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The impact of transition to adulthood on health and wellbeing in young people with intellectual disabilities

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Thesis submitted for the degree of Doctor of  
Philosophy

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## Abstract

**Background:** Transition to adulthood is recognised to be a difficult period for young people with intellectual disabilities, and there is evidence to suggest that outcomes across vocational and social domains may be worse for this population compared to the typically developing population. It is possible that the turbulence of the organisational transition to adulthood, including leaving school and entering adult services, combined with the social aspects of becoming an ‘adult’ may conspire to result in negative health outcomes during transition. Despite significant concern being attached to the transition period in both the scientific literature and governmental policy, there is little evidence on health outcomes during this period in the population with intellectual disabilities.

**Aims:** (1) To investigate whether transition to adulthood affects health and wellbeing in young people with intellectual disabilities, and in what particular ways; (2) to investigate whether the impact of transition on health and wellbeing is similar or different for young people with intellectual disabilities compared to those without intellectual disabilities; (3) to investigate whether the impact of transition on health and wellbeing is similar or different for young people with profound and multiple intellectual disabilities, compared with those with mild to moderate intellectual disabilities; (4) to identify what supports are helpful for families undergoing transition.

**Method:** A systematic review of the literature on health and wellbeing during transition to adulthood for young people with intellectual disabilities, and a mixed methods project, utilising both quantitative and qualitative methodologies. Secondary analysis of Scotland’s Census (2011) was conducted in order to compare health outcomes between the populations with and without intellectual disabilities undergoing transition. The Census data was then further analysed to compare health in young people with intellectual disabilities who were still in school (aged 13-18 years) with that of those who had transitioned from school (aged 19-24 years). Additionally, semi-structured interviews were conducted with young people with intellectual disabilities (n = 17) aged 16-27 years, and with parents of young people with intellectual disabilities (n = 23) aged 16-26 years, in order to uncover insights into the experience of transition from multiple perspectives. Additionally, an ethnographic study of a service for young adults with intellectual disabilities undergoing transition was completed. Interview transcripts and the ethnographic field diary were analysed using thematic analysis, deploying both emic and etic coding categories.

**Results:** Across all of the health outcomes investigated through the Census (2011) analysis, those with intellectual disabilities fared worse compared to those without intellectual disabilities. Mental health was significantly worse in the population with intellectual disabilities who had left school compared to those who were still in school. The qualitative studies revealed transition to be an anxious time for young people with intellectual disabilities, with many experiencing significantly increased anxiety during the period prior to and following school exit. This phenomenon was attributed to a lack of post-school meaningful activity; inadequate organised support during the transition to adulthood; and complex issues associated with ‘growing up’ with intellectual disabilities. Additionally, parents raised concerns regarding their children’s post-school weight gain, which was also attributed to a lack of post-school daytime activity, contributing to a more sedentary lifestyle.

**Conclusions:** Health in the population with intellectual disabilities undergoing transition to adulthood is poor, and significantly worse than in the typically developing population. Mental health especially may be negatively affected by the experience of transitioning to adulthood, and changes in lifestyle following school exit may result in weight gain leading to obesity and secondary health conditions. Improving support during transition to adulthood, as well as increasing the availability of post-school opportunities for meaningful activity, may help to combat these negative health and wellbeing phenomena. Future research should include a longitudinal study following a representative sample of young people with intellectual disabilities throughout the course of transition to adulthood in order to clarify the ways in which this important life period affects health and wellbeing.

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## Publications

Young-Southward, G., Philo, C., Cooper, S.-A. (2017) What effect does transition to adulthood have on health and wellbeing in young people with intellectual disabilities? A systematic review. *Journal of Applied Research in Intellectual Disabilities*: 30 805-823 (Appendix Q)

Young-Southward, G., Rydzewska, E., Philo, C., Cooper, S.-A. (2017) Physical and mental health during transition to adulthood in young people with and without intellectual disabilities: Analysis of a whole population of 815,889 young people in Scotland. *Journal of Intellectual Disability Research*: 61 984-993 (Appendix R)

Young-Southward, G., Cooper, S.-A., Philo, C. (2017) Health and wellbeing during transition to adulthood for young people with intellectual disabilities: A qualitative study. *Research in Developmental Disabilities*: 70 94-103 (Appendix S)

## Published conference proceedings

Young-Southward, G., Philo, C., Cooper, S.-A. The impact of transition on health and well-being in young people with intellectual disabilities: A qualitative investigation. *Journal of Intellectual Disability Research*, 60, 766. The 15<sup>th</sup> IASSIDD World Congress: Melbourne, Australia (Appendix T)

Young-Southward, G., Philo, C., Cooper, S.-A. Transition and health in young people with intellectual disabilities: Secondary analysis of existing data. *Journal of Intellectual Disability Research*, 60, 766. The 15<sup>th</sup> IASSIDD World Congress: Melbourne, Australia (Appendix T)

Young-Southward, G., Philo, C., Cooper, S.-A. What is the impact of transition to adulthood on health and well-being in young people with intellectual disabilities? A systematic review. *Journal of Intellectual Disability Research*, 60, 822. The 15<sup>th</sup> IASSIDD World Congress: Melbourne, Australia (Appendix T)

Young-Southward, G., Philo, C., Cooper, S.-A. Transition to adulthood has negative consequences for mental health in individuals with intellectual disabilities: Results from qualitative interviews and secondary analysis of existing data. *Journal of Mental Health Research in Intellectual Disabilities*, 10, 42. The 11<sup>th</sup> European Congress Mental Health in Intellectual Disability: Luxembourg (Appendix T)

## **Additional conference presentations**

### **Oral presentations**

Young-Southward, G. (2016) Health and wellbeing during transition from school: A qualitative study. Seattle Club conference, annual meeting: Glasgow

### **Poster Presentations**

Young-Southward, G., Philo, C., Cooper, S.-A. (2017) The impact of transition on health and wellbeing in young people with intellectual disabilities: A systematic review. Scottish Learning Disabilities Observatory conference: Glasgow (Appendix U)

Young-Southward, G., Cooper, S.-A., Philo, C. (2017) The impact of transition to adulthood on health and wellbeing in young people with intellectual disabilities: A qualitative investigation. Scottish Learning Disabilities Observatory conference: Glasgow (Appendix U)

Young-Southward, G., Philo, C., Cooper, S.-A. (2017) Health during transition to adulthood in the population with intellectual disabilities: Analysis of Scotland's Census (2011). Scottish Learning Disabilities Observatory conference: Glasgow (Appendix U)

## **Authors 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.”

Genevieve Young-Southward  
July 2017

## Chapter 1: Introduction

This aim of this chapter is to outline theories of transition to adulthood in relation to people with intellectual disabilities and to review the literature on transition outcomes in this population. In doing so, theories of infantilisation will be discussed, alongside UK policies of social inclusion. Running throughout the chapter will be a discussion of the ways in which the experience of transition may affect health and wellbeing in this population. Finally, the epidemiological literature on health and wellbeing in children and adolescents with intellectual disabilities will be described.

### 1 Defining intellectual disabilities

An intellectual disability is a reduced intellectual ability compared to the general population and difficulty with everyday tasks, such as socialising or managing money, with onset before adulthood. The tenth edition of the World Health Organisation's International Classification of Diseases (ICD-10) describes an intellectual disability as:

“A condition of arrested or incomplete development of the mind, which is especially characterized by impairment of skills manifested during the developmental period, skills which contribute to the overall level of intelligence, i.e. cognitive, language, motor, and social abilities.” (WHO, 1992)

The core criteria for identifying an intellectual disability therefore include significant impairment of intellectual functioning; significant impairment of adaptive/social functioning; and age of onset before adulthood (The British Psychological Society, 2000).

An intellectual disability is identified through an IQ score that is two or more standard deviations below the mean for the individual's chronological age cohort, and through performance on a standardised measure of adaptive behaviour, normed on the general population, that is two or more standard deviations below the mean (American Association on Intellectual and Developmental Disabilities, 2010). Adaptive behaviour is a collection of social, conceptual and practical skills that have been learned and are performed by individuals in their everyday lives (American Association on Intellectual and Developmental Disabilities, 2010). Adaptive behaviour can be assessed through the Vineland Adaptive Behaviour Scale (see also Chapter 4), an assessment tool for measuring the level of adaptive functioning in an individual across three domains:

- Communication (receptive, expressive and written);

- Socialisation (interpersonal relationships, play and leisure time and coping skills);
- Daily living skills (personal, domestic and community).

Standard deviations from population means are used to establish boundaries of intellectual disabilities, reflected in standard scores. Different classifications of intellectual disabilities can therefore be identified:

- Mild disabilities: 50–69
- Moderate disabilities: 35–49
- Severe disabilities: 20–34
- Profound disabilities: below 20.

## 1.1 Prevalence of intellectual disabilities

A meta-analysis of studies published between 1980 and 2009 found a prevalence of intellectual disabilities in children and adults combined of 10.37/1000 population globally, and 9.21/1000 population in high income countries (Maulik et al., 2011). For adults alone, the prevalence of intellectual disabilities was 4.94/1000 (Maulik et al., 2011). Scotland's Census (2011) demonstrated that 0.6% of school-age children in Scotland had intellectual disabilities and 0.49% of all adults in Scotland had intellectual disabilities (Scottish Learning Disabilities Observatory, 2016).

Prevalence rates of intellectual disabilities do not remain fixed across the lifespan. An intellectual disability is a label assigned by social systems (Greenspan, 1999); as such, an individual is more likely to be given the label of an intellectual disability at school, since individuals with low IQ are more likely to struggle with the demands of the education system. In this way, attaining the label of an intellectual disability when at school may be advantageous in that such a label affords access to supports in and out of school. However, such supports may no longer be needed during adulthood for those with milder disabilities who have acquired sufficient skills for independent living over time, and so prevalence estimates may be different for children and adults. Indeed, in a meta-analysis of prevalence studies, estimates were higher for children than for adults (Maulik et al., 2011). Emerson (2011) cites a number of reasons why prevalence rates of intellectual disabilities may



decline between childhood and adulthood, including: a decrease in health surveillance in post-educational settings; a possibly less disabling impact of intellectual disabilities in non-educational settings; a rationing of specialised supports to adults with intellectual disabilities; and the stigma around intellectual disabilities that may result in a reluctance to self-identify as having intellectual disabilities, all of which may result in less use of specialised services, which are often used to identify individuals with intellectual disabilities in order to estimate prevalence rates. Furthermore, premature death in individuals with intellectual disabilities may also contribute to decreased prevalence rates in adulthood.

This thesis concerns young people with intellectual disabilities undergoing transition in Scotland. Across Scotland, the prevalence of people with intellectual disabilities aged 16–24 years is currently measured at 0.66% (Scottish Learning Disabilities Observatory, 2016). This figure is higher than the 0.6% prevalence for all school-aged children (Scottish Learning Disabilities Observatory, 2016) because some individuals will not have been identified as having intellectual disabilities at the point of entry to school.

## **2 Conceptual definitions of transition**

### **2.1 Traditional models of transition**

Conceptually, transition can be described as the movement from childhood to adulthood. The traditional Western model of transition encompasses a number of markers typically associated with adulthood: leaving school and entering the workplace; moving out of the parental home into independent living; getting married and having children. These markers encapsulate the fundamental shift from dependence to independence implied by transition; and central to all components of transition, including establishing a career, creating one's own home and developing a network of social relationships, is the ability to make effective decisions independently. Thus, this ability is central to conceptualisations of adulthood.

Traditionally, transition in an economic sense – specifically progressing from school to work – has been regarded as pivotal to transition, with young people deemed to be adults upon entering the workplace (Pollock, 2002). In this way, a full-time job is seen as the gateway to adulthood: on a practical level the income generated allows young people to gain independence from their parents; to move in to their own home, and to fund marriage and children, and on an individual level the traditional personal qualities of adulthood,

including responsibility and independence, are conferred through participation in the labour market.

## 2.2 Contemporary models of transition

Pollock (2002) points to the difficulty of conceptualising transition in purely economic terms, arguing that this traditional model of transition is based on a working-class male paradigm which necessitates excluding whole sections of society, including those with disabilities, who may not have the opportunity to transition from school to employment, and who may not make the assumed shifts towards independence upon leaving school. Furthermore, Bynner (2005) argues that the recent recession has stimulated a shift from traditional transition, with young people now experiencing an extended childhood, with prolonged education and later entrance into the workplace, independent living and parenthood. Arnett (2000) argues that young people experience a period of ‘emerging adulthood’ during the transition years, which is distinct from both childhood and adulthood. This period, occurring between the ages of 18 and 25, constitutes a separate, semi-autonomous space where young people have left behind the dependence of childhood but do not yet have the long-term responsibilities of adulthood. This position leaves them free from social roles and normative expectations, and allows them to explore multiple identities before taking on the long-term responsibilities of adulthood, such as parenthood. This is an exploratory period, and the demographic variability of this age group reflects the scope of individual choice available during this time. It is crucial to acknowledge that this phenomenon may be class based, and is more likely to characterise industrialised cultures where desirable career paths require considerable educational achievements (Arnett, 2000), wherein a prolonged period of education allows young people to amass experience before fully entering the workplace.

These conceptualisations of transition focus on occupational/economic gains and the changes in identity in terms of independence and responsibility that these necessitate. However, this is only one of many ways of defining adulthood; alternatively, personal qualities such as self-esteem and efficacy may be emphasised in conceptualising adulthood (Worth, 2009). Valentine (2003) stresses the difference between a biological and performative understanding of age: biological age does not necessarily correlate with emotional maturity, and it is qualities of character that convey the maturity associated with adulthood. King et al. (2005) conceptualise transition as a change in roles, which highlights the idea that transition is not necessarily a straightforward, linear move from school to

work, but is in actuality a complex developmental process involving the construction of multiple identities: from student to employee; child to adult; dependence to independence. Indeed, some of these experiences overlap, with, for example, many young people pursuing part-time work while still at school (Wyn & Dwyer, 2000). This phenomenon calls attention to the fact that many young people are balancing a range of personal, occupational and educational commitments while still at school, and that school does not constitute a separate space where young people are prepared for life. Thus, in some respects adulthood is delayed and in others it arrives sooner: the picture of transition is complex, even for individuals considered to be following a 'normal' trajectory. This argument leads to Worth's (2009) re-formulation of transition as 'becoming', emphasising the fluid nature of time and identity, and thereby challenging the idea of transition as movement in a linear fashion from one fixed position to the other. In this way 'becoming' is continually open to the future, and constitutes an evolving sense of one's self and one's position in the social world. Thus, multiple transitions can happen at once and on different timescales.

These multiple, co-occurring transitions can have profound implications for the psychology of those experiencing them. Erikson (1968) describes transition as an identity crisis as young people explore multiple possibilities in love, work and worldviews (Arnett, 2000). During such exploration, identity conflicts are negotiated by young people as they navigate changes in their sexual, peer and family relationships (Bynner, 2005), adjusting to new roles and identities as they develop the skills and characteristics necessary for entry into adulthood.

## **2.3 Transition as a universal concept**

Hudson (2006) emphasises that transition is a universal phenomenon, with the biological changes associated with adolescence affecting people throughout history and across societies. However, some cross-cultural differences in the experience and demarcation of transition may be apparent. Arnett (1998) compares contemporary American conceptualisations of transition to cross-cultural and historical conceptualisations, finding both similarities and important differences. In Western culture, entry into adulthood is predicated on the development of individualistic qualities of character; in particular, accepting responsibility for one's self and exercising independence in decision-making. Anthropologists such as Schlegel and Barry (1991) have demonstrated that traditional non-Western cultures also regard the development of these traits as a key component of

transition to adulthood, but crucially, for these cultures the transitional period culminates in a definitive and unambiguous marker of adulthood: marriage. Indeed, in a qualitative investigation exploring perspectives on transition from 16 Latina mothers in Los Angeles, Rueda et al. (2005) found that mothers were averse to the idea of their children attaining independence in decision-making or living arrangements without marriage, which was considered a clear, sanctioned gateway to adulthood. Following this model of transition, ‘childhood’ could be extended chronologically well in to the 20s, 30s and beyond.

The idea that cultural norms dictate experiences of transition calls attention to the notion that, across cultures, there is no one set path to adulthood that one should follow. The ‘normal’ conceptualisation of transition is queered by all kinds of people for a variety of reasons. Thus, there are deficiencies in this model of transition, with individuals with intellectual disabilities comprising just one, admittedly very particular, challenge to it. The description of certain practices as being associated with adulthood as ‘normal’ is value-laden (Murphy et al., 2011) since it presents them as universal rather than different versions of reality that individuals can choose to accept or reject. In this way, ‘normal’ risks becoming normative, which has problematic connotations: an assumption of normativity suggests an exertion of power over those who do not conform, with an array of governmental expectations designed to ‘normalise’ such people. This argument is especially relevant in the context of considering transition in individuals with intellectual disabilities, who in many ways do not fit into society’s conceptions of ‘normal’.

## **2.4 The age range of transition**

The above discussion calls attention to the wide age range that can potentially be included in a discussion of transition to adulthood, with differences hinging on how ‘adulthood’ is conceptualised, and thus when it is reached. As aforementioned, traditional models of transition regard adulthood as being demarcated by participation in the labour market, but cross-cultural models of transition suggest that adulthood is not reached until marriage. As this chapter will discuss in detail throughout the next sections, the concept of adulthood may be complicated for individuals with intellectual disabilities, and so transition may span a longer period for this population than in the typically developing population.

The purpose of this thesis is to explore the impact that this complicated transition experience has on health and wellbeing in individuals with intellectual disabilities. As such, a wide age range will be considered to incorporate transition, with school exit – an

event around which ‘transition planning’ in the context of services and support is organised (see Section 3.1) – being considered a key reference point, but also acknowledging that ‘adulthood’ may not be reached until much later. The term ‘youth’ is defined as “the period between childhood and adult age” (Oxford English Dictionary). Henceforth, this thesis will use the terms ‘young people’ and ‘young adults’ to refer to individuals undergoing transition to adulthood, including those from the early teens to the late 20s.

