt that its

inclusion would risk generating response-fatigue, undermining the reliability of the collected data.

In order to find the most appropriate methods for the study, a scoping review was undertaken to find papers and chapters concerning the advantages and disadvantages of various research methods when conducted with individuals with intellectual disabilities. Several papers were found, most notably Nind (2008), Coons and Watson (2013), and Hillier, Johnson and Traustadóttir (2007). Conversations with experts in the field were also undertaken. As a result of this process, two methods were found that met the desired criteria: Talking Mats (flash-card activities) and vignettes.

7.2.1 Talking Mats

'Talking mats' are a picture-based resource designed to facilitate conversation with individuals whose communication skills are impaired or under-developed (J. Murphy, 1998). The system was developed in the late 1990s by speech and language therapists at the University of Stirling and is used in a range of clinical, educational, and support settings.

As shown in Fig. 4, a 'mat,' which may be a physical mat or a digital representation, is placed in front of the individual. The topic of discussion, such as 'what would you like to do today?' or 'how do you feel about X?' is placed at the bottom of the mat as a memory aid. Picture cards portraying thumbs-up, thumbs-down, and a 'shrugging' character are used to represent Likert-style attitudes, and are placed along the top of the mat to form a 'top scale.' Participants are given 'option cards' one at a time and asked how they feel about that option. They are then invited to place the card onto the mat underneath the appropriate top-scale symbol; however, the top-scale can also be used continuously to indicate varying degrees of preference or feeling.
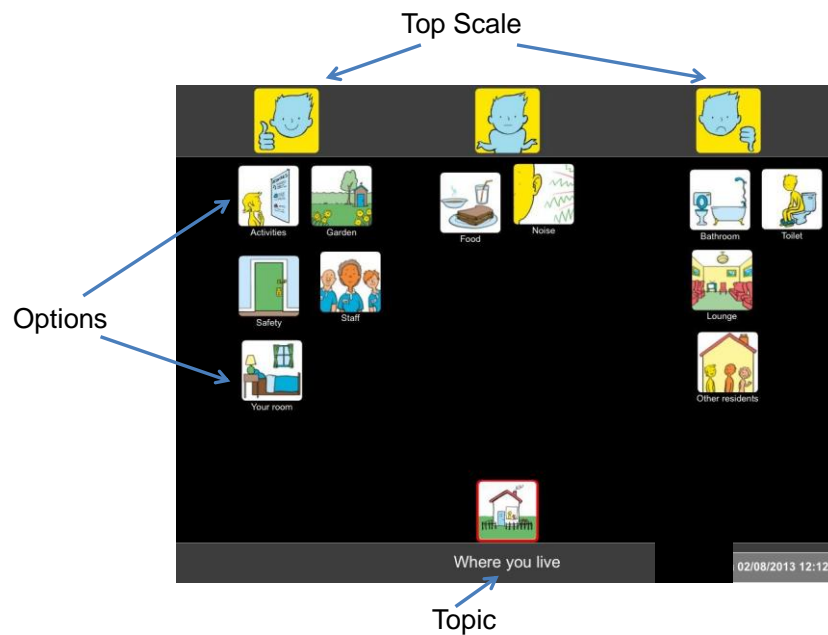
Figure 4: Example Talking Mat (Copyright Talking Mats Ltd.)

Importantly, Talking Mats require a specific manner of delivery for optimal results. Before each session, participants are told that the mat is theirs to control. Therefore, the mat must be placed directly in front of them rather than remaining with the facilitator. The topic and top scale must be clearly and explicitly explained before commencement, and each option card must be introduced with the phrase 'how do you feel about X?' Cards should also be handed to the participant for them to put down, rather than being controlled by the facilitator. Sessions should last no longer than five minutes to avoid fatigue and should be concluded with a recap of each card to allow participants the opportunity to change their minds.

Murphy and Cameron (2008) undertook a study investigating the effectiveness of Talking Mats as a communication aid for adults with intellectual disabilities. Their results suggest that the richness and clarity of communication, as well as participant confidence and engagement, improved significantly for participants capable of understanding two or more information-carrying words per sentence. While talking mats may not be particularly appropriate for use with individuals with very low linguistic comprehension, the system can be more valuable than traditional communication methods for individuals with mild to moderate intellectual disabilities.

Several qualitative studies have successfully been undertaken using Talking Mats to support interviews with individuals with intellectual disabilities and their families (Bell &

Cameron, 2008; Cameron, 2015; G. H. Murphy & O'Callaghan, 2004). However, despite the potential for the top-scale to be used like a Likert scale, no quantitative studies could be found that used Talking Mats in this fashion.

7.2.2 Vignettes

Designed to emulate real-life situations, vignettes require participants to make judgements about, or to share their reactions to, story-based hypothetical situations. As such, vignettes can be used to explore participants' values, norms, and beliefs regarding specific issues or phenomena (Finch, 1987). Vignettes can be presented in first or third-person and can be accompanied by closed or open lines of questioning depending on the particular variables under investigation (Hughes & Huby, 2004). Furthermore, vignettes can be presented through a variety of media, including but not limited to writing, pictures, photography, and film (Hughes, 1998).

Vignettes have several advantages over other methods. Questionnaires, for example, can often be interpreted in a variety of ways, undermining validity. In contrast, extraneous variables and stimuli can be controlled more easily in vignettes, allowing for better standardisation between participants (Gould, 1996). Furthermore, some writers have argued that vignettes are preferential for socially-sensitive research (Finch, 1987), particularly as participants may be more inclined to reply honestly to hypothetical scenarios than self-report measures (McKeganey, Abel, & Hay, 1996).

While long vignettes can cause problems for participants with intellectual disabilities, short vignettes have been shown to be equally as valid for members of this group as for typically developing individuals (Weisman & Brosgole, 1994). The narrative nature of vignettes is often more engaging than direct questioning and may feel less intrusive and judgemental than interviews or questionnaires (Kayser-Jones & Koening, 1994). This makes vignettes particularly appropriate for use with young adults with intellectual disabilities, whose performance may be negatively affected by activities with test-like connotations (Zigler & Balla, 1982). Furthermore, vignettes can often be represented visually (Hughes, 1998), helping to make research more accessible for individuals with moderate communication difficulties. Vignettes have therefore been used to study a variety of topics with individuals with intellectual disabilities, including decision-making competence (Hickson, Golden, Khemka, Urv, & Yamusah, 1998; Khemka et al., 2009); social goals and outcome

expectations (Kirk, Jahoda, & Pert, 2008; Parnell, 2010), and perceived stigma and social comparisons (G. Cooney et al., 2006).

However, it should be noted that vignettes carry a number of risks to validity that must be accounted for in the design process. The hypothetical nature of the scenarios, for example, can lead participants to provide riskier responses that do not reflect their real-life tendencies (McKeganey, 1995). Similarly, social desirability can influence participant responses, particularly in relation to first-person vignettes or those that relate to controversial topics (Constant, Kiesler, & Sproull, 1994). Furthermore, it may be difficult to accurately distil the inherent complexities of real-life into a brief vignette (Hughes & Huby, 2004), resulting in simplistic responses, or poor participant engagement. Yet, providing too much detail can generate demand characteristics that influence participants and distort results (Hughes, 1998).

To account for these risks, vignettes must provide enough detail to allow participants to empathise with the scenario while leaving sufficient room for participants to respond with authenticity. Recommendations have included avoiding extreme or eccentric scenarios (Finch, 1987; Hughes, 1998), keeping situations simple and easy to follow (Weisman & Brosgole, 1994), supporting the narrative with visual prompts where appropriate (Parnell, 2010), thorough piloting with the target populations to ensure ecological validity (Swartzman & McDermid, 1993), and discussing the scenarios with experts in the field (Gould, 1996).

7.3 Development of measures

7.3.1 Session overview

Having decided that Talking Mat-style picture cards and vignettes would form the basis of the study, it was then necessary to consider the number, content, order, and duration of the activities. Having calculated that between 24 and 42 participants would be required per group for a power of 80-85% (See Section 7.5.1 for details), it was agreed that the total session time should last no more than half an hour, including the administration of the WASI-II IQ screening exercises, induction, and debriefing session. This decision was taken because it was felt that longer sessions may deter schools and potential participants from committing to the study, and would also risk extending the data-collection period beyond its allocated timescale.

In light of the results from the interviews, several areas of interest arose that warranted further investigation. These included, but were not limited to:

1. Experiences of, and attitudes towards, the adoption of roles, activities, and responsibilities associated with growing up.

2. Outcome expectations and social goals in relation to decision-making without parental support

3. Constructions of adulthood and subjective adult identity

For this reason, it was decided that the study should have three phases, each relating to one of these areas.

7.3.2 Phase 1 Development: The Autonomy Task

Provisional findings from the interviews suggested that the young adults with intellectual disabilities engaged in far fewer 'transition activities,' such as going out independently, experimenting with restricted activities, and managing their own affairs than the typically developing peers. Moreover, while parental restrictions accounted for some of this disparity, the majority of the participants with intellectual disabilities expressed low interest in increasing their independence or engaging in positive risk-taking. Similarly, while neither group showed particular desire to increase their levels of responsibility at home, members of the typically developing group were more likely to express feelings of familial obligation and guilt at their lack of contribution. The participants with intellectual disabilities, in contrast, tended to expect to be protected and provided for by their parents and were more likely to actively resist responsibility. The first phase of the quantitative phase of the project was therefore designed to investigate the relationship between actual and desired behavioural autonomy.

Importantly, due to unanticipated delays with recruitment, data collection and analysis of results from the qualitative studies occurred concurrently with a significant proportion of the Study 2 development phase. Findings from the interviews continued to influence change throughout the development phase, which is why certain items were removed and replaced before the Study 2 pilot.

7.3.2.1 Item development and Question Format: Draft 1

As with the interview schedules, the content of the first phase (The Autonomy task) was initially developed using items from the Choice Questionnaire (Stancliffe & Parmenter, 1999), as well as from the Autonomous Behaviour subsection of the ARC Self-determination scale (Wehmeyer & Kelchner, 1995). However, in response to the participant interviews and the wider literature (Seale et al., 2013), it was decided that risk-taking and experimentation form essential parts of the transition process. Consequently, a subset of items relating to restricted or 'rebellious' activities was introduced. A full list of the first draft of items can be found in Table 6.

Everyday Decisions	Restricted/Rebellious Decisions
What clothes I wear	If I can get a crazy haircut
What I eat and drink	If I can smoke
Who I can be friends with	If I can get piercings
What time I go out and come home	If I can get a tattoo
What I do during the day	If I can drink alcohol
What time I go to bed	If and when I can swear
What TV and films I'm allowed to watch	
Where I go out	
If I can spend time alone with a boyfriend/girlfriend	
Who looks after my money	
Who buys my clothes	

Table 6: First Attempt at Autonomy Task Items

In order to investigate the level of actual autonomy experienced by each participant, the question structure utilised in The Choice Questionnaire was initially chosen to underpin the Autonomy task. The Choice Questionnaire presents a selection of everyday choices and asks participants to pinpoint who it is that makes those decisions in their lives. Points are allocated depending on whether the participant takes sole responsibility for the decision (1 point), decides with help (2 points), or someone else decides for them (3 points), thus providing a total score for decision-making autonomy. For the Autonomy task, these options were used to create three "top-scale" picture cards, under which participants could place each activity card.

To investigate participants' desired autonomy, the everyday choice cards were re-sorted under a new top-scale made of the following cards:

I *want* to choose on my own / I *want* a bit of help / I *want* someone else to choose for me.

Finally, the cards were again sorted into top-scale categories relating to perceived self-efficacy in decision-making:

I am good at making these decisions (I know best) / My decisions are okay / I am bad at making these decisions (other people know better)

7.3.2.2 Item Development and Question Format: Draft 2

However, a number of problems quickly became apparent with this structure. First, it was felt that the repetitive nature of the three tasks would lower participant engagement and risk response fatigue. Second, by focussing on decision-making rather than actual behaviour, individuals who had assumed responsibility could not be differentiated from those who had chosen to avoid responsibility. For tasks like cooking, managing finances, doing chores, we felt that it is not the *decision* that indicates self-determination, but rather engagement with the activity itself (behavioural autonomy). It was therefore felt that a less independent individual who chooses *not* to undertake these tasks should not receive the same score as someone who does adopt more responsibility.

Equally, altering the framework to I do x/ I get a bit of help to do x/ someone else does x for me, though better suited to the aforementioned tasks and responsibilities, could not be applied to 'having sex', 'drinking alcohol', and 'getting a tattoo'. While alterations to phrasing were considered, it was also felt that individuals who have not, or do not wish to engage in these riskier behaviours should not be 'penalised' with lower final scores. This led to the third problem; namely, that scoring individuals carries inappropriate normative overtones (more points = better). By failing to account for the underlying reasons behind the participants' autonomous behaviour (or lack thereof), we felt that this approach would provide an overly simplistic view of autonomy that would fail to adequately address the aims of the study.

For these reasons, the three activities were amalgamated and changed from scale data to categorical data. Furthermore, the items were changed from 'every choices' to 'everyday activities'. It should also be noted that some changes were made to the items at this stage in response to findings from the first study. A full list of these can be found in Table 7.

Everyday Activities	Restricted Activities
Choosing my clothes in the morning	Having sex
Staying up as late as I want	Drinking alcohol
Choosing my friends	Watching 18-rated films
Spending my money how I want	Smoking
Tidying my room without being asked	Getting a tattoo
Going out at night alone	
Cooking my meals	
Going into town alone	
Using Facebook or Twitter	
Deciding what I do during the day	
Doing housework without being asked	
Going to other cities alone	
Looking after my money	
Using public transport on my own	
Making my own appointments	
Staying at home on my own overnight	

Table 7: Second attempt at Autonomy Task items

In the first instance, participants were asked to sort the transition activities into two categories:

I do or have done this / I don't do this or haven't done this

All activities that had been placed into the 'I don't' category were then further divided into:

I don't want to / I'm not allowed / I just don't or haven't

This alteration allowed for more insight into the reasons underlying the participants' levels of autonomy. Furthermore, an additional category - "I just don't or haven't" - was included to cover items that were not considered relevant to the participants' lives.

While this may be considered an overly simplistic representation of the motivations underlying the participants' behaviour, it was felt that too many nuanced categories would risk confusing participants with lower levels of linguistic competence. Furthermore, as categorical data requires a minimum number of participants per option, increasing the number of available categories would also interfere with statistical testing.

In order to reduce the likelihood of order effects bias, the cards were deliberately ordered to 'ease' participants into the task. Simpler everyday activities like picking one's own clothes and bedtime were therefore put at the beginning. Furthermore, the restricted activities were deliberately spaced throughout the pack to prevent participants from developing a particular response set.

Moreover, two additional questions were added to measure participants' overall feelings towards their levels of freedom and responsibility at home:

How bothered are you about these rules/ not being allowed to do stuff?

Not at all bothered / A little bothered / Not at all bothered

How happy are you with the amount of opportunity you have to make choices at home?

Happy / Want a bit more / Want a bit less

Results from the pilot can be found in Section 7.4.3.

7.3.3 Phase 2 Development: Vignette

Phase two was primarily based upon work undertaken by Pert and Jahoda (2008), and Pownall (2009) on the impact of social goals and outcome expectancies on the behaviour of young adults with intellectual disabilities. The aim of Pownall's study was to determine differences between individuals with physical, intellectual, and no known disabilities on three main areas: "1) Expected evaluations from unknown peers, close friends, and parents for either engaging in or refraining from potentially health-risking behaviour… 2) how much these evaluations matter to them…[and] 3) participants' salient goals within potentially health-risking situations" (Pownall, 2010). The participants were presented with two vignettes, both of which involved going to a party with a friend. In the first vignette, participants were asked to imagine that they were feeling drunk/dizzy, and a guest offers them another drink. In the second scenario, participants were asked to imagine that a potential sexual partner invites them back to his/her home to "be alone".

Participants were asked to provide the responses they would expect to receive from three groups (unknown peers, close friends, and parents) in relation to four outcomes: 1) their decision to take an alcoholic drink when already drunk 2) their refusing the drink 3)

accepting an offer to go home with a stranger, and 4) refusing the stranger's offer. Participants were also asked to report the extent to which these opinions mattered, and what they would choose to do in both the vignette situations.

While the overarching focus of Pownall's study was on expected outcomes of health-risking behaviour, results suggested that substantive differences regarding the emotional and motivational characteristics of decision-making exist between young adults with intellectual disabilities and their typically developing peers. Whilst there was insufficient power to generate statistically significant results, trends emerged that suggest that young adults with intellectual disabilities place greater value on the opinions of others, especially the views of their parents. In particular, wishing to avoid parental disapproval seemed to be a common motivator amongst the participants with intellectual disabilities, even when asked to imagine that there would be no punitive repercussions from their actions. These findings are to some extent substantiated in the literature. Whitaker and Hughes (2003), for example, found that the main reason underlying the decision to either begin or refrain from smoking in this population was wanting to be accepted by friends and family.

Pownall also found differences in the types of negative reactions expected from parents. The majority of participants without disabilities, for example, predicted parental *disappointment*, whereas more of the individuals with disabilities assumed that their parents would become *angry*. One possible explanation for this is that, being more dependent upon their parents and carers for support, individuals with disabilities may perceive themselves - rightly or wrongly - to be subject to more rules and restrictions. As a result, they may be more likely to interpret participating in risky behaviour as a form of disobedience, prompting a more fiercely negative reaction from parents.

The potential implications of these findings for self-determination are significant. The purpose of the Phase 2 vignette was consequently to expand this work to explore how participants' outcome expectations and social goals affect their willingness to make a decision that was against their parents' wishes.

7.3.3.1 Scenario Development: Draft 1

In order to ensure that the vignette scenarios were ecologically valid, the first draft was designed with two key criteria in mind: 1) the 'decision' around which the vignette revolved had to be considered important and relevant to each participant, and 2) the decision's outcome had to be contrary to the known wishes of the participants' parents, and

thus be a source of conflict. However, being too specific about the nature of the decision risked lowering the scenario's relevance to some participants. For this reason, the initial draft utilised a vague framework that encouraged participants to "fill in the gaps" with subjectively relevant details:

*Imagine that you have a big decision to make – something really important to you, for example, maybe you need to apply for a job [picture], or college [picture], move somewhere [picture], or start a relationship [picture]. You make a decision that you **know** your parents won't like*

Participants would then have been asked to the following fixed-response questions:

How do you think you would feel if you made a decision that you knew your parents wouldn't like? Pick one card that represents how you would feel:

Proud / Grown-up / Happy / Not bothered / Sad / Guilty / Worried

How do you think your parents would feel if you made a decision that you knew they wouldn't like? Pick one card that represents how your parents would feel:

Proud / Supportive / Happy / Not bothered / Sad / Angry / Disappointed

If you thought that doing something you want to do would make your parents feel bad, would you still do it?

Yes / No / Don't Know

However, pre-pilot trials during the Study 1 interviews demonstrated that the scenario was too vague for participants of either group to engage with. Furthermore, concerns were raised that the fixed responses were both too numerous and risked being too subtle for participants with more moderate intellectual disabilities to choose between.

7.3.3.2 Scenario Development: Draft 2

For the second draft, it was decided that the vignette should concern a specific, concrete decision. However, it was then necessary to develop a decision-making scenario that was a) appealing to members of both groups and b) had the potential to cause conflict within the families of both groups. Numerous scenarios were considered, the majority of which were either too mundane to engender conflict within the typically developing group, or too "risky" to be considered realistic for members of the group with intellectual disabilities.

Preliminary responses during the Study 1 interviews, for example, suggested that going on a holiday with friends rather than family was a scenario that members of both groups found appealing, and that had the potential to cause conflict between themselves and their parents. However, further investigation during pre-pilot discussions revealed that responses were often contingent upon specific details about the holiday, including length, duration, location, planned activities, and company, that could not be included in the scenario. Furthermore, it also became apparent that the majority of young people lack the financial independence to go on holiday without parental support. For these reasons, the holiday scenario was rejected.

7.3.3.3 Scenario Development: Draft 3

The process of developing and subsequently rejecting the 'holiday' scenario highlighted the need to account for any practical obstacles that might otherwise affect participants' responses. Two scenarios were identified that met all three criteria: The Cinema Trip, and The Meet Up:

A new film has come out that you really want to see. Your friends invite you to go to the cinema with them to see it after school. As a treat, they will pay for your ticket, and make sure you get home afterwards. When you ask your Mum if you can go, she says that she thinks the film looks a bit inappropriate (too grown up for you), but says it's up to you.

A new friend asks you to hang out at their house after school. You really want to go. When you ask your mum if you can go, she says she's not too happy about you going, because she's never met them before. However, it's up to you if you go or not.

In these scenarios, "parents" were replaced with "mum", as even though the number of mothers in full-time employment continues to increase, mothers in both two-parents and lone-parent families are more likely to act as the primary carer (ONS, 2012; J. Scott & Clery, 2012). In addition, the initial fixed-response questions were replaced with questions closer to those used in Pownall's study (2010), as it was felt that this format of questioning would work more effectively with the target groups:

Imagine that you say <u>yes</u> to your friends and go to the cinema.
After choosing not to listen to your mum, do you think that your friends would:

Like you more / Like you less / Not be bothered

How much would this bother you?

A lot / A little / Not at all

Do you think your Mum would think you did the:

Right thing / Wrong thing / Not be bothered

How much would this bother you?

A lot / A little / Not at all

*Now imagine that you say __no__ to your friends and **do not go** to the cinema [questions repeat]*

What would you do and why?

These scenarios were further developed throughout the piloting process, results from which can be found in section 7.4.4.

7.3.4 Phase 3 Development: Adult Identity Task

Phase three had two main objectives: 1) to investigate how young adults with mild intellectual disabilities conceptualise adulthood in comparison to their typically developing peers, and 2) to see how these conceptualisations relate to their subjective adult identity. To assess the first objective, it was decided that the task would involve participants picking their own 'definitions' of adulthood from a collection of pre-established criteria.

During the interview studies, more of the young adults with intellectual disabilities appeared to conceptualise adulthood in terms of fulfilling the obligations associated with social role transitions, whereas the participants without disabilities tended to discuss adulthood in terms of self-sufficiency and maturity. It was therefore decided that the activity should include a range of possible criteria for adulthood. A scoping literature review was undertaken to find studies on adulthood criteria that could be used to inform the content of the activity. As a result of this process, one study was found in which older participants were asked to describe instances in which they had come to feel like adults (Lowe et al., 2013). A range of social role transitions and other milestones (hereafter referred to as 'life-stage markers') and personal characteristics were referenced in this study, the most frequently cited and relevant of which were adapted for the task. However,

as a number of the interview participants had also aired slightly idealistic beliefs about adulthood, a further six items pertaining to 'unrealistic expectations' were also devised. A full list of the pre-pilot criteria can be found in Table 8.

Category	Criteria from Lowe et al. (2013)	Adapted for Study
Personal Characteristic	Taking responsibility for oneself	Owns up to their mistakes
Personal Characteristic	Taking responsibility for others	Looks after other people
Personal Characteristic	Decision-making	Makes important decisions
Personal Characteristic	Assertiveness	Does not let other people push them around
Personal Characteristic	Personal strength	Can cope with life's challenges
Personal Characteristic	Goal/future orientation	Plans for the future
Lifestage Marker	Marriage/proposal	Gets married/finds a partner
Lifestage Marker	Child rearing	Has children
Lifestage Marker	Employment	Gets a job
Lifestage Marker	Educational degree	Leaves school
Lifestage Marker	Home ownership	Move out of parent's house
Lifestage Marker	Chronological age	Is over 16
Unrealistic Expectation	N/A	Never gets anything wrong
Unrealistic Expectation	N/A	Is always happy
Unrealistic Expectation	N/A	Is really rich
Unrealistic Expectation	N/A	Does whatever they want
Unrealistic Expectation	N/A	Has no worries
Unrealistic Expectation	N/A	Does not have to follow any rules

Table 8: Original and Adapted Transition Criteria, from Lowe et al. (2013)

7.3.4.1 Procedure for Pilot

Eighteen picture cards were created, each depicting one of these possible criteria. The planned procedure involved asking participants to pick the criteria that they considered the best indicators of adulthood. To reduce the cognitive load of the task, the participants were

given one card from each category per turn, resulting in six rounds of three cards. Moreover, the order in which the cards were called, and their position on the table, was changed each time to avoid the development of a particular response set (i.e., always picking the card on the left, always picking the card read-out last). After the final round, participants were given the opportunity to swap their cards until they were happy with their final selections. Finally, they would be asked to rank their final six in order of importance.

To achieve the task's second objective, participants were asked to pick out every card from their chosen six that they felt could be used to describe themselves, to see how 'adult' they were according to their subjective definitions of the term. Finally, participants were asked if they felt more like an adult or a child, and what would make them feel more like an adult.

Results from the pilot can be found in Section 7.4.5.

7.3.5 Parent Questionnaire

After discussions with experts in the field, it was decided that the first phase of the study would benefit from gaining parents' perspectives. A questionnaire was designed to ascertain how much opportunity parents reportedly give to their young people to undertake transition activities, as it was felt that this information could be used to contextualise other results. Each transition activity in the Autonomy task was included in the questionnaire and therefore did not require additional piloting. However, the question framework itself required careful consideration to ensure validity. Initially, the same phrasing used in The Choice Questionnaire and the first draft of the Autonomy Task was adopted:

The following questions concern the types of choice-making opportunities parents give to their adolescent young persons. Importantly, there are no right or wrong answers. For each question, please circle the option that best matches your general experience.