### **3 Care provision for the population with intellectual disabilities in Scotland**

Health care services differ considerably between those for children and young people and those for adults with intellectual disabilities. Regarding physical health care of children and young people with intellectual disabilities, there are comprehensive paediatric services in the UK, including community paediatric teams, and hospital based general paediatric services and the full range of paediatric specialties, offering out-patient care, in-patient care and, in some areas, respite care. Most children with intellectual disabilities receive health support through paediatric services, including medical care and care from professionals in a range of other disciplines depending upon need, for example speech and language therapists. Regarding mental health care, there is a mixed economy of support across the UK, with some areas providing highly specialist intellectual disabilities child and adolescent mental health services (CAMHS), whilst others adopt a child-first approach offering health care for children with intellectual disabilities via mainstream CAMHS. Each child and young person is registered with a general practitioner (GP), and the GPs and associated primary care services are supported by the secondary care professionals in paediatric and CAMHS services. Additionally, schools and school nurses may play a vital role in signposting families to relevant sources of support elsewhere.

Health provision differs for adults with intellectual disabilities from that for children and young people, with the biggest change being that there is no adult equivalent of community paediatric services and secondary care general paediatricians. Care therefore transfers to general practitioners, and the loss of paediatric care may be a challenging time; indeed, often paediatric services continue providing care into adulthood (NHS Greater Glasgow and Clyde Learning Disability Health Needs Assessment, 2011) due to the lack of an equivalent alternative to hand over to. While hospital based services offer out-patient and inpatient care across a range of specialties, these are focussed on single medical systems (for example, respiratory or neurological) and do not address the multi-morbidity that is so

common and complex for people with intellectual disabilities. Mental health services, however, are well developed for adults with intellectual disabilities across the UK, including in rural areas, typically provided via community intellectual disability teams (Jess et al., 2008), which include professionals from a range of disciplines, such as psychiatry, clinical psychology, nursing, speech and language therapy, physiotherapy, and occupational therapy. The main gap in service provision for adults is therefore the lack of generalist physicians in secondary care, and this is typical of that seen in developed countries across the world. In contrast, the Netherlands health service provides general practitioners who are trained specialists in intellectual disabilities, whose practice is focussed solely on people with intellectual disabilities. No equivalent exists in the UK.

In the UK, all health services, aside from general practitioners, are either for children and young people or for adults, meaning that at the point of transition a hand over of care must take place, which can be a huge change in a person's life. Furthermore, due to the complex co-morbidities often experienced by people with intellectual disabilities, many frequently attend hospital, and must also change from a paediatric to a general hospital at the point of transition.

## **4 Policy definitions of transition**

For the population with intellectual disabilities, 'transition' is a recognised term for the period of time during which young people leave school and move from children's to adult health and social services. To facilitate this transition, Individualised Education Plans (IEPs) are provided for young people with intellectual disabilities in secondary schools in the UK. IEPs are introduced when a young person is still at school, with the aim of mapping out his or her transition to adulthood. They contain both short-term and long-term targets, and are reviewed yearly in order to monitor progress and to identify challenges. Numerous transition planning guidelines have been issued to encourage service providers to plan transition to adulthood in a person-centred way. For example, the Department of Health, London (2006) highlights that transition is a process for young people rather than a single event, emphasising the need for flexibility in terms of transition planning and service provision, with support being tailored to each individual. Additionally, the National Institute for Care Excellence (NICE) guidelines on transition (NICE, 2016) state that transition planning must take into account an individual's cognitive abilities, psychological status and long-term health needs in order to ensure that transition is developmentally appropriate. In this way, person-centred approaches are advocated in order to empower

young people to make their own decisions, thus ensuring that they are fully involved in the process and that their needs and wishes are met.

## **4.1 Scottish policy on transition from school for the population with intellectual disabilities**

Scottish policy on care for individuals with intellectual disabilities has in recent years focussed on the need for individuals and their families to exercise choice and control over their care. In 2000, the Scottish Government published *The Same as You?*, a review of Scotland's intellectual disability strategy. This document called for a shift towards more person-centred and needs-led approaches, putting the person with intellectual disabilities at the centre of decisions being made about them. The importance of Local Area Coordinators (LACs), who were appointed by local authorities, and whose role should be to provide localised support to all individuals with intellectual disabilities, was highlighted. This role included arranging a 'Personal Life Plan', which includes details of an individual's healthcare needs as well as any other supports, including education, transport and activities, that are needed and how these needs should be met. In this way, choice regarding supports and services is given to individuals with intellectual disabilities and their families or carers, rather than state provision of a pre-ordained suite of services, with service provision now coming from a mix of state, voluntary and private providers.

Another attempt to increase implementation of person-centred and needs-led approaches has been the introduction of Self-Directed Support. Since 1997, direct payments have been in place; these involve local authorities giving money directly to families so that they can purchase the help they need for their family member with intellectual disabilities themselves. The Scottish Government's most recent (2013) intellectual disability strategy, *The Keys to Life*, outlines the Social Care Self-Directed Support (Scotland) Act (2013), which aims to provide individuals with intellectual disabilities with greater choice and control over the services they receive through direct payments, allowing them to purchase services themselves or by facilitating greater decision-making over the services that are provided.

A variety of planning services specifically for children and young people with intellectual disabilities are identified in both *The Same as You?* and *The Keys to Life*. All children who have a 'record of needs' must have a Future Needs Assessment at the age of 14 years, identifying what provision in terms of education and care is required after school exit. The

record is discontinued either when a person leaves school or turns 18. *The Same as You?* identified numerous problems with Future Needs Assessments, including healthcare seldom being included, as well as a lack of long-term planning. The transition from school was highlighted as being of particular importance in *The Same as You?*, and, since local authorities are responsible for meeting post-school needs, such as education, health or respite services, a need for partnerships between local authorities and NHS boards in planning services was identified. *The Keys to Life* further reinforced the importance of information exchange between education authorities and other agencies, such as social work, to support transition planning. It was also emphasised that transition planning should occur no later than one year prior to the transition itself. Hence, within Scottish policy transition from school has been identified as an area requiring more comprehensive care and greater emphasis on individual choice for this population, and efforts have been put in place to facilitate a smoother transition experience.

Outside of governmental policy, third-sector organisations have also directed resources towards producing guidance on transition. The Scottish Transitions Forum, supported by the Association for Real Change (ARC) Scotland – a charity promoting person-centred support for individuals with intellectual disabilities or other support needs – was set up in 2008 and includes professionals supporting young people with additional support needs, as well as young people, parents and carers. The aim of the forum is to improve experiences of young people with additional support needs between the ages of 16 and 25 years undergoing transition through working collaboratively with young people, parents and professionals in order to identify gaps in support and to inform and offer guidance on approved approaches to transition. The forum produces documents outlining the *Principles of Good Transitions*, which serve as a framework to inform support for young people throughout transition.

## **5 Transition to adulthood in the population with intellectual disabilities**

While transition to adulthood for the population with intellectual disabilities involves substantial shifts in institutional support when individuals leave school and move from child to adult health services, conceptual components of transition, including increased independence, may also be evident. Young people with intellectual disabilities undergoing transition may hence experience the practical components of transitioning from school and to adult supports and services, as well as navigating changes in their roles and identities as



they approach adulthood. Despite substantial focus in Scottish policy on transition planning and support, the existing literature on the experience of transition for individuals with intellectual disabilities and their families, and on transition outcomes for the population with intellectual disabilities, is largely negative, with those with intellectual disabilities experiencing poor outcomes compared to the typically developing population across various measures of transition success, including social relationships (e.g. Hamilton et al., 2015), work and independent living (e.g. Luftig & Muthert, 2005). The following section will review this literature.

## **5.1 Existing literature on transition outcomes in the population with intellectual disabilities**

The legal distinctions associated with adulthood, such as being able to marry, drive and vote reflect an implicit assumption about the correspondence between chronological age and the ability to exercise critical, reflective thought (Murphy et al., 2011), which Reinders (2000) refers to as “rational moral agency”. Some theorists argue that when the capacity for such rational thought is impaired, as may be the case to some extent for some individuals with intellectual disabilities, then the opportunities for self-determination and choice that are usually available in adulthood are – and maybe should be – limited (Murphy et al., 2011). The normal avenues open to adults in the typically developing population hence become blocked to those with intellectual disabilities. However, social inclusion, which is outlined in *The Keys to Life* (2013), the Scottish government’s intellectual disability strategy, is the foremost social policy in the UK. This policy argues that people with intellectual disabilities should have equal access to participation in the community and society as people without disabilities, and is guided by the principles of rights, independence, choice and control (Department of Health, 2001). These competing ideologies may serve to complicate transition experiences for young people with intellectual disabilities, as the adults around them struggle to strike a balance between facilitating their independence, a supposedly ‘normal’ life, and catering to their additional support needs. Indeed, it must be acknowledged that some individuals with multiple and profound intellectual disabilities may never transition to adulthood in the sense of being able to exercise independent decision-making, even with support. The experience of transition is hence complex for this population; indeed, Hudson (2006) describes the transition experiences of young people with intellectual disabilities as being characterised by longer duration and more attenuated experiences than those of their non-disabled

counterparts, arguing that such characteristics threaten to slow transition down or even to prevent it from happening at all.

### **5.1.1 Independence**

Self-determination, synonymous with self-governance, has been referred to as the ability of an individual to control their own life (Wehmeyer, 2001). In this way, self-determination can be regarded as a form of empowerment, with numerous psychological benefits. The push towards choice and control for individuals with intellectual disabilities and their families over services demonstrated in governmental policy (see Section 3.1) clearly recognises the importance of individuals with intellectual disabilities experiencing control over their own lives. Furthermore, transition to adulthood is a period of time during which one might expect levels of personal control, or self-determination, to increase. However, research demonstrates that during this period, young people with intellectual disabilities still experience limited opportunities to exercise independence.

This phenomenon may be attributed to the position of individuals with intellectual disabilities in society. Baron et al. (1999) describe society as ‘ableist’, wherein disabled individuals are constructed as being vulnerable and in need of care and protection, lacking the ability to negotiate adulthood autonomously. These perceptions can lead to infantilisation, wherein people with intellectual disabilities are characterised as lacking the required capacities for adulthood, hence being rendered eternally childlike. Indeed, Greenspan (1999:6) proposes that an “ongoing need for supports and protections” and “vulnerability to potential exploitation and manipulation” are key components of the very definition of intellectual disabilities. These qualities stand in direct opposition to some key characteristics of adulthood, including independence and autonomy.

Attributions of vulnerability of people with intellectual disabilities are evident in the literature, with parents’ concerns for their teenage/adult child’s safety prevalent. Hamilton et al (2015) conducted a focus group study with six parents of adolescents with intellectual disabilities recruited from a disability services database in Australia. They found that while parents expressed a desire to increase independence in their child, they worried too about their safety when doing so. Parents worried specifically about their child’s ability to assess risky situations, prompting concerns about their ability to navigate community and interpersonal relationships independently without risk of exploitation or harm. While this study involved parents of teenagers who were experiencing a range of emotional and

behavioural difficulties alongside their intellectual disabilities, the sample is small and all informants were mothers. Thus, perspectives from other family members or carers are excluded. In a larger qualitative study involving ethnography and interviews with 77 parents and 64 young people with intellectual disabilities who were undergoing transition, recruited from community and healthcare settings in California, an overarching theme for parents was ensuring a safe environment for their child, including: housing, financial security, legal protection, personal safety and freedom from exploitation (Rehm et al., 2012). In this way, parents' highest priority during the transition to adulthood was to ensure that their child had a safe environment from which to enjoy a high quality of life as an adult. This study benefits from an ethnically diverse sample; therefore, it was able to capture differing cultural expectations regarding independence. While many parents hoped for some form of independent living for their child, for example supported accommodation, ethnic minority families explicitly envisioned continued interdependence and cohabitation with their child into adulthood as both normal and desirable (Rehm et al., 2012). Despite the diverse sample, participants were limited to those who could speak English and were primarily well-educated and middle class. Thus, perspectives from families of lower socioeconomic status were not included, so subtler cultural differences may not be apparent.

Concerns over a young person's safety can have implications for the relationship between young people and their parents. Hamilton et al. (2015) describe young people with intellectual disabilities as having asymmetrical relationships with their parents in that they are helpful and supportive but also overprotective and dominant. Docherty and Reid (2009) conducted qualitative interviews with eight mothers of young adults with Down syndrome who were recruited from a national Down syndrome organisation in Scotland. Although mothers expressed a desire for their children to continue to develop towards a full adult identity, they reported being heavily involved in arranging activities for them. In this way, they were simultaneously serving as both gatekeepers and facilitators to their child's engagement with wider society, taking responsibility for assessing and accessing local resources for them. As parents are accustomed to being relied upon by their child in this way, it may be difficult for them to relinquish some of this protection as the young person transitions to adulthood. There may thus be a tension between parents and their adolescent children about autonomy and independence, since these characteristics can sometimes contradict teenagers' need for ongoing family support and involvement through to adulthood (Blacher, 2001).

In relation to fears about safety, the gradual opportunities to make choices and to take on responsibilities, usually facilitated in and for typically developing children as they get older, are often delayed in young people with intellectual disabilities, or not expected at all, since it may be difficult for parents to encourage responsibility in their child when they are unaware of the upper limits of their capabilities (Hallum, 1995). For instance, simple yet empowering tasks that are often assigned to typically developing children, such as going to the local shop alone, are often not considered appropriate for children or young people with intellectual disabilities. This scenario can reinforce a sense of incompetency and a childlike status, which can have profound effects on young people's ability to exercise independence as they transition to adulthood, for they are accustomed to other people intervening when they are struggling. This scenario conflicts with the notion that functioning as independently as possible is a key component of adulthood (Rehm et al., 2012); and, because professionals working with young people with intellectual disabilities may begin to emphasise this characteristic as their clients get older, a tension may occur between parents and professionals during this life stage. For example, in an ethnographic study of a unit for school leavers within a special education school in the UK, Todd (2009) observed teachers adopting a moralistic teaching style, urging students to take more responsibility for themselves and to appreciate the needs of others. Although this study represents practices from a single programme for students with intellectual disabilities, and the findings cannot be generalised to other curriculums, this finding can be contrasted to a parenting style that may perpetuate dependence.

Indeed, Rehm et al. (2012) conducted an extensive qualitative study involving both parents ( $n = 77$ ) and young people with intellectual disabilities ( $n = 64$ ) in the USA, in which problems in facilitating independence for young people were identified. Parents who were accustomed to being relied upon found it difficult to increase independence in their child during the transition to adulthood; consequently, young people with intellectual disabilities exhibited ongoing reliance on their parents. Rogers (2010) refers to this tension between practitioners in intellectual disability services and parents as 'mother blaming', a phenomenon whereby mothers are regarded by professionals as perpetuating infantilised roles in their children through placing obstacles in the way of their independence. It must be noted that none of the qualitative studies described in this section included a non-disabled comparison group, and the views expressed by parents could simply reflect fears that all or most parents of adolescents at this age experience. Indeed, Ungar (2009) describes an increasingly widespread phenomenon of 'overprotective parenting', wherein parents of typically developing children and young people demonstrate increased

surveillance of their children and denial of opportunities for independence. These behaviours are attributed to the stresses of modernity and heightened expectations for children to achieve (Ungar, 2009). However, it is reasonable to assume that the situation for young people with intellectual disabilities is especially complicated, given their more limited capabilities relative to their peers without intellectual disabilities.

Despite potentially dependent relationships with parents, and fears about moving beyond those relationships, evidence suggests that some young people with intellectual disabilities do wish to assume more adult characteristics as they grow up. In a qualitative study of nine adolescents with severe intellectual disabilities undergoing transition to adulthood recruited from a school in the USA, young people expressed a desire for the adults in their lives to recognise that they were capable of making rational decisions, and hence a wish for more independence from the authority figures in their lives (Cooney, 2002). Additionally, in a qualitative study of 43 young people with intellectual disabilities recruited from schools and colleges in England who were interviewed at two time points, one year apart, young people acknowledged the importance of family in their lives, but still expressed a desire for greater independence (Small et al., 2013). Both of these studies captured views from young people with intellectual disabilities directly; this evidence therefore suggests that discordant attitudes towards facilitating independence between young people and their parents may cause problems as expectations for young people with intellectual disabilities among the adults in their lives change – or, indeed, do not change.

Thus, when young people with intellectual disabilities leave school, the shift towards independence which is central to conceptual definitions of transition, and which is assumed to occur gradually for typically developing young people following school exit, may not occur. This phenomenon may be primarily attributed to young people's perceived incapability relative to the typically developing population, and hence parents' concerns for their safety in the adult world.

### **5.1.2 Transition planning and transition between services**

As mentioned previously, transition planning occurs for young people with intellectual disabilities before leaving school, and some services are devoted to supporting young people and their families through the transition. Despite such services, evidence suggests that families' needs are not necessarily met. A mixed methods study by Clarke et al. (2011) involved qualitative interviews with 130 staff across five transition services in England and

a postal survey of parents and young people with complex health needs, including intellectual disabilities, who were receiving these services (pre-transition;  $n = 110$  parents and 73 young people) or had received these services within the last two years (post-transition;  $n = 33$  parents and 24 young people). The findings identified areas in which transition services failed to fulfil families' requirements, including a lack of information about future options, such as education or employment, a lack of help to access leisure and social activities, and a lack of support to develop independent living skills (Clarke et al., 2011). Staff acknowledged some gaps in support, while also calling attention to the ways in which their services attempted to support young people and their families. Indeed, while there were examples of good practice, these were patchy and were not exemplified across the services under study.