1. In general, who decides X?
a. I do
b. We negotiate/do it together/I help them
c. My young person can decide for themselves

However, much as in the Autonomy task, it was felt that this framework might fail to differentiate restrictive or protective parents from those whose children chose to avoid undertaking certain activities. For this reason, several changes were adopted. First, a 4-

point Likert scale was introduced so that a total "opportunities for autonomy" score could be calculated for each young participant. While five and seven-point Likert scales are commonly used in questionnaires of this type, evidence suggests that having a 'middle option' increases the risk of central tendency bias. Scales that force participants to choose a side are often more informative as a result (Stone, 2004).

The following list of possible questions was also developed:

- *If they wanted to, I would allow my young person to X.*
- *I allow my young person to X*
- *My young person is allowed to X*
- *I do not interfere with X*
- *X is up to them*
- *I give my young person opportunity to X*
- *I encourage my young person to X*

Subtle differences between the connotations of each phrase were discussed with colleagues in the department. As a result of this process, the following phrasing was chosen for most clearly communicating the desired responses:

On a scale of 1 to 4 (4 = strongly agree, 1 = strongly disagree), how much do you agree with the following statements?

"If they wanted to, I would allow my person to…"

A copy of the final questionnaire can be found in Appendix K.

7.3.6 Resources

A combination of clipart pictures and photographs were chosen for the flashcards and vignettes to augment participant understanding. Care was taken to choose images that were clear, simple, and age-appropriate. However, visual aids are only useful when their meaning is appropriately negotiated between the facilitator and the participant, particularly when used to communicate more abstract concepts (Banks, 2001). For the most part, only images licensed for free commercial or non-commercial usage were used. However, the rights to use three images were bought from approved online image vendors for use in the study. Each card was colour printed, numbered, cut out, and laminated.

For the vignettes, key images and sentences were colour printed onto separate sheets of A4 and arranged in a dedicated display book.

7.4 Pilot

7.4.1 Participants and Recruitment

Young adults with moderate to borderline intellectual disabilities (N=4) and young adults without disabilities (N=4) were invited to participate in the pilot study. Recruitment occurred in one special school and one mainstream school in Edinburgh. Furthermore, four of the participants had also been interviewed in Study 1. This prior knowledge was used to help inform the validity of each item in the pilot activities. Please note that none of the pilot participants were invited to participate in Study 2. Participant characteristics can be found in Table 9.

Sex	Age	IQ Bracket	Involved in Study 1?
Male	16	Mild	No
Female	17	Moderate	No
Female	16	Moderate	No
Male	17	Borderline	Yes
Male	16	Normal	Yes
Female	16	Normal	Yes
Female	17	Normal	Yes
Female	16	Normal	No

Table 9: Pilot Participant Characteristics

7.4.2 Resources

The study's materials were piloted separately to ensure that they were both appropriate and accessible. For the phase 1 (Autonomy Task) and phase 3 (Adult Identity Task) materials, participants were shown flashcards depicting stand-alone images and asked, "What is this a picture of?" to ensure that the images themselves were clear. However, as a number of the images were designed to convey figurative rather than literal meaning, responses were followed-up with the question "does the picture represent X or Y?" where X and Y represented two similar but distinct abstract ideas. Answers were noted on a tailored answer sheet. Body language was carefully watched to determine if the participants were unsure or just guessing. No changes were made at this stage.

Phase 2 (vignette) used A4 colour images presented landscape in a display book. These were piloted using a mixture of descriptive questions and more interpretive questions relating to the images' connotations. Items such as "How does this lady feel?", "What does this mean?" and "Tell me about these people" were included to ensure that the pictures inspired appropriate thoughts and feelings from the participants. The image initially chosen to represent 'Mum' was replaced after participants described her as looking too 'angry.' Furthermore, having two images visible across a double-page spread appeared to be distracting for the participants. This was changed so that only images designed to be seen together were visible at any one time.

7.4.3 Phase 1 - Autonomy Task Pilot

Several changes were made to the phrasing of the items in the Autonomy Task. 'Going out at night alone' and 'Going into town alone', for example, were changed to 'Staying out late with friends' and 'Going around Edinburgh without an adult' respectively, as it became clear that members of neither group could imagine going out at night alone without good reason. Furthermore, some items were removed completely. 'Choosing my friends', for example, was removed after it became clear that some participants with intellectual disabilities were unaware of the extent to which their social circles were being controlled. 'Spending my money on what I want' was also removed for failing to differentiate between participants who did and did not have significant financial independence. Finally, 'Deciding what I do during the day' was removed, as participants found this to be too vague to answer, even with prompts. However, enough participants described engaging in evening or weekend employment that a new card, 'Work at a job/volunteer' was introduced instead.

In addition, "How happy are you with the amount of opportunity you have to make choices at home?" was separated into two separate questions: 'How do you feel about the amount of freedom you have at home to do what you want to do?' And 'How do you feel about the amount of responsibility you have at home?' after it became clear that the initial phrasing was too complex for the less linguistically competent participants to engage with fully.

Moreover, during the later pilots, it became clear that the 'I do/have done' category was insufficiently discriminating. This wording was initially chosen to make it clear that activities such as getting a tattoo could be counted after a single experience, rather having to be undertaken regularly. However, as a result of this ambiguity, typically developing

participants used the category for *any* activity that they had undertaken once in their lives. To better distinguish participants' actual levels of autonomous behaviour, the category was rebranded 'I do this a lot'. All activity cards were also rewritten from the gerund tense (cooking my meals) to the present tense (cook my meals) for grammatical accuracy. For clarity, participants were told during the sessions that they only needed to have been tattooed once to place the 'tattoo' card into the category.

Finally, on several occasions, participants felt that an activity card could fit under more than one category. In these cases, participants were first asked to pick the category that best explained why they do not undertake those activities. When necessary, participants were asked the follow-up question:

"What would happen if your parents said you *are* allowed?"

In cases where they responded that they *would* try the activity in those circumstances, they were told to place it under "not allowed". In cases where they felt that they would still not do the activity, even with permission, they were asked to place it under "Don't want to".

A full outline of the final measure can be found at the beginning of Chapter 8.

7.4.4 Phase 2 – Vignette Pilot

As the vignette evolved considerably over the piloting process, results from each session are reported separately.

7.4.4.1 Pilot 1

During the first full pilot, two vignettes were presented to the participant, amounting to four separate scenarios. As described in Section 7.3.3, the participant was first invited to imagine going to the cinema without her Mum's permission. She was then asked how she thought her parents and peers would react, and how much these opinions 'bother' her. The participant was then asked to imagine herself ignoring her own wishes in favour of her Mum's, and the questions were repeated. However, several problems emerged with this format. First, the participant was quick to assert that she would never do anything without permission, and therefore struggled to empathise with the initial round of questions. Once it had been clarified that she did indeed have permission, the participant opted for the 'not bothered' option in every case. Once the negatively-framed scenario was presented, the

same pattern emerged. When probed, the participant responded that "it depends who's going" and "what the film was", suggesting that the scenario itself was too ambiguous for her to engage with fully.

For the second vignette, the participant was asked to imagine going to a new friend's house without permission (details presented in Section 7.3.3). Much as with the first vignette, the participant was adamant that she would never go to a stranger's house and therefore refused to engage with the first scenario. Despite additional clarification that the individual was a new friend, rather than a stranger, the participant again opted for the 'not bothered' option in every question. As well as struggling to empathise with the scenarios, the participant also seemed to become fatigued by the repetitive nature of the questions and lost interest before the end.

7.4.4.2 Pilot 2

In both vignette stories, the mother's reaction was re-written as "I'm not sure I'm happy with that" to avoid being considered overly patronising by more independent participants. Furthermore, it was felt that the introduction of this phrase had the potential to reveal more about participants' perceptions of, and feelings towards, opportunities for negotiating autonomy with a figure of authority. It was also decided that the negatively-framed scenarios were less relevant to the research question, and were therefore removed. Furthermore, questions relating to friends, as well as expected beliefs about right and wrong were replaced items relating to the anticipated emotional impact on mum, again to bring the study closer to the research question. Finally, more open questions were introduced to allow the participant greater scope to discuss the scenarios in a manner that was meaningful to her:

1. What would you say to your mum?

2. What would you do?

3. Why?

Imagine that you say, "I'm going anyway"

4. How do you think your mum would feel?

5. How much would this bother you?

A lot / A little / Not at all

Unfortunately, the participant's responses to the second vignette appeared to be heavily influenced by our discussion of the first; specifically concerning the possibility of saying "I'm going anyway".

7.4.4.3 Pilot 3

For the third iteration of the vignettes, the phrase 'Imagine that you say, "I'm going anyway"' was replaced with 'Imagine that you decide to go and see the film anyway,' to make the scenario less overtly confrontational. No significant changes were made after the third pilot.

7.4.4.4 Pilots 4 and 5

Pilots 4 and 5 - the first to be undertaken with typically developing students – revealed several problems that had yet to be accounted for. First, it was felt that the question 'what would you say to your mum' failed to provide enough insight into the participants' immediate emotional responses to the scenarios.

Second, the participants explained that stringent cinema policies necessarily prevent them from seeing 18 rated films in the movie theatre. As a result, the only films that they could possibly see would necessarily be unproblematic for their parents. Finally, the second vignette elicited very context-dependent responses from the participants, making answers hard to generalise as a result.

7.4.4.5 Pilot 6

To elicit more information about the participant's emotional reaction to the scenarios, the question 'How would you feel' was asked immediately after each vignette. Furthermore, in response to the feedback from the previous two pilots, the location of the screening was left unspecified to remove concerns about cinemas' age-restriction policies. The updated vignette was described as follows:

> *Your friends invite you to watch a film with them after school. The film looks really cool. When you ask your Mum if you can go, she says "I'm not sure I'm happy with you watching that film"*

The participant engaged with the scenario and provided answers that were consistent with her responses during the Study 1 interview. However, the second vignette was dropped in response to participant feedback.

A description of the final task is included at the start of Chapter 9.

7.4.5 Phase 3 – Adult Identity Task Pilot

The piloting process resulted in two types of changes to the Adult Identity Task: linguistic and procedural.

7.4.5.1 Linguistic changes

Despite apparent success during the materials-pilot, three of the cards caused problems during the dry runs of the study. The following linguistic changes were introduced to improve comprehension:

- 'Can look after other people' was changed to 'takes care of other people'

- 'Does not let other people push them around' changed to 'stands up for themselves'

- 'Can cope with life's challenges' changed to 'doesn't give up when things get hard'

- 'Does whatever they want' was changed to 'does whatever they want all the time' to exaggerate its unrealistic nature.

Furthermore, all potentially ambiguous cards were reprinted with additional information on the back to help scaffold understanding should further comprehension-issues arise.

7.4.5.2 Procedural changes

No changes were made to the initial procedure; however, the ranking process proved to be very challenging for participants, and it was felt that the results were unreliable as a result. Moreover, ranked data was not considered necessary to the research question. In light of these problems, this aspect of the study was removed. Furthermore, forcing participants to choose between adult and child status created a false dichotomy, undermining the reliability of results. A third category 'a mix of adult and child' was added as a result.

The final task is described in detail at the start of Chapter 10.

7.4.6 Questionnaire

Unfortunately, due to the difficulty in recruiting parents, the questionnaire could not be piloted prior to the start of the data collection period. A copy of the questionnaire can be found in Appendix K.

7.4.7 Demographic Information

Demographic questions, including date of birth, gender, postcode, residential status, and autism diagnosis were asked after the end of the Autonomy Task to determine the composition of each group. Furthermore, in order to effectively screen participants, the 2-Scale WASI-II IQ test was also included in the session. The matrix reasoning and vocabulary comprehension tasks were separated and undertaken between each phase, both to increase variety, and to prevent the compound stress effect of sitting two 'tests' back-to-back.

7.4.8 Debrief and Session Close

After the end of the Adult Identity task, participants were asked the same closing question used in Study 1 to reduce the possibility of rumination:

If you could have a superpower, what superpower would you have?

After this, participants were given the opportunity to ask any questions or make additional comments. Finally, participants were presented with the parent questionnaire in a stamped self-addressed envelope and told that it represented an optional, rather than a mandatory part of the study.

7.5 Recruitment strategy

A convenience sample of young adults with moderate to borderline intellectual disabilities (n=56) and young adults without disabilities (n=49) was recruited from schools and colleges across Edinburgh, Midlothian, and South Lanarkshire. One special school and one mainstream school from Study 1 volunteered to participate in the second study. Furthermore, their support facilitated the development of a snowball recruitment technique that extended across schools in Edinburgh and Midlothian. In total, 16 schools in four counties were contacted, either by the researcher directly or by one of the participating

Headteachers. Six schools agreed to participate in the study. However, three school pupil male participants without intellectual disabilities were recruited through the researcher's personal networks once all other avenues had been exhausted. In addition, three colleges, totalling eight separate campuses, were contacted by the researcher and invited to participate. Of these, four volunteered to take part in the study. A full list of the participating institutions can be found in Table 10.

Institution ID	Institution Type	No. participants with intellectual disabilities seen	No. Included	No. participants without intellectual disabilities seen	No. Included
1	Special School	19	17	2	0
2	Special School	4	4	0	0
3	Special School	11	5	0	0
4	Special School	2	2	0	0
5	Mainstream School with Support Dept.	1	1	17	15
6	Mainstream School	0	0	12	12
7	College Campus	17	15	7	7
8	College Campus	4	3	0	0
9	College Campus	15	13	7	7
10	College Campus	0	0	3	3
11	Personal Networks	0	0	3	3

Table 10: Participating Institutions

Prior to data collection, meetings were held between the researcher and key figures within each institution, including head teachers, deputy heads, departmental heads, or specialist teachers. This provided an opportunity for the researcher to explain the study's activities and inclusion criteria, and to establish rapport with each institution.

For the group with intellectual disabilities, all eligible participants were identified by their institutions and directly invited to participate. Teachers distributed information sheets to each candidate before data collection sessions were arranged to allow the students and their families time to consider the study and withdraw if so desired. Information about the study was distributed to students without intellectual disabilities during assemblies or in class by either the researcher or a teacher. Sign-up sheets were then circulated to allow volunteers

to 'opt in' to the study. Data collection sessions were arranged with the pupils directly according to their preferences.

7.5.1 Power Calculation

In 2014, the population of 16 to 20-year-olds with intellectual disabilities in Scotland was 2665 (The Scottish Consortium for Learning Disability, 2017). From this, it was calculated that the study required between 24 and 43 participants to have a margin of error between ±20 and ±15 (80-85% power). However, categorical data requires a minimum number of participants to appear in each cell of an item's contingency table, depending on the statistical test being used (A. Field, 2014). For this reason, it was decided that the sample size should be increased to fifty individuals per group.

7.5.2 Inclusion and Exclusion Criteria (Young Adults with intellectual disabilities)

Students were eligible for participation if they met the following criteria:

a. Aged 16 – 19 years old
b. Living at home
c. Currently at school or in college
d. IQ scores within the moderate to borderline intellectual disability range
e. Capable of providing their own consent to participate

Participants were recruited from four special schools, one mainstream school with a Support for Learning Department, and three college campuses. As in Study 1, the WASI-II was used to screen participants according to their IQ scores. Furthermore, demographic information was collected using participants' postcodes. Sixty-eight sessions were undertaken in total, of which 56 could be used. Despite the minimum age criterion being 16-years-old, one 15-year-old participant was included in the study once parental consent had been granted, as they were only one week away from their 16th birthday at the time of data collection. However, eleven participants were excluded for either failing to meet the eligibility criteria or failing to engage with the activities. Moreover, data from one participant was removed from the study at the request of her parents. Additional details about these exclusions can be found in Table 11.

Reason for Exclusion	Number of Participants Excluded
IQ Score in Normal Range	7
Too Young	1
Parental consent withdrawn	1
Insufficient comprehension	1
Poor behaviour during session	2
Total	**12**

Table 11: Reasons for exclusion from group with intellectual disabilities

7.5.3 Inclusion and Exclusion Criteria (Young Adults without Intellectual Disabilities)

The college students were selected from a range of courses, including social sciences, automotive engineering, computing, and childcare. The students were eligible for participation according to the following criteria:

a. Aged 16 – 19 years old

b. Living at home

c. Currently at school or in college

d. IQ scores within the normal range

e. No recorded disabilities

In total, 55 sessions were undertaken, 49 of which were included in the final study. Six participants were excluded for failing to meet the study's eligibility criteria, details of which can be found in Table 12. Importantly, two female participants were included in the typically developing group despite attaining low scores on the WASI-II IQ assessment tasks. This decision was taken for several reasons. First, the combination of test-stress and low confidence prevented the participants from engaging fully with the activities, resulting in scores that were lower than expected. Second, neither participant was registered as having an intellectual disability, and both had only ever experienced mainstream education. Finally, the participants' other academic achievements and life experiences indicated typical levels of cognitive and adaptive capacity.

Reason for Exclusion	Number of Participants Excluded
Very low IQ score	4
In full time employment	2
Total	**6**

Table 12: Reasons for exclusion from typically developing group

7.6 Procedure

7.6.1 Ethical Approval

The University of Glasgow's School of Medical, Veterinary, and Life Sciences Research Ethics Committee and Edinburgh Council granted permission for both the first and second studies simultaneously. However, additional ethical approval for Study 2 was sought from the education authorities in Midlothian, West Dunbartonshire, South Lanarkshire, and East Renfrewshire. Of these, permission to recruit in schools was granted by Midlothian Council and East Renfrewshire Council.

7.6.2 Session Procedure

The majority of the sessions were held in private spaces on the site of the institution from which the participants were recruited. However, a minority of participants were recruited through personal networks. In these cases, sessions were undertaken at a location of their choice, such as at their own home or the home of a friend also participating in the study. In these cases, The University of Glasgow's lone working guidelines were followed.

For the most part, the sessions were conducted one-to-one in a private location; however, four participants requested the presence of a teacher or carer in the room to provide communication and emotional support during the session. In these cases, accompanying adults sat separately to limit interference, and the participants were reminded that there would be no punitive repercussions from anything said in the interview. Prior to commencement, the nature of the activities was reiterated to the participants, as well as their rights to withhold information and withdraw at any time. Consent forms were signed at this stage; however, the sessions did not begin until the researcher was confident that the young adults were comfortable to proceed. The order of the activities was as follows:

1. Phase 1 – Autonomy Task

2. Demographic Questions

3. Matrix Reasoning Task

4. Phase 2 - Vignette

5. Vocabulary Comprehension Task

6. Phase 3 – Adult Identity Task

7. Debrief and Session close

Additional details about the specific procedures involved in each phase are presented at the beginning of each results chapter.

7.6.3 Subgroup Testing

Due to the niche nature of the target populations, participant recruitment occurred at both school and college level. As these represent different life-stages, the possibility that school and college students represent separate populations had to be investigated. Furthermore, previous studies have shown differences in the levels of self-determination displayed by male and female participants (Nota et al., 2007; Wehmeyer, 1996); therefore, the participants' responses were also sub-grouped by sex and tested independently.

Subgroup tests were performed separately for each phase using key items. Results are reported in Sections 8.3, 9.3, and 10.3 respectively.

7.6.4 Data Entry, Coding, and Analysis

Closed-question answers were entered into Excel for Mac 2011 and imported into SPSS v.22 for statistical analysis. Answers to the open questions were subject to an initial content analysis, from which codes were developed and applied. Following this, the majority of these data were analysed descriptively. Moreover, as a paired set, Questions 4 and 5 in the vignette were analysed using probability tree-diagrams.

The first question invited participants to say how they would feel if their Mum said: "*I'm not sure I'm happy with you watching that film.*" During the content analysis, it was found that the responses primarily fell into three of the emotional categories proposed by Shaver, Schwartz, Kirson, and O'Connor (1987): Anger (irritation, annoyance, frustration, rage), Sadness (disappointment, regret, unhappiness), and Surprise (confusion). Appropriate responses were therefore coded as 'angry', 'sad', and 'surprised'. However, two additional categories, Not Bothered and Other, were introduced to account for the remaining responses. In cases where participants' answers had the potential to overlap categories,

verbal cues and additional information picked up during the sessions were used. More forceful responses as determined by tone of voice and subsequent answers, for example, tended to be classified as 'angry', even if the participant also employed terms relating to sadness.

Question 2 (What would you say to your Mum?) responses were coded into seven categories: Negotiate, Challenge, Show hostility, Say Nothing, Pester, Mislead, and Don't Know. Question 3 asked participants what they would do in the situation. Three coding categories were created: Go to see the film anyway, Not go, Unsure/Depends. In some cases, participants were labelled as 'Go anyway' even if voicing some uncertainty. These decisions were taken if it was felt that the participants' uncertainty was based on the >0 possibility that a highly unlikely or catastrophic circumstance may stop them from going. Question 4 pertained to how they thought their Mum would feel if they went to the cinema without her blessing. Shaver et al.'s (1987) classifications of emotion were again used to create four categories: Anger, Sadness, Fear (worry, anxiety, nervousness), and Not Bothered. Illustrative quotes and frequencies for all codes can be found in Table 21.

For the Adult Identity task, participants' answers to the question "what would make you feel more grown-up?" were also coded for analysis. Initial coding resulted in 20 separate categories being created; however, these were collapsed into 16 categories after the second round of analysis. The frequency each category was mentioned was then tallied for the group with intellectual disabilities and the group without and used to generate percentages. Ambiguous and multi-faceted responses were placed into as many relevant categories as deemed appropriate. As such, the tallies do not equal the number of participants. Illustrative quotes and frequencies for all codes can be found in Table 26.

7.7 Summary

The purpose of this chapter was to provide an overview of the Study 2 development process. The chapter began with a discussion of the methodological considerations salient to researching young adults with and without intellectual disabilities. Overviews of Talking Mats and Vignettes were presented in Section 7.2, after which the development process for the study's three phases was explained. Results from the pilot studies were reported in Section 7.4. The chapter concluded with an overview of the study's recruitment strategy, procedure, and analysis plan. Results from each phase of the study, including the final measures and participant characteristics, are presented separately in Chapters 8 – 11.

Chapter 8   Results from Study 2.1 – Autonomy Task

8.1 Aims and Objectives

As outlined in Chapter 7, the first phase of the study was designed to address the following research questions:

1) Which transition activities do young adults with intellectual disabilities undertake in comparison to their typically developing peers, and what are the predominant obstacles to these activities?

2) How do young adults with intellectual disabilities feel about their levels of freedom and responsibility in comparison to their typically developing peers?

The following chapter will outline both the quantitative and qualitative findings from this phase. A description of the final task can be found in Section 8.2, after which the participant characteristics are presented. Results are presented in Sections 8.5 and 8.6, and followed by a brief discussion of the main findings. Please note that the following abbreviations will henceforth be used in all of the following results chapters to refer to the different groups:

Group with intellectual disabilities: ID
Group without intellectual disabilities: TD

8.2 Finalised Task

Two 'top-scale' picture cards were placed onto the table in front of the participant:

I do this a lot / I don't really do this

Participants were then given the following instruction:

"I'm going to give you some cards with activities on them. If the activity is something you do a lot, I want you to put it under here [indicates]. If the activity is something you haven't done, or you don't do it very often, it goes under here [indicates]. If you're not sure, let me know and we can discuss it."

In turn, twenty-one picture cards (16 everyday activities, 5 restricted activities) were handed to the participant to place under the appropriate category. A complete list of the items can be found in Table 13.

Everyday Activities		Restricted Activities	
1	Choose my clothes in the morning	4	Get a tattoo
2	Stay up as late as I want	12	Have had sex
3	Go around Edinburgh without an adult	14	Smoke
5	Cook my meals	17	Drink alcohol
6	Go shopping without an adult	19	Watch 18-rated films
7	Go out with someone (girlfriend/boyfriend)		
8	Go to other cities without an adult		
9	Stay at home on my own overnight		
10	Use Facebook / Twitter		
11	Use a bus or train on my own		
13	Look after my own money		
15	Work at a job/volunteering		
16	Make my own appointments		
18	Tidy my own room without being asked		
20	Do housework without being asked		
21	Stay out late with friends		

Table 13: Final list of items included in the Autonomy Task

In situations where the participant demonstrated uncertainty, prompt questions such as "have you ever done that?" and "how often do you do that?" were asked to facilitate discussion. Notes were made of any salient information elicited during this process. Once every card had been placed, all those under the "I do this a lot" category were removed from the table. The top-scale was then replaced with three new cards reading:

I'm not allowed / I don't want to / I just don't

Participants were then asked to repeat the task, this time putting cards into the category that explained why they did not engage in each activity:

Now we're going to talk a little bit about why you don't do these things. Is it because you're not allowed [indicates], because you don't want to [indicates], or because you just don't [indicates]. This last one if for things that you haven't had the chance to do yet, or you've never really thought about before. If you're not sure, let me know, and we can talk a bit about it, ok?

Once the task had been completed, activities placed under the 'don't want to' and 'just haven't' categories were removed from the table. The remaining 'not allowed to' activities were indicated and the following questions asked:

> *So you're not allowed to [*names activities*]. Can you think of anything else you're not allowed to do at home that we haven't discussed?*

Question: How bothered are you about not being able to do these things?