In a review of good practice in transition services for young people with intellectual disabilities, Barron and Hassiotis (2008) identified inter-agency coordination, comprehensive planning and involvement of young people and their families in the process as key factors in facilitating a positive transition experience. However, qualitative evidence from both young people with intellectual disabilities and their families suggests that these factors are not always experienced in practice. In a longitudinal study following 28 young people with moderate to profound intellectual disabilities who had left schools in two local authorities in England through their transition to adult services, young people and their carers reported a lack of involvement in the process, and a sense that the choices of the young people were not always recognised as legitimate (Murphy et al., 2011). Beresford (2004) conducted a review of the evidence on families' perspectives of transition planning, finding that low expectations and limited aspirations from both young people and transition staff were reported. Furthermore, young people were given constructed choices based on what was deemed to be 'realistic' for them to achieve, rather than relating to what they actually aspired to achieve. In this way, transition planning did not pay sufficient attention to the things that were most important to young people, such as friendships and leisure activities. Barriers to a young person exercising choice over their transition options may also be imposed by parents: Pilnick (2011) conducted conversation analysis on 16 transition planning and review meetings in England, revealing that, in cases where parents' desires were at odds with their child's, it was the parents' preferred outcome that was pursued by the chair of the meeting. In these scenarios, young people were presented as unreasonable and unable to make rational decisions by their parents in order to justify their argument. In contrast to these experiences, in an action research study involving young people with intellectual disabilities in England, young people undergoing transition

expressed a desire to make decisions themselves; indeed, this was regarded as one of the best things about being an adult (Williams & Heslop, 2005). In reality, however, young people reported feelings of being channelled into a particular role rather than being able to make their own choices during their transition planning (Williams & Heslop, 2005).

This lack of regard for young people's choices in transition planning may affect their engagement with the process. Shogren and Plotner (2012) conducted a secondary analysis of the first wave of data collection of the National Longitudinal Transition Study-2 (NLTS-2), a national study conducted in the USA to examine transition experiences of students with disabilities, in order to compare transition planning for students with intellectual disabilities and other disabilities. Significantly fewer students with intellectual disabilities attended their Individualised Education Plan (IEP) meetings compared to those with other disabilities. Furthermore, only 62% of families of students with intellectual disabilities had received information about the services available to them after high school, even though students with intellectual disabilities had more identified support needs than students with other disabilities. Moreover, in a qualitative study examining the educational transition of adolescents with both physical and intellectual disabilities involving interviews and focus groups with 13 students who were recruited from a self-advocacy group in New York, and nine of their parents, Hetherington et al. (2010) discovered that most students were not actually aware of being involved in transition planning. Parents were equally disengaged from the process, with many reporting that the school had failed to engage them in transition planning and that their receipt of support had been 'too little, too late' (Hetherington et al., 2010). Furthermore, parents characterised their involvement with educational professionals as a 'battle' (Hetherington et al., 2010), with parents having to nag schools to proceed with transition planning. It must be noted that participants for this study were recruited from a single self-advocacy group in New York; these results may therefore represent characteristics of schools specifically within this geographical area. In addition, although the study provides perspectives from both young people with intellectual disabilities and their parents, the authors note that due to an interview procedure involving purely verbal responses, some young people struggled to provide detailed responses to interview questions. This study might therefore only provide limited views from young people with disabilities.

Animosity between parents and professionals during the transition process has been reported in other studies. Todd and Jones (2003) interviewed 30 UK mothers of young people with intellectual disabilities, recruited from social services departments and support

groups, about their experiences of dealing with professionals during transition, a time at which significant changes in the professional network may occur as young people leave school and move to adult services. Mothers described conflict and struggle with professionals as being anticipated and routine; consequently, professionals were regarded as barriers to progress rather than facilitators. This study supports negative findings elsewhere regarding the relationship between professionals and parents as in the Hetherington et al. (2010) inquiry reported above, which suggests that this negativity may be a widespread feature. This conclusion is concerning given that transition is a crucial juncture which necessitates close collaboration between parents and intellectual disability services to ensure positive outcomes for young people. Indeed, in a study involving interviews and questionnaires administered to 128 parents of young adults with severe intellectual disabilities identified from the Southern California Regional Center system, parents' satisfaction with their level of involvement in transition planning significantly predicted their level of satisfaction with transition planning overall (Neece et al., 2009).

In contrast to these negative findings, Kramer and Blacher (2001) conducted interviews with 52 families with transition-aged children with severe intellectual disabilities and found that the majority reported a high degree of involvement during the transition process, with 96.2% describing themselves as feeling like an equal partner during transition planning and 88.5% reporting feeling as though they made final decisions during transition planning. For these families, the overriding difficulty was the lack of post-school options available for their child, rather than problems experienced during transition planning. Similarly, in Shogren and Plotner's (2012) analysis of the NLTS-2, parents of students with intellectual disabilities ranked transition planning as more useful than did parents of students with other disabilities.

Similarly to transition planning experiences in schools, evidence suggests that the transition between child and adult health and social services is experienced negatively by both young people with intellectual disabilities and their parents. This is a period in which a significant change in the professional network occurs but is also, paradoxically, a time when families need more support (Todd & Jones, 2003). Hudson (2006) conducted interviews with professionals working within child and adult intellectual disability services in England ( $n = 18$ ), young people at different stages of transition identified through social services, and their parents ( $n = 23$ ). Reports from young people and parents indicated that the transition period was characterised by discontinuity, and families expressed frustration and confusion during this time, with differences in style and philosophy between child and



adult services contributing to difficulties. This situation may be exacerbated by inappropriate transition timescales: the point at which young people ‘age out’ of child services may not coincide with the point at which they no longer need service input (Beresford, 2004). Furthermore, children’s services may be more suited to providing care for individuals with intellectual disabilities than adult services, perhaps through providing a more family-oriented style of service (Barron & Hassiotis, 2008). Indeed, McDonagh and Viner (2006) highlight the need for adult health care providers to develop a greater understanding of and confidence in providing adolescent health care; in this way they envision the key challenge related to healthcare during transition as being to bridge the gap in service provision style between paediatric and adult health teams.

A less supportive atmosphere may result in less contact with services; in a study of 74 young people with cerebral palsy undergoing transition, recruited from the Cerebral Palsy register in Liverpool, England, diminished contact with health services was reported once young people had left school (Stevenson et al., 1997). Additionally, Reiss et al. (2005) conducted interviews and focus groups with 143 young adults with various disabilities and special health care needs, their families, and health care providers. Participants were recruited from children’s hospitals, outpatient clinics, community medical centres, and professional meetings across the USA. The cognitive ability of the young person was a central concern, with more difficulties experienced for those with more severe cognitive impairments; in these instances, families found it difficult to find adult health care providers who could work with the young person and collaborate with the family. In addition, young people and families reported a hesitancy to ‘start all over again’ with a new practitioner who did not necessarily understand the nuances of their disability. Furthermore, paediatric staff were regarded as more available for psychosocial support than staff from adult services, and were considered to offer a more collaborative approach, respecting parents’ expertise in their child and their condition. Although this study had a large sample size and covered a variety of disabilities, the authors note that only a small number of individuals from each disability category responded; therefore, this study may only represent the views of a small number of families and young people with intellectual disabilities.

Some of the animosity between parents and professionals during transition between services may be related to differences in perceptions of appropriate roles during the transition. Geenen et al. (2003) surveyed 753 parents of adolescents with various disabilities, including intellectual disabilities, residing in Oregon. The aim of the research

was to assess parents' perceptions of their health care providers' level of involvement in transition, and the extent to which they felt that it was their role to participate in certain transition activities. In addition, 141 physicians identified through the Oregon Pediatric Society completed a similar survey. Discrepancies between professionals' and parents' opinions were evident; for example, professionals recommended that young people begin to assume responsibilities such as attending appointments alone at a younger age than parents did. It must be considered that this study involved a self-selected sample, the response rate being 31% for parents and 34% for practitioners; as such, it may be the case that those practitioners who responded represent those who were more heavily engaged with transition activities than those who did not. In addition, it is not possible to elucidate perspectives of both parents and practitioners on transition for young people with intellectual disabilities, as opposed to other disabilities, within this data.

Hudson (2006) undertook in-depth interviews with professionals ( $n = 18$ ) working within intellectual disability services in the UK, as well as with young people with intellectual disabilities and their parents at different stages of transition ( $n = 23$ ), in order to examine why the experience of transition is often experienced as negative. Themes identified as contributing to discontinuous and chaotic experiences included competing priorities in intellectual disability services, with no sense of urgency or priority given to transition, and confusion and disagreement over who should take responsibility for the task of long-term planning. In addition, Stevenson et al. (1997) interviewed 74 parents of young people with cerebral palsy undergoing transition in England, and found that the two main areas of concern for these parents were a lack of coordinated planning and poor channels of communication between different services. Significantly, dissatisfaction with services increased as young people left school.

These difficulties in the organisational transitions from school to adult services may therefore further complicate the overall transition experiences of individuals with intellectual disabilities, potentially undermining their ability to assume adult roles if they are not supported adequately to do so.

### **5.1.3 Daytime activity**

Classic conceptualisations of transition focus on entrance into the labour market as a discriminating factor of adulthood. In this view, work is much more than just having a job; it is a symbol of achievement of adult status (Cooney, 2002). Work may also contribute to

feelings of community inclusion and belonging as a result of engagement in social relationships within the workplace. However, paid work may not be an appropriate or realistic option for some young people with intellectual disabilities, and alternative options, such as sheltered employment, further education, or day centres, must be considered. One purpose of transition planning is to ensure that appropriate daytime activity is in place to replace the school routine. Despite this effort, however, evidence suggests that the population with intellectual disabilities experience poorer vocational outcomes than the typically developing population, who tend to pursue postsecondary education or competitive employment on leaving school.

A systematic review of the empirical literature on community participation by people with intellectual disabilities found that those with intellectual disabilities were 3–4 times less often employed than their non-disabled peers, less likely to be employed competitively and more likely to work in sheltered workshops or segregated settings than those with other disabilities (Verdonschot et al., 2009a). Van Naarden Braun et al. (2006) administered a questionnaire to examine the relationship between developmental disability and the acquisition of adult social roles to a sub-sample ( $n = 635$ ) of the Metropolitan Atlanta Developmental Disability (MADDs) cohort, a cross-sectional study of ten-year-old children born with a developmental disability (including intellectual disabilities, cerebral palsy, vision impairment, hearing loss and epilepsy) and an age-matched non-disabled comparison group, who were then followed up into adulthood at age 21–25 years. Being competitively employed, being a full-time student, or being a caregiver were conceptualised as adult social roles and normative markers of transition. Young adults with developmental disabilities were less likely to have acquired an adult social role than were young adults without disabilities. Furthermore, the severity of cognitive impairment was an important characteristic in the relationship between disability and acquiring an adult social role: individuals with severe intellectual disabilities were less likely to have any daytime activity than individuals with mild intellectual disabilities. Regardless of the type of impairment that an individual experienced, limitations in activities of daily living (e.g., dressing, doing laundry, making meals) significantly predicted not having an adult social role. However, while the majority of individuals with severe intellectual disabilities were not participating in an adult social role as conceptualised by the authors, 33–37% of young people with severe intellectual disabilities were participating in a vocational, activity or educational programme. Therefore, although the majority were excluded from the adult social roles conceptualised by the authors, around half were still participating in society in

some way, even if it was through an impairment-related programme rather than through traditional means.

Gray et al. (2014) drew on data from the Australian Child to Adult Development Study, a longitudinal study of 536 individuals with intellectual disabilities who were aged 4–18 years at the first wave of data collection, and aged 20–37 years at the fifth and final wave, to identify the daytime activities of the population with intellectual disabilities into adulthood. At Wave 1, 17.5% of the sample were involved in mainstream daytime activity, such as paid employment, vocational training, or mainstream school; by Wave 5, this figure had dropped to 14.1%. Furthermore, at Wave 1, 82.0% of the sample were attending activities specifically for people with intellectual disabilities, such as a special school, sheltered workshop or day centre, while 79.1% were attending these programs at Wave 5. This finding supports Van Naarden Braun et al.'s (2006) assertion that many adults with intellectual disabilities are engaged in some activity, but that this activity tends to be specifically for those with intellectual disabilities. However, Gray et al. (2014) also found that while at Wave 1 all young people were participating in some form of organised daytime activity, by Wave 5, 6.8% had no form of organised daytime activity, suggesting that in the absence of school at least some individuals with intellectual disabilities are left with no organised daytime activity. Participants were recruited to this study from health, family and educational agencies providing services to individuals with intellectual disabilities; the authors acknowledge that case ascertainment of individuals with mild intellectual disabilities could therefore have been limited due to such individuals perhaps being less likely to utilise such services. Indeed, 63.8% of the sample assessed at Wave 5 had moderate to profound intellectual disabilities. This sample is therefore slightly biased towards those with more severe disabilities who are possibly more likely to be involved in activities specifically for those with intellectual disabilities as opposed to mainstream activities.

In a secondary analysis of the National Longitudinal Transition Study-2 (NLTS-2), students with intellectual disabilities were less likely than their peers with other disabilities to have worked at any point after high school, or to have attended a vocational school or college; 46% of students with intellectual disabilities were employed at the time of completing the survey, compared to 74% of students with other disabilities, such as sensory impairment, traumatic brain injury or emotional disturbance (Grigal et al., 2011). Although this study benefits from a longitudinal design, facilitating comparison of employment outcomes for students across a number of years after high school exit, it is not

possible to establish the severity of disability in this cohort. As such, it may be the case that this figure represents employment outcomes for individuals with mild intellectual disabilities, and those with more severe disabilities may fare worse.

Employment figures for individuals with intellectual disabilities in the UK are worse: Scotland's Census (2011) indicated that, among individuals with intellectual disabilities aged 16 to 24 years, only 4.0% were in paid employment full-time and just 5.6% were in paid employment part-time (Scottish Learning Disabilities Observatory, 2016). Similarly to the NLTS-2, Scotland's Census (2011) does not differentiate between disability severity, so the functional status of those in employment cannot be established.

The policy of social inclusion assumes that paid employment is an ideal outcome for individuals with intellectual disabilities, since inclusion in the labour market is a fundamental part of mainstream society. However, evidence on perceptions of paid employment among young people with intellectual disabilities and their families is mixed. Interviews with 52 families of young adults with severe intellectual disabilities recruited from the Regional Center system in California revealed that parents had largely 'normal' aspirations for their children (Kraemer & Blacher, 2001): 63.5% of parents wanted their child to work, and ideal work environments were considered to be independent work or an individually supported environment; few parents reported sheltered workshops or day centres as ideal options for their child, and none reported staying at home as ideal. However, parents recognised that realistically the latter were the more likely options, and there was a significant difference between their realistic and idealistic vocational expectations for their child.

Butcher and Wilton (2008) conducted a qualitative study of six young people with intellectual disabilities who were involved with a disability service organisation providing a vocational training centre, a sheltered workshop, and supported employment placements in Toronto. While these spaces were a vital source of meaningful activity for young people, who missed the routine and sociability of school, a tension occurred between parents, some supposing that their child's progress was inhibited by engagement in a vocational environment exclusively for disabled people, and the young people who enjoyed the inclusion and sense of community that such a sheltered space afforded them. The authors did not specify the severity of intellectual disabilities that the young people in this study experienced, which limits the generalisability of the findings, since an individual's functional status is likely to have important implications for the type of daytime activity

that is most suitable for them. However, despite this issue and the small sample size, this study raises important questions regarding the purpose that daytime activity serves for young people with intellectual disabilities; for example, whether feelings of social connectedness or a challenging environment are more important. Furthermore, none of the studies reviewed here investigated the type of employment in which people with intellectual disabilities were engaged, nor the amount that they earned. These factors may have important implications for the quality of life that people with intellectual disabilities enjoy and may affect their feelings regarding work.

A key component of transition for the population with intellectual disabilities is finding appropriate daytime activity following school exit. Given that work is assumed to be a central component of adulthood, and the low employment figures for this population, those with intellectual disabilities may be excluded from this important component of adulthood. Furthermore, additional benefits of work, including increased social connectedness, may also be unavailable to adults with intellectual disabilities, further inhibiting opportunities to engage in adult social roles.

#### **5.1.4 Community participation**

According to the International Classification of Functioning, Disability and Health (ICF), community participation is defined as performance in activities across social life domains through interactions with others, including domestic life, interpersonal life, education and employment, and community, civic and social life (Verdonschot et al., 2009b). Such activities are perhaps more necessary when young people leave a school environment that itself offers opportunities to socialise. However, a systematic review of the empirical literature on community participation among people with intellectual disabilities found that those with intellectual disabilities were less likely to be involved in community groups than those without disabilities, and that leisure activities reported by individuals with intellectual disabilities were primarily solitary: the authors concluded that the level of community participation among individuals with intellectual disabilities was lower than that of both non-disabled and other disabled groups (Verdonschot et al., 2009a).

Due to limited community participation, social isolation upon leaving school may be a particular issue for individuals with intellectual disabilities. In a qualitative study of 43 young people with intellectual disabilities recruited from schools, colleges, disability organisations and social services in England, young people described limited social

networks, with few young people being able to socialise independently (Small et al., 2013). Furthermore, school was considered a central aspect to young people's social worlds, with few individuals accessing leisure activities outside of school, and teachers and support assistants often being regarded as friends. Confusion and sadness was expressed at the cessation of these friendships when young people left school; indeed, the authors stressed that outside of the family, school appeared to be the only significant social network in these young adults' lives (Small et al., 2013). This study involved an ethnically diverse sample of young people aged 14-22 years with mild to severe intellectual disabilities. As such, diverse experiences were recorded from young people at varying stages of the transition from school, capturing the profound shift in social networks that occurs upon school exit. In addition, Zeitlin and Turner (1985) conducted life history interviews with 25 young adults with mild intellectual disabilities and their parents, recruited through public services for individuals with intellectual disabilities in Los Angeles. They found that 23% of the young people had no friends; significantly, most young people expressed sadness at this lack of personal relationships.

A key factor in the maintenance of post-school isolation in young people with intellectual disabilities may arise from continuing to live in the parental home. Gray et al. (2014) drew on data from the Australian Child to Adult Development Study to demonstrate that at the fifth and final wave of data collection, when individuals were aged 20–37 years, 61.5% of adults with intellectual disabilities were being cared for in the family home, 29.7% were living in care, and just 9.0% were living independently. The authors postulate that continuing to live in the family home may be related to a lack of community involvement, wherein dependent, sheltered relationships with parents may serve to undermine opportunities for community involvement. Indeed, only 36.5% of a sample of 52 families of young adults with severe intellectual disabilities identified from the Regional Center system in California thought that their child would live away from the family home within five years after leaving school, and even under ideal circumstances few parents envisioned their child ever living with a partner or friends (Kraemer & Blacher, 2001) as would often be a normal arrangement for individuals without intellectual disabilities.

### **5.1.5 Sexuality**

Kraemer and Blacher (2001) conducted interviews with 52 families of young adults with intellectual disabilities in California, finding that few parents imagined their child with intellectual disabilities ever living with a partner. This reluctance to imagine young people

with intellectual disabilities engaging in romantic relationships may reflect a broader societal discomfort with the notion of people with intellectual disabilities experiencing sexual relationships. Individuals with intellectual disabilities do not necessarily fit into social and political norms, and are therefore often socially excluded; perhaps even feared, which may severely inhibit the exploration typically experienced during transition to adulthood. Rogers (2010) contrasts the typical image of young adulthood – energy, good looks, virility – with the typical image of disability – frailty, ugliness, asexuality – to argue that society's discomfort with such 'difficult' bodies means that individuals with intellectual disabilities are prevented from enjoying the privileges typically associated with adulthood, such as intimacy with a partner. The issue of sexuality especially highlights the moral polarities regarding self-determination/choice and protectionism in people with intellectual disabilities, with parents and caregivers striving to strike a balance between facilitating independence and protecting young people from risk.

In a focus group study involving six parents of young adults with intellectual disabilities recruited from a disability services database in Australia, parents reported specific parenting difficulties related to aspects of adult behaviour such as sex and masturbation, admitting how they struggled to balance the need to provide their child with appropriate privacy to explore their sexual identity with the need to keep them safe from exploitation in the outside world (Hamilton et al., 2015). All of the participants in the focus group were mothers, and the findings of the study represent the views of only a small number of people. However, a focus group was concurrently conducted with nine practitioners providing services to young people with intellectual disabilities, including local area coordinators, social workers, speech pathologists and a clinical psychologist. A high level of consistency was found between parents and practitioners in the themes identified. Furthermore, as the practitioners who participated had extensive experience working with individuals with intellectual disabilities, their responses may represent the experiences of many more families (Hamilton et al., 2015).

Moreover, in a review of the literature on transition for young people with disabilities, Hallum (1995) emphasises the anxiety that many parents experience about their children's emerging sexual behaviour, with parents of sons worrying that their son might behave inappropriately or aggressively, and parents of daughters worrying that they might be vulnerable to abuse and exploitation. These fears encapsulate two distinct but equally important dimensions of sexual relationships: the emotional aspect of being engaged in an intimate relationship, and practical concerns regarding sexual health, such as preventing



sexually transmitted diseases and unwanted pregnancies. In a qualitative meta-synthesis of 17 papers, Rushbrooke et al. (2014) explored the competing demands and roles of caregivers of people with intellectual disabilities in relation to supporting sexuality. Caregivers saw themselves as protectors, with a responsibility to safeguarding those in their care, but also as facilitators, with a responsibility to allowing those who they supported to take risks. Striking this balance between empowerment and protection could result in contradictory messages for people with intellectual disabilities regarding the appropriateness of their sexual behaviour. Again, it is evident that for individuals with intellectual disabilities, this important dimension of adulthood may be blocked due to a desire to protect them from harm.

### **5.1.6 Cultural differences**

It is important to consider that cultural differences regarding transition norms for both typically developing and disabled young people may be apparent. Rueda et al. (2005) ran focus groups with 16 Latina mothers of adolescents with intellectual disabilities recruited from a public agency serving Spanish-speaking communities in Los Angeles. For these women, the importance of family was stressed over individualisation. These mothers considered marriage to be a clear, sanctioned transition marker: prior to this point it was considered unacceptable for young people to make their own decisions, irrespective of whether they had a disability or not. Furthermore, marriage and independent living were not considered appropriate goals for their children with intellectual disabilities, who, they assumed, would continue to live in the family home. In this way, the world outside the family setting was characterised by discrimination and fear, and transition was conceptualised as entailing sheltered adaptation rather than independence.

While this study represents views from only a small number of mothers with a similar cultural background, these results echo findings from Rehm et al.'s (2012) inquiry, which found similar attitudes towards independence in young people with intellectual disabilities among ethnic minority families in California. Such cultural differences in norms and values call attention to potential limitations of the Western emphasis on individualisation during transition, which may not be an appropriate model from which to approach individuals with intellectual disabilities. Indeed, Small et al. (2013) have suggested that *interdependence* is at the heart of people with intellectual disabilities' engagement with the social world, and argue that to push them towards independence is inappropriate because

they rely so heavily on carers, an argument which questions the desirability of normal transition goals for young people with intellectual disabilities.

### **5.1.7 Final remarks on the literature on transition in the population with intellectual disabilities**

From this review of the literature on transition for the population with intellectual disabilities, it is evident that while the organisational system in which individuals are placed anticipates a shift to adulthood by implementing school exit and a move to adult services, young people with intellectual disabilities may actually be prevented from accessing important components of adulthood – including work, a network of social relationships, and a partner – due to their cognitive impairments, and practical arrangements that do not always facilitate independence. In this way, differences in conceptual and organisational meanings of transition become apparent, and questions surrounding the meaning of ‘transition’ and what it will achieve in this population, are posed. This discussion provides a basis from which to understand how transition may affect health and wellbeing in this population. The following section will examine the literature on health in children with intellectual disabilities in order to describe health in this population prior to transition.

## **6 Health of children/young people with intellectual disabilities**

A systematic review of 31 studies on chronic health conditions in children with intellectual disabilities under the age of 19 years concluded that prevalence rates of chronic health conditions, including physical, developmental, behavioural or emotional conditions were much higher in this population than in the general population (Oeseburg et al., 2011). Prevalence rates of epilepsy were between 5.5% and 35.0%, visual problems between 2.2% and 26.8%, hearing problems between 0.0% and 7.1%, and gastro and oesophageal diseases 6.9%, with differences between studies largely due to sampling and methods of detection. With regards to mental health, the most frequently mentioned disorders were: conduct disorder, with prevalence rates between 0.6% and 8.4%; oppositional defiant disorder, with prevalence rates between 11.1% and 13.9%, and anxiety disorders, with prevalence rates between 11.4% and 39.0% (Oeseburg et al., 2011). Furthermore, a review of the evidence on prevalence and determinants of health conditions among children and young people with intellectual disabilities in the UK conducted by Allerton et al. (2011)

concluded that there was an increased prevalence of numerous health conditions among children with intellectual disabilities, and further that these health inequalities were associated with environmental factors which are ultimately preventable.

Indeed, this health inequality between people with and without intellectual disabilities may be attributed to a number of factors, including:

- Increased risk of exposure to negative social determinants of health, such as poverty, poor housing conditions, social disconnectedness and discrimination;
- An increased risk associated with specific biological causes of intellectual disability, such as a risk of congenital heart defects in Down syndrome;
- Communication difficulties and reduced health literacy;
- Personal risk behaviours, such as poor diet and lack of exercise;
- Deficiencies in both access to and quality of healthcare (Emerson et al., 2011).

Higher prevalence rates of health conditions contribute to lower ratings of general health status in children with intellectual disabilities. In a secondary analysis of data from the Department of Work and Pension's Families and Children study, involving a sample of 12,916 British children under the age of 16 (n with intellectual disabilities = 593), those with intellectual disabilities were significantly more likely to be reported to have poorer health than their age- and sex-matched peers without intellectual disabilities (Emerson & Hatton, 2007c). In another secondary analysis of the 1999 Office for National Statistics survey (ONS) of the health of children and adolescents in the UK with (n = 641) and without (n = 17,774) intellectual disabilities, having an intellectual disability significantly predicted a parental rating of poorer health status (Emerson & Hatton, 2007b). Both of these studies utilised parents' reports of general health status, and the actual health of children may be worse than that reported by parents. However, an epidemiological study by Waters et al. (2003) that collected parent and adolescent (n = 2096) (mean adolescent age = 15 years) health ratings on the Child Health Questionnaire indicated an acceptable level of agreement between parents' and adolescents' ratings of the adolescents' health. Thus, parents may have an accurate insight into their children's health, at least in the case of typically developing children.

## 6.1 Physical health

In addition to the health inequality described above, which may be largely attributed to social factors, individuals with intellectual disabilities are particularly vulnerable to some specific physical health issues. While there is less evidence in the child literature on physical health issues in the population with intellectual disabilities compared to the adult literature, there is evidence that children and young people with intellectual disabilities are more vulnerable to some physical health conditions than those without intellectual disabilities, including epilepsy, sensory impairments, gastro-intestinal disorders, and obesity. In addition, some individuals with intellectual disabilities are also likely to be vulnerable to syndrome specific health conditions, such as congenital heart defects in Down syndrome (Freeman et al., 1998).

The prevalence of epilepsy is particularly high among children with intellectual disabilities. Forsgren et al. (1990) assessed all individuals with intellectual disabilities in a Swedish county identified through the Board for Provisions and Services for the Mentally Retarded, discovering that 20–25% of individuals under the age of 19 ( $n = 96$ ) had epilepsy. Furthermore, a longitudinal study of children and young people with intellectual disabilities ( $n = 151$ ), identified via IQ tests on children from four birth cohorts in Finland and followed from age 9 to age 22, found that by the age of 22, the cumulative risk of having epilepsy was 21% (Airaksinen et al., 2000). In addition, the probability of developing epilepsy in those with severe intellectual disabilities was increased fivefold compared with those with mild intellectual disabilities (Airaksinen et al., 2000).

As well as increased prevalence rates of epilepsy in children and young people with intellectual disabilities, children with intellectual disabilities are likely to experience earlier age of epilepsy onset. Steffenburg et al. (1996) examined the medical files of young people with intellectual disabilities aged 6–13 years ( $n = 378$ ) recruited from diagnostic registers of paediatric clinics in Sweden, and performed a clinical examination on a sub-sample ( $n = 90$ ). The median age of seizure onset was 1.3 years; and children with severe intellectual disabilities had significantly earlier seizure onset than children with mild intellectual disabilities. This age of onset can be compared to a mean age of onset of 4 years found in typically developing children in Sweden by Sidenvall et al. (1996). In addition, an observational study of children with epilepsy ( $n = 62$ ) attending secondary schools in England found that seizures were well controlled in 78% of children without special educational needs, but in only 41% of children with special education needs (Swiderska et

al., 2011). Despite efforts to ensure a representative sample, most of these studies consist of a relatively small sample size. Nevertheless, the high prevalence of epilepsy in children and young people with intellectual disabilities, and lack of seizure control, is concerning given that the presence of epilepsy significantly raises mortality rates for individuals with intellectual disabilities, as identified in a longitudinal study following all known people with intellectual disabilities ( $n = 1,478$ ) in one Swedish province for seven years (Forsgren et al., 1996).

Sensory impairments are also more prevalent in children with intellectual disabilities. In a cross-sectional study involving children with borderline to profound intellectual disabilities aged 5-15 years ( $n = 923$ ) who were identified from routine assessments by child psychologists and paediatric clinics in Denmark, the prevalence of visual impairment, assessed via ophthalmological examinations, was 10.5% across the sample, and 22.4% in those children with an IQ of below 50 (Nielson et al., 2007). As this study captured almost all of the estimated number of children with intellectual disabilities living within a geographical region which comprises 11.5% of the Danish population, the authors concluded that visual impairment is highly increased in children with intellectual disabilities, compared to children without intellectual disabilities, and further that it is correlated with low IQ.

In a longitudinal study involving three waves of data collection, one year apart, from individuals with intellectual disabilities living in institutional care in Sweden, including 101 individuals under the age of 19, a 6.9% prevalence of hearing impairment, identified through questionnaires completed by care staff, was found in individuals aged 19 or under (Van Schrojenstein Lantmen-de Vaulk et al., 1997). The fact that care staff completed questionnaires may have led to an undercount of some disorders; therefore, the actual prevalence rates may be higher than those reported. Although this study involved individuals living in institutional care, which means that the findings cannot be generalised to individuals living in the community, the high prevalence rates of these conditions are concerning given the increased burden on the individual that they produce. For example, a systematic review of prevalence studies of sensory impairments in individuals with intellectual disabilities suggested that the combination of intellectual disabilities and sensory impairment may render an individual more vulnerable to psychopathology (Carvill, 2002), which further adds to the burden of an individual's functional limitations.

Higher rates of gastric and oesophageal diseases can also be found in children with intellectual disabilities compared to their typically developing peers. A study of individuals with intellectual disabilities in institutional care found a 6.9% prevalence of gastric and oesophageal diseases in individuals under the age of 19, as identified by questionnaires completed by care staff (Van schrojenstein Lantman-de Vaulk et al., 1997). This figure may represent an undercount, since care staff may have failed to identify issues in some individuals; actual prevalence rates of gastric and oesophageal problems may hence be higher in this population.

Obesity is a risk factor for numerous negative health outcomes, and evidence suggests that children with intellectual disabilities are at higher risk of obesity than their non-disabled peers. Ells et al. (2008) measured height and weight of children aged 5-15 years (n with intellectual disabilities = 33; n with physical disabilities = 2; n without any disability = 88) at five schools in England. BMI data indicated that 29% of children with disabilities were obese, compared with 19% of children without disabilities. Although the prevalence of obesity was higher in children with disabilities, it failed to reach statistical significance, perhaps due to the small sample size. However, similar prevalence rates of obesity have been identified in children and young people with intellectual disabilities elsewhere. For example, an NHS health screening programme for children (n = 86) and adults with intellectual disabilities in receipt of services in one geographical area of Northern Ireland found that 26% of 10-19 year olds with intellectual disabilities were overweight or obese, as defined by their BMI (Marshall et al., 2003). Again, though, this study should be approached with caution since the sample size is small. Nevertheless, the higher rates of obesity in individuals with intellectual disabilities may reflect trends in health behaviours in this population: data from the Millennium Cohort Study, a longitudinal study of over 18,000 children in England, demonstrated that children with intellectual disabilities at the age of 7 were 3.7 times more likely to never exercise or participate in sports than those without intellectual disabilities (Emerson et al., 2011).

Comorbidity of health issues is also more common among children with intellectual disabilities than in the typically developing population. Data from the Millennium Cohort Study found that 52% of children with intellectual disabilities reported three or more health problems, compared to only 28% of children in the general population (Emerson et al., 2011). This finding has implications for the management of conditions, which may become complex if an individual suffers from multiple health conditions requiring different

treatments. This is of particular concern during transition, when moving from child to adult health teams may disrupt the management of conditions.

The evidence reviewed highlights that children and young people with intellectual disabilities may experience poorer health than the general population as a result of social inequalities, physical vulnerabilities and lifestyle risk factors. Hence, management of these health conditions is required throughout the life course. However, the transition between child and adult services, as well as the change in daily routine that occurs as young people leave school, may disrupt management of health conditions and result in an increase in unhealthy lifestyle behaviours such as physical inactivity, potentially exacerbating existing health problems and leaving individuals vulnerable to additional health concerns. Furthermore, as this chapter has identified, transition is typically a period of exploration; poor general health status may create barriers to participation in new activities, which in turn may aversively affect an individual's psychological wellbeing.

## **6.2 Mental health**

As this chapter has discussed, transition may involve multiple changes in a young person's life that may conceivably have a negative impact on their mental health or wellbeing. Mental health disorders substantially add to the morbidity of intellectual disabilities, for example through affecting an individual's adaptation to the workplace or independent living (Einfeld et al., 2011), and are higher in children and adolescents with intellectual disabilities relative to the general population. In a systematic review of prevalence studies of mental ill-health in children and adolescents with intellectual disabilities, Einfeld et al. (2011) identified nine studies; four comparing the prevalence of mental health disorders in children with and without intellectual disabilities, and five estimating the prevalence of mental health disorders in children with intellectual disabilities. Taken together, the studies estimate a prevalence of mental ill-health in children and adolescents with intellectual disabilities of between 30% and 50%, and a relative risk of mental ill-health in children with intellectual disabilities between 2.8 and 4.5. Table 1 details studies investigating mental health conditions in children and adolescents with intellectual disabilities (ID).