Three new cards were then placed onto the table:

Not at all bothered / A little bit bothered / Very bothered

After the participants gave their answer, the cards were replaced by another three cards:

Happy / Want a bit more / Want a bit less

Two final questions were then asked: "How do you feel about the amount of freedom you have at home to do what you want to do?" and "How do you feel about the amount of responsibility you have at home?" Additional information was given to participants who showed signed of struggling to understand, such as "responsibilities are things *you have to do,* like Mum has to pay the bills, and you *have to do* your homework." Participants were invited to pick one of the three fixed-choice options, but could also elaborate on their answers in more detail if so desired.

8.3 Subgroup Testing

Before the main analysis, subgroup tests were undertaken within both the ID and TD groups to identify whether sex or education-level affected group homogeneity. Using a key item (Everyday Activity Score), ID college students (Mdn = 9) were shown to have significantly higher scores on than the ID school pupils (Mdn = 7), U = 524.5, z = 2.2, p=.028. No other sub-groups were significantly different. Consequently, all between-group analyses for this task were undertaken separately for the school and college students.

8.4 Participant Characteristics

A full list of the participants' demographic details can be found in Table 14. All ID participants were aged between 15.9 and 19.7 years (M = 17.3, SD = 0.1). All TD participants were aged between 16.0 and 19.9 years (M=17.4, SD =1.01). An independent samples t-test showed that TD mean age was non-significantly older than the ID group M =.027, 95% CI [.344 to .399] $t(103) = .147$, $p = .424$. As IQ and neighbourhood deprivation scores were not normally distributed, Mann Whitney U tests were used to examine group differences. IQ scores were significantly different between the TD group (Mdn = 91) and ID group (Mdn = 56), U = 13.0, z = 8.7258, p >.01. Neighbourhood deprivation was non-significant between the TD (Mdn = 6) and ID (Mdn = 5) groups, U = 907, z = -.795, p = .427. Moreover, all participants were living at home at the time the data were collected.

Table 14: Participants' Demographic Characteristics for Autonomy Task (Study 2.1)

Sex	ID Total (56)	TD Total (49)	ID Sch (29)	TD Sch (30)	ID Col (27)	TD Col (19)
Male	30	26	15	15	15	11
Female	26	23	14	15	12	8
IQ score						
Mean	56	89.7	53.9	93.1	58.1	84.3
Median	56[a]	91[b]	53[a]	94[b]	57[a]	86[b]
Range	45-71	63*-116	45-71	84-116	45-69	63*-106
SD	7	10.15	7.52	8.45	5.59	10.46
Age						
Mean	17.3[a]	17.4[a]	16.9[a]	17.0[a]	17.8[a]	18.0[a]
Median	17.2	17.3	16.9	17.2	17.6	17.8
Range	15.9-19.7	16.0-19.9	15.9-17.7	16.0-18.3	16.5-19.7	16.0-19.9
SD	0.1	1.01	0.6	0.65	0.93	1.21
SIMD score						
Median (/10)	5[a]	6[a]	6[a]	6.5[a]	5[a]	6[a]
High Deprivation (1-2)	22%	16%	32%	17%	11%	16%
Moderate Deprivation (3-4)	20%	16%	5%	13%	36%	21%
Average (5-6)	24%	18%	23%	20%	26%	16%
Moderate Affluent (7-8)	15%	33%	9%	43%	21%	16%
High Affluent (9-10)	20%	16%	32%	7%	5%	31%
Autism Diagnosis (n)	16	0	7	0	9	0

For Age, IQ-Score, and SIMD score, group means/medians that are not statistically significantly different are represented by sharing the same superscript, [a]. Group means that are significantly different from one-another are represented by having differing superscripts, [a][b].

*Two female participants were included in the TD group despite having WASI-II scores in the Mild ID range. Justification can be found in Section 7.5.3.

8.5 Quantitative Results

8.5.1 Activity Levels

Participants were asked to sort 16 everyday activities and 5 age-restricted activities into two groups: 'I do this a lot' and 'I don't really do this'. As demonstrated in Table 15, cross-tabulation analyses found significant differences for 12/21 activities amongst the school pupil groups, all of which were undertaken by a higher proportion of TD participants. Post hoc odds ratios suggest that the TD school pupils were nearly 24 times more likely to go to other cities without an adult, ten times more likely not to have a bed-time, and six times more likely to drink alcohol.

| | School pupil | | | | |
Activities	ID (%)	TD (%)	Sig.	OR	95% CI
Choose my own clothes	86.2	100	.52		
Stay up late**	58.6	93.3	**.002**	9.88	1.97 - 49.6
Go around home city**	27.6	100	**.000**		
Cook	48.3	63.3	.244		
Go shopping without an adult**	58.6	90	**.006**	6.35	1.56 - 25.8
Be in a relationship	58.6	50	.506		
Go to other cities without an adult**	10.3	73.3	**.000**	23.83	5.63 - 101
Stay at home on my own overnight**	34.5	70	**.006**	4.43	1.49 - 13.2
Use Facebook / Twitter**	55.2	100	**.000**		
Use a bus or train on my own**	37.9	100	**.000**		
Look after my own money*	69.0	100	**.02**		
Work / volunteer**	20.7	56.7	**.005**	5.01	1.58 - 15.9
Make appointments**	10.3	63.3	**.000**	14.97	3.67 - 61.1
Tidy own room without being asked	72.4	70	.838		
Housework without being asked	62.1	60	.871		
Stay out late with friends*	51.7	80	**.022**	3.73	1.18 - 11.8
Tattoos	3.45	0	N/A		
Have sex	17.2	23.3	.198		
Smoke	20.7	6.67	.116		
Drink alcohol**	13.8	50	**.004**	6	1.67 - 21.5
Watch 18s	75.9	73.3	.824		

*<.05 **<.01

Table 15: Cross-tabulations for everyday and age-restricted activities (school pupils)

As shown in Table 16, within the college student group, significant differences were only found for 6/21 activities, all of which were again undertaken by more TD than ID participants. Moreover, of the activities that retained significant group differences, the odds ratios were less pronounced, with the TD group being just under four times more likely to choose their own bedtime and go to other cities without an adult, nine times more

likely to go around the city in which they live and look after money, twice as likely to use public transport without an adult, and 3.5 times more likely to drink alcohol.

Activities	College student ID (%)	TD (%)	Sig.	OR	95% CI
Choose my own clothes	96.3	100	1.0		
Stay up late*	44.4	73.7	**.049**	3.5	.981 - 12.5
Go around home city*	66.7	94.7	**.031**	9	1.03 - 78.6
Cook	44.4	47.4	.845		
Go shopping without an adult	59.3	84.2	.097		
Be in a relationship	59.3	36.8	.134		
Go to other cities without an adult*	22.2	52.6	**.033**	3.89	1.08 – 14.0
Stay at home on my own overnight	48.1	57.9	.515		
Use Facebook / Twitter	81.5	94.7	.377		
Use a bus or train on my own*	70.4	100	**.014**	.5	.364 - .687
Look after my own money*	66.7	94.7	**.031**	9	1.03 - 78.6
Work / volunteer	59.3	68.4	.526		
Make appointments	37.0	52.6	.293		
Tidy own room without being asked	66.7	52.6	.337		
Housework without being asked	63.0	52.6	.483		
Stay out late with friends	37.0	63.2	.081		
Tattoos	14.8	10.5	1		
Have sex	25.9	36.8	.528		
Smoke	18.5	15.8	1		
Drink alcohol*	37.0	68.4	**.047**	3.47	.994 - 12.1
Watch 18s	74.1	89.5	.435		

*<.05 **<.01

Table 16: Cross-tabulations for everyday and age-restricted activities (college students)

The numbers of everyday activities, age-restricted activities, and the combined everyday and restricted activities undertaken by each participant were totaled to create three aggregate scores. As shown in Tables 17 and 18, Mann-Whitney U tests indicated that both TD groups reportedly undertook significantly more everyday activities than the ID groups. Moreover, the college student TD group had significantly higher combined activity scores.

| | Median | | Mean Rank | | | | |
	ID	TD	ID	TD	U	Z	p
School							
Everyday**	7	12.5	17.74	41.85	79.5	-5.414	<.01
Restricted	1	1.5	26.54	30.2	339	-0.878	0.38
Combined	11	10	30.22	29.78	441.5	.099	.921

Table 17: Aggregate activity scores (school pupils)

| | Median | | Mean Rank | | | | |
	ID	TD	ID	TD	U	Z	p
College							
Everyday*	9	11	19.29	28.08	150.5	-2.231	.026
Restricted	1	2	20.77	26.05	189	-1.384	.166
Combined**	10	16	16.52	31.87	78.5	-3.888	<.01

*<.05 **<.01

Table 18: Aggregate activity scores (college students)

8.5.2 Obstacles to Activities

Likelihood ratios and post hoc tests were conducted to investigate the reasons preventing the groups from engaging in each activity. Amongst the school pupils, statistically significant differences were found in the proportion of ID participants who were 'Not allowed' cook (n = 7, 46.7%, versus n = 0, 0%), 'Not allowed' to have a relationship (n = 5, 41.7% versus n = 1, 6.67%), 'Not allowed' to get a job (n = 8, 34.8% versus n = 0, 0%), and 'Not allowed' to make their own appointments (n = 10, 38.5% versus n = 0, 0%). Moreover, a significantly higher proportion of the TD group stated that they 'Just don't' cook (n = 9, 81.8% versus n = 6, 40%), 'Just don't' go out with someone (n = 10, 66.7% versus n = 1, 8.33%), 'Just don't' work (n = 10, 76,9% versus n = 9, 31.1%), and 'Just don't' have sex (n = 10, 43.5% versus n = 2, 9.1%). Amongst the college students, the ID group were significantly more likely to 'Don't want to' cook (n = 7, 46.7% versus n = 0, 0%) and 'Don't want to' go to other cities without an adult (n = 8, 38.1% versus n=0, 0%), whereas a significantly higher proportion of the TD group 'Just don't' cook (n = 9, 90% versus n = 6, 40%). No other differences were significant.

Additional aggregate scores were created for the everyday, age-restricted, and combined activities labelled as 'Not allowed,' 'Don't want to,' and 'Just don't.' As shown in Table 19, the median number of everyday activities allocated to the 'Don't want to' group was significantly higher for both ID groups. Moreover, the ID school group classed

significantly more everyday and restricted activities as 'Not allowed' than the TD school pupils, while the TD group categorised more restricted activities as 'Just don't'.

			Median		Mean Rank		U	Z	Sig.
			ID	TD	ID	TD			
School pupil Groups	Not Allowed	Everyday**	3	0	40.59	19.77	742	4.911	**<.01**
		Restricted*	2	0	30.69	21.12	447	2.394	**0.017**
		Combined	2	3.5	29.81	30.18	429.5	-0.084	0.933
	Don't Want	Everyday*	1	0	34.64	25.52	569.5	2.131	**0.03**
		Restricted	1	2	22.58	29.56	236	-1.742	0.082
		Combined	3	2	31.21	28.83	470	0.536	0.592
	Just don't	Everyday	2	2	30.95	29.08	462.5	0.426	0.67
		Restricted*	0	1	25.59	34.27	307	-2.136	**0.033**
		Combined	3	2.5	29.64	30.35	424.5	-0.161	0.872
College student Groups	Not Allowed	Everyday	1	0	25.85	19.11	321	1.807	0.071
		Restricted	0	1	22.35	23.89	230	-0.423	0.627
		Combined	1	0	25.77	19.21	319	1.71	0.087
	Don't Want	Everyday**	2	0	27.25	17.18	357.5	2.627	**0.009**
		Restricted	1	1	25.65	19.37	316	1.642	0.101
		Combined	3	2	25.48	19.61	311.5	1.507	0.132
	Just Don't	Everyday	2	3	21.69	26.08	207.5	-1.106	0.269
		Restricted	0	0	21.31	26.61	197.5	-1.588	0.112
		Combined	2	4	21.56	26.26	204	-1.182	0.237

*<.05 **<.01

Table 19: Aggregate obstacles to activity scores

8.5.3 Attitudes towards Rules

Approximately half of the ID and TD school pupils felt 'Not at all bothered' by their parents' rules. Moreover, the ID group (mean rank = 30.29) and TD group (mean rank = 24.5) were not significantly different, U = 442, z = 1.505, p = .132. In the college student groups, only 10.6% of the TD participants felt either a bit or very bothered by their parents' rules, in comparison to 26.9% of the ID participants. In part, this was because 57.9% of the TD and 30.8% of the ID participants felt that there were no longer any rules to have to follow. Moreover, results from a Mann-Whitney U test suggest that attitudes towards parental rules were not significantly different between the ID (mean rank = 21.17) and TD (mean rank = 25.5) groups, U = 199.5, z = -1.505, p = .269.

To investigate whether the number of restrictions placed on the school pupils (Total Not Allowed Score) was related to how bothered they felt about rules, separate ordinal

regressions with proportional odds were run for each disability group. With every additional prohibited activity, the odds of members of the ID group feeling more bothered increased 1.3 times, 95% CI [1.023, 1.582], Wald χ^2 (1) = 4.686, p = .03. However, this association was not significant within the TD group.

8.5.4 Attitudes towards Freedom and Responsibility

Participants were asked how they felt about their current levels of responsibility and freedom to make their own choices at home. Subgroup testing revealed that all participants within each disability category could be treated as homogeneous for both items. No participants in either group wanted less freedom; however, 41.1% of the ID participants wanted additional freedom in comparison to only 12.2% of the TD participants. A Fishers Exact test and odds ratio confirmed that the ID group was five times more likely than the TD group to want more freedom CI [1.83, 13.7], *p* = .001. Separate binomial regressions were run to see if the number of parental restrictions placed on participants (Total 'Not Allowed' Score) was associated with their attitudes towards rules. However, none of the models were significant.

A quarter of the ID group wanted additional responsibility in comparison to only 8.2% of the TD group. However, the majority of members of both disability groups were happy with their current levels of responsibility (ID = 66.1%, TD = 81.6%), and the difference was not significant between the ID (Mdn = 2) and TD (Mdn = 2) participants, U = 1595.5, z = 1.854, *p* = .064. Separate ordinal regressions with proportional odds were run to see if the participants' everyday activity levels were associated with their attitudes towards responsibility, none of which were statistically significant.

8.6 Qualitative Findings

The participants' comments during the Autonomy task were predominantly used to justify their responses to specific items, or to provide context-specific information:

[I can't stay out] *Not after, like, 3am*
[On drinking] *They like to know what I'm drinking, but as long as I'm not smashed...* (ID, female, college)

I can't stay up late, I'm on meds (ID, male, college)

However, in several cases, the responses gave additional insight into the participants' hopes, fears, and self-efficacy beliefs:

I'll be getting the bus soon, just not yet (ID, female, school)

I'm not really ready for the work environment [ ] I'm not that good at, like, timing and scheduling, so mum's been doing that (TD, male, college)

[Going shopping] *I'd mess it up*. [Make appointments] *I'd screw it up* (ID, male, college)

The majority of the ID individuals who claimed to be 'not bothered' or "a bit bothered" about their parents' rules and restrictions saw themselves as benefitting from the rules in some capacity:

Rules are there for a reason (ID, male, school)

I respect the rules because they've turned me into a self-disciplined individual (ID, female, school)

They're just trying to look out for me (ID, female, college)

In contrast, several of the typically developing participants who chose 'not bothered' did so because they no longer considered themselves to be impacted by the rules. This was either because they had no interest in pursuing the restricted activities, the rules were never enforced, or because they no longer recognised their parents' authority:

I don't feel like I need to do any of them (TD, female, college)

They'd moan if I did some of these, but they're not proper rules (TD, male, school)

I'm not allowed a boyfriend, but I have one anyway [ ] I rebel a lot [ ] I guess I can just do a lot of it without them knowing (TD, female, college)

8.7 Discussion

8.7.1 Participation in Everyday and Restricted Activities

Both the school pupil and college student groups with intellectual disabilities undertook significantly fewer activities than the typically developing groups, including being less

likely to choose their own bedtimes, travel independently, drink alcohol, and go shopping and use money without adult support. Moreover, a significantly higher proportion of the school pupils with intellectual disabilities referred to themselves as 'not allowed' to cook, have relationships, work, or make their own appointments. In many ways, these findings are unsurprising, as young adults with intellectual disabilities are well documented to live more restricted and protected lives (Townsend, 2011).

However, the differences between the ID and TD participants were *less* pronounced in the college student groups than they were in the school pupil groups. The numbers of ID participants using social media, gaining work or voluntary experience, and staying out with friends, for example, increased between school and college age, closing the gap with the TD participants. This was particularly surprising as evidence suggests that the transition process is often delayed for young adults with intellectual disabilities (Hudson, 2006). Consequently, it was expected that the differences between the two groups would increase between the ages of 16 and 19. In contrast, our findings may suggest that, in some cases, the period encompassing the transition from school to college could coincide with a 'catch-up' period, during which young adults with intellectual disabilities start to undertake the sorts of activities experienced by younger people without disabilities.

To some extent, this is supported by the fact that the college students with intellectual disabilities had significantly higher everyday activity scores than their school pupil equivalents, and were 'not allowed' to undertake approximately the same number of activities as their typically developing peers. Moreover, it is also important to acknowledge that the transition period is increasingly likely to be delayed or elongated amongst typically developing young people (Billari, 2004). One possible consequence of this is that the biggest differences between young adults with and without intellectual disabilities may only become apparent towards the end of the 'emerging adult' period. However, it should also be acknowledged that the data were not collected longitudinally. It is therefore possible that these findings reflect specific differences within the samples, and are not representative of their respective populations. As a result, it is advised that these conclusions are treated with caution.

Another interesting finding was that, with regards to the aggregate scores, a significantly higher proportion of the ID participants referred to themselves as not wanting to engage in the activities. In particular, cooking and going to other cities without an adult appeared to have little appeal for the college students. Previous research within ID populations has

often focussed on active participation as a primary indicator of empowerment and self-determination. As explained in Chapter 2, the ARC self-determination scale measures behavioural autonomy according to the frequency with which individuals take advantage of opportunities for independent behaviour. Yet, it has been argued that discussions about personal liberty must give equal space to the rights to refuse, to withdraw, and even to behave irresponsibly (Bannerman, Sheldon, Sherman, & Harchik, 1990). Individuals who choose to isolate themselves, or to avoid responsibility, may by some definitions be considered equally as self-determined as those who embrace participation. This raises questions about which aspects of self-determination are in the best interest for young people, their families, and society in general.

It also highlights the importance of investigating attitudes towards specific activities and responsibilities. Going to other cities without an adult, for example, may not be considered as important to functional development as being capable of doing housework or going shopping. As a result, efforts to promote this as an outcome need only be prioritised for individuals who have this as a personal goal. In contrast, cooking is an important life-skill, training in which could reduce the burden of domestic labour on families and other carers. Consequently, individual preferences play an important role in the achievement of self-determination, but must be weighed against practical considerations and the needs of others.

8.7.2 Attitudes to rules, freedom, and responsibility

One of the most positive findings was that the majority of participants in all groups were happy with their current levels of freedom and responsibility. Interestingly, the number of ID participants who claimed to have low-level responsibilities was higher than expected, which may have contributed to their overall satisfaction. Room tidying and housework, for example, were in the top five most commonly undertaken activities for the school pupil ID group. Previous research has found that, while typically developing teenagers tend to be more involved in household tasks and chores, adolescents with Downs Syndrome and Cerebral Palsy still make significant contributions at home (Amaral, Drummond, Coster, & Mancini, 2014). The fact that the majority of the ID group claimed to take responsibility for tidying their own rooms and doing housework - equal to the number of TD participants - partly supports this other literature.

Similarly, looking after money featured in the top five activities undertaken by every group. The proportion of ID participants who claimed to manage their own money was higher than expected, as financial independence can be difficult to attain for members of this group (Williams, Abbot, Rodgers, Ward, & Watson, 2007). Importantly, when asked, the majority had only handled small amounts of pocket money and travel fares, rather than managing a bank account. This finding therefore corresponds with the typical level of financial responsibility held by individuals with intellectual disabilities in the UK (Williams et al., 2007). However, it is possible that even low levels of responsibility can make significant contributions to self-image. Findings from a small qualitative study found that housework can play a significant role in the development of adult identity for young adults with intellectual disabilities, particularly amongst women (Midjo & Aune, 2016). This may explain why 25% of the ID participants wanted even more responsibility.

Also of interest was how many of the school pupils claimed not to be bothered by their parents' rules and restrictions. This was surprising, as parental interference in personal matters is often met by resistance (Kakihara & Tilton-Weaver, 2009). However, possible explanations for this trend can be found in the qualitative comments collected during the task. Several of the ID participants, for example, described themselves as benefitting from their parents' rules, while several TD participants suggested that they no longer felt particularly affected by such restrictions. Importantly, these comments were only made by a few of the participants in each group, and therefore cannot be extrapolated to the wider samples, or to the populations that they represent. However, support for the suggestion that young adults with and without intellectual disabilities may have slightly different perspectives on parental interference can be found in the fact that higher numbers of prohibitions (Total 'Not Allowed' Score) were associated with feeling more bothered about rules in the ID school pupil group, but not in the TD group. Moreover, despite the majority of all groups feeling happy with their levels of freedom, the school pupil ID group was nevertheless five times more likely to want more freedom than their TD peers.

8.8 Key Findings

- In both age groups, the TD participants were more likely to say that they regularly undertake more transition activities than the ID participants. However, the difference between the ID and TD was much smaller at college student than at school pupil.

- The ID school students were significantly more likely to say that they are 'not allowed' to undertake transition activities. The ID college students were significantly more likely to say that they 'don't want' to undertake transition activities. The TD students were significantly more likely to say that they 'just don't' undertake transition activities.

- The majority of all the participants said that they were 'not bothered' about their parents' rules. However, the ID school pupils were slightly more likely to feel bothered by rules if they lived with more restrictions at home.

- Most of the participants were happy with their levels of freedom and responsibility, though the ID participants were five times more likely to want more freedom.

- Some of the ID participants viewed themselves as benefitting from their parents' rules, whereas some of the TD participants felt that the rules no longer affected them.

Chapter 9   Results from Study 2.2 – Vignette

9.1 Aims and Objectives

As suggested in Chapter 7, the vignette was designed to address the following research question:

1) How do social goals and outcome expectations impact the desire for autonomy in young adults with intellectual disabilities compared to their typically developing peers?

An overview of the finalised activity can be found in Section 9.2, after which the results of each question are given in turn. The chapter concludes with a brief discussion of the main findings.

9.2 Final Task

The vignette consisted of five questions. The first three were designed to tap into the participants' social goals; namely, how they would choose to react in the situation and why, while the final two questions concerned the expected outcome of defying their parent. In cases where the participant did not live with their mother, an important parental or authority figure was discussed instead. The task was introduced by telling participants that they would be asked to think about an imaginary situation. The following vignette was then presented:

[Picture 1] Your friends invite you to watch a film with them after school.

[Picture 2] The film looks really cool. [Picture 3] But, when you mention it to your Mum, she says "I'm not sure I'm happy with you watching that film"

Three open questions were then asked:

Question 1: How would you feel?

Question 2: What would you say to your mum?

Question 3: What would you do?

Participants were then asked to imagine defying their mum:

Imagine that you decide to go and see the film anyway

One further open, and one further closed question were then asked:

Question 4: How do you think your mum would feel?

Question 5: How much would this bother you?

Not at all / A little / A lot

9.3 Subgroup Testing

Likelihood ratios were used to assess group homogeneity with regards to educational-level and sex. As shown in Table 20, neither education level nor sex had significant effects on the groups for Questions 3, 4, and 5. Consequently, males and females, and school and college students were treated as a single population for these questions. However, ID females and ID males scored significantly different results ($p = .035$) for question 1; therefore, the analysis of this question was undertaken separately for boys and girls. Similarly, ID school pupils and ID college students gave significantly different responses to question 2 ($p = .01$); and were therefore treated as distinct populations for the analysis of this question.

	ID school x college	TD school x college	ID girl x ID boy	TD girl x TD boy
Q1	0.895	0.065	**0.035***	0.847
Q2	**0.01***	0.642	0.167	0.121
Q3	0.883	0.583	0.138	0.346
Q4	0.328	0.957	0.477	0.188
Q5	0.234	0.141	0.214	0.624

*<.05 **<.01

Table 20: Subgroup testing for Vignette

9.4 Participant Characteristics

The same participants were used in all three phases of Study 2. As such, the participant characteristics can be found in Section 8.4.