**Table 1: Studies examining prevalence of mental health conditions in children and adolescents with intellectual disabilities**

<b>Authors/ Date</b>	<b>Design</b>	<b>Participants</b>	<b>Method/ Measures</b>	<b>Findings</b>	<b>Critique</b>
Birch et al. 1970	Cross-sectional	Children with ID (n = 104) recruited from a birth cohort in Aberdeen, Scotland Aged 8-10 years	Interviews conducted with teachers/ carers	Prevalence of psychopathology was 30%	Teachers/carers may have underreported problems No typically developing comparison group
Rutter et al. 1970	Cross-sectional	Children with ID (n = 59) recruited from a birth cohort in England General population children (n = 2,334) Aged 9-10 years	Behavioural questionnaires completed by teachers/ parents Interview with parent and child	Prevalence of psychopathology in children with ID was 30% and in children without ID 8%	Small sample of children with ID
Einfeld & Tonge 1996	Cross-sectional	Children with ID (n = 454) recruited from services for people with ID in five regions of New South Wales, Australia Aged 4-18 years	Developmental Behavioural Checklist – Primary Carer Version (DBC-P)	41% of the sample was potentially classifiable as having severe emotional and behavioural disorder or as being psychiatrically disordered	Sample may be biased towards those with more severe ID; may have been under ascertainment of children with mild ID No typically developing comparison group
Linna et al. 1999	Cross-sectional	Children with ID (n = 90) recruited from special education schools in Finland General population children (n = 5,714) recruited from schools in Finland Aged 8 years	Rutter Parent Questionnaire (RA2) Rutter Teacher Questionnaire (RB2) Children's Depression Inventory (CDI)	Prevalence of psychopathology in children with ID was 32% and in children without ID 11%	Small sample of children with ID Measures not validated for use with ID population
Stromme & Diseth 2000	Cross-sectional	Children with ID (n = 178) recruited from birth cohort in Norway Aged 8-13 years	Semi-structured clinical interview with parents Clinical child interview Review of previous psychiatric case notes	Prevalence of psychopathology was 37% Significantly higher prevalence rates of mental ill-health were found in males than in females	Only those with mild or severe ID included



Molteno et al. 2001	Cross-sectional	Children with ID (n = 355) recruited from special education schools in Cape Town, South Africa Aged 6-18 years	Developmental Behaviour Checklist – Teacher Version (DBC-T)	Prevalence of psychopathology was 31% Higher levels of mental disorder were found in younger children and in participants with more severe ID	No typically developing comparison group
Dekker et al. 2002	Cross-sectional	Children with mild to moderate ID (n = 968) recruited from Dutch schools for the educable and trainable General population children (n = 1,855) recruited from Dutch schools Aged 6-18 years	Child Behaviour Checklist (CBCL) Teacher's Report Form (TRF)	Prevalence of emotional/behavioural problems in children with ID was 50% and in children without ID 18%	Measures not validated for use with children with ID Children with severe or profound ID excluded
Dekker & Koot 2003	Longitudinal: two phases of data collection, one year apart	Children with ID (n = 474) recruited from Dutch special education schools Aged 7-20 years	Anxiety, mood and disruptive disorder modules of the Diagnostic Interview Schedule for Children (DISC-IV-P)	39% of children met criteria for at least one disorder	No typically developing comparison group
Emerson & Hatton 2007a	Cross-sectional (secondary analysis)	Children with ID (n = 641) General population children (n = 17,774) Part of the 1999 and 2004 Office for National Statistics Surveys of the mental health of children and adolescents Aged 5-16 years	Development and Wellbeing Assessment (DAWBA)	Prevalence of psychopathology in children with ID was 36% and in children without ID 8% Prevalence rates were significantly higher in males with ID than in females Older children with ID (aged 11-16) were more likely to have an emotional disorder Younger children with ID (aged 5-9) were more likely to have hyperactivity	Measures not validated for use with children with ID
Emerson & Einfeld 2010	Cross-sectional (secondary analysis)	Children (n = 15,995) Part of the first two waves of the Millennium Cohort Study	School Readiness composite of the Bracken Basic Concept Scale Strengths and Difficulties	Higher rates of emotional and behavioural difficulties found in the lowest 3% of the cognitive	Within the Australian sample children were identified on the basis of delayed verbal cognitive

		and the first two waves of the Longitudinal Study of Australian Children Aged 2-3 years	Questionnaire (SDQ) Problem scale of the Brief Infant Toddler Social Emotional Assessment Scale (BITSEA)	performance distribution	development; this may have led to an underestimation of the strength of association between developmental delay and emotional/behavioural difficulties
Emerson et al. 2010	Longitudinal: two phases of data collection, one year apart (secondary analysis)	Children (n at Wave 1 = 4,983; n at Wave 2 = 4,464) recruited from Medicare enrolment database (part of the Longitudinal Study of Australian Children) Aged 4-5 then 6-7 years	Peabody Picture Vocabulary Test (PPVT) Strengths and Difficulties Questionnaire (SDQ)	Children with ID or borderline intellectual functioning showed increased prevalence rates on all indicators of possible mental health problems	IQ not measured directly to establish ID sample
Hassiotis & Turk 2012	Cross-sectional	Children with ID (n = 75) recruited from a UK Local Education Authority, health services, social services and the Fragile X Society Aged 12-19 years	Vineland Adaptive Behaviour Scale (VABS) Developmental Behaviour Checklist (DBC) Service utilisation questionnaire	Prevalence of psychopathology was 51% Those with more severe disabilities were more likely to experience psychopathology	Small sample No typically developing comparison group

Throughout middle childhood, a prevalence rate of psychopathology of around 30% in children with intellectual disabilities has been consistently found in a number of studies spanning different countries. Birch et al. (1970) reported a mental health disorder prevalence rate of 30% in a birth cohort of children with intellectual disabilities (n = 104) aged 8-10 years in Scotland. Additionally, Rutter et al. (1970) reported a prevalence rate of 30% in an English birth cohort including 59 children with intellectual disabilities aged 9-10 years. This contrasts to a prevalence rate of 8% found in the general population at the same age (n = 2,334). Linna et al. (1999) recruited children aged 8 years with (n = 90) and without (n = 5,714) intellectual disabilities from schools in Finland, and identified a 32% prevalence of psychopathology in those with intellectual disabilities, compared to 11% in those without. Furthermore, Stromme and Diseth (2000) identified a 37% prevalence of

mental health disorders in children with intellectual disabilities ( $n = 178$ ) aged 8-13 years recruited from a birth cohort in Norway.

It is important to note that the above studies were all conducted on small samples. However, similar prevalence rates of mental ill-health have been reported in larger samples of children and young people with intellectual disabilities across wider age ranges. In a secondary analysis of the first two waves of the UK's Millennium Cohort Study, and the first two waves of the Longitudinal Study of Australian Children, involving 15,995 children aged 2-3 years, rates of emotional and behavioural difficulties were especially elevated in the lowest 3% of the cognitive performance distribution: the segment typically used to define the presence of intellectual disabilities (Emerson & Einfeld, 2010). In a secondary analysis of the 1999 and 2004 Office for National Statistics (ONS) surveys of mental health in children and adolescents in the UK, both with ( $n = 641$ ) and without ( $n = 17,774$ ) intellectual disabilities aged 5-16 years, Emerson and Hatton (2007a) reported a 36% prevalence rate of psychopathology among children with intellectual disabilities, compared to a rate of just 8% in children without intellectual disabilities. Indeed, children with intellectual disabilities accounted for 14% of all British children with a diagnosable psychiatric disorder. Nevertheless, this study used the Development and Wellbeing Assessment (DAWBA) to identify the presence of psychiatric disorder, and this measure has not been validated for use with individuals with intellectual disabilities. This is of relevance when assessing psychopathology in children with intellectual disabilities, since disorders such as depression and anxiety may manifest differently in this population to how they might appear in the typically developing population due to cognitive differences (Dekker et al., 2002).

Different patterns of psychopathology may be evident across different ability levels. Einfeld and Tonge (1996) examined the prevalence of psychiatric disorders in children aged 4–18 years in Australia ( $n = 454$ ) recruited from services for people with intellectual disabilities: 41% of the sample was potentially classifiable as having severe emotional and behavioural disorder or as being psychiatrically disordered through the Developmental Behaviour Checklist (DBC). Disruptive and antisocial behaviours were more prominent in those with mild intellectual disabilities, while self-absorbed and autistic behaviours were more prominent in those with severe intellectual disabilities. Those with profound disabilities had lower levels of disturbance overall compared to those with mild, moderate and severe intellectual disabilities, and the authors speculate that this may be due to lower levels of observable behaviours and impaired capacity to communicate emotional problems

among those with severe and profound intellectual disabilities. Despite this finding, the level of intellectual disability failed to reach statistical significance in affecting the prevalence of psychiatric disorder. Moreover, the disruptive and anxiety subscales of the DBC increased with increasing IQ, suggesting that higher intelligence is required for the specific manifestation of these behaviours identified by the DBC. Interestingly, antisocial behaviour increased significantly with increasing age, which could perhaps be a reflection of developmentally appropriate reactions to circumstances, such as a reaction against the stresses of growing up and increased expectations to become more independent. These findings are crucial to consider when examining prevalence studies of mental health conditions in this population, since some studies do not include all severities of intellectual disabilities within their samples (Table 1).

In addition to these findings, Molteno et al. (2001) found higher levels of mental disorder in children with more severe intellectual disabilities among a sample of children ( $n = 355$ ) recruited from special education schools in South Africa. Furthermore, Hassiotis and Turk (2012) examined the prevalence and predictors of mental health needs in British adolescents with intellectual disabilities aged 12-19 years ( $n = 75$ ) recruited from a Local Education authority, health services, social services and the Fragile X Society. They found a 51% prevalence of mental health needs, with the most common disorder reported being conduct disorder. Those individuals identified as psychiatric cases had significantly greater deficits in adaptive functioning; i.e. those with more severe disabilities were more likely to experience psychopathology. This evidence supports the notion that low IQ is associated with at least some mental health disorders. Considered in the context of transition, this association is especially problematic: young people with intellectual disabilities may be inadequately equipped to tackle the social and emotional challenges faced during transition, leading to heightened risk of psychiatric disorder, increased functional impairment, and poor transition outcomes as a result.

Dekker et al. (2002) examined the type of mental health problems that were most problematic in children with and without intellectual disabilities in a large sample ( $n = 968$ ) of children aged 6–18 years recruited from schools for the educable and trainable in the Netherlands: 50% of the sample with intellectual disabilities scored in the clinically significant range of mental health problems compared to 18% of the typically developing sample. The largest differences between intellectually disabled and non-disabled children were found among social problems, attention problems and aggressive behaviour, leading

the authors to suggest that these issues in particular might be attributable to cognitive impairments.

The high rates of mental health disorder in this population have important implications for functional impairment. Dekker and Koot (2003) examined the prevalence, co-morbidity and impact of disorders defined in the Diagnostic and Statistical Manual of Mental Disorders-IV (DSMIV) in 7-20 year old individuals ( $n = 474$ ) from Dutch schools for children and young people with intellectual disabilities: 39% of children and young people met criteria for at least one disorder, with the most prevalent disorders being specific phobia, attention deficit hyperactivity disorder (ADHD) or obsessive compulsive disorder (OCD). Additionally, 56% of diagnosed children were significantly impaired in at least one area of their everyday functioning due to their psychiatric condition. This finding is especially important to consider in light of the fact that individuals in this population are already likely to be impaired by their intellectual disabilities, and the increased impairment caused by psychiatric disorder could result in worse outcomes across social, vocational and educational domains. Furthermore, 37% of children in this sample had a co-morbid disorder; a level similar to that in the typically developing population, but the presence of a co-morbid disorder on top of an intellectual disability may present considerable additional functional impairments.

As this section has identified, children and young people with intellectual disabilities are more likely to experience mental health problems than the typically developing population. Transition may be a period of time during which vulnerability to mental health issues increases; the negative transition outcomes described earlier in the chapter, such as limited opportunities for community participation, may increase the risk of isolation, potentially leading to depression or anxiety. Furthermore, Hulbert-Williams and Hastings (2008) conducted a critical review of the literature on life events occurring for children and adults with intellectual disabilities, such as moving house or staff changes within residences, arguing that life events are associated with, and may play a causal role in, psychological problems in this population. Transition is a period of time during which a number of significant life events, including leaving school, will occur, which may increase the risk of psychopathology. Moreover, given the evidence presented earlier in this chapter that support during transition may be inadequate (see section 4.1.2), the experience of transition overall may be chaotic. Furthermore, Luthar (2003) argues that the association between low IQ and psychiatric problems may be mediated by the role of IQ in determining a child's vulnerability or resilience when faced with adversity. Hence, those young people

who are unable to cope with stressful transition experiences may be especially vulnerable to mental health disorders.

## 7 Defining wellbeing

As well as impacting on health, transition to adulthood may have important implications for young people's overall wellbeing, and this thesis concerns the impact that transition might have on both health and wellbeing in young people with intellectual disabilities. Wellbeing is a related but distinct construct from health. The Oxford English Dictionary defines wellbeing as: "the state of being comfortable, healthy and happy." Thus, both physical and mental health are important components of wellbeing (Dunn, 1973), but other factors, including life satisfaction, are also implicated, leading to a more holistic definition of overall wellness. Within the scientific and philosophical literature, wellbeing has been defined in various ways. Early attempts to define wellbeing included Bradburn's (1969) research on psychological wellbeing, which focussed on the reactions of ordinary people in their daily lives; here, high psychological wellbeing was related to high positive affect, and low to high negative affect. Diener and Suh (1997) added to this argument, proposing that wellbeing consists of life satisfaction (a cognitive sense of satisfaction with life), pleasant affect, and unpleasant affect (relating to moods or emotions).

In this way, wellbeing is closely related to mental health, but actually reflects a more general term, related to aspects of one's whole life. Ryff (1995) argues that fulfilment and positive functioning are key to defining wellbeing, as well as the presence of positive affect and the absence of negative affect, and Shah and Marks (2004:2) describe wellbeing thusly:

"Well-being is more than just happiness. As well as feeling satisfied and happy, well-being means developing as a person, being fulfilled, and making a contribution to the community."

This definition of wellbeing is in line with some definitions of quality of life; indeed, a key difficulty in defining wellbeing is that the term is often used interchangeably with quality of life (Dodge et al., 2012); defined by the World Health Organization as:

"An individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, personal

beliefs, social relationships and their relationship to salient features of their environment” (World Health Organization, 1997).

Although use of the terms ‘wellbeing’ and ‘quality of life’ may cause confusion, this conceptualisation captures the wide ranging aspects of the terms quality of life or wellbeing, and has allowed both terms to move away from conceptualisations of illness when considering a person’s overall wellness. Indeed, Herzlich (1975) asserts that it is critical to establish what is ‘normal’ for an individual when thinking about ill-health or good health. This notion has particular consequences when considering the population with intellectual disabilities, whose normal health and functional status may be profoundly different to someone in the typically developing population. These subtleties have led to the use of the term “flourishing” (Seligman, 2011), which refers to those aspects that allow somebody to lead a good life. Seligman (2011) argues that the key components of a positive life include positive emotion, engagement, relationships, meaning and accomplishment.

In recognition of these broad conceptualisations, wellbeing may be best thought of as a state of equilibrium (Herzlich, 1975), which allows individuals to return to their normal state even after they have experienced challenging life events. In this way, wellbeing is related to the resources people have to draw on to allow them to return to equilibrium after challenges have occurred, and can hence be regarded as a fluctuating state rather than a stable trait (Headey & Wearing, 1991). Building on previous models (e.g. Headey & Wearing, 1991; Cummins et al., 2010), Dodge et al. (2012) propose a new model of wellbeing, with wellbeing resting at the central point of a seesaw, and resources (psychological, social and physical) and challenges (psychological, social and physical) sitting at opposite ends. Hence, stable wellbeing occurs when an individual has sufficient resources to tackle the challenges they face (Dodge et al., 2012).

Wellbeing is a useful construct to consider in addition to health in the context of transition in individuals with intellectual disabilities, since the key issue during transition is how an individual is situated in their environment and their reaction to this situation. Hence, the key components of wellbeing, including affect, fulfilment and development, may all be affected during transition, as well as health. This focus therefore facilitates a consideration of the broad implications of transition for a young person’s whole life, with specific focus on how the transition to adulthood affects them within the context of their normal functional abilities.

## **8 The effect of transition on health and wellbeing in individuals with intellectual disabilities**

The evidence reviewed suggests largely negative transition outcomes for young people with intellectual disabilities across the domains of work, social relationships and independent living, all of which could conceivably impact negatively on a young person's health and wellbeing. Even without the complications of an intellectual disability, transition in itself can be a disruptive and stressful experience. Leaving school constitutes a huge change in a young person's daily routine, and multiple reports highlight the lack of options available to young people with intellectual disabilities upon leaving school (e.g. Cooney, 2002; Stevenson et al., 1997). This issue may translate into few post-school options for meaningful activity or socialising, which may trigger isolation, anxiety or depression, or exacerbate existing mental health conditions. These wellbeing issues may be further exacerbated by problems encountered in negotiating new adult roles within families and social networks; many parents of young people with intellectual disabilities report struggling to adjust to their child's increasing independence, particularly with regards to sensitive – but important – issues such as sex and relationships (e.g. Hamilton et al., 2015).

Child services and special education schools often provide a high level of support to young people with intellectual disabilities and their families, for instance in the form of family oriented services or functional skills programmes. When a young person leaves school, they transition from a position of entitlement to one of eligibility regarding services (Neece et al., 2009), which potentially limits the amount of support available. This lack of support may result in the manifestation of lifestyle risk factors, such as poor diet or lack of exercise, or in health problems going untreated. Furthermore, after leaving school there may be a rationing of specialised supports to adults compared to children with intellectual disabilities (Emerson, 2011). This decrease in available services might result in less use of services and poorer health. Indeed, in a secondary analysis of the Adults with Learning Difficulties in England survey (2003/4), Emerson (2011) found that, among adults with mild intellectual disabilities ( $n = 1,022$ ), those who were not receiving services were more likely to experience a number of social determinants of poor health, including material hardship and being less likely to have participated in community activities in the past month, compared to adults with mild intellectual disabilities who were receiving services. In addition, those who were not receiving services were significantly less likely to have visited a dentist in the previous year and were significantly more likely to smoke. Although there may be other variables accounting for this effect, the association between a lack of



service input and negative health outcomes may suggest that if such input is limited when a young person leaves school, they may be more likely to experience negative health outcomes.