9.5 Results

As explained in Chapter 7, answers to the open questions were subject to a content analysis, from which codes were developed and named according to the emotion-categorisation system proposed by Shaver et al. (1987). Codes and illustrative quotes can be found in Table 21. Reliability checks were carried out for each open question with a

			ID	TD	Quote
Q1** How would you feel?	Anger	'Annoyed', 'mad', 'frustrated'	M 14 F 9	M 13 F 14	*There's a very bad... Can I say a bad word? Pissed. I'd be really pissed. ID, Male, Col.*
	Sadness	'Disappointed', 'sad', 'bad', let down'	M 5 F 4	M 4 F 4	*Disappointed and sad, 'cos I couldn't go, but she knows what's best. TD, Male, Sch.*
	Surprise	'Confused'	M 5 F 1	M 4 F 3	*Surprised, seeing as I'm 18. I'd laugh. TD, Male, Col.*
	Not Bothered	'Meh', 'nothing' 'not fussed'	M 2 F 10*	M 2 F 1*	*I'd be alright, like, not bothered. ID, Female, Col.*
	Other	Misc.	M 6 F 4	M 4 F 3	*Apprehensive, it shouldn't be a problem now. TD, Male, Col.*
Q2** What would you say?	Negotiate	Reason with, persuade	4	5	*I'm old enough and I'll keep in contact ID, Female, Sch.*
	Challenge	Question authority, demand justification	7	18	*Erm, excuse me? I feel comfortable, so you should to. TD, Female, Sch.*
	Become Hostile	Curse, storm off, put down	6	3	*Shut up! TD, Male, Sch. 'Fuck off' type thing ID, Male, Sch.*
	Say nothing	'Okay', 'No fuss',	3	1	*I'm not really that bothered ID, Male, Col.*
	Pester	Keep asking, beg	1	1	*Pleeease!!! ID, Female, Col.*
	Mislead	Going anyway,	1	2	*Say I won't watch it, but I would TD, Male, Sch.*
	DK	'Don't know'	7	0	
Q3 What would you do?	Go anyway		21	29	*Go anyway, unless I wasn't interested in the film. TD, Female, Sch.*
	Not go		33	19	*I wouldn't go, but I wouldn't speak to her. I'd do what I could to annoy her. TD, Male, Sch.*
	Depends		2	1	*Persuade her, though I'm not sure if I'd go or not. But I don't lie - I'd never lie. ID, Male, Col.*
Q4 Maternal Reaction	Anger	'Annoyed', 'mad', 'frustrated'	25	20	*Not happy with me OR my friends and their parents. ID, Male, Sch.*
	Sadness	'Disappointed', 'betrayed', 'hurt', 'sad'	15	19	*Disappointed. I don't know, I feel like I disappoint her a lot, so the same as usual. That's really bad, actually, maybe she feels horrible about it, but I never really think about that. TD, Female, Col.*
	Fear	'Worried', 'nervous', 'anxious'	7	2	*Pretty worried, and a wee bit unsure about my friends and that. ID, Male, Col.*
	Not Bothered	'Not fussed', 'okay', 'fine'	9	8	*Not be that bothered, she'd be meh. ID, Male, Sch.*

**<.05, *Significant with Bonferroni adjusted alpha

Table 21: Coding and Illustrative Quotes for Responses to Vignette

departmental colleague using Cohen's Kappa to measure inter-rater reliability (1960). Across the four questions, 19 categories were identified, and using the guideline provided by Landis and Koch (1977), one had moderate agreement (0.41 - 0.6), one had substantial agreement (0.61 - 0.8), and 17 had almost perfect agreement (0.81 – 1).

9.5.1 Social Goals: Question 1 (How would you feel?)

Two likelihood ratios were calculated to investigate whether the proportions of responses chosen by the ID and TD participants were significantly different for Question 1. All participants were involved in the analyses; however, the tests were carried out separately for males and females.

No significant difference was found between the ID and TD boys, χ^2 (4) = .117, p = .998 answers to Question 1, and post hoc analyses using Bonferroni adjusted pairwise Fishers Exact tests found no significant differences for Anger (p = 1.0), Sadness (p = 1.0), Surprise (p = 1.0), Not Bothered (p = 1.0), or Other (p = 1.0). However, the proportions for ID girls and TD girls were significantly different χ^2 (4) = 10.845, p = .028. Moreover, post hoc pairwise comparisons using Bonferroni adjusted Z-tests showed that the proportion of ID girls responding with 'not bothered' was statistically significantly higher (n = 10, 38.5% versus n = 1, 4.3%), p <.01. However, none of the other pairwise comparisons were significant.

9.5.2 Social Goals: Question 2 (What would you say?)

A third likelihood ratio was calculated to investigate whether the proportions of responses chosen by the ID and TD participants were significantly different for Question 2. In response to the initial subtest findings, data from school and college students were analysed separately. The ID and TD school groups were significantly different χ^2 (6) = 17.214, p = .009. Furthermore, Bonferroni-adjusted post hoc analysis revealed that the proportion of TD participants choosing to challenge their parents was significantly higher (n = 18, 60.0% versus n = 7, 24.1%), p = <.00714. Amongst the college student students, the proportion of TD participants opting to challenge their Mums did not have significance using a Bonferroni-adjusted alpha (p = .025). However, in response to these findings, answers coded as 'negotiate' and 'challenge' were recoded as 'adaptive responses', while 'become hostile' and 'say nothing' were combined into 'maladaptive responses.' An additional fishers exact test was run between the disability groups, and found that there

was a borderline possibility that TD participants were 4.14 times more likely to respond adaptively than the ID participants ($p = .008$). However, despite representing an alternative hypothesis, this finding nevertheless relied upon conditional knowledge and multiple comparisons, and should therefore be treated with caution.

9.5.3 Social Goals: Question 3 (What would you do?)

A further likelihood ratio was calculated to investigate whether the proportions of responses chosen by the ID and TD participants were significantly different for Question 3. As the initial subtests found no significant differences between each of the ID and TD subgroups, data from all of the participants were involved in the analysis. However, no significant group difference was found for Question 3 $\chi^2(2) = 4.974$, $p = .083$, and all pairwise comparisons were non-significant ($p > .03$).

9.5.4 Outcome Expectations (Q4 and Q5)

Data from all participants were involved in the analysis of Questions 4 and 5. Using a likelihood ratio, group differences for answers to Question 4 (How would your mum feel if you went anyway) were non-significant, $\chi^2(3) = 3.562$, $p = .313$, as were all of the post hoc Fishers Exact Test pairwise comparisons ($p > 0.1$). For Question 5 (How much would her reaction bother you?), the categories 'a bit bothered' and 'very bothered' were collapsed into a single category, 'bothered', after it became clear from cues and comments during the data collection process that these categories were being used interchangeably by the participants. To explore how bothered the participants felt about angering, upsetting, or worrying their respective Mums, a Fishers Exact test was run, and an Odds Ratio calculated. Forty members of the ID group (72.7%) and 40 members of the TD group (81.6%) expected to feel bothered by their Mum's reaction, a non-significant difference in proportions ($p = .353$).

However, as the results from Question 5 were paired with Question 4, probability tree diagrams were used to assess the significance of each expected maternal reaction. For this process, only participants who had predicted a negative reaction were included. Probabilities were calculated by finding the percentage of participants who answered each combination of responses i.e. 7 out of 88 participants chose both 'angry reaction' and 'feeling not bothered', thus the probability = 7/88 = .0795. As can be seen in Table 22, participants in both groups were much more likely to feel bothered than not bothered at the

prospect of angering, upsetting, or worrying their mums. The probability of predicting an angry reaction and being bothered by it was approximately equal for both the ID group (44.7% probability) and the TD group (41.5% probability), as was the probability of *not* being bothered by it (8.5% and 7.3% respectively). However, the likelihood of members of the TD group predicting a sad reaction and being bothered by it was 1.6 times higher than the ID group (43.9% vs. 27.7% probability). Moreover, while very few participants in either group predicted a worried reaction, of those who did, only members of the ID group claimed not to be bothered by this.

	Combined Group N = 88		ID Participants N = 47		TD Participants N = 41	
	Not Bothered	Bothered	Not Bothered	Bothered	Not Bothered	Bothered
Anger	.0795	.432	.085	.447	.073	.415
Sad	.0341	.352	.043	.277	.024	.439
Fear	.0227	.0795	.043	.106	0	.049

Table 22: Values associated with expected maternal reaction when disobeying her

9.5.5 The relationship between outcome expectations and social goals

A binomial logistic regression was run to see if expected maternal reaction was associated with whether the participants would go to the cinema or not. For this analysis, participants labelled as 'unsure' were removed. The model was statistically significant $\chi^2(3) = 7.919$, $p = .048$, but only explained 10% (Nagelkerke R^2) of the variance for 'going anyway.' It correctly classified 60.8% of cases, sensitivity was 34.0%, specificity was 86.5%, the positive predictive value was 70.83%, and the negative predictive value was 57.5%. Participants who expected their mums to worry were 9.21 times more likely to say that they would go to the cinema anyway than participants who expected an angry reaction, a significant effect Wald $\chi^2(1) = 399.0$, $p = .046$. No other variables were significant.

9.6 Discussion

9.6.1 Social Goals

One of the main findings was that 37.5% of the ID group suggested that they would defy their mum to see the film. While not as high as the TD participants (59.2%), the group difference was not statistically significant. This result was surprising, as previous research has found that young adults with intellectual disabilities may be less inclined to act without

parental support (Pownall, 2010). However, as suggested in Chapter 7.2.2, the hypothetical nature of vignettes can lead participants to provide 'riskier' answers that do not reflect their actual behavioural tendencies (McKeganey, 1995). Furthermore, despite efforts to reduce bias in the study design, it is possible that the previous discussions about autonomy and freedom served to prime participants to provide overly 'independent-sounding' responses. Consequently, this finding must be treated with caution.

It is also worth noting that a higher proportion of our TD participants suggested that they would attempt to negotiate or challenge their Mum's decision - assertive responses - while a greater number of the ID participants exhibited hostile/aggressive, or passive responses. Previous findings have found that individuals with intellectual disabilities more commonly exhibit passivity and aggression than other populations (Crocker et al., 2006; van Nieuwenhuijzen, Orobio de Castro, Wijnroks, Vermeer, & Matthys, 2004). Furthermore, both communication styles are associated with feelings of disempowerment (Baumrind, 1966). As some young adults with intellectual disabilities have been shown to exhibit poorer frustration tolerance (Brown, Brown, & Dibiasio, 2013) and may be more likely to live restricted lives, the possibility that these behaviours may be more prevalent amongst ID populations should be considered (Crocker et al., 2006; Linn, Goodman, & Lender, 2000).

Yet, it is essential to acknowledge that the markers of aggression and passivity found in this study were infrequent, and may not represent the true behavioural tendencies of the participants. Moreover, the statistical significance of these findings should be read very cautiously, as multiple comparisons increase the risk of Type 1 error (A. Field, 2014). As a result, this finding in particular ought to be interpreted with an appropriate level of scepticism.

9.6.2 Outcome Expectations

One of the main findings was that far more participants claimed to feel 'bothered' than 'not bothered' at the prospect of angering, upsetting, or worrying their mums, and that there was no significant difference between the ID and TD groups. This chimes with findings from the interview studies that young people both with and without disabilities wish to protect their parents from unnecessary harm. However, the probability of participants feeling bothered about causing their mum to feel sad or disappointed was 1.6 times higher for TD participants than for ID participants. Moreover, only ID participants claimed not to

feel bothered about causing their mums to worry. This was particularly surprising, as previous studies have found that young people with intellectual disabilities are more likely to worry about their parents' wellbeing (Forte et al., 2011), and to care about their parents' opinions (Pownall, 2010; Whitaker & Hughes, 2003).

It is also worth noting that results from the logistic regression suggest that participants who predicted a 'worried' reaction appeared to be 9.21 times more likely to say that they would go to the cinema than those who predicted an 'angry' reaction. One possible explanation for this finding concerns the domain-specificity of attitudes towards parental authority. Particularly for older individuals, watching films is generally considered to be a low-risk activity. Subsequently, it is possible that these participants viewed their mum's hypothetical worries as unjustified, overprotective, and inappropriate. Meanwhile, participants who predicted an 'angry' reaction might have been more concerned with potential punitive repercussions, and less likely to want to go as a result. However, there is insufficient data to draw such conclusions with any confidence.

9.7 Key Findings

- The ID and TD participants did not differ with regards to the types of emotions they expected to feel if their Mum said, "I'm not sure I'm happy with you seeing that film."

- The TD participants were significantly more likely to respond adaptively (attempting to negotiate or challenging her) than the ID participants, more of whom suggested that they would become hostile or respond passively.

- Both groups were equally likely to say that they would go to see the film anyway.

- In general, the participants were equally likely to feel bothered about angering, worrying, or upsetting their Mum. However, more of the ID participants said that they would not be bothered if they upset or worried their Mum.

- Participants who expected their Mum to worry were much more likely to go to see the film anyway than those who predicted an angry reaction.

Chapter 10   Results from Study 2.3 – Adult Identity Task

10.1 Aims and Objectives

The third phase was intended to answer the penultimate research question:

2) How do young adults with intellectual disabilities conceptualise adulthood in comparison to their typically developing peers, and how do these conceptualisations relate to their subjective adult identity?

An overview of the final task is presented in Section 10.2, followed by details from the subgroup tests and the participant characteristics. The quantitative results and qualitative findings are reported in Sections 10.5 and 10.6 respectively, after which the main findings are briefly discussed in Section 10.7.

10.2 Final Task

Participants were introduced to the final task with the following instruction:

Everyone has a slightly different idea about what adulthood means, and I want to know what it means to you. I'm going to give you some descriptions, and I want you to pick the one that you think is the best way to describe what an adult is, ok? There are no right or wrong answers. Once we're done, I'll let you make any swaps you want to make. You can only pick one card each time.

Three cards were placed on the table in front of the participant: one psychosocial characteristic, one life-stage marker, and one unrealistic expectation. A full list of the final cards can be found in Table 23. Each card was introduced with the phrase "an adult is someone who…" As there were a total of 18 cards, this process was undertaken six times.

Psychosocial Characteristics	Life-stage Markers	Unrealistic Expectations
Takes care of other people	Gets married	Does whatever they want all the time
Owns up to their mistakes	Moves out of their parents house	Is really rich
Doesn't give up when things get hard	Gets a job	Has no worries
Makes important decisions	Leaves school	Never gets anything wrong

Plans for the future	Has children	Is always happy
Stands up for themselves	Is over the age of 16	Doesn't have to follow any rules

Table 23: Adult Criteria options for the Adult Identity Task

Once the six rounds had been completed, participants were invited to swap any cards in their selection. They were then asked to pick out every card from their selection that described themselves. Prompts regarding known answers, such as "have you got married?" were given when the participants failed to understand the instructions.

Two final questions were asked before the session's conclusion and debrief:

Question 1: Would you call yourself a child, and adult, or a mix?

Question 2: What would make you feel more like an adult?

10.3 Subgroup Testing

As in Chapters 8 and 9, subgroup testing was undertaken to ensure that sex and education-level did not affect the homogeneity of the ID and TD groups. As can be seen from Table 24, all groups could be considered homogenous.

	# Cells <5	Test	Sig.
ID school X college	0	X^2	0.177
TD school x college	3	Likelihood Ratio	0.607
ID boy x ID girl	0	X^2	0.297
TD boy x TD girl	2	Likelihood Ratio	0.315

Table 24: Subgroup cross-tabulations for adult identity task

10.4 Phase 3 Participant Characteristics

The same participants were used in all three phases of Study 2. As such, the participant characteristics can be found in Section 8.4.

10.5 Quantitative Results

10.5.1 Which criteria for adulthood were chosen?

To determine which specific criteria were more or less likely to be chosen by the participants, separate contingency tables for each item were created. As can be seen in Table 25, a higher proportion of the TD than ID participants picked psychosocial characteristics, whereas the ID participants' choices were more evenly spread across the three groups. However, very few unrealistic expectations were chosen overall, and less than half of all participants considered getting married, having children, leaving school, and moving out as defining characteristics of adulthood.

Cross-tabulation analyses suggest that the TD group was 4.8 times more likely to pick "plans for the future", 2.6 times more likely to pick "makes important decisions", and 2.4 times more likely to pick 'doesn't give up', whereas the two most frequently chosen criteria amongst the ID group were 'takes care of other people' and 'gets a job'. Moreover, the ID participants were 13 times more likely to pick 'being happy'. No other criteria measured significant differences between the two groups.

	Item	ID (%)	TD (%)	Sig.	OR	95% CI
Psychosocial	Takes care of other people	58.9	67.3	.373	.696	.313 - 1.55
	Owns up to mistakes	51.8	63.3	.236	.624	.285 - 1.26
	Doesn't give up*	35.7	57.1	**.028**	.417	.19 - .915
	Makes important decisions*	57.1	77.6	**.027**	.386	.164 - 907
	Plans for future**	51.8	83.7	**.001**	.21	.083 - .527
	Stands up for themselves	41.1	42.9	.853	.929	.427 - 2.20
Life stage	Gets married	25	12.2	.097	2.39	.839 - 6.80
	Moves out	41.1	42.9	.502	1.31	.593 -2.9
	Gets job	57.1	40.8	.095	1.93	.89 - 4.21
	Leaves school	33.9	24.5	.29	1.58	.674 - 3.72
	Has children	28.6	22.4	.474	1.38	.569 - 3.35
	Is over 16	46.4	46.9	.958	0.98	.454 - 2.11
Unrealistic	Does whatever they want	14.3	20.4	.406	0.65	.234 - 1.81
	Is really rich	7.1	2.0	.369	3.69	.399 - 34.2
	Has no worries	8.9	0	.059	N/A	N/A
	Never gets anything wrong	8.9	0	.059	N/A	N/A
	Is always happy**	21.4	2.0	**.003**	13.1	1.63 - 105
	Doesn't have to follow any rules	10.7	2.0	.118	5.76	.668 - 49.6

*<.05 **<.01

Table 25: Cross-tabulations for each Adult Criterion

10.5.2 Self-Select Scores

Each participant received a self-select score of between 0 and 6 according to the number of their six selected criteria that they felt could be used to describe themselves. The average score for the TD group (M=3.9, SD=1.49) was higher than the ID group (M=3.16, SD=1.69). Moreover, results from a Mann-Whitney U test suggest that this difference is statistically significant (Mdn = 3) and the TD group (Mdn = 4), U = 1036.5, z = -2.202, p = 0.028.

10.5.3 Do disability or self-select score predict subjective adult identity?

Within-group testing suggested that school and college students could not be considered homogeneous, and were therefore tested separately. The majority of participants in all groups referred to themselves as a mix between an adult and a child, with 'adult' representing the second most popular category. Two cumulative odds ordinal logistic regressions with proportional odds were run to determine the effect of disability category and self-select score on adult status. Amongst school pupils, every additional adult criteria card the participants applied to themselves increased the odds of identifying as more of an adult by 1.7 times, 95% CI [1.051, 2.614], Wald $\chi2(1) = 4.721$, $p = .03$. However, disability group did not significantly contribute to the model, Wald $\chi2(1) = .035$, $p = .852$. When undertaken with the college students, neither variable made a significant contribution to the model.

10.5.4 Expected conditions for feeling more like an adult?

Participants were asked what would make them feel more like an adult. Answers were subject to a content analysis and coded. As can be seen in Table 26, the most frequently mentioned condition within the ID group concerned being treated more like an adult, which was raised by just under one-quarter of the participants. This category included factors such as being trusted with more freedom and independence and not being treated 'like a kid' by parents and other authority figures. The other most popular categories included getting married (16.1%), getting a job (16.1%), behaving more maturely (12.5%), moving out (12.5%), and having more responsibilities (12.5%). In contrast, 40.8% of the TD group mentioned moving out, followed by getting a job (28.6%), and leaving education (20.4%).

Category	Includes	Illustrative Quote	%	
			ID	**TD**
Being treated like an adult	Fewer rules, more freedom, more respect, more opportunity	*More ability to do stuff, making my own decisions [ ] I feel like we have the skills, but we don't have the chance to, like, do stuff.* (ID, male, college)	23.2	18.4
Behaving more maturely	Getting into less trouble, behaving sensibly and responsibly	*Make the right decisions, don't get yourself in a bother, don't annoy the cops* (ID, male, school)	12.5	4.1
Having more responsibilities	Self-sufficiency	*Ironing my own clothes* (TD, male, school)	12.5	16.3
Better peer relations		*If nobody started hassling me all the time* (ID, female, school)	3.6	0.0
Emotional changes		*Working on my self-confidence* (TD, female, school)	5.6	2.0
More life-experience	Achieving goals, knowing more	*More idea of what I want to be, so a clearer idea of the future* (TD, male, school)	1.8	16.3
Being older	Legal drinking	*Being able to drink legally, going out, turning 18* (TD, female, school)	1.8	2.0
Physical changes	Looking older	*Taller.* (TD, male, school)	0.0	4.1
Leaving education		*Going to college* (ID, male, school)	3.6	20.4
Moving out		*Living alone* (TD, female, school)	12.5	40.8
Getting a job		*Part time job somewhere?* (ID, male, college)	16.1	28.6
Getting married/partner		*Having a girlfriend or something* (TD, male, college)	16.1	4.1
Having kids/pets		*Own a house, kids, pets…* (ID, female, college)	1.8	2.0
Car ownership/driving		*Start driving - that gives you a lot of independence* (TD, female, school)	0.0	8.2
I already feel grown up	Nothing	*I already feel grown up - I've left school, got a job…* (TD, female, college)	3.6	4.1
Don't Know			19.6	4.1

Table 26: Anticipated conditions for feeling more like an adult

While statistical analyses could not be performed on the data, a notably larger proportion of the typically developing participants made reference to gaining additional life experience (16.3% vs. 1.8%), leaving education (20.4% vs. 3.6%), and moving out (40.8% vs. 12.5%). However, it is also important to acknowledge that approximately 1/5 members of the ID group were unable to respond to the question.

10.6 Qualitative Findings

Several members of both the TD and ID groups expressed competing intuitions about the nature of adulthood, and therefore found the adulthood criteria selection task to be too simplistic to engage with. In a couple of cases, participants could not decide if they should pick normative or descriptive characteristics:

"It depends if you want me to pick ones that adults are, or what they should be, 'cos not all adults are responsible, even though they probably should be, if you know what I mean?" (TD, male, school)

Other participants acknowledged that the items had neither a necessary nor a sufficient relationship to 'adulthood', as they saw it. Several noted that the psychosocial characteristics could be used to describe mature "children", while not all adults undertake the social-role changes that are legally exclusive to over 16-year olds. In some cases, this led the participants to question their own intuitions about what adulthood *could* mean:

"You can do a lot of these when you're younger. It depends what you consider an adult." (TD, female, school)

"You can be in school at 18, not all adults get a job, and some adults don't have kids, so… Mmmm. This is hard." (ID, male, college)

To get around these issues, several of the participants chose to use themselves as reference points, and therefore chose cards that they thought could be used to describe themselves. This was even the case for cards that may otherwise be considered irrelevant to adult identity:

[Picking the 'making my own decisions' card] *I'm starting to make my own decisions* (ID, female, college)

[Picking the 'always happy' card] *Aye, I'm always happy, I am. Always happy.* (ID, male, college)

Moreover, with regards to how grown-up the participants felt, a couple of the participants acknowledged that their self-perceived maturity fluctuates with the context.

It changes day by day (ID, female, school)

It depends on the situation (TD, female, school)

One participant, for example, felt very grown up, but could not refer to himself as an adult. In this case, the discrepancy was said to be based on the difference between maturity and experience:

I'm responsible; I just haven't had enough hardship in my life yet. I haven't had to make decisions yet… (TD, male, school)

However, for others, subjective adult identity appeared to be very strongly influenced by specific factors that the participant associated with maturity:

[Having picked "very grown-up" and "adult"] *I make teas and coffees for mum and dad!* (ID, female, school)

10.7 Discussion

10.7.1 Constructions of Adulthood

In line with previous findings (Arnett, 1997, 2001, 2016; Nelson & Barry, 2005), the typically developing participants did appear to prioritise individual-level psychosocial characteristics over life-stage markers as the most salient criteria for adulthood. However, the TD group was 4.8 times more likely to pick 'plans for the future,' 2.6 times more likely to choose 'makes important decisions,' and 2.4 times more likely to pick 'doesn't give up' than the ID group. As both decision-making and planning can be cognitively demanding tasks, parents of young adults with intellectual disabilities may be more likely to remain involved in, if not entirely responsible for, these aspects of their children's lives (Mitchell, 2012).

Moreover, though no statistically significant difference was found, the ID group's choices appeared to be more evenly spread across the three categories. Moreover, 'takes care of other people' was the most selected criterion in this group. It is therefore possible that young adults with intellectual disabilities utilise broader, or more personalised definitions of adulthood with a greater focus on interpersonal characteristics than might be found within the general population. However, it is also important to acknowledge that the

measure has not been validated, and that the results may have been affected by the manner in which the items were described and presented. Consequently, the data in this study is currently insufficient to draw conclusions either way. Further research into the adulthood criteria used by young adults with intellectual disabilities is therefore warranted.

10.7.2 Subjective Adult Identity

It is worth noting that the ID group had statistically significantly lower self-select scores than the TD group. To some extent, this finding is in line with expectations. A higher number of ID participants included life-stage markers such as 'marriage' and unrealistic expectations in their final selections; therefore, it is unsurprising that these individuals had lower self-select scores than those whose chosen criteria were more easily attainable. Moreover, as suggested in Section 10.7.1, young adults with intellectual disabilities may find a number of the psychosocial characteristics harder to develop (Khemka et al., 2009), or may have insufficient confidence to ascribe these qualities to themselves (Wehmeyer, 1994).

Within-group testing revealed that TD college students were significantly more likely to refer to themselves as 'adults' than their school pupil counterparts. In fact, the proportion of self-described 'adults' in the TD college group was twice that in the school group. However, adult status appeared to be stable between the ID groups. One possible explanation for this is that going to college is a more effective catalyst for adult status in typically developing young people. To some extent, this would be surprising, as young adults with intellectual disabilities and their families are thought to be particularly affected by the process of leaving school (Cheak-Zamora et al., 2015). However, the college courses attended by young adults with disabilities typically cover many of the same subject areas as at school, and may initially be conducted in a more 'school-like' manner. Therefore, the move from school to college is in some ways designed to reduce the emotional impact of transition.