As well as a decrease in the level of support available, evidence suggests that the transition between child and adult health services itself may be inadequate for this population. Analysis of the 2009-2010 National Survey of children with special health care needs, a cross-sectional survey covering 40,242 US children aged 0 to 17 years (n with intellectual disabilities alone = 1,070; n with physical health conditions and mental health conditions = 1,144; n with intellectual disabilities and mental health conditions = 1,174; n with physical and mental health conditions and intellectual disabilities = 1,521) found that children with intellectual disabilities alone or in combination with mental or physical health conditions were significantly less likely to have received care which met each of the six indicators of quality and accessibility of care identified by The Maternal Child Health Bureau (Cheak-Zamora & Thullen, 2017). These indicators included families being partners in decision-making; receiving coordinated, comprehensive care within a medical home; receiving organised community-based services; having adequate health insurance; experiencing early and continuous health screening; and receiving healthcare transition services. Importantly, those with intellectual disabilities had the lowest odds of receiving healthcare transition services compared to those with physical or mental health conditions. Although the data relied on caregiver reports and are therefore subjective, the results suggest that individuals with intellectual disabilities are particularly at risk of not receiving support during their transition to adult health services, which may jeopardise the management of existing health conditions.

Young people with intellectual disabilities may experience additional difficulties during transition in struggling with the normal issues of adolescence such as emancipation and self-concept, but with the cognitive competencies of much younger children (Zeitlin, 1985). Furthermore, the discrepancy between chronological age and physical maturity in young people with intellectual disabilities may lead to conflicting role expectations from the family, peers and the self, which might contribute to poor psychological adjustment (Zeitlin, 1985). Indeed, in a qualitative study involving life history interviews with 25 individuals with mild intellectual disabilities aged 22-33 years, recruited from California Regional centres, residential facilities, sheltered workshops and training programmes, and their parents, Zeitlin and Turner (1985) demonstrated that individuals with intellectual disabilities voiced concern over the same issues as did those without intellectual

disabilities, including personal identity and autonomy. However, limited or unclear expectations from their parents, combined with an absence of peer support, exacerbated existing adjustment disturbances: 84% of the sample had displayed behavioural or emotional problems during school, including temper tantrums, self-abusive behaviour or withdrawal. While this study only represents views from individuals with mild intellectual disabilities, comparable difficulties might also be experienced by those with more severe intellectual disabilities.

In addition, the social experience of having a disability may contribute to mental illness in people with intellectual disabilities. A social model of mental distress regards the source of mental health problems to be the excluding role of disability in society; in this way, manifestations of social distress, exhibited in mental illness, are regarded as survival strategies in response to difficult situations (Williams & Heslop, 2005). In support of this idea, Williams and Heslop (2005) draw on evidence from an action research study involving young people with intellectual disabilities, their families and service providers, in which families focussed not on medical issues when discussing their problems, but instead on social issues. Indeed, individuals with intellectual disabilities may experience stigma and exclusion within mainstream society, and this may be particularly evident when a young person transitions to adulthood spaces, since society is perhaps more accepting of difference in children than in teenagers or young adults (Hamilton et al., 2015). These experiences of stigma can have profound consequences for mental health. A cross-sectional questionnaire study of adults with mild to moderate intellectual disabilities ( $n = 59$ ) recruited from community intellectual disability services, day centres, social clubs, supported accommodation and voluntary organisations in England, found that high levels of self-reported stigma were strongly related to experiences of psychological distress, including anxiety and depression (Ali et al., 2015). People with intellectual disabilities may therefore be especially vulnerable to psychological distress as a result of discrimination, due to the combined effects of social adversities and poor coping strategies (Ali et al., 2015).

With this social model of mental illness in mind, the trauma of leaving school may serve as a trigger for mental health difficulties. Indeed, in a review of the prevalence, nature and determinants of problem behaviours in people with intellectual disabilities, O'Brien (2003) asserts that the transition to adulthood is generally considered to be a risk stage for problem behaviours, perhaps because changes in an individual's immediate environment can precipitate behavioural change.

## 9 Final remarks

In many ways, the ‘normal’ model of transition may be inappropriate when applied to young people with intellectual disabilities. As such, transition may be a difficult period for many individuals with intellectual disabilities, with negative implications for health and wellbeing. The evidence reviewed here suggests that support to transition is often inadequate, and that young people with intellectual disabilities may struggle to adopt ‘adult’ roles. Indeed, Clegg and King (2006) argue that the push towards autonomous adulthood is often confusing and inappropriate for young people with intellectual disabilities, and that to ignore their dependence on those around them puts them in an untenable position, which fails to recognise their current needs and identity, during transition. In addition, the population with intellectual disabilities experience increased vulnerability to some physical and mental health problems, some of which may be triggered or exacerbated by a disruptive transition experience and, potentially, a resultant change in lifestyle. Young people with intellectual disabilities may therefore experience a turbulent transition period, which they must face with limited cognitive competencies, and often whilst also managing existing health conditions.

This chapter has reviewed the evidence on transition outcomes and health status in young people with intellectual disabilities, demonstrating that both physical and mental health is poorer in this population than the typically developing population, and that transition experiences and outcomes may also be worse in this population. Furthermore, evidence has been presented which suggests that the difficulties experienced during transition may render this period one of particular risk in terms of health and wellbeing for young people.

Considering the divergent components of transition examined in this literature review, including organisational components, such as leaving school, and more conceptual components, such as developing independence, it is critical to consider health and wellbeing in holistic as well as clinical terms. In this way, the effect that transition to adulthood has on a young person’s life as a whole must be considered alongside diagnoses of physical and mental illness. In order to provide a coherent picture of the current evidence base on the impact that transition may have on young people with intellectual disabilities in this way, a systematic review to examine the current literature on transition and health and wellbeing outcomes in young people with intellectual disabilities is required in order to determine whether, and in what ways, transition affects health and wellbeing in

this population. The following chapter will outline the process and results of conducting such a review.

## Chapter 2: Systematic review

### 10 Introduction

The previous chapter reviewed the literature on transition outcomes for young people with intellectual disabilities, and the epidemiological literature on health in children and adolescents with intellectual disabilities. Given the poor outcomes documented across both conceptual and organisational components of transition, and their potential consequences for health and wellbeing, it is necessary to investigate more vigorously the effect of this period on health and wellbeing in this population. Existing systematic reviews highlight a gap in this area: Foley et al. (2012) conducted a systematic review of the literature examining transition for young adults with intellectual disabilities using the International Classification of Functioning and Health (ICF) as a guiding framework, finding significant gaps in the literature. In addition, Robertson et al. (2015) recently conducted a systematic review of systematic reviews on health and healthcare of people with intellectual disabilities to identify gaps in the evidence base. They found no review examining transition and health in this population. Therefore, the aim of this review was to systematically review evidence about the effect that transition to adulthood has on health and wellbeing in young people with intellectual disabilities.

### 11 Method

Both Preferred Reporting Items for Systematic Reviews and Meta-Analyses and Meta-Analysis Of Observational Studies in Epidemiology (PRISMA/MOOSE) guidelines were followed. The trial was registered on the international prospective register of systematic reviews (PROSPERO): CRD42015016905.

#### 11.1 Electronic search of databases

Electronic searches of six databases were conducted: Embase (Ovid; 1947 - 2016), Medline (Ovid; 1946 – February 2016), ASSIA (1987 - 2016), ERIC (1966 – 2014), PsycINFO (1887 – 2016) and CINAHL (1981 - 2016). The final search was conducted on 19<sup>th</sup> January 2016. The searches were undertaken with librarian advice. Key word searches utilising the following terms, including historic terms, were performed:

1. Mental AND (handicap\* OR disab\* OR difficult\* OR impairment OR deficien\*  
OR incapacit\* OR delay OR problem OR subaverage)

2. (Intellectual OR learning OR developmental OR neurodevelopmental OR cognitive) AND (handicap\* OR disab\* OR difficult\* OR impairment OR deficient\* OR incapacit\* OR delay OR problem OR subaverage)
3. (Intellectual OR learning OR developmental OR neurodevelopmental OR cognitive) AND (disorder OR condition)
4. Subnormal OR feeble-minded OR imbecile OR idiot OR moron OR oligophreni\* OR aphreni\* OR defective OR retard\*
5. Transition\* OR “school to work” OR “child\* to adult\*” OR “child\* to adolescence” OR “life changes”
6. (Mental OR psych\* AND health) OR health\* OR wellbeing OR anxiety OR worry OR stress OR depress\* OR emotion\* OR mood OR “common mental disorders” OR “challenging behaviour” OR “complex needs” OR p?ediatric OR hospital OR respite OR “sensory impairment” OR deaf OR blind OR sight OR vision OR hearing OR mobilit\* OR “cerebral palsy” OR “down’s syndrome” OR autism OR epilepsy OR respiration OR incontinence OR pain OR welfare

## 11.2 Hand search of grey literature and key journals

Additionally, grey literature, including the UK Health Technology Assessment (HTA) and National Institute for Health and Care Excellence (NICE) guidelines were hand searched.

Key word searches in the following relevant journals were also performed:

- Journal of Applied Research in Developmental Disabilities
- Research in Developmental Disabilities
- Journal of Intellectual Disability Research
- American Journal on Intellectual and Developmental Disabilities
- Journal of Intellectual Disabilities
- Journal of Intellectual and Developmental Disability

Reference sections of articles were hand searched to ensure that no relevant articles had been missed.

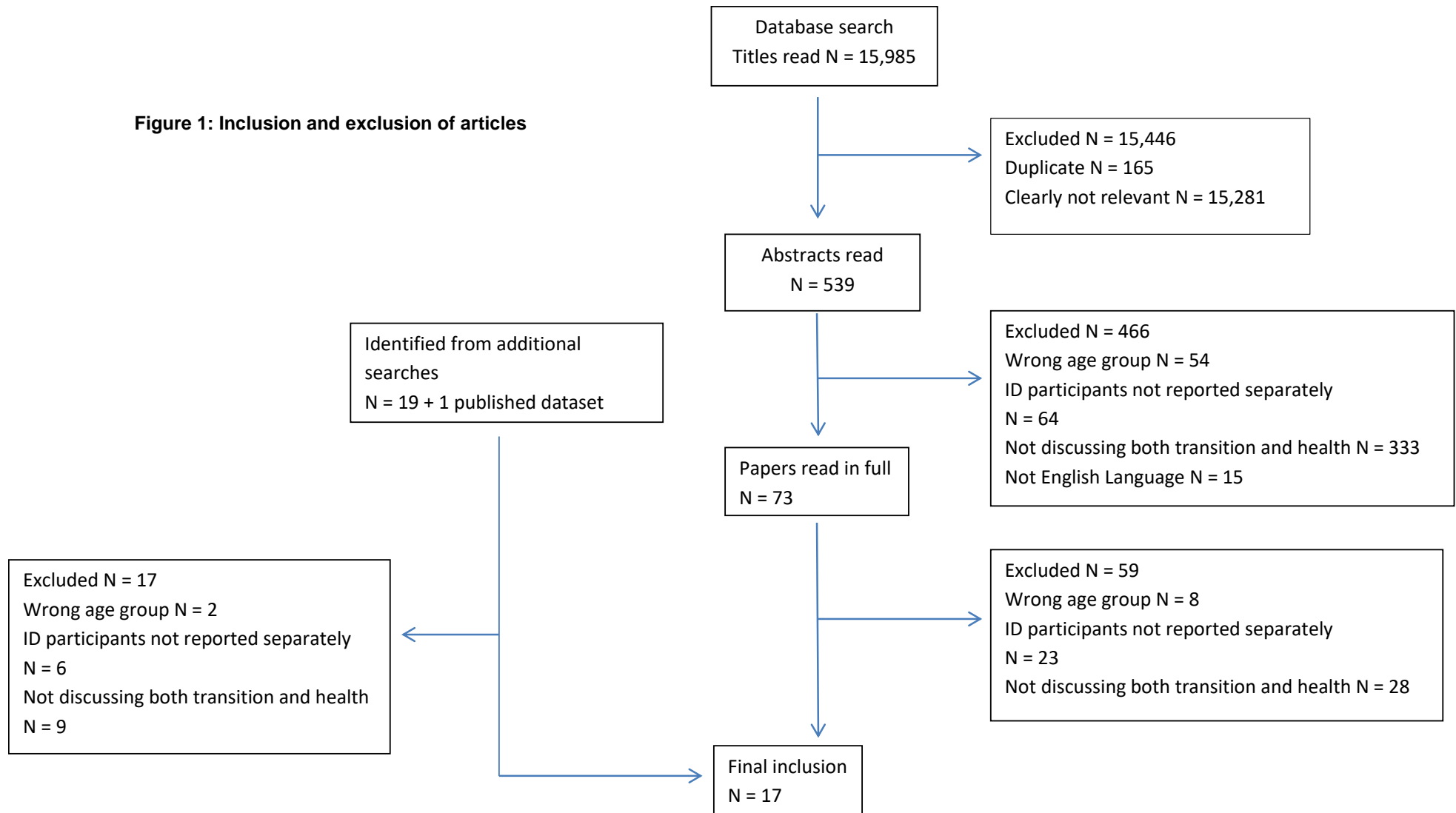
### **11.3 Inclusion criteria**

All study methodologies were included. Articles were selected on the basis of meeting the following inclusion criteria:

1. The age of participants was within the range 13-24 years. For articles with a wider age range, results were separately reported for ages 13-24 years, or more than 50% of participants were aged 13-24 years.
2. Participants had intellectual disabilities. Where articles included both participants with and without intellectual disabilities, data for participants with intellectual disabilities were reported separately from those without intellectual disabilities.
3. Both transition and health or wellbeing were discussed.
4. English language.

### **11.4 Article selection**

The search strategy was run in each database, and the resulting article citations were examined in relation to the research question. The abstracts of the citations that were considered to be potentially relevant to the research question were then read. If the abstract was considered to be relevant to the research question, the article was read in full (Figure 1). A random sample of 10% of the titles retrieved and of the abstracts that were deemed to be potentially relevant were reviewed by a supervisor to check agreement.

**Figure 1: Inclusion and exclusion of articles**



## 11.5 Data extraction of selected articles

Key information was extracted from the selected articles under the following headings: study location, participants (including number, age, sampling and level of intellectual disabilities), study design, study aims, measures, findings, and limitations.

## 11.6 Quality assessment

The quality of selected studies was systematically assessed using the Critical Appraisal Skills Program (CASP) tools; the Qualitative Checklist (2014) was used for the qualitative studies, and an amended version was used for the quantitative studies (Appendix L). They each include 10 items, from statement of aims, methodology, design, participants, study size, measures, data collection, analysis, results, bias, generalisability, value, relationship with researcher and ethics. Each item is scored either 0 or 1, with a score out of 10 indicating the overall assessed quality.

## 12 Results

Figure 1 shows the process of article selection. The search produced a total of 15,985 articles. 165 duplicates were removed and 15,281 titles were excluded as they were clearly not relevant, leaving 539 abstracts. There were differences in agreement on only 6 titles and 2 abstracts; consensus was reached (to be over-inclusive), and none of these articles were retained at the final stage. Those abstracts that clearly did not meet the inclusion criteria were excluded, leaving 73 articles which were read in full, yielding a total of 14 articles that met the inclusion criteria. A search of the reference sections of all selected articles and journals yielded 2 more articles, neither of which referred to transition in the title or abstract, and a dataset from the National Longitudinal Transition Study-2 (NLTS-2) (2003), leaving the final number of articles/dataset for inclusion at 17. The articles are summarised in Table 2.

**Table 2: Summary of articles included in the systematic literature review**

<b>Authors/ Year</b>	<b>Location</b>	<b>Participants (n, age, sampling, level of ID)</b>	<b>Study type</b>	<b>Study aims</b>	<b>Measures</b>	<b>Findings</b>	<b>Limitations and assessed quality score</b>
Chamberlain et al. 1984	Ohio, USA	Females (n = 87) Aged 11-23 years Mild ID n = 41; Moderate ID n = 23; Severe ID n = 23 Drawn from a single multiservice clinic providing adolescent healthcare including gynaecology and family planning Mothers (n = 69) of these females with ID	Cross-sectional	To examine issues in fertility control of young women with ID	Patient chart data from 87 females reviewed; 69 mothers completed questionnaires and interviews	Mothers reported difficulty teaching daughters menstrual hygiene (for 88% of daughters with severe ID; 41% moderate ID; 27% mild ID) 22 females had known history of sexual assault (14 mild ID; 6 moderate and 2 severe) and 9 of these were victims of incest 42 females had used contraception but medical and psychosocial problems complicated their choice of method	Potentially biased sample as the clinic specifically dealt with family planning No typically developing comparison group 6
Hepper & Garralda 2001	London, UK	Individuals in their final year of a special school (n = 10) Age 16 years Moderate ID Recruited through letters from author/department head	Mixed methods prospective cohort study Parental questionnaire completed at 2 time points, 6 months apart	To investigate psychiatric morbidity increases at transition from school to adult education/services	Semi-structured questionnaire to parents (on child's social functioning, emotional/behavioural problems, contact with psychological services); SDQ	High frequency of emotional/behavioural difficulties prior to transition but no increase/decrease in psychiatric morbidity 6 months after leaving school (median SDQ score = 14 at Time 1 and 14.5 at Time 2)	Small sample and taken from a single school No typically developing comparison group Limited time scale (6 months) Initial measure taken at final term of school – could reflect anticipatory anxiety Self-selected sample (those

							who responded to letters) 10 out of 15 sets of parents participated in full study 6
Kraemer et al. 2003	California, USA	Young adults (n = 188) Age 18-26 years Moderate – severe ID Drawn from Regional Centre System in California (provide case management to individuals with ID)	Cross-sectional	To examine the quality of life of young adults with ID during transition	Postal survey: Family Data Sheet; Vineland structured interview; SIB-R; Problem Behaviour Scale; Family Impact Questionnaire QRS-F; F-COPES; Informal questionnaire on support; Parent Involvement in Transition Planning questionnaire Transition Experiences Survey interview; QoL-Q	Young people who had exited high school (n = 85) had significantly higher quality of life scores (Mean = 76.3) and empowerment/independence subscale scores (Mean = 18.5) than those still in school (n = 103) (Mean total QoL = 71.6; mean empowerment = 16.5) Young people working in the community had significantly higher quality of life scores (Mean = 85.2) and competence/productivity scores (Mean = 21.1), empowerment/independence (Mean = 20.1) and social belonging/community integration (Mean = 20.9) subscales than those working in sheltered workshops (Mean total QoL = 75.3; mean competence = 15.0; mean empowerment = 17.1; mean social belonging = 19.7) or not working at all (Mean total QoL = 73.4; mean competence = 11.9; mean empowerment = 19.5; mean social belonging = 18.2) Those in community work did not have higher subjective quality of life scores (satisfaction) than	Parents completed majority of questionnaires Findings could be related to functioning – higher functioning more likely to be able to keep community work No typically developing comparison group 9

						those in sheltered workshops or not working at all	
NLTS-2 (SRI International) 2003	Across USA	N = >11,000 of whom ~ 1,000 had ID at first wave of data collection Age 13-16 years at first wave of data collection Sample drawn from USA special schools, weighted to be nationally representative	Longitudinal cohort, with five waves of data collection spanning 8 years	To document the experiences of a national sample of special education students as they moved from secondary school into adult roles	Parent/ student phone interview or postal questionnaire Student assessment including short versions of WJ-III; SIB-R; Purpose-designed Teacher Survey; Purpose-designed School Program Survey; Purpose-designed School Characteristic Survey	24.3% parents rated their child with ID's general health as 'excellent' and 12.7% parents rated 'fair or poor' 28.2% young people with ID rated their own health as 'excellent' and 12.8% rated 'fair or poor'	Level of ID not reported Data are weighted estimates of respondents nationally N not reported No non-disabled comparison group 6
McIntyre et al. 2004	California, USA	Mothers of young people with severe ID (n = 30) Young people were aged 18-24 years Recruited through Southern California Regional Centres (provide case management services to individuals with ID)	Mixed methods Qualitative interview and questionnaire	To examine quality of life of young people with severe ID from carers' perspectives	QoL-Q; Semi-structured interview	Most mothers reported child had good quality of life (mean score = 71.6) Themes identified affecting quality of life: activities, having basic needs met, social contact, happiness, health, family life, vocational opportunities, emotional/behavioural problems	Proxy reporting No typically developing comparison group 7

Ruran-girwa et al. 2006	Atlanta, USA	Individuals with DD (n = 482) n with isolated ID = 128 n with ID and coexisting impairment (e.g. cerebral palsy or epilepsy) = 35 Mild ID n = 132 Severe ID n = 32 Age 21–25 years Part of the MADDS and MADDS-FU cohorts Recruited via record review Comparison group with no disability (n = 124) Recruited from public school rosters	Cross-sectional	To measure leading health indicators (physical activity, obesity, tobacco use, substance use, responsible sexual behaviour, injury and violence, access to health care) in young adults with and without a history of developmental disabilities	Structured questionnaire administered face to face or via telephone	Young adults with ID had a 6-fold increased risk for not receiving sex education in school or by parents compared with adults without ID Young adults with ID had a 7-fold increased risk for having been attacked or beaten in the last 12 months Young women with ID had a 9-fold increased risk for never having a Pap smear or pelvic exam	Responses given by proxies excluded, so responses are biased towards those with mild ID ID diagnosed in original MADDS study when individuals were age 10 8
Yu et al. 2008	Across USA	Random sample of students receiving special education from rosters of LEAs and state-supported schools (n = 2,640) Age 18-21 years	Cross-sectional	To provide national picture of prevalence rates of smoking, alcohol and illegal drug use in young adults with disabilities	Telephone interview or postal survey Questionnaire on substance use – asked to report frequency of use in last 30 days	Young people with ID less likely than the general population to report smoking, drinking or marijuana use Cocaine use same as general population Young people with ID more likely than those from other disability categories to report smoking, drinking and marijuana use	Response rate 67% Statistics are weighted estimates of national population of young people in this age group receiving special education Level of ID not reported n participants with ID not reported

							No non-disabled comparison group 6
Davies & Beamish 2009	Queensland, Australia	Parents of children (early 20s) with ID and high support needs who had completed school (n = 218) Drawn from schools (transition staff identified potential parents) Their children had: ID (n = 182) ASD without ID (n = 28) ASD and ID (n = 30)	Mixed methods Qualitative – ‘life stories’ approach and Quantitative – postal survey	To allow parents to report on experiences and outcomes of their young adults in post-school transition	Purpose-designed postal survey to gather parental perspective on transition experience/outcomes	Current life satisfaction reported positively (‘much’, ‘a great deal’) by 64% 13% indicated child not currently satisfied with life (‘not at all’, ‘a little’)	Proxy reporting Response rate 27% Self-selected sample - highly motivated and well placed to communicate difficulties Level of ID not reported No typically developing comparison group 7
Rimmer et al. 2010	Across USA	Parents of children with mild to moderate ID (n = 461) age 12-18 years Recruited from multiple sources Families were directed to visit Survey website Comparison group: data from 2007 Youth Risk Behaviour Survey (Centers for Disease Control and Prevention, 2008)	Cross-sectional	To explore prevalence of obesity and related secondary conditions (and compare to published data of young people without disabilities)	Purpose-designed web-based survey	Parents of adolescents with autism and Down syndrome 2-3 times more likely to have reported obesity than general population and to report secondary conditions e.g. high blood pressure/cholesterol, diabetes, depression, fatigue, low self esteem	Proxy reports rather than actual weights may under-estimate obesity Non-representative sample – people who use the internet May be other secondary conditions (e.g. loneliness) not reported Potential bias in comparison group

							7
Taylor & Seltzer 2010	Wisconsin and Massachusetts, USA	Mothers of children with ASD with/without ID (n = 242) age 10-23 years Recruited through service agencies, schools and clinics	Longitudinal	To examine whether exiting high school is associated with alterations in rates of change in autism symptoms and maladaptive behaviours	ADI-R; Behaviour Problems subscale of the SIB-R; Vineland Screener; WRIT; School record review	Autism symptoms and maladaptive behaviours were improving over time while young people were in high school, but less so for those with ID Improvement in internalised behaviours stopped after high school exit, and improvement in externalised behaviours became more pronounced after high school exit Individuals with ID had more repetitive behaviours, verbal communication impairments, internalised behaviours and externalised behaviours	Volunteer sample skewed towards those with higher socioeconomic status Level of ID not reported All participants had autism 8
Bhaumik et al. 2011	Leicester, Leicestershire and Rutland, UK	Parents of young people (n = 79) Aged 16–19 years Recruited from mental health services, community paediatric services, social services, education services and Connexions service	Cross-sectional	To estimate the number of teenagers with ID age 16-19 years with significant mental and physical healthcare needs	Postal questionnaire including Vineland; Qualitative interview with a sub-sample of 24 carers	86% had physical problems and/or mental health or behaviour problems and/or epilepsy On average teenagers used 5 different services, and carers reported that they needed 4 more	Level of ID not reported for questionnaire data No typically developing comparison group No data from teenagers or professionals 6
Forte et al. 2011	Scotland, UK	Young people (n = 52) (ID n = 26; non-ID n = 26) Age 17-20 years Mild ID Recruited from a single Further Education College	Between-groups cross-sectional qualitative study: photographic materials to stimulate semi-	To examine context/salience of worries experienced by young people with ID as they transition to adulthood	Semi-structured purpose designed 'worry' interview; GSES – 12; GAS-ID	ID worries include being bullied, losing someone they are dependent on, failing in life, making/keeping friends ID worries based more on previous/current circumstances whereas non-ID based more on uncertainties regarding future	Measures taken at a single point in time Participants recruited from a single college 8

		Had to have 6 months left on course	structured interview			Higher rumination in ID group than non-ID group Higher distress in ID group than non-ID group Strong significant positive correlation ( $r = .76$ , $p = .001$ ) between distress scores and GAS-ID in ID group	
Pownall et al. 2011	Scotland, UK	Mothers with 1 child with mild-moderate ID aged 17-19 years and at least 1 child without ID (>5 years older/younger) (n = 9) Recruited through Enable (voluntary organisation)	Cross-sectional, qualitative study	To contrast mothers' experiences of supporting sexuality in ID and non-ID siblings	Semi-structured interview	Themes: difficulty of striking a balance between independence and control; dependency of ID young people (few opportunities to socialise); difficulty adjusting to physical changes; vulnerability; parental control over sexuality	Small sample Sample biased towards higher functioning ID 8
Larkin et al. 2012	Scotland, UK	Young people (n = 26) Mild to moderate ID Age 16-20 years Recruited from two further education colleges Non-ID comparison group (n = 20) Age 16-20 years Recruited from two colleges, one youth club and one secondary school	Cross-sectional, qualitative study	To investigate experiences of interpersonal conflict in young people with ID at transition, compared with experiences of non-ID young people	Semi-structured interview about recent experiences of interpersonal conflict; CEBA interview; WASI; CCB	ID young people more likely to encounter conflict with strangers/peers outside friend group (over half described incidents of physical or verbal aggression) and to characterise other people globally as 'bad'; more likely to feel victimised than non-ID young people	Socio-demographic differences between groups that could explain results e.g. ID group from more deprived backgrounds than non-ID group 8
Barron et al. 2013	London, UK	Young people (n = 27) Age 16-18 years Mild ID n = 11 Moderate ID n = 11 Severe ID n = 5 Identified by a transition social worker	Cross-sectional	To examine the sociodemographic and clinical characteristics of young people with ID and challenging behaviour at transition to adult services, as well	Interview included SDQ; mini PAS-ADD; CSRI; CBCL	88% of the sample were living at home with parents or foster carers 24 individuals were in full time education 23 individuals had a mental health diagnosis (emotional disorder was the most prevalent)	Participants were from an inner city service so the findings are not generalizable No typically developing



				as pattern of service use and associated costs of care		18 had a physical diagnosis Mean total cost of all services per week was £2543	comparison group 5
Biggs & Carter 2016	Tennessee, USA	Parents/caregivers of young adults with disability aged 13–21 years (n = 389) ID (n = 157) Autism and ID (n = 54) Recruited from family/disability organisations Normative comparison group (n = 16,888) proxy respondents from European KIDSCREEN field survey	Cross-sectional	To examine the subjective health and wellbeing of transition age young people with autism or ID	Postal survey including KIDSCREEN-27; Santa Clara Strength of Religious Faith questionnaire AIR self-determination scale, parent version; ASPeCT-DD	Parent reported wellbeing of young people with ID was significantly lower than for the normative sample in physical wellbeing (p < .0001), psychological wellbeing (p = .0002), and social support and peers (p<.0001) Lowest ratings were in social support and peers Having autism, high support needs or challenging behaviour was negatively associated with quality of life domains	Proxy reports Level of ID not reported 8
Young et al. 2016	West of Scotland, UK	Adolescents with mild to moderate ID (n = 25) Adolescents without ID (n = 27) Age 15–18 years Recruited from schools	Cross-sectional	To examine the content and emotional impact of worries amongst adolescents with and without ID at the time of leaving school	Background information sheet; Worry interview; GAS-ID; WASI	Adolescents with ID were significantly more anxious than their non-disabled peers (p = 0.03) No significant difference between the two groups' level of rumination or distress was found Adolescents with ID were more concerned about death, relationships, bullying and decisions than their non-disabled peers Those without ID were more concerned about failure, family, college and money than those with ID	Those with severe/profound ID excluded Between groups analysis was underpowered 6

Abbreviations: ABS-Adaptive Behaviour Scale; ADI-R-Autism Diagnostic Interview-Revised; ASPeCT-DD-The Assessment Scale for Positive Character Traits-Developmental Disabilities; ASD-autism spectrum disorder; CCB-Checklist of Challenging Behaviour; CEBA-Cognitive Emotional Behavioural Assessment; CSRI-Child Service Receipt Inventory; DD-developmental disability; F-COPES-Family Crisis Oriented Personal Evaluation

Scale; GAS-ID-Glasgow Anxiety Scale-Intellectual Disability; GSES-12-General Self Efficacy Scale; ID-intellectual disabilities; LEA-local education authority; MADDS-Metropolitan Atlanta Developmental Disabilities Study; MADDS-FU-MADDS Follow-Up of Young Adults; PAS-ADD-Psychiatric Assessment Schedule for Adults with Developmental Disability; QoL-Q-Quality of Life Questionnaire; QRS-F-Questionnaire on Resource and Stress – Short form; SDQ-Strengths and Difficulties Questionnaire; SIB-R-Scales of Independent Behaviour Revised; STI-sexually transmitted infection; WRIT-Wide Range Intelligence Test; WASI-Wechsler Abbreviated Scale of Intelligence; WJ-III-Woodcock-Johnson III

## **12.1 Review of selected articles**

As the studies varied in design and methodology, a narrative synthesis of the findings was conducted.

### **12.1.1 Physical health**

Three studies examined physical health outcomes (Rurangirwa et al., 2006; Rimmer et al., 2010; Bhaumik et al., 2011) through a web survey (Rimmer et al., 2010) and questionnaires (Bhaumik et al., 2011; Rurangirwa et al., 2006). A high rate of health problems, including physical and mental health problems, behavioural problems, and epilepsy was identified, and consequently individuals with intellectual disabilities were in receipt of an average of five health services, with parents reporting needing more service input (Bhaumik et al., 2011). Obesity and related secondary conditions, including diabetes and depression, were indicated as being a particular problem for young people with intellectual disabilities (Rimmer et al., 2010). Access to health education and services was limited, with individuals with intellectual disabilities at a higher risk of not receiving sex education or pelvic exams than their non-disabled peers (Rurangirwa et al., 2006). While these studies all obtained data from parents' reports, the NLTS-2 (2003) surveyed both young people and their parents, obtaining ratings of young people's health from both perspectives and finding a disparity between the two.

The studies reviewed reveal data related to some specific physical health concerns, yet there is no comprehensive picture of physical health for this population during and following transition; for example, information on a variety of crucial factors, such as diet, exercise, oral hygiene, or ongoing health problems, is lacking.

### **12.1.2 Mental health**

Five studies examined behavioural and mental health (Barron & Hassiotis, 2008; Bhaumik et al., 2011; Hepper & Garralda, 2001; Taylor & Seltzer, 2010; Yu et al., 2008) through questionnaires and interviews. A high frequency of emotional and behavioural problems was identified in this population (Barron & Hassiotis, 2008; Bhaumik et al., 2011; Hepper & Garralda, 2001) and, while persisting into adulthood, these did not seem to worsen following transition. Improvements in the autism behavioural phenotype in people with co-morbid autism spectrum disorder and intellectual disabilities continued to be slow before

and after transition from school (Taylor & Seltzer, 2010). Substance use was also considered but was not indicated as being problematic for this population in comparison to the non-disabled population (Yu et al., 2008)

### **12.1.3 Wellbeing**

Quality of life was the primary outcome measure for four studies (Biggs & Carter, 2016; Davies & Beamish, 2009; Kraemer et al., 2003; McIntyre et al., 2004): most parents reported that their child with intellectual disabilities had a good quality of life; however, Biggs and Carter (2016) identified that parent reports of wellbeing and quality of life were significantly lower for young people with autism or intellectual disabilities than for a typically developing sample. Themes reported as contributing to quality of life included having social relationships and vocational opportunities, and health (McIntyre et al., 2004). The NLTS-2 (2003) considered wellbeing more generally; asking participants how many times health or emotional problems had recently caused them to miss school or social activities. More than half reported that this had ‘never happened’.

### **12.1.4 Relationships and sexual health**

Six studies examined relationships and sexual health (Forte et al., 2011; Larkin et al., 2012; Chamberlain et al., 1984; Pownall et al., 2011; Rurangirwa et al., 2006; Young et al., 2016), with outcomes having important implications for young people’s overall wellbeing. Methodologies in these studies were primarily qualitative, including semi-structured interviews (Forte et al., 2011; Larkin et al., 2012; Chamberlain et al., 1984; Pownall et al., 2011; Young et al., 2016) and questionnaires (Rurangirwa et al., 2006). Interpersonal problems and their effects on mental health were revealed to be of concern, with young people with intellectual disabilities experiencing higher rates of interpersonal conflict than their non-disabled peers (Larkin et al., 2012; Rurangirwa et al., 2006) and reporting being worried about social issues, such as being bullied and making friends (Forte et al., 2011; Young et al., 2016). Young people with intellectual disabilities ruminated more about these worries and were more distressed by them than a control group without intellectual disabilities (Forte et al., 2011) and were significantly more anxious than their non-disabled peers (Young et al., 2016). Sexual health was revealed as a key issue, both in terms of practical considerations, such as fertility control and menstrual hygiene in girls (Chamberlain et al., 1984), and in psychosocial considerations, such as discussing

appropriate sexual behaviour with parents and having opportunities to form romantic or sexual relationships (Pownall et al., 2011).

While the studies reported in the last two subsections reveal a more comprehensive picture of mental health and wellbeing outcomes, including relationships and quality of life, for young people with intellectual disabilities, more detailed data exploring the ways in which transition impacts mental health and wellbeing, including mood and life satisfaction, is absent.

## **13 Discussion**

### **13.1 Overview of findings**

This systematic review of the literature has identified evidence suggesting that health and wellbeing in young people with intellectual disabilities may be poor during transition, with obesity, sexual health and interpersonal conflict being three areas of particular concern.