Yet, it is also possible that a higher proportion of ID participants feel comfortable referring to themselves as 'adults' at a younger age. Amongst the school pupil groups, 39% of the ID participants felt adult in comparison to only 23% of the TD participants. The percentage increase between the TD school and TD college groups is therefore more akin to the school group 'catching up' to the baseline, rather than the college group 'pulling away.'

10.7.3 Expected conditions for feeling more like an adult

Amongst the TD group, the most frequently mentioned criteria included moving out, getting a job, and leaving education, while the most common criterion amongst the ID group included factors related to being treated more like an adult, such as being trusted more, and no longer being treated 'like a kid'. This may provide support for Shanahan et al.'s (2005) suggestion that certain criteria for adulthood influence subjective age identity even when the individual does not consider them necessary for adulthood. However, it may also reflect differences in the progress of transition for young adults with and without intellectual disabilities. By mid to late adolescence, most typically developing young people will have begun to experience many of the behavioural and interpersonal changes associated with adulthood. In contrast, young people with developmental delay may take longer to develop the cognitive and emotional maturity required to either act or be treated like an adult. To some extent, support in favour of this can be found in the results from the interviews and other activities, during which both ID groups reportedly undertook significantly fewer everyday transition activities than their TD peers.

This provides further evidence in favour of the suggestion that both subjective adult identity and criteria for adulthood must be understood within the specific life contexts of the individuals in question. However, it is important to acknowledge that approximately 20% of the ID participants unable to think of an answer to the question. Consequently, responses within this group were lower than ideal, and the findings should be treated with caution as a result.

10.8 Key Findings

- The TD participants were significantly more likely to choose 'makes important decisions,' 'plans for the future,' and, 'doesn't give up' than the ID participants.

- The ID participants were 13 times more likely to choose 'being happy,' and a higher proportion picked 'takes care of other people' and 'gets a job.'

- The TD participants were more likely to have achieved a greater number of their chosen adult criteria than the ID group.

- Achieving a greater number of one's chosen adult criteria was associated with feeling more adult, but only amongst the ID school pupils.

- When asked what would make them feel more adult, more of the ID participants mentioned being treated like an adult or learning to behave more maturely, whereas more of the TD participants referred to gaining life experience. However, 20% of the ID group was unable to answer the question.

Chapter 11   Results from the Parent Questionnaire

11.1 Aims and Objectives

The parent questionnaire was designed to investigate how comfortable parents felt with their offspring undertaking the everyday and restricted activities detailed in the Autonomy Task. Consequently, the aim was to use each parent's composite score as a marker of their support for autonomy – a predictor of transactional self-determination. Consequently, the research question underpinning this chapter is as follows:

3) How does parental support for autonomy relate to their young peoples' everyday activity levels, outcome expectancies, and how grown-up the young people feel?

A description of the final task is presented in Section 11.2, after which details of the participant characteristics are detailed. The results have been divided into quantitative (11.4.1) and qualitative (11.4.2) findings. The chapter concludes with a short discussion of the main findings.

11.2 Final Task

A copy of the parent questionnaire can be found in Appendix K. Each item was scored according to the following question:

On a scale of 1 - 4 (1 = Strongly Disagree, 4 = Strongly agree), how much do you agree with the following statement: *If they wanted to, I would allow my child to X*.

Parents were then asked to score the same everyday and restricted activities used in the Autonomy Task.

11.3 Participant Characteristics

Importantly, the following participant characteristics are for the young people whose parents returned the questionnaire. Details of the parents themselves, beyond their relationship to the young person, were not requested.

In total, 27 questionnaires were returned; however, only one questionnaire was returned from the ID school group compared to 8 from the TD school group. Consequently, only

data from the college students were included in the group-comparison analysis, as it was important to ensure that education level did not confound the results. However, data from all 27 questionnaires were included in the regression analyses, as these did not require that Parent Support for Autonomy scores were differentiated for the ID and TD participants.

Table 27: Participants' Demographic Characteristics for Parent Questionnaire

	ID Group (U-Test)	TD Group (U-Test)	ID Group (Regression)	TD Group (Regression)
No. School pupils	0	0	1	8
No College students	9	9	9	9
Total Number	9	9	10	17
Sex				
Male	4	7	5	11
Female	5	2	5	6
IQ scores				
Mean	58.3	89.6	59.6	90.7
Median	56[a]	89[b]	56.5[a]	91[b]
Range	53-69	79-106	53-71	77-106
SD	5.29	8.83	6.40	8.30
Age				
Mean	18.37[a]	18.62[a]	18.23[a]	17.86[a]
Median	18.58	18.83	18.54	17.83
Range	17.0-19.0	17.75-19.5	17.0-19.0	16.0-19.5
SD	.69	.67	0.7	1.09
SIMD Score				
Median (/10)	4[a]	9[b]	4[a]	7[b]
High Deprivation (1-2)	0.0%	0.0%	10.0%	5.88%
Moderate Deprivation (3-4)	62.5%	0.0%	50.0%	5.88%
Average (5-6)	12.5%	22.2%	10.0%	29.4%
Moderate Affluent (7-8)	25%	22.2%	30.0%	29.4%
High Affluent (9-10)	0.0%	55.6%	0.0%	29.4%
Responding Parent				
Mother	4	9	4	15
Father	2	0	3	1
Grandparent	1	0	1	0
Other / Not Specified	2	0	2	1

For Age, IQ-Score, and SIMD score, group means/medians that are not statistically significantly different are represented by sharing the same superscript, [a]. Group means that are significantly different are represented by having differing superscripts, [a][b].

As expected, IQ scores were significantly different between the two groups, while age was not. However, the participants' levels of deprivation were also significantly different; therefore, results from the analysis should be treated with caution.

11.4 Results

11.4.1 Parent Questionnaire Quantitative Results

Total Parent Support for Autonomy scores were calculated by totalling the parents' Likert responses. Higher scores therefore reflect higher parent support for autonomy. These scores were non-parametric, as established by visual inspection and Shapiro-Wilkes tests ($p < .05$). A Mann-Whitney U test was performed to see if results differed significantly between the parents of the ID and TD participants. Visual inspection of the resulting pyramid diagrams suggested that the groups were not similarly distributed. Results indicate that Parent Support for Autonomy scores for the ID group (mean rank = 6.33) were significantly lower than for the TD group (mean rank = 212.67), U = 12.0, z = -2.524, $p = .011$.

A scatterplot was generated to see if there was a linear relationship between Parent Support for Autonomy scores and the participants' Everyday Activity scores from the Autonomy task. As shown in Fig. 5, there was not a sufficiently linear relationship between the two variables to continue with the linear regression.
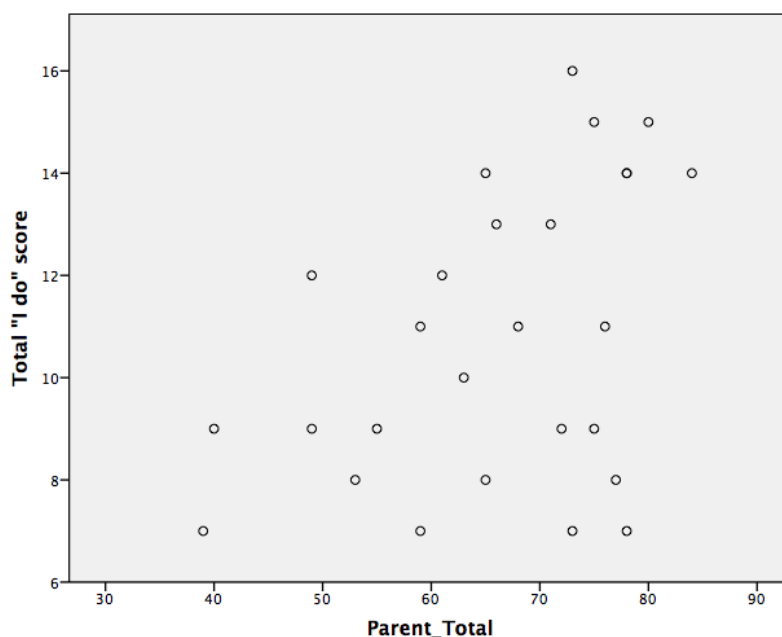

Figure 5: Scatterplot exhibiting the relationship between Everyday Activity score and Parent Support for Autonomy score.

To investigate if Parent Support for Autonomy score could be used to predict how bothered the participants felt about rules and restrictions, an ordinal logistic regression was carried out. However, while the assumption of proportional odds was met, $\chi^2(2) = 3.768$, $p = .152$, the model did not sufficiently predict the dependent variable, $\chi^2(1) = 73.777$, $p = .332$.

Two questions from the vignette were chosen for analysis in relation to Parent Support for Autonomy score: Question 3 (What would you do?) and Question 4 (How do you think your Mum would feel if you saw the film anyway?) These were chosen as it was felt that parental support for autonomy might influence the participants' social goals and outcome expectations. A binary logistic regression was conducted to see if parent score could predict whether or not the participants would go to the cinema. However, the model was not statistically significant, $\chi^2(1) = 3.313$, $p = .069$. A multinomial logistic regression was then performed for Question 4. While the deviance goodness of fit suggested that the model fit the observed data well $\chi^2(54) = 52.642$, $p = .527$, 71.3% of the cells had zero frequencies. Moreover, the model did not predict the dependent variable above the intercept-only model $\chi^2(3) = 57.037$, $p = .838$.

Finally, a cumulative-odds ordinal regression was attempted to see if parent scores were associated with how grown-up their young people felt (Adult Identity Task). The assumption of proportional odds was met, $\chi^2(1) = 2.458$, $p = .117$. However, the final model did not statistically significantly predict grown-up category above the intercept model $\chi^2(1) = .856$, $p = .355$.

11.4.2 Parent Questionnaire Qualitative Responses

Nine respondents (5 ID caregivers, 4 TD caregivers) chose to contextualise their scores by providing additional information at the end of the questionnaire. In a couple of cases, the comments were used to explain unusual or atypical scores unique to the young person's particular circumstances:

Where I have indicated 1, this is due to an on-going heart condition that would be potentially severely affected by participation in these activities (Mother, TD son, Score 76)

My child needs accompanied when going places as he has only recently moved back to Scotland after 7 years in England, and doesn't know the buses yet. He also takes melatonin, so staying up late isn't an option (Mother, ID son, Score 53)

For the most part, however, carers used the comments to express more general opinions relating to appropriate parenting, and in the majority of cases, did so to justify lower scores. Importantly, the carers of the ID girls were more likely to do so by drawing attention to their young person's inherent deficits, such as their vulnerability, financial ignorance, or general lack of capacity:

Needs prompting and direct supervision to carry out most tasks. Self-travel is a huge issue. No concepts and understanding of money. Socially very vulnerable. (Mother, ID daughter, Score 77)

The 2s are things she would not manage to do. (Foster parent, ID daughter, Score 72)

However, one carer acknowledged the possibility that she may be overly protective.

[Name] is unaware that she is vulnerable, and I might be too protective because of it. (Grandmother, ID granddaughter, Score 40)

In contrast, several of the mothers of boys both with and without intellectual disabilities explained their scores in terms of their personal beliefs about age-appropriate behaviour, rather than making direct reference to their sons' capacity:

Re alcohol - [Son] is allowed 1 - 2 cans of cider on holiday or Xmas day and will be 18 next month so can watch 18 related films (Mother, ID son, Score 59)

Mostly 4s now my son is 18 and could be living away from home. Many of these would NOT be a 4 when he was 17, and few when he was 16. The 2s reflect my views, which he currently shares. (Mother, TD son, Score 75)

The question regarding staying at home on their own overnight has been interpreted as for 1 night. I think that that would be okay, but a longer period would not. (Mother, TD son, Score 59).

11.5 Discussion

In line with expectations, the parents of TD participants had significantly higher Parent Support for Autonomy scores than the parents of ID participants. This finding is unsurprising, as parents of young adults with intellectual disabilities are well documented as often feeling unable to facilitate the level of independence that they otherwise may like to (Carter, Lane, Cooney, Weir, Moss, & MacHalicek, 2013; Pownall et al., 2011). As suggested in both the questionnaire responses and interviews, parental restrictions tend to

be enforced because of genuine concerns about competence. However, in some cases, authoritarian parenting philosophies or abstract fears may result in overprotection (Spokas & Heimberg, 2008).

Moreover, it is interesting to note that parents of both participants with and without intellectual disabilities chose to use the qualitative comments section of the parent questionnaire to justify lower, as opposed to higher scores. This may be explained by the fact that independence, autonomy, and personal responsibility are typically considered to be normative outcomes of the transition process. Parents are generally expected to undergo the process of relinquishing control as their offspring transition to adulthood. Failure to do so may be considered indicative of a range of maladaptive traits, such as the need to retain control, or an acute lack of trust (Skowron et al., 2009). In light of this, it is thus possible that some of the parents may have felt compelled to either justify or to defend lower scores that may be perceived as autonomy-limiting.

To some extent, it was surprising that Parent Support for Autonomy scores did not significantly predict any of the dependent variables analysed. However, it is important to acknowledge that small sample sizes increase the risk of a Type II error occurring. As only nine parents were included in each group, the possibility that significant differences were simply overlooked should not be ignored. Therefore, the findings from this phase of the study should be treated with great caution.

11.6 Key Findings

- The caregivers of young people with intellectual disabilities had much lower support for autonomy scores than the caregivers of young people without disabilities.

- Parent support for autonomy scores did not predict the young peoples' attitudes towards rules, responses to the vignette, or subjective adult identity. However, 27 cases results in a sample that is very small for regression, and the tests may have been underpowered as a result.

- Parents tended to use the open-response section of the questionnaire to justify lower scores rather than higher ones.

Chapter 12   Discussion

The following chapter outlines the main findings from the thesis and considers their implications for theory, policy, and practice. Furthermore, the strengths and limitations of the study are critically appraised, and avenues for further research presented.

12.1 Main Findings

Within the typically developing literature, young adults' attitudes towards growing up and adulthood have received considerable research interest. However, to date, there has been very little work undertaken to investigate how young adults with intellectual disabilities' think and feel about their own transition experiences. This is despite the fact that young people with intellectual disabilities typically encounter a wider variety of challenges throughout the transition process that may impact their ability to develop an adult identity. To address this gap in the research, a variety of both quantitative and qualitative methods were used to explore parents' and young peoples' beliefs about, experiences of, and attitudes towards the transition to adulthood. In total, over 100 participants were involved in the project.

Arguably, the most important finding from the project was that young adults with and without intellectual disabilities represent two incredibly diverse populations, particularly with regards to transition outcomes. Though some group trends were found across the studies, it is important to acknowledge that heterogeneity has impacted the number and nature of the conclusions that can be drawn from our findings. However, variety and contradiction can be thought of as inevitable parts of research into the human experience. The transition to adulthood is a multifaceted process involving a range of complicated emotional, cognitive, and social outcomes. Therefore, to help contextualise the complexities of the topics under investigation, the findings from each study have been synthesised into overarching themes. These will be discussed in reference to one another, as well as to the wider literature.

12.1.1 Opportunities for autonomy

In line with expectations, the typically developing participants mostly reported experiencing higher levels of everyday autonomy than the young adults with intellectual disabilities. Moreover, the parents of typically developing participants were significantly more likely to promote independent decision-making across the majority of items.

Consequently, the biggest obstacles to this group undertaking everyday and restricted activities appeared to be lack of opportunity and lack of interest, rather than parental restriction. In contrast, the school pupil group with intellectual disabilities were significantly more likely to claim to be 'not allowed' to have the same freedoms and responsibilities. This perspective was triangulated by the parent interviews and questionnaire responses, and corresponds with suggestions that young adults with intellectual disabilities experience fewer opportunities to take risks than their peers without disabilities (Almack et al., 2009; Seale et al., 2013).

While these findings may not be considered particularly unique, no other research regarding the *types* of activities regularly undertaken by young people in Scotland could be found from within the past few years. Importantly, the norms and experiences that characterise daily life can fluctuate between different geographical or cultural areas, and may evolve over relatively short periods of time. As such, rather than making assumptions based upon potentially out-dated or non-generalizable literature, we felt it important to collect these data directly.

However, one of the most interesting findings from the second study was that the differences between the participants with and without intellectual disabilities appeared to become less pronounced at college student than they were at school pupil. As suggested in Section 8.7.1, it is possible that the post-school period may represent an opportunity for some young people with intellectual disabilities to 'catch-up' with their typically developing peers before the next stage of social role changes typically begin in the mid to late 20s (Billari, 2004; ONS, 2014, 2017a). Unfortunately, no interviews were undertaken with college students to corroborate these findings, and very little additional research could be found that has compared the everyday experiences of school and college student young people in this manner. As a result, this finding should be considered preliminary, and therefore treated with caution.

12.1.2 Working towards independence

One of the most surprising findings from the studies was how similar the groups' attitudes towards independence and self-determination appeared to be, particularly in light of their differing levels of everyday autonomy. Regardless of disability status, the majority of participants represented themselves as working towards independence. To some extent, this corresponds with the literature. Autonomy, for example, has been posited as being a

"basic psychological need", and in combination with 'self-determination, is considered to be an important developmental outcome (Clark et al., 2004; Dyke et al., 2013; S. Field et al., 1998a; Kilcommons et al., 2012; Mill et al., 2010; Mitchell, 2012). Therefore, one would expect that achieving both the practical and emotional aspects of 'independence' would be important aspirations for young people transitioning to adulthood. Furthermore, as suggested by Midjo and Aune (2016), today's young adults with intellectual disabilities have been brought up in time that places great emphasis on equal rights and opportunities. Consequently, it may not be surprising that many young people with disabilities have grown to expect that they will lead 'ordinary' lives in the long run.

Broadly speaking, the main difference between the two groups appeared to concern the timeframe within which they expected to achieve this goal. For the typically developing young people, moving out represented both an inevitable and an increasingly imminent outcome. In contrast, the majority of young people with intellectual disabilities appeared to view independence as a long-term, somewhat vague notion – one that they hoped to achieve *at some point in the future*, but not anytime soon. The possibility that young adults with intellectual disabilities may transition over a more extended period has previously been posited (Hudson, 2006; Van Naarden Braun, Yeargin-Allsopp, & Lollar, 2006). Expectations for a slower transition also mirror the demographic trends observed within their respective populations, such that, of those individuals with intellectual disabilities who do 'launch,' the majority typically do so at an older age (Woodman, Mailick, & Anderson, 2014).

However, when combined with some of the other findings from across our studies, both groups of young peoples' attitudes towards, and expectations of self-determination and independence appear to be more complicated than certain previous models have suggested. Self-determination may not be the universal dispositional phenomenon it is often characterised to be, and is likely to be influenced by additional social, socio-cognitive and affective factors that are frequently neglected from the relevant literature. The following sections will discuss some of these complexities in greater detail.

12.1.3 The domain-specificity of parental interference

Were it the case that autonomy is a basic psychological need (Deci and Ryan, 2017), one may expect that any attempts to limit a young person's liberty would become a source of frustration and resent. In fact, much of the early research into parent-adolescent relations

treated the tension between young peoples' desire for autonomy and their parents' unilateral authority as the main reason behind the increased conflict during the teenage years (Selman, 1980). However, some of the most interesting findings from across our studies included that the participants' attitudes towards their parents' authority a) were mostly positive, b) appeared to differ between different domains, and c) appeared to differ between restrictions already in place and hypothetical new rules or restrictions. The majority of participants within both groups, for example, did not appear to feel particularly bothered by their parents' current rules. Moreover, while number of rules was weakly associated with negative affect amongst our school pupils with intellectual disabilities, this relationship was non-significant in all other groups.

Several factors were alluded to throughout the data collection process that may explain this trend. The school pupils with intellectual disabilities, for example, described being subjected to significantly more restrictions than the typically developing participants and the college students with intellectual disabilities. A surprising proportion of the participants in these other groups failed to name a single rule or restriction that they were subjected to at home. From this perspective, it is unsurprising that so many participants claimed to feel 'not bothered' about rules. Similarly, anecdotal data collected during the quantitative studies and interviews suggests that a number of the typically developing participants did not feel particularly beholden to their parents' rules, and were therefore not emotionally affected by them to the same extent.

Moreover, a surprising proportion of the participants had little interest in pursuing the 'restricted' activities. In some cases, said activities were considered anxiety-inducing or boring, and therefore held little interest anyway. In others, the participants appeared to share their parents' beliefs that pursuing the restricted activity would be irresponsible, or simply viewed themselves as benefitting from their parents' better judgement. In any case, the majority of participants both with and without intellectual disabilities appeared to accept their parents' authority where it was currently being applied.

However, both groups of young people were reportedly willing to resist their parents' attempts to interfere in matters that were considered 'out of bounds.' Personal domains were mostly considered to be 'red-lines' for members of both groups, evidenced within the interviews and by the fact that both were equally as likely to defy their Mums to see a film with their friends. Similarly, the young people suggested that they would resist the creation of new rules, as these were thought to indicate an unwarranted reduction in parental trust.

As discussed in Chapter 5, similar patterns have been recorded elsewhere. Youniss and Smollar (1985) found that, as they get older, young people are increasingly likely to view personal matters such as going to social events, sartorial choices, and friendship decisions as falling under their own jurisdiction. Similarly, Smetana (1988) found that, while both parents and adolescents view the legitimacy of parental jurisdiction as declining with age in relation to personal and multifaceted[5] matters, young people often reach this conclusion a few years before their parents do. Moreover, in the same study, both parents and young people were found to agree that parental jurisdiction should persist over moral[6] and conventional[7] matters. Consequently, the domain-specificity of our participants' attitudes towards their parents' rules, combined with generally positive attitudes towards parental authority, is in line with previous findings.

Nevertheless, there appeared to be nuanced differences between how the young people with and without intellectual disabilities perceived parental interference. Many of the typically developing participants, for example, appeared to assess the legitimacy of their parents' authority according to how persuasive they found the underlying justification. During the interviews, the majority of these participants described needing to be convinced that any interference in their lives was warranted, and several suggested that they would ignore any rules or restrictions that they considered to be unfounded. Similarly, during vignette, the TD group were significantly more likely to say that they would either challenge or negotiate with their Mum about seeing a film with friends, and would base their decision to go or not upon the perceived validity of her response. In contrast, the young people with intellectual disabilities appeared to be more concerned with outcomes alone, and were less likely to consider their parents' reasoning when evaluating the fairness of a situation. Moreover, during the vignette, a greater number of participants with intellectual disabilities suggested that they would either accept their Mum's position without question or would immediately become hostile.

One possible explanation for these group differences concerns the perceived balance of power within the parent-child relationship. As suggested, power typically equalises throughout the transition to adulthood (Erikson, 1950). Behavioural responses such as challenging a parent, attempting to negotiate a better outcome, and demanding justification

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[5] Domains that have a personal and a moral/conventional component, such as seeing friends rather than going to a family gathering, hanging out with a disapproved-of friend, and not tidying one's room

[6] Measured using items such as stealing money from parents and lying to parents

[7] Everyday domains, such as neglecting chores and failing to keep in contact with parents

can all be thought of as empowered stances, ones that are more likely to be adopted by individuals who view themselves as able to influence change (Spitzberg, Canary, & Cupach, 2009). However, young people with intellectual disabilities typically remain both practically and emotionally dependent upon their parents for longer, preserving the imbalance of power (Baron et al., 1999; Mitchell, 2012). Furthermore, members of this population may not always have the rhetorical abilities or confidence to successfully assert themselves during conflicts. Disempowerment is a known antecedent of frustration (Baumrind, 1966), increasing the likelihood of hostility. Moreover, repeated experiences of disempowerment and failure can result in the development of learned hopelessness (Haney, Banks, & Zimbardo, 1973; Zigler & Balla, 1982). Under such circumstances, young adults with intellectual disabilities may be more likely to assume that, regardless of the underlying reasoning, a parent's decision is irrevocable, and that there are only two available responses: unquestioning acceptance or aggression.

It is also possible that these group differences reflect the participants' divergent levels of comprehension or maturity. Evaluating another person's decisions, and using these judgements to inform one's own behaviour involves a variety of cognitively and emotionally complex processes that may be difficult for some individuals with intellectual impairments to implement. Moreover, emotional development is thought to be closely related to cognitive development (Pessoa, 2010). While there is surprisingly little research into the factors such as empathy and theory of mind in adults with intellectual disabilities, the possibility that cognitive empathy decreases with IQ score has been posited (Proctor & Beail, 2007). Furthermore, it is also important to recognise that several of our participants had autism, which is associated with impairments to both empathy and theory of mind (Leyfer et al., 2006). Therefore, it is possible that some of our participants – particularly those with autism - focussed their attention on the impact of restrictions on themselves because they were either less able or less inclined to empathise with their parents' perspectives.

If this were the case, emotional and cognitive immaturity may also be used to explain why the ID group was significantly more likely to say that they would not care if they hurt or worried their Mum during the film vignette. This finding was particularly surprising, as previous literature has found that young people with intellectual disabilities are much more concerned about their parents' wellbeing than individuals without disabilities (Forte et al., 2011; Pownall, 2010). However, as noted in Section 7.6, methodological weaknesses might explain this seemingly contradictory finding. Vignettes of the sort used in this study

require participants to imagine hypothetical scenarios, predict behaviours, and report their answers accurately and honestly. There are therefore a number of ways in which the validity and reliability of the data could have been compromised. Similarly, having already undertaken an activity concerned with independence and autonomy, the participants may have been primed to respond in ways that emphasised these qualities. Therefore, it is advised that this finding is treated with caution.

12.1.4 Wanting an easy life

Despite both groups presenting themselves as working towards independence, the majority of participants both with and without intellectual disabilities reported that they were happy with their current levels of freedom and responsibility. Moreover, when the typically developing participants and the college student members of the group with intellectual disabilities claimed to *not* regularly undertake everyday activities, they were more likely to say that they 'just don't' or 'don't want to', rather than being 'not allowed to'. Consequently, from the participants' perspectives, the biggest obstacles to independence appeared to be psychological and habitual, rather than environmental. For the participants with intellectual disabilities, this finding is consistent with the group's general tendency to want independence at some point, *just not right now*. Yet, prima facie, one may wish to question the sincerity of the typically developing group's commitment to greater independence and self-determination.

However, it is essential to acknowledge that both groups' attitudes towards growing up were complex. In some cases, the prospect of additional responsibility was met with a degree of anxiety. Some participants suggested that they prefer to share or delegate decision-making to those around them, for example. While the participants with intellectual disabilities typically did so with parents, the young adults without disabilities were more likely to utilise a range of sources, including immediate and extended family members, friends, and teachers.

Interestingly, the reasons underpinning this desire to share/delegate responsibility may have differed between the groups. For the young adults with intellectual disabilities, responsibility anxieties mostly appeared to stem from concrete concerns about their capacity to cope without support. In some cases, the young peoples' desire for independence was motivated by the recognition that their parents could not remain carers forever, rather than by the genuine desire for greater self-determination. As already

discussed, self-determination and independence are complex outcomes for individuals with intellectual disabilities. Conder, Mirfin, and Vietch (2015), for example, found that some of the women with intellectual disabilities involved in their study chose to forego their autonomy to maximise their overall happiness. It is therefore possible that some individuals consider autonomy to be incompatible with other positive outcomes.

For the young adults without disabilities, independence anxieties appeared to stem from the more general fear of responsibility and accountability. During the interviews, several of the female participants in particular referred to themselves as prone to rumination, particularly regarding decision-making. To some extent, this is unsurprising, as decision-making has been found to be one of the most significant sources of worry amongst Scottish teenagers (Forte et al., 2011). Moreover, the prospect of any change has the potential to induce feelings of anxiety and excitement simultaneously (Brooks, 2014; Burks & Martin, 1985). Therefore, it is equally possible that the participants' attitudes towards increased responsibility were genuinely mixed.

It is also important to acknowledge that members of both groups were honest about wanting their parents to retain responsibility for domestic and financial matters for the sake of having an 'easier life.' Some participants described such chores as being a natural part of the parental role,' and therefore felt no obligation to help. However, in the majority of cases, the participants appeared to view themselves as passive recipients of support - benignly benefitting from a longstanding household routine in which the division of labour was heavily weighted towards their parents and older siblings doing the work. While these participants did not appear to actively resist responsibility, they were nevertheless happy to maintain the status quo for as long as possible, as doing so prolonged their more comfortable lifestyle. While this attitude was most evident during the interviews, a similar trend may have been echoed in the number of participants during the Everyday Autonomy activity who claimed that they 'just don't' do chores, make their own appointments, or work.

Arguably, this could be said to mirror the 'freedom without responsibility' conceptualisation of Emerging Adulthood presented by Arnett (2001). However, emerging adults are typically thought to avoid the responsibilities associated with social role changes (marriage, independent living, employment etc.), rather than low-level domestic chores. As will be discussed in Section 12.3.2, it is possible that, in some cases, circumstantial changes are <u>necessary</u> catalysts for the adoption of additional responsibility. Either way,

while self-determination and independence may be considered important aspirations for young people transitioning to adulthood, these aspirations may be qualified by genuine concerns, as well as the desire for comfort and convenience.

12.1.5 Concern for parents

Despite many of the participants seemingly preferring to live 'an easier life', a notable proportion expressed guilt about not contributing more at home. This guilt appeared to stem from the possibility that they may be taking advantage of their parents' generosity, as well as the recognition that their parents already had enough responsibilities. One possible explanation for this concerns the social expectation of mutual reciprocity. Social exchange theories assume that reciprocity is governing norm of social relationships, and as such, debts are expected to be repaid (Molm & Cook, 1995). Within small social structures such as families, mutual dependence can be thought of as a way to build cohesion (R. M. Emerson, 1962), and is therefore an important social force. However, in parent-child relationships, there is often an acceptance that repayment will be delayed until the child has reached adulthood (Antonucci, 1990).

In these cases, reciprocity has been modelled along the lines of investment (care is reciprocated unconditionally and in proportion to what was given) and insurance ('repayment' is given on a needs basis only), as well as altruism and gratitude (Stark & Falk, 1998). In a longitudinal study on parent-child reciprocity, Silverstein and colleagues (2002) found evidence that different domains of care were likely to be reciprocated in different ways. Social support, for example, followed an 'investment' model, whereas practical and financial support more closely resembled the 'insurance' model. Importantly, this study investigated adult familial relationships - little research could be found on attitudes towards reciprocity amongst adolescents and young adults. Nevertheless, differing attitudes towards repayment obligations may account for why some of the participants felt emotionally beholden to their parents but did *not yet feel the need to* reciprocate their parents' practical and financial support.

It is also important to acknowledge that several of the typically developing participants described their parents as *wanting* to remain in the carer/protector role for as long as possible. In these cases, the participants justified their lack of contribution in the home as ways to protect their parents from the adverse effect of 'losing a child' sometimes associated with transitioning to adulthood. While the evidence suggests that parental

quality of life and wellbeing can improve when their children leave home (Dennerstein, Dudley, & Guthrie, 2002; Mazzuco, 2006; White & Edwards, 1990), the run-up to this point can be emotionally difficult for parents (Karp et al., 2004), and fears of the 'empty nest' are well established (Bart, 1971). Evidence also suggests that the leaving home period may be particularly difficult for parents from cultures with strong intergenerational ties (Mazzuco, 2006). It is therefore possible that some young people may even deliberately infantilise themselves to satisfy their parents' need to 'parent'. Yet, as will be explained in the following section, it is also possible that some of the participants' comments were motivated by social desirability. Consequently, while these findings are in line with expectations, it is nevertheless advised that they are treated with caution.

Interestingly, the desire to protect parents from harm was a reoccurring theme throughout the project. As suggested in the above example, many of the typically developing participants presented themselves as keen to protect their parents from experiencing unnecessary emotional harm during the transition process. Moreover, the TD group were significantly more likely than the ID group to feel bothered about upsetting their Mum in the film vignette. In contrast, the young people with intellectual disabilities were seemingly more concerned about their parents' physical health and mortality.

Importantly, there is insufficient data to conclude the reasons underpinning this finding; however, similar findings have been found elsewhere. In a study on adolescent worries, for example, Forte, Jahoda, and Dagnan (2011) found that Scottish young adults with intellectual disabilities were more worried about the deaths of the people they depended upon (parents, family etc.) whereas the young people without disabilities exhibited greater concern about their own mortality. Moreover, during the interviews, several of our participants with intellectual disabilities demonstrated high levels of risk-aversion safety-consciousness. There is some evidence that cognitive biases, such as fear, can be passed from parents to children (Remerswaal, Muris, & Huijding, 2016); therefore, it is possible that parent anxieties about the safety and security of their children may, on some level, end up becoming reciprocated.

It is also worth noting that, in Scotland, a higher proportion of individuals with intellectual disabilities live in single-parent families compared to the general population (Scottish Learning Disabilities Observatory, 2018b). There is some research to suggest that both parents and children view parent-child relationships within single-parent families as highly intense and exclusive (Nixon, Greene, & Hogan, 2012). Therefore, this finding may reflect

differences between individuals of different family compositions, rather than between young people with and without intellectual disabilities. There is currently insufficient data to conclude either way.

12.1.6 Social Desirability

It is important to acknowledge that social desirability may have influenced a number of the findings within this project. As suggested, social exchange theories assume that reciprocity is a dominant social norm. Consequently, while the guilt voiced by some participants may have been genuine, it is also possible that social expectations may have influenced how the participants chose to present themselves in these discussions. To some extent, the same may be said about the participants' responses about self-determination and autonomy. Both the participants with and without intellectual disabilities appeared to be cognisant of the social pressures to become independent and self-sufficient individuals. As suggested in Chapter 1, self-determination, independence, and self-sufficiency are generally considered to be normative outcomes of the transition process.

Moreover, over the past couple of decades, educational reforms in Scotland have placed increasing emphasis on developing the competencies required for self-determination (Government, 2006). Consequently, it is possible that social pressures and expectations may have compelled some of the participants to present themselves as keener for independence than they actually felt. For this reason, it is advised that all findings relating to independence and parental relations are interpreted with care.

12.1.7 Adult Identity

12.1.7.1 Definitions of Adulthood

In line with the literature (Arnett, 1997; Côté & Bynner, 2008; Nelson & Luster, 2016), both groups appeared to place responsibility and maturity at the heart of their criteria for adulthood. However, it is possible that the groups' definitions of 'responsibility' and 'maturity' had different foci. During the interviews, several of the young adults with intellectual disabilities appeared to define adulthood in terms of the fulfilment of familial responsibilities, such as being a *good* husband or wife and *looking after* children. Similarly, during the Adult Identity Task (Study 2.3), the most frequently chosen adulthood criterion within the ID group was 'takes care of other people'. It is also worth

noting is that several of the participants with intellectual disabilities appeared to equate 'maturity' with compliance. While this may indicate passivity, compliance can also be viewed as a form of social competence and a way to maintain familial cohesion. In combination, these findings may suggest that our participants with intellectual disabilities had a greater tendency to focus on *interpersonal* dimensions of maturity, and viewed 'responsibility' as a manifestation of the normative fulfilment of one's social/familial responsibilities.

While much of the literature has painted individuals with intellectual disabilities as passive recipients of care, suggestions have been made that the care dynamic should be viewed in more relational terms (Lloyd, 2003). Knox and Bigby (2007), for example, found that families including an adult with intellectual disabilities placed significant value on interconnectedness and interdependence, and considered contributions by all family members – including the individual with disabilities - to be critical to the cohesion and wellbeing of the family unit. Importantly, this was a qualitative study that utilised purposive sampling, and therefore cannot be considered representative of all such families. However, it is possible that young people who benefit from their parents' care for longer may be more likely to associate growing up with the adoption of caring roles and responsibilities - particularly if other markers of adulthood (i.e. independence) are seen as harder to attain.

In contrast, the typically developing interviewees appeared to place greater emphasis on self-sufficiency and causal agency. Similarly, in Autonomy Task, the TD group were significantly more likely to choose 'makes important decisions', 'plans for the future', and 'doesn't give up', all of which have a more individualistic focus. This echoes suggestions that the transition process has steadily become more 'individualised' for the majority of young people in the West (Wyn & Dwyer, 2002), with factors such as independence and self-sufficiency receiving the greatest focus (Bynner, 2005).

It is important to acknowledge that decision-making, planning, and resilience represent some of the more conceptually complex items in the activity. Therefore, it is possible that the participants with intellectual disabilities felt more comfortable choosing more concrete, less abstract criteria such as getting a job or getting married. An alternative explanation stems from the view offered by Kirkpatrick Johnson et al. (2007) that individuals conceptualise adulthood in a way that they consider to be both relevant and achievable to themselves. As demonstrated, many of our participants with intellectual disabilities viewed

independence and self-sufficiency as long-term, rather than current goals. Similarly, competencies such as independent decision-making and planning for the future can be challenging to develop for individuals whose cognitive capabilities are, by definition, limited. As the vast majority of these participants wished to attain an adult identity within the normative timeframe, it makes sense that interpersonal growth and development may take precedence over criteria for adulthood that may be harder to attain.

However, it is also worth noting that the group with intellectual disabilities picked a broader selection of criteria than their typically developing peers. Moreover, in some cases, the most salient criteria were esoteric and unique to the individuals in question. It is therefore also possible that attitudes towards adulthood are more heterogeneous in this group than in the typically developing population. Currently, there is insufficient data to draw conclusions either way. Nevertheless, our findings suggest that further research into how young adults with intellectual disabilities conceptualise adulthood is warranted.

12.1.7.2 Subjective Adult Identity

Both groups of young people were equally as likely to refer to themselves as an adult, and very few participants self-identified as children. This suggests that young adults with intellectual disabilities may be equally as likely to consider themselves 'on track', and to have appropriate age identities. Moreover, participants within both groups described the development of subjective adult identity as non-linear and context-dependent.

Yet, amongst the young adults with intellectual disabilities, feeling older appeared to rest upon the achievement of personally salient transition goals, which typically included an interpersonal element of some kind. 'Not being treated like a kid', for example, was a reoccurring theme within this group that included factors such as being trusted with responsibilities, receiving more privacy, and not feeling patronised. Learning to *behave* more maturely - by telling the truth and listening to authority figures - was also raised by several of the participants with intellectual disabilities.

In contrast, the typically developing participants suggested that their subjective adult identities were more influenced by life experience and context. A notable proportion of members of this group suggested that they felt most grown up when in an 'adult context' (i.e. at work), and felt unable to feel more grown up until they experience more of life's challenges - particularly those associated with independence, self-sufficiency, and social

role changes. Moreover, a significantly higher proportion of the college students without disabilities felt 'adult' compared to their school pupil peers. This finding may suggest that leaving school has a bigger impact on typically developing young peoples' subjective adult identity than it does on young people with intellectual disabilities.

One explanation for this difference could stem from differences in the groups' transition progress. Results from the first study suggest that the participants without disabilities considered themselves to be mature individuals, and had already begun the process of de-individuating from their parents. As a result, a number of the interpersonal criteria referenced by the ID group may already have been achieved by the TD participants. This might result in social role transitions becoming the most likely future contributors to subjective age identity. In contrast, several of the participants with intellectual disabilities appeared to occupy the social roles typically associated with pre-teens and younger teenagers. Opportunities to adopt even low levels of responsibility and to have more 'adult-like' interpersonal interactions may therefore have a comparatively high impact on subjective age identity in this population.

It is also important to acknowledge that 20% of the ID group was unable to provide answers to the question 'What would make you feel more grown up?' Moreover, cross-sectional methods are not ideal for investigating the catalysts of adult identity. Consequently, the findings from this study are provisional only, and any conclusions drawn should be treated with caution.

12.1.8 Obstacles to transition

The difficulties parents experience when trying to support young people with intellectual disabilities throughout the transition to adulthood are well recognised (Bhaumik et al., 2011; Docherty & Reid, 2009; Dyke et al., 2013). Findings from both the interviews and the questionnaire suggest that obstacles to a successful transition are numerous, and can include both environmental challenges and concerns about their young persons' competence and confidence. Particularly for parents of high school students, the transition to the post-school phase can be particularly daunting (Cheak-Zamora et al., 2015). In Scotland, college courses that cater to the academic support needs of young adults with mild intellectual disabilities often focus on basic employment skills. Young adults who wish to pursue courses in alternative or creative fields may consequently struggle to find suitable opportunities, even if the fields themselves do not demand high levels of cognitive

ability. For parents, infrastructural challenges such as limited opportunities and poor information communication can thus become a considerable source of stress and frustration, particularly when failure has the potential to knock their child's confidence and result in disappointment (Docherty & Reid, 2009).

An additional source of frustration was said to stem from the difficulty in accessing information about appropriate services, an issue frequently faced by parents of adolescent children with disabilities (Bhaumik et al., 2011; Heslop et al., 2002). During the interviews, all of the parents described having to spend considerable time researching charities, youth groups, and educational establishments to find suitable options for their children. While the participants' high schools were mostly praised for their commitment to supporting their students with additional support needs, the parents often felt that the schools lacked the experience and information to support families with this research process. Unsurprisingly, this issue appeared to be more acute in the mainstream schools where the provision of additional support was relatively limited. Several of the parents described encounters with school staff that highlighted a distinct lack of specialist knowledge. In some cases, this was said to lead to their children being inadvertently victimised and patronised by teachers and support staff.

However, the parents acknowledged that many of the obstacles to transition stemmed from their children's own behaviours and attitudes. As suggested, social transitions form a key part of the growing up process; however, three of the parents described their children as being insufficiently concerned about how their behaviours are likely to be perceived by the outside world. This was despite the fact that the young people were said to feel isolated from their peers.

Cognitive skills deficits may be associated with some of the biggest obstacles to transition. Handling money and taking responsibility for household management, for example, were viewed by some of the parents to be unrealistic goals for their young people to achieve over either the short or middle term. Moreover, several parents felt that their son or daughter could cope in less demanding or hazardous environments, but acknowledged that the world is becoming an increasingly complicated and dangerous place in which to operate. Similar concerns have been raised in the literature about the increasing numbers of societal barriers to participation for individuals with disabilities, particularly in regards to individuals with milder forms of intellectual disability (Oliver, 1996; Whitaker, 2013).

12.1.9 Parental attitudes towards facilitating greater autonomy

Results from both the interviews and the questionnaire suggest that the parents of young adults with intellectual disabilities were also cognisant of the social expectation to facilitate autonomy and independence. As reported elsewhere (Pilnick et al., 2010; Pownall et al., 2011), this can result in a 'catch-22', with parents feeling unable to give their young people the level of freedom that they may otherwise wish to. As suggested, genuine fears about their young people's capacity to recognise and respond to danger contributed significantly to this. For two of the interviewed parents, in particular, concerns were exacerbated by their children's inability to recognise their own limitations. However, other parents appeared to adopt stricter positions by default, either in response to unwarranted abstract fears or simply as the result of a more conservative parenting approach. As suggested in Section 6.6, the "need to be needed" can contribute to parents' acts of generativity. Moreover, results from Chapter 5 suggest that young adults without disabilities can be aware of this fact, and may even want to delay aspects of their own transition in part to appease their parents' desires to remain in the caregiver role.

In either case, parents of children with intellectual disabilities are often forced to acknowledge that they may never be able to transition fully beyond the parent role. In some cases, this can be a source of disappointment for parents (Docherty & Reid, 2009), and may even have the potential to lead to feelings of ambivalence towards their children (Fingerman, Cheng, Tighe, et al., 2012). However, trends suggest that parents of typically developing children continue to retain some parental responsibilities well into adulthood (Fingerman, 2000), indicating that the issue is not specific to families of individuals with disabilities. Moreover, while being 'off-schedule' has negative implications, it should also be acknowledged that the increased emotional interdependence between adult family members can have beneficial effects on health and wellbeing (S. Cohen & Janicki-Deverts, 2009).

Despite their concerns, the parents involved in the interviews were committed remaining optimistic about the future. This was particularly evident amongst those whose social support networks were most active. For parents of individuals with disabilities in particular, the provision of continued care can have a variety of positive outcomes for families (Knox & Bigby, 2007; Rapanaro et al., 2007). Therefore these findings very much correspond to the current literature.

12.2 Implications for Theory

12.2.1 Implications for self-determination research

To date, research on low levels of functional self-determination in young adults with intellectual disabilities has predominantly focussed on environmental barriers and skills deficits. However, as an inherently social behaviour, self-determined behaviour may manifest in response to the same self-reinforcing developmental processes described within Social Information Processing theory (Crick & Dodge, 1994). As explained in Chapter 2, social information processing theory suggests that individuals develop response patterns over time in response to the process of interpreting and encoding social cues, and forming social goals. As a result, individuals are only likely to exhibit self-determined behaviours when doing so is perceived as furthering the individual's social agenda. To some extent, our findings add to previous suggestions that young adults with and without intellectual disabilities can have priorities that compete with, or over-shadow, self-determination. Participants who did not feel a *need* to take on additional responsibility were much less likely to do so, for example.

Moreover, the compound effect of past failures may lead some young people with intellectual disabilities to doubt their own potential for causal agency, even when the environment appears to facilitate autonomy. While capacity is a crucial factor in discussions about self-determination, it is equally as important to acknowledge that young people are unlikely to exhibit self-determination if they do not want to (for fear or lack of interest), or do not feel compelled to. As it stands, young adults with intellectual disabilities are less likely to face the same social pressures and expectations that compel typically developing individuals to 'take the leap.' Greater research into these more complex socio-cognitive and emotional factors may, therefore, contribute to the potential efficacy of future self-determination interventions.

Self-determination is also often considered to be a universal dispositional trait. However, our findings highlight the domain-specificity of young peoples' attitudes towards autonomy and parental interference. For young adults with intellectual disabilities, in particular, it is important to acknowledge that not all 'everyday' activities are equally important with regards to functional independence. The potential consequences of not wanting to cook, for example, may be more significant to an individual's independence than going on holiday without adult supervision. Moreover, the psychological and social

barriers to activities are also likely to differ between different types of activities and outcomes. Consequently, separate strategies may be required to encourage young people to exhibit self-determined behaviour regarding activities they feel anxious about compared to those that they find boring or irrelevant.

12.2.2 Implications for adult identity research

With regards to the typically developing participants' constructions of adulthood, our findings corroborate with the majority of the recent literature undertaken in the USA and Europe (Arnett & Padilla-Walker, 2015; Nelson & Luster, 2016). However, it is crucial to acknowledge that many of our participants struggled to engage fully with the questions and activities about definitions of adulthood. In many ways, this finding is not surprising. Adulthood is a deceptively complex notion about which many individuals hold competing intuitions. Research on such a phenomenon is therefore at risk of presenting vague insights as clear and definitive opinions. Nevertheless, the fact that our findings match the patterns found in similar studies provides some support for the argument that typically developing young people are more likely to consider psychosocial maturity as more salient to adult status than other factors. However, the slightly stronger emphasis on interpersonal factors found amongst the participants with intellectual disabilities suggests that salient differences may exist between different subgroups based within the same cultural context.

With regards to subjective adult identity, our findings provide mixed support for the confluence model proposed by Shanahan and colleagues (2005). Amongst the typically developing participants, psychosocial maturity and self-sufficiency were used to judge an individual's adult status; yet, social role changes were seen as fundamental for facilitating opportunities for personal development. This corroborates with the confluence model's suggestion that both aspects of transition contribute to subjective adult identity, albeit moderated by the individual's personal and social context.

Amongst the participants with intellectual disabilities, however, subjective adult identity appeared to be more closely linked to each participant's personal definition of adulthood. Social role transitions, such as leaving school and going to college, did not seem to have as significant an impact upon these participants' self-identification as an adult as they did on the typically developing participants. In contrast, some participants suggested that little things, such as making tea at home, made more significant contributions to how 'adult' they felt. If so, these findings demonstrate that research with young adults with intellectual

disabilities can be used to test and challenge assumptions within general fields of enquiry as well as those with a disability-specific focus.

12.3 Implications for Policy and Practice

12.3.1 Supporting the development of personal responsibility

Our findings suggest that young people with borderline to moderate intellectual disabilities aspire to work towards autonomy and independence, albeit over a slightly longer period than their typically developing peers. Yet, over the short-term, members of both groups demonstrated a degree of reluctance to take complete control over their lives, preferring to rely upon external support in domestic and financial domains, as well as when making significant decisions. Despite efforts to improve transition-planning, evidence suggests that the move from child to adult services for young adults with intellectual disabilities can often be challenging (Genevieve Young-Southward, Philo, & Cooper, 2017). Upon turning 16 or leaving school, some young people find that the level of support available to them drops, which has been shown to become a source of stress (Genevieve Young-Southward, Cooper, & Philo, 2017). It is therefore paramount that young people continue to receive guidance and support, including opportunities to prepare – both emotionally and in terms of skills development – for the various practical and social transitions that occur throughout this period.

Moreover, the domain-specificity of our participants' attitudes towards parental support and interference, combined with their apparent preference for convenience, suggests that young people may not always be proactive in seeking additional opportunities for autonomy. As suggested during the interviews, a number of the young people also actively resisted responsibility, increasing their parents' burden of labour at home. Supporting young adults both with and without intellectual disabilities to develop expectations of personal responsibility may, therefore, have positive outcomes for both themselves and their families.

As suggested, this is a particularly complex outcome to achieve, as it depends upon a variety of social, psychological, and practical factors. Our findings suggest that social pressures and environmental changes, such as getting a part-time job or moving out, may have the potential to propel young people into adopting greater responsibility. However, these opportunities are often less readily available to young adults with intellectual

disabilities. In Scotland and across the UK, for example, economic austerity measures are thought to have had a significant impact upon the availability of social care (Ormston et al., 2017). Opportunities for supported accommodation are decreasing as a result, leaving many young people with no option but to continue living in the family home.

Moreover, despite the current emphasis placed on self-determination in policies such as *Valuing People* and *Keys to Life*, narratives of risk and vulnerability remain pervasive. As discussed in Chapter 1, services providers have been accused of prioritising safety over all other outcomes (Seale et al., 2013). Moreover, parents may not trust their young people to respond appropriately to risk, and therefore feel unable to provide opportunities for independence that they may otherwise wish to (Mitchell, 2012; Pownall et al., 2011).

Yet, evidence suggests that when such opportunities do arise, individuals with intellectual disabilities often cope with independence better than expected. Much as in our interviews, Midjo and Aune (2016) found that young people living at home viewed housework as their parents' responsibility until they had a residence of their own, at which point it became their own responsibility. Similarly, Isaacson, Cocks, and Netto (2014) investigated the launching experiences of two young men with intellectual disabilities, who not only coped with independence better than expected, but actively engaged in activities that – according to their parents - they would never have attempted while living at home.

In line with other literature, these combined findings suggest that positive risk-taking may serve as an important catalyst for personal growth and development. Importantly, however, they also suggest that young people may not always *seek* such opportunities, and may even resist them at first. Consequently, it is possible that some young people need to be encouraged to face positive risks *before* they appear to be ready for them, as personal development demands a degree of challenge and adversity. Parents and services need to be supported in finding the courage to allow young adults with intellectual disabilities chances to take risks and make mistakes, as failure to do so may be more harmful in the long run.

12.3.2 Supporting young peoples' aspirations for adulthood

In line with previous research (Midjo & Aune, 2016), it became clear that the participants with and without intellectual disabilities shared similar aspirations for the future. These included making social role transitions, such as getting jobs, moving out, and – albeit to a

lesser extent – falling in love and having children. However, as discussed in Chapter 1, Scottish adults with intellectual disabilities are significantly less likely to undertake a number of these transitions (Ormston et al., 2017; Scottish Learning Disabilities Observatory, 2018a, 2018b). Moreover, with regards to independent living and employment, in particular, concerns have been raised that opportunities may even be *decreasing* for individuals with mild intellectual disabilities (McMurray, 2017; Ormston et al., 2017). As mental ill-health in young adults with intellectual disability has been shown to increase between the ages of 13 and 44 (Hughes-McCormack et al., 2017; G Young-Southward, Rydzewska, Philo, & Cooper, 2017), there are grounds for thinking that poor transition experiences may directly affect these outcomes.

Lack of opportunity for meaningful daytime activity has been raised as a particular concern (Genevieve Young-Southward, Philo, et al., 2017). As suggested, approximately 1/3rd of applicants with intellectual disabilities fail to attain a place at college each year. Moreover, post-college opportunities are often perceived to be limited (Genevieve Young-Southward, Cooper, et al., 2017). For many young people with intellectual disabilities, this can have a range of negative impacts. Lack of purposeful activity can lead to boredom, frustration, and lack of meaning in peoples' lives, and also limits opportunities for community engagement (Verdonschot et al., 2009). Furthermore, these effects may be compounded for individuals who feel that they have little control or command at home. There is also some evidence that unmet educational and employment aspirations may independently predict depressive symptoms (Greenaway, Frye, & Cruwys, 2015; Hardie, 2014). As a result, the adverse outcomes associated with lack of occupation may be exacerbated when accompanied by unmet goals.

Lack of purposeful daytime activity can also be particularly difficult for parents. Parents of adolescents with intellectual disabilities may feel forced to give up work to provide care, which can in some cases have negative impacts on both family finances and emotional wellbeing (Ouyang et al., 2014; Rapanaro et al., 2007). Importantly, this is not to say that providing long-term care is always perceived to be a burden. Several studies have shown that caring for an adult with intellectual disabilities can have an actively positive impact on family life (Knox & Bigby, 2007; Yoong & Koritsas, 2012). However, families should not feel forced to adopt full-time caring responsibilities purely to account for a deficit in meaningful daytime activity options.

Yet, it is worth noting that in some cases, successful goal attainment can also have *negative* consequences for young people and their families. As suggested, individuals with intellectual disabilities who work typically do so in low paid jobs that often have unsociable working hours (Verdonschot et al., 2009). In these cases, families may become responsible for providing transport and other forms of support, increasing rather than decreasing the care responsibilities. Several parents raised concerns of this kind during the interviews, a couple of whom believed that employment outcomes might not be in the best interests of their children. Consequently, not only do more options need to be made available, but the options themselves must also be sensitive to the needs of young people and their families.

12.3.3 Improving communication throughout the transition process

The transition to adulthood involves numerous service changes for families with adolescents with intellectual disabilities. In Scotland, efforts have been made to improve the school to post-school transition for all young people, with particular attention being paid to individuals with disabilities. However, these policies have been criticised for being too vague and simplistic to provide practicable guidance (Conlon, 2014). Moreover, the reduction in funding for further education colleges in Scotland is thought to have disproportionately affected individuals with disabilities (McMurray, 2017). As a result, the quality and consistency of transition planning and execution are thought to vary significantly between education authorities. Efforts to simplify and clarify these processes may help to reduce the number of stressors faced by families and young people during this already turbulent period.

In addition, the majority of clubs and societies aimed at young people with disabilities typically have upper age limits of 16, 18, and 25. At the age of 18, opportunities for adult services may become available; however, these typically cater for adults of all ages and disability levels. While inter-generational socialising can be beneficial (Gualano et al., 2017), social connections are typically formed between people whose life stages and experiences are similar (McPherson, Smith-Lovin, & Cook, 2001). Moreover, as social participation tends to be limited for young adults with intellectual disabilities (Raghavendra, Newman, Grace, & Wood, 2015), opportunities to form friendships with peers become a priority. Social networking is becoming an increasingly important part of the young adult social experience (Kennedy & Lynch, 2016); however, our findings

suggest that school pupil young adults with intellectual disabilities may be significantly less likely to use social networking sites than their typically developing peers.

Several factors may contribute to this lack of participation. The majority of social networking sites require moderate levels of computer-specific and general literacy to use effectively, for example. Moreover, concerns about online safety and security can also be a barrier to social media usage in this population (Caton & Chapman, 2016). However, the number of websites designed specifically for individuals with intellectual disabilities is on the rise. Continuing to facilitate safe and accessible online social networking may help to bridge the widening divide between people with and without intellectual disabilities, increasing opportunities for social participation as a result (Chadwick, Wesson, & Fullwood, 2013).

Moreover, poor dissemination of information prevents many young adults with disabilities from accessing age and disability appropriate extra-curricular activities. As suggested, lack of information can be a particular source of stress and frustration for parents during the transition period (Bhaumik et al., 2011). Improving the flow of information about the available services and options for young adults with disabilities has the potential to make a notable difference to both parents and their young people alike. Additionally, as information systems are typically low-cost and low maintenance, they can be some of the most cost-effective interventions to implement.

12.4 Ethical implications

Several of the topics covered during the study have the potential to be emotive. The transition to adulthood represents a uniquely stressful life-stage for many people, and the process of leaving school can be a particular source of worry for young adults with intellectual disabilities (Genevieve Young-Southward, Philo, et al., 2017). A number of controversial age-restricted activities, such as sex and drinking alcohol, were included for discussion, which can cause participants or their families' discomfort. Furthermore, discussions about independence and responsibility have the potential to trigger fears of the future and to draw attention towards factors like competence and capacity that may affect confidence and self-esteem. As members of this population are also at increased risk of rumination (Forte et al., 2011), it was important that these risks were minimised wherever possible.

Several strategies were adopted to achieve this goal. All participants were informed about the nature of the study both verbally and in writing before the start of each session to ensure that they were emotionally prepared for the topics under discussion. During the induction, the rights to withdraw and skip questions were emphasized several times. Participants were also told that they would not be judged or reprimanded for anything they said during the sessions and that their anonymity was assured. Sessions did not begin until the researcher felt confident that each participant was happy to proceed, at which point the most emotive topics were handled sensitively. During the data collection process, three participants did become upset. On these occasions, body language was used to gauge comfort levels, and offers to stop or change topic were made at the earliest appropriate opportunity. In all cases, the participants chose to continue.

Despite considerable effort to minimise risk wherever possible, it is important to acknowledge that the research committees at Glasgow Council and West Dunbartonshire Council rejected the study on ethical grounds. Two concerns raised included the offensive nature of the term "intellectual disability", and the prospect of intelligence testing. To some extent, this represents a fundamental difference in the philosophies underpinning clinical and educational fields. Clinically orientated researchers often use diagnostic testing and labelling to help identify the characteristics and needs of different populations. In contrast, the prevailing view within education is that every pupil has unique strengths and weaknesses. From this perspective, the use of IQ testing and terms such as "intellectual disability" are viewed as not only unhelpful but potentially harmful to the best interests of the child.

In many ways, these concerns were justified. Several participants felt nervous at the prospect of sitting the WASI-II and did not perform as well as they otherwise could have done. Moreover, people with intellectual disabilities represent a heteronomous population; therefore, one may wish to question the utility of treating them as a single group. However, it is well established that individuals with intellectual disabilities continue to remain disempowered within society (Goodley, 2005), and opportunities to contribute to the policies that pertain to them are often tokenistic (Frawley & Bigby, 2011). Importantly, activists have long argued that individuals with disabilities have a right to be meaningfully included in these conversations (Beresford & Croft, 1993; Hammel et al., 2008), and positive changes are unlikely to be made until this point is reached. As a result, this project has represented an opportunity for young people to voice their views, which is necessary to ensure that their position is both understood and respected.

12.5 Challenges, Strengths, and Limitations

12.5.1 Study Design

Mixed methods research has been criticised for combining approaches that are thought by some to be built upon logically incompatible notions of truth (J. K. Smith & Heshusius, 1985). However, the epistemological paradigm underpinning this thesis is Pragmatism, which rejects the assumption that 'truth' lies at the heart of real-world inquiry (Feilzer 2010). Instead, research is carried out "to achieve agreement among human beings about what to do" (Rorty, 1999, p. 25), and is therefore concerned with action and outcomes, rather than 'Knowledge'. Importantly, pragmatism was not *chosen* for this project, but rather reflects the epistemological and ontological beliefs of the researcher.

Pragmatist researchers choose methods that are relevant and appropriate to the questions asked and data sought (Hanson 2008; Feilzer 2010; Howe 1988). The overarching aim of this project was to investigate how young adults with and without intellectual disabilities think and feel about self-determination and adult identity. It was believed that these phenomena were likely to have sufficient group overlap to justify the adoption of quantitative methods. However, as complex, multifactorial phenomena, it was believed that the study would also benefit from the more in-depth subjective analysis that only qualitative methods can deliver.

Moreover, a sequential exploratory design was chosen to determine the order in which the studies were carried out. According to this design, qualitative data is collected first and used to help develop an instrument for subsequent quantitative analysis (Creswell et al., 2003). The strength of this approach is that it allows novel measures, such as the one involved in the quantitative phase of the project, to be developed 'ground-up' from the populations of interest, increasing relevance and ecological validity as a result. However, the strategy fails to account for the reasons underpinning participants' answers to those quantitative items, limiting the strength of the conclusions that can be drawn from the data. While some qualitative data was collected during the second study, a deeper exploration of participants' responses would likely have resulted in more meaningful findings. However, time restrictions prevented this possibility.

12.5.2 Methodological considerations

12.5.2.1 Study 1

During the first study, the process of transcription revealed that the researcher was not always able to explore the participants' accounts as deeply or as broadly as desired, particularly as the interviews were frequently time-pressured. However, great efforts were made to develop trust and rapport with the participants, which allowed a number of valuable insights to be gained that might otherwise not have been.

Finally, factors such as the end of the school year, sickness, and exams prevented conformability audits from being undertaken, which risks increasing the influence of the researcher's judgement on the data. However, interpretative methods acknowledge that the researcher is an active participant in both the data collection and analysis processes; therefore, conclusions should always be treated with caution.

12.5.2.2 Study 2

The measures used in the second study were novel, and as such, were not psychometrically validated. Observations and comments during the tasks suggest that several of the participants found the content to be too simplistic to account for the nuances of the topics under investigation. Moreover, there are grounds for thinking that some responses may have been influenced by social desirability and priming. It is possible that the test-retest validity of the forced-choice questions will be low in some cases as a result. However, as suggested, autonomy, responsibility, adulthood, and identity are cognitively complex phenomena, about which many individuals have competing intuitions. As our findings suggest that attitudes towards these phenomena can change with context, test-retest reliability may never be satisfactorily achieved. Furthermore, as an exploratory project, the studies were not designed to find conclusive answers to the research questions, but rather to pave the way for future research.

Additionally, these obstacles are compounded when undertaken with populations whose abstract thinking skills and linguistic competence are impaired. The challenges involved in designing measures that are valid, accessible, and engaging to ID populations are numerous, which is why a considerable amount of quantitative research on young adults with intellectual disabilities is undertaken by proxy report (H. M. Scott & Havercamp,

2018). One of the study's biggest strengths was the level of time and attention given to the development and piloting process, which lasted approximately eight months. In this time, several iterations of the study were considered and rejected. Data collection did not begin until the researcher and her supervisors were confident that the activities were feasible, appropriate, and likely to result in valuable findings. Study 2 was specifically designed to account for a number of the known obstacles to communication and engagement for this population. Visual aids and options for alternative phrasing were used throughout to help scaffold understanding where necessary. Flashcards introduced an interactive element to two of the tasks to help increase engagement, and also allowed participants to respond non-verbally if so desired. This careful approach was invaluable in helping to ensure that the study would work well with both groups of young people.

12.5.3 Participants

Questions remain about the homogeneity and representativeness of the ID and TD groups involved in these studies. Participants were regarded as having a borderline to moderate intellectual disability on the basis of diagnostic information provided by their institutions, as well as their scores on the 2-scale WASI-II. This instrument is only capable of providing a general indicator of an individual's cognitive ability and does not assess levels of adaptive capacity. As a result, the screening process was incomplete and insufficient to conclusively determine that every ID participant had intellectual disabilities and that every TD participant did not. However, the WASI-II is a standardised IQ measure with good validity and reliability (Wechsler, 1999), and all participants within the ID group were registered with an intellectual disability and were currently receiving special education at the time the data was collected. Moreover, the study's inclusion and exclusion criteria were strictly adhered to, resulting in 18 participants being removed from the data set before analysis.

Part of the difficulty in undertaking a study of this type is that young adults with intellectual disabilities represent a heterogeneous population. Despite all members having cognitive deficits and limited adaptive capacity, conditions associated with intellectual disability can manifest in a variety of ways and have different social, physical, emotional, and behavioural presentations. The majority of the participants in our study had been diagnosed with one or more additional conditions, such as cerebral palsy, autism, and epilepsy, all which have a potentially confounding influence on the findings. However, as

the population of individuals with non-specific intellectual disabilities is very small, options for homogenous research are limited.

It is also worth noting that the decision to recruit post-school participants from colleges may have resulted in a non-representative typically developing sample. The decision was deliberately made to help ensure that the ID and TD groups were composed of individuals with comparable neighbourhood deprivation statuses and life-stage experiences. However, only a minority of non-disabled school leavers in Scotland choose to go to college, with the vast majority choosing to go to University or to go straight into employment (The Scottish Government, 2017). Consequently, it is possible that college students represent a unique sub-group within the general population, and that our findings are not generalizable to other young adults as a result.

Finally, though considerable efforts were made to recruit appropriate sample sizes, the non-significant findings in Study 2 may have been the result of Type II errors. As suggested, the ID group sample size was above the level required for a ±15 margin of error. However, it is possible that a higher number of TD participants may have been required to power the study adequately. Unfortunately, college students without disabilities were a particularly difficult population to access, as the majority of individuals who attend college in Scotland are over 20 years old. Nevertheless, as an exploratory study, our results can be used to indicate appropriate sample sizes for future studies on similar topics of investigation.

12.5.4 Limitations

- More significant differences between the young adults with and without intellectual disabilities may have been found had a slightly older population been recruited into the study.

- The interviews were analysed using interpretative thematic analysis. While the versatility of thematic analysis is one of its strengths (Braun & Clarke, 2006), the approach may be criticised for failing to align to any one particular epistemology. Furthermore, the lack of adherence to either IPA or the traditional thematic analysis approaches may risk undermining the quality of the research that employs it.

- Social desirability may have had significant impacts upon the reliability of the findings. Future studies on topics such as independence and autonomy would be advised to incorporate strategies for overcoming this issue.

- The data upon which this study's power calculation was based was derived from Local Authorities (The Scottish Consortium for Learning Disability, 2017). However, the 2011 Scottish Census indicates that the number of young adults with intellectual disabilities in Scotland may be much higher than their data suggests (National Records of Scotland, 2011). On this basis, the quantitative phase of the study is underpowered. Moreover, a moderate number of participants were excluded from the studies for failing to meet the studies inclusion criteria. As a result, the non-significant findings may have occurred as the result of Type II errors.

- In some cases, parents suggested that they felt unable to grant the level of independence that they may otherwise wish to as a result of their child's health. Chronic illness and physical disability may therefore represent confounding variables in the studies. It is advised that, wherever possible, future studies control for this variables.

12.6 Further Research

Attitudes towards growing up and adulthood have been shown to change over the life-course (Arnett, 2001; Lowe et al., 2013). Moreover, the general tendency to delay social role transitions until the mid to late twenties and beyond may mean that the most significant differences between young adults with and without intellectual disabilities only become apparent at these later ages. Extending the study longitudinally, or repeating the study with adult groups, may reveal the most interesting findings.

Several changes to the materials are nevertheless recommended. In the Everyday Activities task, participants were asked if they do or do not regularly undertake a series of everyday and age-restricted activities. Activities that were *not* undertaken regularly were then divided into those that the participant is not allowed to undertake, does not want to undertake, and 'just doesn't' undertake. However, no additional information was collected about the activities participants *do* undertake regularly. Future iterations of the study may

wish to include questions about whether these activities are done out of choice, obligation, or habit.

Similarly, several ID participants struggled to label activities that they were simply incapable of undertaking. An additional category of 'I can't do this' may increase the validity of responses. However, it is important to note that too many categories can cognitively overburden ID participants; therefore, changes of this variety would have to be piloted carefully. Future research involving the Phase 2 vignette may wish to explore participants' social goal and outcome expectations relating to friends, as included in the work by Pownell (2010) upon which this task was based. Similarly, additional scenarios may help to separate the participants' social cognitions from other beliefs and attitudes specific to watching films with friends.

While parents' views were sought during both studies, additional research into the transactional relationship between parents' and their children's attitudes may shed light on the developmental antecedents to self-determined behaviour and adult identity. Similarly, it would be interesting to involve additional stakeholders, such as teachers, extended family members, and professionals, in the research process, to explore the interaction effects across individuals' wider social ecologies.

Importantly, young adults with intellectual disabilities represent a diverse population composed of individuals with a range of additional diagnoses. It is possible that conditions with atypical social or behavioural characteristics may have a greater influence on the outcomes of interest than intellectual disability. Repeating the study with participants from more specific populations, such as individuals with Autism spectrum disorders, may result in more explicit findings. Moreover, as suggested, this study represents one of only a few studies that have investigated psychosocial factors involved in self-determined behaviour and adult identity. It is therefore also recommended that greater research attention is given to the impact of social goals and outcome expectations, self-efficacy beliefs, and personal priorities, particularly in relation to young adults with intellectual disabilities.

12.7 Concluding remarks

Moving forward, it is important to acknowledge that young adults with and without mild intellectual disabilities share many of the same experiences, hopes, and aspirations as they make the transition to adulthood. Rather than representing two strictly binary groups, every

participant exhibited unique levels of independence, autonomy, maturity, and responsibility, regardless of whether or not an intellectual disability was also present. Yet, there were nevertheless a number of qualitative differences between these groups of young adults that should not be overlooked.

The social narratives that continue to surround intellectual disability, for example, may affect the transactions and negotiations that occur between young people and those around them during the transition process - particularly in relation to risk, independence, and autonomy. Social and societal barriers to participation may also affect young peoples' development, as well as their general quality of life – particularly after the completion of formal education. These obstacles may not always be linked to the cognitive and adaptive difficulties associated with intellectual disabilities. Yet, they are likely to affect, if not define, the transition experiences of young people in this group.

Our findings demonstrate that young adults with borderline to moderate intellectual disabilities are both willing and able to make invaluable contributions to the literature. Furthermore, the relevance of such contributions is not limited to disability-specific issues, but instead has implications for researchers across a variety of fields. It is therefore critical that in future, researchers continue to not only investigate the transition experiences of young people with mild intellectual disabilities, but to do so by including the views of young people themselves. More knowledge is required to find out which outcomes are and are not important to people at this age and stage so that members of this population can be supported to both set and achieve goals that are personally salient. Doing has the potential to maximise their opportunities for leading happy and fulfilled lives, which in turn, is likely to have positive implications for society as a whole.

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Appendices

Appendix A: Example data extraction form for systematic review

Systematic Review

Factors Predicting increased self-determination in 16 to 30 year olds with Mild to Moderate Intellectual Disability

Data Extraction Sheet

Title:	
Authors:	
Journal:	**Year**:
Country of Study:	
Keywords:	
Aims:	
Study Type:	
Study Design:	

Total Sample: [   ]

Primary Sample N:	**Age Range:**	**IQ range:**	**Known Comorbidity?**	**Gender**: N/A

Measures:

Dependent Measure (Self Determination):

Choice/ Decision Making	Goal setting/ Attainment	Problem solving	Relations with others	Self-advocacy	LoC/ empowerment	Self-regulation	Self-realization/ awareness

Instrument:

(1) Self-report   (2) Proxy report   (3) Behavioural Observation   (4) Performance Measures

Independent Variable/s:

Intervention? ( ) Yes / ( ) No	
If yes, name of intervention:	**If no, list IVs:**
No. Sessions / Week:	
Instrument/s used:	
Additional details:	

Statistical Tests:

Tests used:	
Significant? (Y) / (N) / (U)	**Details:**
Confidence intervals:	
Power of test:	

Results:

Author	Reviewer
Is there a relationship? (Y) / (N) / (U)	**Is there a relationship? (Y) / (N) / (U)**
Nature:	**Nature:**
Direction?	**Direction**?
Strength?	**Strength?**

M/M variables?	M/M variables?
Limitations:	**Limitations**:

Other comments:
261

Appendix B: The Standard Quality Assessment Criteria for Evaluating Primary Research Papers From a Variety of Fields (Kmet et al., 2004)

	Criteria	YES (2)	PARTIAL (1)	NO (0)	N/A
1	Question / objective sufficiently described?				
2	Study design evident and appropriate?				
3	Method of subject/comparison group selection or source of information/input variables described and appropriate?				
4	Subject (and comparison group, if applicable) characteristics sufficiently described?				
5	If interventional and random allocation was possible, was it described?				
6	If interventional and blinding of investigators was possible, was it reported?				
7	If interventional and blinding of subjects was possible, was it reported?				
8	Outcome and (if applicable) exposure measure(s) well defined and robust to measurement / misclassification bias? means of assessment reported?				
9	Sample size appropriate?				
10	Analytic methods described/justified and appropriate?				
11	Some estimate of variance is reported for the main results?				
12	Controlled for confounding?				
13	Results reported in sufficient detail?				
14	Conclusions supported by the results?				

Appendix C: Information Sheet about the study

![University of Glasgow | College of Medical, Veterinary & Life Sciences logo]

Psychosocial Maturity and the Development of an Adult Identity: A Comparison Between Transition-Age Individuals With and Without Intellectual Disabilities.

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything you do not understand, or if you would like more information.

What is the purpose of the study?

When we grow up and become adults, people may start to treat us differently to how they treated us as children. I want to know how much opportunity you have to make your own decisions, how you feel about making your own decisions, and what being an adult means to you. I will also ask your parents some questions to find out how much opportunity they think they give you to make your own decisions.

Why have I been chosen?

We're really interested to find out how young adults like you feel about growing up, and whether or not that's different to other people your age. That's why we've asked you to help us out!

Do I have to take part?

You do not have to take part if you don't want to – the decision is up to you. However, we have designed the interview to be fun and interesting, so hopefully you will want to join in. Also, if you decide to take part, but decide half way through that you don't want to do it anymore, you can drop out at any time, and you don't have to tell us why.

What will happen to me if I take part?

We will have a chat about what your everyday life, the decisions that you tend to make, and what growing up means to you. You may also be asked to participate in another session, when there will be three main activities for you to do, all of which involve using flashcards to talk about decision-making and growing up. I will ask you a few questions, and you will use the flashcards to help answer them. These questions are not part of a test, though. There are no right and wrong answers. I'm just interested to find out what you think and feel about becoming an adult.

The sessions will take place in a quiet classroom during the school day or at your community group, and should last no more than an hour. The day and time of the session will be arranged with you once the attached consent form has been signed and returned.

What do I have to do?

Unless have a legal guardian, all you have to do is make sure that you sign and return the consent form attached to this letter. If you do have a legal guardian, you must ask them to complete the legal guardianship form. Ask your parents if you're not sure.

What are the possible disadvantages and risks of taking part?

The studies have been designed to have no risks. The only disadvantage is that you will have to give up a little time during the day to take part in the interview.

What are the possible benefits of taking part?

Hopefully you will find the activities fun and interesting to do, and will also be able to tell people that you've been involved in University research. You will also be helping me to find out a bit more about how you and your classmates feel about growing up, which may help to improve how people like you are treated by parents / teachers / carers in the future.

Will my taking part in this study be kept confidential?

All information which is collected about you, or responses that you give me during the course of the research will be kept strictly confidential. That means that no one else will know what you said. Your name and personal information will also be kept secret so that you cannot be recognised from it. The only situation in which we will have to tell other people what you said is if we think you're at risk of serious harm. If that happens, the University may have to let other people know, because we want you to stay safe.

What will happen to the results of the research study?

The answers you give me will form part of my PhD research, and may get published in a journal article. However, you will not be named in any report or publication. If you're interested, I will tell you what the study found out.

Who is organising and funding the research?

The Scottish Government have paid for this research, which is being completed through the University of Glasgow.

Who has reviewed the study?

The project has been reviewed by the University of Glasgow College of Medical, Veterinary and Life Sciences Ethics Committee.

Contact for Further Information

Emily Salt
e.salt.1@research.gla.ac.uk
07818414340

Appendix D: Consent Form

University of Glasgow | College of Medical, Veterinary & Life Sciences

Psychosocial Maturity and the Development of an Adult Identity: A Comparison Between Transition-Age Individuals With and Without Intellectual Disabilities.

Name of Researcher(s):
Emily Salt: PhD candidate
Professor Andrew Jahoda: Professor of Learning Disabilities
Doctor Craig Melville: Senior Lecturer in Learning Disabilities Psychiatry and Postgraduate Convenor

Please initial box

I confirm that I have read and understand the information sheet
(version 1.1) for the above study and have had the opportunity to ask questions. ☐

I understand that my participation is voluntary and that I am
free to withdraw at any time, without giving any reason. ☐

I agree to take part in the above ☐

I agree that the session can be audio recorded. ☐

I agree to be contacted in the future to take part in a possible follow-up project. ☐

_____   _____   _____

Name of Participant   **Date**   **Signature**

_____   _____   _____

Researcher   **Date**   **Signature**

Appendix E: Ethical Approval

06/10/2016

MVLS College Ethics Committee

Project Title: Psychosocial Maturity and the Development of an Adult Identity: A Comparison Between Transition-Age Individuals With and Without Intellectual Disabilities
Project No: 200150185

Dear Professor Jahoda / Dr Salt

The College Ethics Committee has reviewed your application and has agreed that there is no objection on ethical grounds to the proposed study. It is happy therefore to approve the project.

- Project end date: End May 2017

- The data should be held securely for a period of ten years after the completion of the research project, or for longer if specified by the research funder or sponsor, in accordance with the University's Code of Good Practice in Research: (http://www.gla.ac.uk/media/media_227599_en.pdf)

- The research should be carried out only on the sites, and/or with the groups defined in the application.

- Any proposed changes in the protocol should be submitted for reassessment, except when it is necessary to change the protocol to eliminate hazard to the subjects or where the change involves only the administrative aspects of the project. The Ethics Committee should be informed of any such changes.

- You should submit a short end of study report to the Ethics Committee within 3 months of completion.

Yours sincerely,

Jesse Dawson
MD, FRCP, BSc (hons), MBChB (hons)
Clinical Reader / Honorary Consultant

Chair MVLS Ethics Committee
College of Medicine, Veterinary & Life Sciences
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Appendix F: Interview Schedule for Young People

NB: Bullet points were prompt ideas only.

YOUNG PERSON INTERVIEW QUESTIONS

DEMOGRAPHICS: Postcode, Date of Birth
LEAD IN:
- Questions about your day-to-day life, how you feel about making decisions, and how you feel about growing up.
- No right or wrong answers, no judgement

Opening
- Just quickly, can you tell me a bit about your family?

Verify whether or not they live with parents
Who tends to make decisions about your life?
- What kinds of decisions does mum/dad make?
- What kinds of decisions do you make?
    - E.g. appearance, what you do, what you watch, life choices etc.

How do you feel about making decisions?

I want you to imagine that you come home one day, and your parents tell you that you've been given an opportunity to go on holiday with a few people your own age. It's entirely paid for, it's completely safe, and you get to choose which country you go to. However, your family won't go with you.
    - How do you think you would feel about making that kind of decision?
    - How do you think you would feel spending 1 month away from your family?
    - What about 1 year?
    - How do you think your family would feel about you going?
    - Would you go?

How independent do you think you are?
- How do your parents feel about you going out on your own?
    - Do you have a house key?
    - Curfew?

Can you tell me a bit about anything that you are not allowed to do? i.e. Rules and restrictions
- Do you have your own TV?
    - Is there anything you're not allowed to watch? How does that make you feel?
- Do you have your own phone?
- Do you have your own computer?
    - Are there any websites you aren't allowed to go on? Even websites with sex or violence?
    - Do you go on them anyway?
- How strict are your mum and dad?
- Do you get told off?
    - What for?
- Are you allowed to swear?
- Do you have a bedtime? How old were you when you stopped?

How independent would you like to be?

How much do your parents know about your life?
- How much privacy are you allowed at home?
- How important is privacy to you?

- How much time do you spend on your own, without any adults around.
- Do you have your own room?
- How would you feel if your parents walked in without asking?
    - How would you feel if you found out your parents had been through your phone?

How do you feel when you're on your own / when there aren't any adults around?
- What's the longest amount of time you've been left on your own at home?

Have you ever had a boyfriend/girlfriend?
- Would you like to have a boyfriend/girlfriend?
- How do you think your parents would feel if you got a boyfriend/girlfriend?
- Have your parents talked to you about sex? How much do you know about sex?
- Have you had sex?
- Would you like to?
    - How would your parents feel if you got a girlfriend/boyfriend?
    - How would your parents feel if you had sex?
        - How would that affect you?
- Drink / smoking?

What are the most important things in your life?
- So, you mentioned that you do X. Can you tell me a bit about why you started doing X?
    - Who decided?
    - When?
- Is there anything else that you would rather be doing?
- How do you like to spend your free time?
- What do you like doing with your friends?

Can you tell me a bit about your responsibilities at home?
- What kinds of chores/housework do you do at home?
- How would you feel about taking on more responsibility at home?
- How do you think your parents would feel about you taking on more responsibility at home?
- Have you ever had your own money?
    - Who looks after your money? Bank account?
    - Is there anything you're not allowed to spend money on?
    - How do you feel about looking after money?
- How would you feel if you had to act like a mum or dad for a day?
- What kind of support would you need to take on more responsibilities?

How do you feel about the future?
- What would you like to do after you leave school/college?
- How do you feel about moving out at some point?
    - How do you think your parents would feel?
- How do you feel about looking for a job?

What do you think being an adult means?
How adult do you feel?
- Are you a girl/boy or man/woman?

What would make you feel more grown up?
How do you get treated now in comparison to how you were treated when you first started high school?
Can you tell me a bit about what it felt like to become a 5th/6th year/leave school?
    - How do you feel about leaving school?
What about what it felt like to turn 16/18?
    - Did anything change?

Closing Question
- If you could have a Superpower, what would it be?

Appendix G: Interview Schedule for Parents

NB: Bullet points were prompt ideas only.

PARENT INTERVIEW QUESTIONS

DEMOGRAPHICS: Postcode, Child's DOB
LEAD IN:
- Questions about your child's day-to-day life, how you negotiate decision-making with them, and about their transition to adulthood.
- No right or wrong answers, no judgement

Opening
- Just quickly, can you tell me a bit about your family?

Who tends to make decisions about X's life?
- What kinds of decisions do you tend to make for them?
- What kinds of decisions do they tend to make on their own?
  - E.g. appearance, what they do, what they watch, life choices etc.

How does X feel about making decisions?
- How do you feel about X making decisions?
- How competent a decision-maker do you think X is?
- How much opportunity would you say you gave X to make decisions about their life?
- How often do they take up the opportunities that you give to them?
  - Do they take ownership, or would they rather that you took responsibility for them?
- I want you to imagine that X has been given an opportunity to go on holiday with a few people their own age. It's entirely paid for, it's completely safe, and X gets to choose the destination. However, neither you, nor any of your family can go with them.
  - How would you manage the decision-making process with X?
  - How do you think X would feel about spending one month away from the family?
  - What about 1 year?
  - How do you think they would feel about going?
  - How would you feel about them going?

How independent do you think X is?
- How independent would you like them to be?
- How independent do you think X would like to be?

Can you tell me a bit about any rules or restrictions that you place on X?
  - Do they have a bedtime? How old were they when they stopped?
  - Do they have their own TV?
    - Is there anything they're not allowed to watch?
    - How would you feel about them watching X/Pornography/Violence?
  - Do they have their own phone?
  - Do they have their own computer?
  - How do you feel about X going out on their own?
    - Do they have a house key?
    - Curfew?
  - How strict do you think you are?
  - Do you punish them??
    - What for?
  - Do you allow them to swear?

How much do you know about their life?
- How much privacy do you allow them at home?

- How important do you think privacy is to them?
- Do they have their own room?
  - How do you feel about walking into their room without asking
  - How do you think they feel about it?
- How much time do they spend on their own, without anyone else around.
- What's the longest amount of time they've been left on their own at home?
- How do they feel when they're on their own / when there aren't any adults around?
- As far as you know, have they ever had a boyfriend/girlfriend?
- Was it a sexual relationship?
- How do you think they feel about finding a partner?
- How would you feel if they found a partner?
- How would you feel if they wanted to start a sexual relationship?
- How do you feel about them drinking / smoking?

What are the most important things in their life?
- How do they like to spend their free time?
- So, you mentioned that they do X. Can they tell me a bit about why they started doing X?
  - Who decided?
  - When?
  - How do you feel about X?
- Is there anything else that they would rather be doing?
- Is there anything else that you would rather they were doing?
- What do they like doing with their friends?

Can you tell me a bit about their responsibilities at home?
- What kinds of chores/housework do they do at home?
- How would you feel about taking on more responsibility at home?
- How do you think they would feel about taking on more responsibility at home?
- Have they ever had their own money?
  - Who looks after their money? Bank account?
  - Is there anything they're not allowed to spend money on?
  - How do they feel about looking after money?
- How would they cope if they had to take on an adult's role for a day?
- What kind of support do you think they would need to take on more responsibility?

How do you feel about the future?
- What would they like to do after they leave school/college?
- How do you feel about them leaving school?
- How do you feel about the prospect of them moving out at some point?
  - How do you think they would feel?
- How do they feel about looking for a job?
- How do you feel about them looking for a job?
- Do any of their other children have additional support needs?
- What, if any, are the challenges of raising children with different needs?
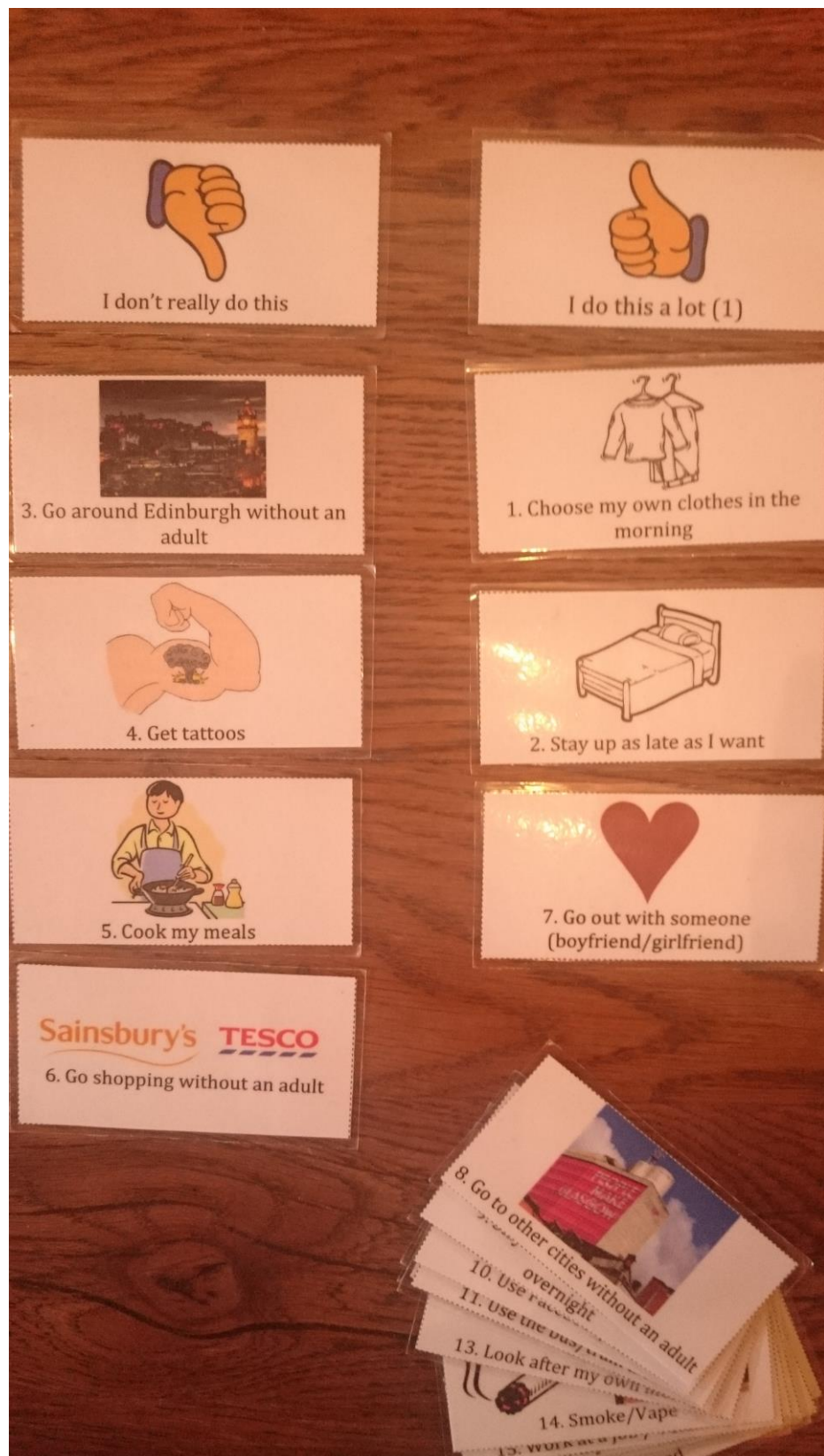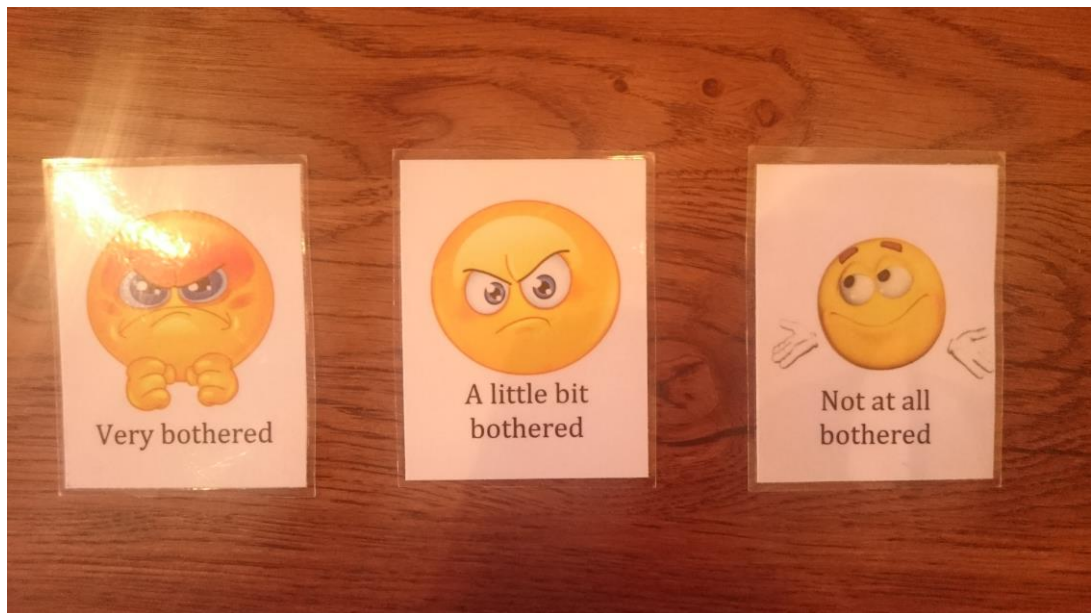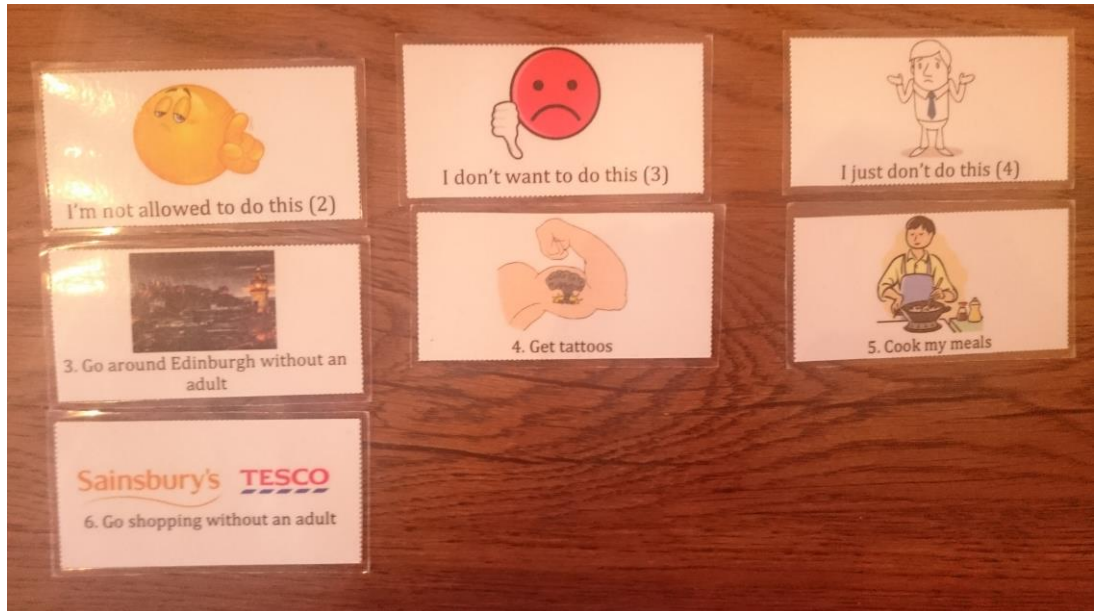
How adult is X?
- What do you think being an adult means?
- Can you tell me a bit about what, if anything, changed when they hit 5th/6th year/leave school?
  - How do you feel about them leaving school/college?
- What about when they turned 16/18?
- How has your behaviour towards them changed since they first started high school?
- What would need to change for they to think of them as being more of an adult?

Closing Question
- If you could have a Superpower, what would it be

Appendix H: Example resources for Autonomy Activity

I'm not allowed to do this (2)

I don't want to do this (3)

I just don't do this (4)

3. Go around Edinburgh without an adult

4. Get tattoos

5. Cook my meals

6. Go shopping without an adult

Very bothered

A little bit bothered

Not at all bothered

I want less

HAPPY

I want more

Appendix I: Supporting visual materials for vignette

Your friends invite you to watch a film with them after school

The film looks really cool
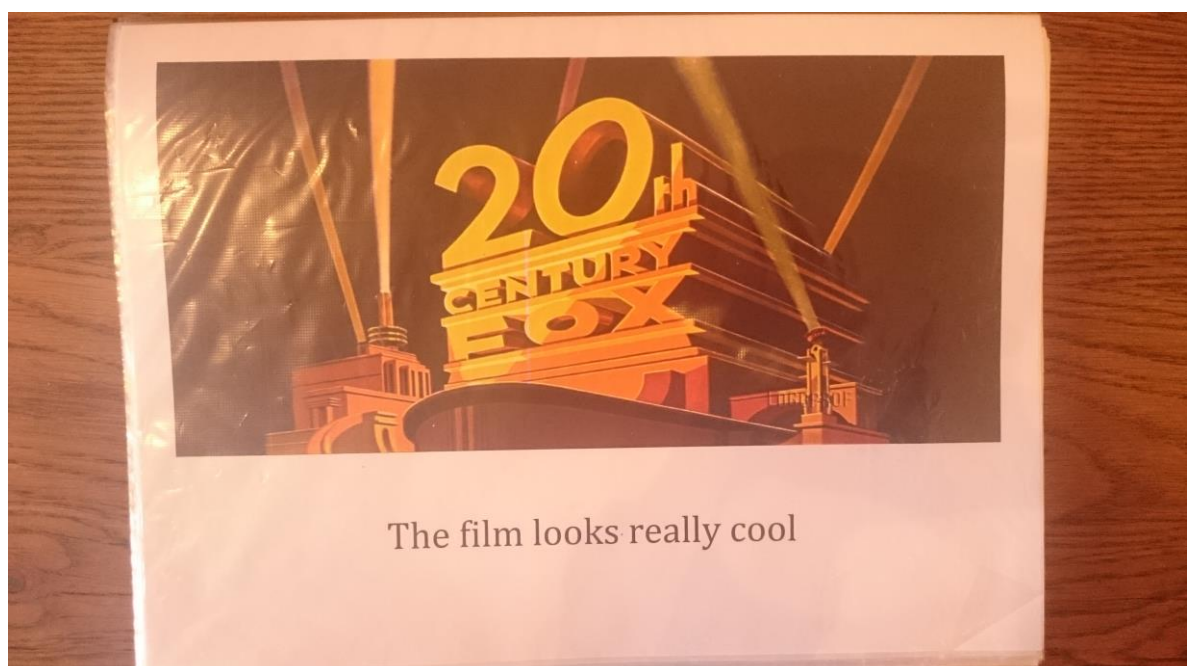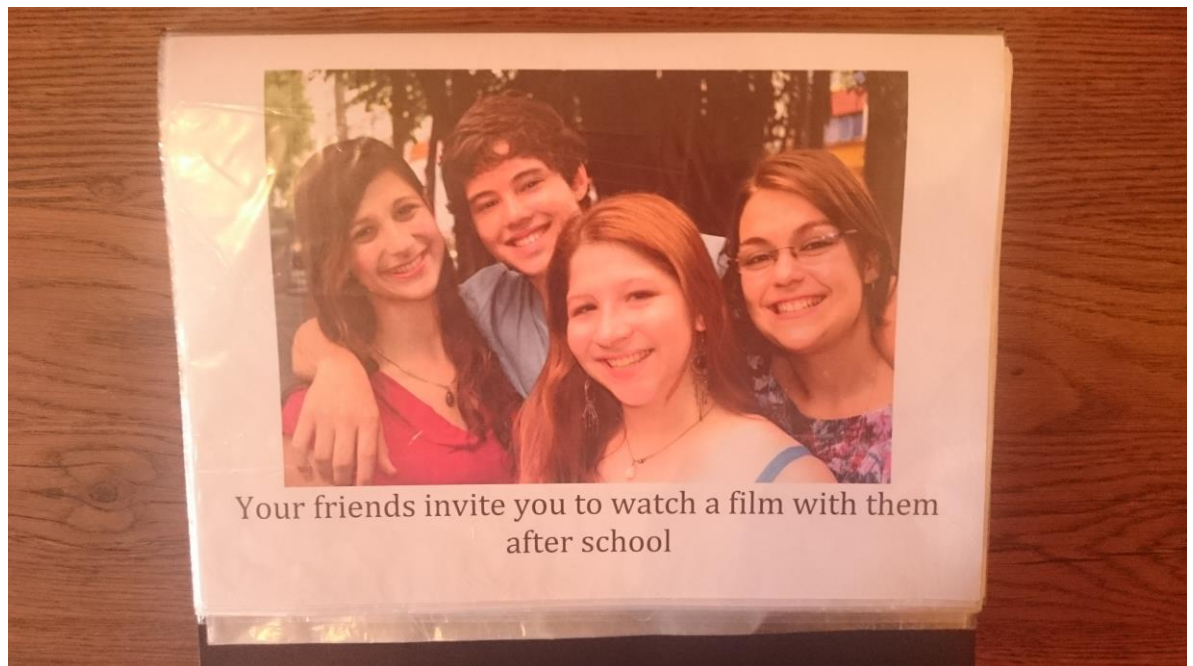
Mum says "I'm not sure I'm happy with you seeing that film"

How would you feel?

Appendix J: Example resources for Adult Identity Task

Appendix K: Parent Questionnaire

<u>Choice-Making in Adolescence: Parent Questionnaire</u>

<u>UID:</u> _____

Please note: Any information provided in this questionnaire is recorded anonymously and will be used for academic purposes only. The researcher will not sell, trade, or transfer an individual's personal information to any third party or entity. If you have any questions or concerns regarding the information you provide in this questionnaire, please contact me at e.salt.1@research.gla.ac.uk.

Part 1: Demographic Questions

Relationship to participating young person: _____

Does your child have a learning disability? Y / N

Does your child have autism? Y / N

Part 2: Opportunities in Decision-Making
On a scale of 1 – 4 (4 = Strongly agree, 1 = Strongly disagree), how much do you agree with the following statement?
If they wanted to, I would allow my young person to:

Wear what they want	1	2	3	4
Stay up as late as they want	1	2	3	4
Go around Edinburgh without an adult	1	2	3	4
Get a tattoo	1	2	3	4
Cook their own meals	1	2	3	4
Go shopping without an adult	1	2	3	4
Start a non-sexual, romantic relationship	1	2	3	4
Go to other cities without an adult	1	2	3	4
Stay at home on their own overnight	1	2	3	4
Use Facebook/twitter	1	2	3	4
Use the bus/train alone	1	2	3	4
Start a sexual relationship	1	2	3	4
Look after money	1	2	3	4
Smoke/use a vape	1	2	3	4
Work / volunteer after school/at the weekend	1	2	3	4
Make their own doctor's appointments	1	2	3	4
Drink alcohol	1	2	3	4
Tidy their room without assistance	1	2	3	4
Watch 18 rated films	1	2	3	4
Do housework without assistance	1	2	3	4
Stay out late with their friends	1	2	3	4

(Optional) If you would like to provide any further information / comments regarding the topics covered in this questionnaire, please feel free to do so here:

Appendices

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