This finding is in contrast to the experience of transition in young people without intellectual disabilities; of the six studies included in the review that included a non-disabled comparison group (Biggs & Carter, 2016; Larkin et al., 2012; Pownall et al., 2011; Rimmer et al., 2010; Rurangirwa et al., 2006; Young et al., 2016), the majority found no significant cause for concern in the non-disabled groups; and, in cases where there were negative findings for those without intellectual disabilities (e.g. Young et al., 2016) those with intellectual disabilities still fared worse.

The most striking overall finding of the review is the limited quantity of research on this topic: no studies specifically examined whether the transition from school to adulthood has negative consequences for health or wellbeing. This limited evidence base is seemingly in contradiction to the concern attached to transition, both in empirical findings from professionals, young people and parents (e.g. Hudson, 2006; Murphy et al., 2011: see Chapter 1) and in government policy documents (see Chapter 1).

Given the large variability in study designs and outcome variables, the findings from the review are somewhat inconclusive. While most parents describe their child's quality of life as good following transition (Davies & Beamish, 2009; Kraemer et al., 2003; McIntyre et al., 2004), those authors who sought the views of young people with intellectual disabilities

uncovered a less positive vision, with high levels of interpersonal conflict experienced (Larkin et al., 2012; Rurangirwa et al., 2006) and worries about social relationships prevalent (Forte et al., 2011; Young et al., 2016). Sexual relationships were also potentially of concern, with sexual health being a key issue for this population during transition (Chamberlain et al., 1985; Pownall et al., 2011). This is concerning given Rurangirwa et al.'s (2006) finding regarding the higher risk of limited access to sex education and pelvic exams in this population. With regards to physical health, obesity (Rimmer et al., 2010) was a key issue for this population during this period. While there are obvious physical health implications following from both of these issues, such as unwanted pregnancy and sexually transmitted diseases in the former, and secondary conditions including diabetes, high blood pressure and high cholesterol in the latter, the implications of these issues for emotional wellbeing must also be considered; notably self-esteem, depression and anxiety.

With regards to mental health, Barron and Hassiotis (2008), Bhaumik et al. (2011) and Hepper and Garralda (2001) support the notion that mental health in this population is poor in general, but problems, although continuing from childhood into adulthood, do not appear to worsen following transition. This finding is consistent with previous epidemiological studies, which have found high rates of behavioural and emotional disturbance from young childhood into adulthood in this population (e.g. Einfeld et al., 2006).

## 13.2 Methodological limitations

There are some key limitations to the studies included in this review. The majority ( $n = 10$ ) utilised parents' perspectives of health and wellbeing outcomes during and following transition for their children; this not only neglects a crucial component of research in this area – the voices of young people with intellectual disabilities themselves – but also introduces a potential bias into the findings. Davies and Beamish (2009) argue that, due to their likely large degree of involvement in their children's lives, parents of children with intellectual disabilities are in an informed position from which to comment on their child's experiences. However, in this context, parents may be likely to describe their child's quality of life positively, since in many cases they assume responsibility for providing care and may therefore be likely to appraise it as good. The NLTS-2 (2003) dataset illustrates this problem: there are differences between parent ratings and self-ratings of general health status among the young people in this cohort, which calls attention to the fact that parents

and their children may be likely to appraise the young person's health differently. McIntyre et al. (2004) conclude that proxy reports for individuals with intellectual disabilities are acceptable for objective but not subjective measures, and the subjective nature of some issues relating to health and wellbeing in the context of transition may present a problem in these studies. Of those studies that did utilise young people with intellectual disabilities as informants, all sought views from those with mild to moderate, rather than more severe, disabilities ( $n = 5$ ). While this is a necessity due to the methodologies utilised in some studies, given that, for instance, participants must have the capacity to understand and respond to an interview, this also means that conclusions may not be relevant for people with more severe disabilities.

The issue of functional status confounding results is also present in studies where the level of participants' intellectual disabilities was not reported ( $n = 6$ ). For example, Kraemer et al. (2003) report on scores on quality of life subscales such as empowerment/independence and social connectedness/inclusion, noting that individuals in community employment scored more highly on these scales than individuals in sheltered work placements or in no employment at all. As individuals in community employment might be expected to be more highly functioning than those not in employment, their scores might reflect their functional status rather than their employment status. As intellectual disabilities cover such a large spectrum of ability, it is crucial that the level of disability is reported in order to provide a cohesive picture of research findings.

Recruitment methods utilised in the studies may also affect the results. The majority of studies in this review ( $n = 14$ ) obtained participants from an administrative sample, such as special education schools, and a large proportion ( $n = 5$ ) recruited participants from a single source. Although the methodological advantages of this sampling method are obvious in that intellectual disabilities constitutes a very particular population who might not otherwise be reached, recruiting participants from a single source is problematic in that any data obtained is only representative of those who come from that particular source, and cannot necessarily be generalised to a larger population. For example, Chamberlain et al. (1984) note that, as they recruited participants solely from a clinic that specifically provided family planning among their services, their data may be biased in that they likely over-represent young women who were specifically in need of family planning services. Furthermore, biases are also potentially present in terms of self-selection in the samples.

In addition to these potential biases, only six studies included a non-disabled comparison group (Biggs & Carter, 2016; Larkin et al., 2012; Pownall et al., 2011; Rimmer et al., 2010; Rurangirwa et al., 2006; Young et al., 2016). Given the notion that transition is a universal phenomenon (Hudson, 2006), this is an important limitation of the studies included, in that it is vital to accurately assess the differential impact that transition has on those with intellectual disabilities compared to those without, in order to inform future care, supports and policy.

### **13.3 Geographical context of the studies**

Although transition has been described as a universal phenomenon (Hudson, 2006), occurring internationally and throughout history, the previous chapter outlined some important cultural differences in the demarcation of transition to adulthood. The geographical setting in which the studies included in the review took place must therefore be considered; the studies included are all from the USA, UK or Australia, and, while these are all Western countries with presumably similar cultural values, subtle differences, which could potentially impact findings, may be apparent. For example, the USA has a large Latino population, and there are cultural differences in the demarcation of transition amongst Latino families, who, in contrast to some Western values, may consider prolonged residence within the parental home as normative and desirable (Rueda et al., 2005), a point raised already in the previous chapter. In addition, the UK benefits from a welfare state and National Health Service, and may therefore differ significantly to other countries in the availability of services and supports for young adults with intellectual disabilities undergoing transition, which could also impact on perceptions of health and wellbeing.

## **14 Conclusion**

The studies in the review reveal a mixed picture of health and wellbeing outcomes during the transition period in young people with intellectual disabilities. While parents tend to report positively on quality of life in their adolescent/young adult children with intellectual disabilities, there are a range of negative outcomes documented, particularly with regard to sexual and social relationships, which could have profound implications for mental health outcomes, including anxiety and depression, and on overall measures of wellbeing.



## 14.1 Gaps identified in the literature

A key finding of the review was the limited quantity of research on health and wellbeing outcomes during transition in young people with intellectual disabilities. No studies reported specifically on general health and wellbeing outcomes throughout transition in this population. Therefore, it is necessary to examine large-scale data to examine health and wellbeing outcomes throughout the transition period, and to compare health during this period in young people with intellectual disabilities to those without intellectual disabilities.

A limitation of some of the studies included in the review was the reliance on parent or carer reports rather than those of young people with intellectual disabilities themselves. As the NLTS-2 (2003) dataset demonstrates, there may be differences between parents and young people in their appraisal of the young person's health. Furthermore, given the sensitive nature of some of the topics relevant to a discussion of transition and wellbeing, including relationships and mental health, it is vital to understand a young person's perspective, besides that of their parents. The NHS and Community Care Act (1990) states that people have a right to be consulted on and involved in research that affects their lives, and involvement in research may be an empowering exercise for people with intellectual disabilities (Gilbert, 2004). Such involvement is possible if the necessary adjustments are made to the research method, which, if successful, strengthens both the quality and relevance of the research (Gilbert, 2004). Given the importance of including people with intellectual disabilities in participatory research, a qualitative investigation of both young people's and their parents' experiences of transition is necessary in order to understand how the experience may affect health and wellbeing.

The following chapter will describe the aims and research questions of this thesis, informed by the general review of the literature, and this systematic review of the literature, which focussed specifically on health and wellbeing outcomes during transition in the population with intellectual disabilities. The next chapter will then outline the methodology employed to answer these research questions, including an analysis of large-scale data to compare health and wellbeing during transition for individuals with and without intellectual disabilities, and a qualitative investigation of young people with intellectual disabilities' own perspectives of transition, as well as that of their parents, as called for above.

## **Chapter 3: Aims and research questions**

### **15 Aims**

#### **15.1 Primary aim**

- To investigate whether, and in what ways, transition to adulthood affects health and wellbeing in young people with intellectual disabilities.

#### **15.2 Secondary aims**

- To examine whether the impact of transition on health and wellbeing is similar or different for young people with intellectual disabilities compared to young people without intellectual disabilities.
- To investigate whether the experience of transition is similar or different for young people with multiple and profound intellectual disabilities and young people with milder intellectual disabilities.
- To examine what supports, both formal and informal, are effective for young people with intellectual disabilities during transition.

### **16 Research questions**

These aims translate into the following research questions, which will be used to structure the presentation of the results throughout this thesis:

1. Does transition to adulthood affect health and wellbeing in young people with intellectual disabilities? In what particular ways? (Chapters 5, 6 and 7)
  - a. From the perspective of young people with intellectual disabilities? (Chapter 6)
  - b. From the perspective of families/carers of young people with intellectual disabilities? (Chapter 7)

2. Is the impact of transition on health and wellbeing similar or different for young people with intellectual disabilities compared with young people without intellectual disabilities? (Chapter 5)
3. Is the impact of transition on health and wellbeing similar or different for young people with profound and multiple intellectual disabilities compared with young people with mild to moderate intellectual disabilities? (Chapters 6 and 7)
4. What supports (formal and informal) are helpful for young people with intellectual disabilities during transition? (Chapters 6 and 7)

## Chapter 4: Methods

### 17 Study design

A mixed methods approach combining the strengths of both qualitative and quantitative methodologies was utilised. Etymologically, quantitative methodologies determine how much of an entity there is, and qualitative methodologies describe the constituent properties of an entity (Gelo et al., 2008). The division between qualitative and quantitative methodologies is underpinned by the differing philosophical assumptions of the methods, which have typically been presented as competing paradigms (Cresswell & Plano Clark, 2007): quantitative methods assume that psychological and social phenomena have an objective, observable reality, while qualitative methods assume that reality is both socially and psychologically constructed. Mixed methods research involves utilising both of these concepts, recognising that phenomena can be “both socially constructed and yet real” (Hacking, 1999: 119).

Mixing qualitative and quantitative methodologies in this way has been referred to as ‘triangulation’ (Olsen, 2004), which allows for a simultaneously deep and broad understanding of a given topic through contrasting what is evident from interviews, ethnographic and survey data, and what differences arise from comparing these different ‘windows’ to the same topic (Olsen, 2004). In this way, the use of mixed methods can draw on the strengths of both methodologies to develop different insights into the same topic, and there has in recent years been an increase in the use of mixed methods research among the health sciences (Cresswell et al., 2004). Indeed, Östlund et al. (2011) conducted a methodological review of mixed methods healthcare studies, concluding that triangulation of qualitative and quantitative methodologies can serve to clarify the presentation of researchers’ theoretical propositions and the basis for their results, ultimately serving to develop a better understanding of the links between theory and empirical findings. Secondary analysis of a large dataset was therefore combined with qualitative semi-structured interviews and ethnography.

Given the methodological limitations of the studies included in the systematic review – in particular, the use of proxies such as parents or caregivers to report on the experiences of young people with intellectual disabilities (see Chapter 2) – it was considered important, wherever possible, to include young people with intellectual disabilities in the research as well as their parents. In this way, the important contributions that individuals with

intellectual disabilities can make to research was respected, while acknowledging that parents might also provide important perspectives on the ways in which transition had affected their child, and also that parents might be the best people to support individuals with severe intellectual disabilities to participate in interviews.

Ethnography of a transition service for young people with intellectual disabilities combined with semi-structured interviews was designed to provide young people with intellectual disabilities and their families with the opportunity to describe their transition experiences themselves, offering crucial insights into a complex and highly personal issue. In conjunction with the qualitative materials derived from the interviews and ethnography, quantitative measures of health and wellbeing were employed in order to provide empirical evidence of the presence of health or wellbeing issues in the sample. In addition, secondary analysis of a large dataset from Scotland was employed to facilitate comparison of health during transition between the population with intellectual disabilities and the general population, and to provide insights into the impact of transition on the health and wellbeing of young people with intellectual disabilities on a wider scale than would be possible using purely qualitative methods. In this way, the use of qualitative and quantitative methodologies provided both deep and broad insights in answering the thesis research questions.

The four component parts of the design are detailed below:

1. Systematic Review to identify existing literature on health and wellbeing outcomes during transition in young people with intellectual disabilities, and to establish gaps in the evidence base (see Chapter 2).
2. Secondary analysis of Scotland's Census (2011): a large scale, cross-sectional study facilitating comparison of health between young people with intellectual disabilities and their age- and gender-matched peers without intellectual disabilities, and also comparison of health in two age cohorts of young people with intellectual disabilities: those aged 13-18 years who were still in school, and those aged 19-24 years who had transitioned from school.
3. Semi-structured interviews with young people with intellectual disabilities aged 16-27 years alongside an ethnography of a transition service for young people with intellectual disabilities to uncover the impact of transition on health and wellbeing

from the perspectives of young people with intellectual disabilities. Interview topic guide and coding framework for the ethnographic field diary informed by a pilot focus group study.

4. Semi-structured interviews with parents/caregivers of young people with intellectual disabilities aged 16-26 years to uncover the impact of transition on health and wellbeing on young people with intellectual disabilities from the perspectives of their parents/carers. Interview topic guide informed by literature reviews.

## **17.1 Ethical approval**

Ethical approval was granted by the University of Glasgow College of Medical, Veterinary and Life Sciences Ethics committee (Appendix A). Access approval was also granted from the National Records of Scotland (NRS) to access the Census data.

The qualitative component of this project involved the inclusion of people with intellectual disabilities in the research, which presented some ethical challenges. Burke et al. (2003) argue that a thorough understanding of research is critical to providing informed consent to participate. Since individuals with intellectual disabilities may not always be able to comprehend the purpose and process of conducting research, and hence be able to provide informed consent, they may be situated as vulnerable and unable to take part in research. Hence, it was important to ensure that every effort was made to facilitate comprehension of the research and what participation would involve. Accessible information sheets were created (Appendix D) and the researcher explained the study carefully and sought consent at the time of the interview. When individuals with intellectual disabilities could not consent for themselves, consent was sought from their parent or guardian, in keeping with the Adults with Incapacity (Scotland) Act (2000). Despite these issues surrounding consent, Gilbert (2004) describes how participation in research can be empowering for vulnerable individuals, and argues that including people with intellectual disabilities strengthens both the quality and relevance of the research. Hence, although research with this population requires thinking carefully about potential ethical issues and ways to overcome them, this issue should not prevent such individuals from being involved in research.

## 18 Systematic review

For a detailed account of the methods used to conduct a systematic review of the literature on the effect of transition on health and wellbeing in young people with intellectual disabilities, see Chapter 2, Section 10.

## 19 Secondary analysis: Scotland's Census (2011)

Scotland holds a census once every ten years, which provides the official estimate of people and households in Scotland. This involves a census questionnaire (Appendix M), created based on methodology developed from the Office of National Statistics. The latest Census was in 2011; it was administered to the population of Scotland in order to provide an accurate picture of their health and household circumstances on 27<sup>th</sup> March 2011. Respondents completed the questionnaire on paper, and it is estimated that the completion rate was around 94% (National Records of Scotland, 2013). Data were collected on education, ethnicity, identity, language and religion, health, housing and accommodation, labour market, population and households, and transport. The 2011 Census questionnaire asked respondents to indicate the presence of intellectual disabilities via the question:

*Do you have any of the following conditions which have lasted, or are expected to last at least 12 months? Tick all that apply.*

- Deafness or partial hearing loss
- Blindness or partial sight loss
- **Learning disability (for example, Down's syndrome)**
- Learning difficulty (for example, dyslexia)
- Developmental disorder (for example, autistic spectrum disorder or Asperger's syndrome)
- Physical disability
- Mental health condition

- Long-term, illness, disease or other condition
- Other condition
- No condition

Intellectual disabilities were therefore distinguished from learning difficulties or developmental disorders. Questionnaires were completed by the householder, or joint householder, on behalf of the whole household. Questionnaires were also completed for all people in communal establishments on the Census date. As the census questionnaire covered the whole population of Scotland, the use of this dataset allows comparisons of health during transition in individuals with intellectual disabilities and their age- and gender-matched peers without intellectual disabilities. In addition, comparisons of health in two age cohorts of young people with intellectual disabilities: those aged 13-18 years who were still in school, and those aged 19-24 years who had transitioned from school, was also possible.

## 19.1 Participants

Analysis was conducted on data from members of the Scottish population aged 13-24 years for whom Census (2011) forms were returned (n with intellectual disabilities = 5,556, n without intellectual disabilities = 810,333). For some analyses the cohort was split into two age groups: those who were aged 13-18 years and were therefore still in school (n with intellectual disabilities = 2,777, n without intellectual disabilities = 375,020), and those who were aged 19-24 years and had therefore left school (n with intellectual disabilities = 2,779, n without intellectual disabilities = 435,313), in order to explore possible differences in health status before and after transition. In this way, leaving school was conceptualised as a central transition point, which might have important implications for health and wellbeing.

## 19.2 Data analysis

The data was requested from the custodian of the data, the National Records of Scotland (NRS), and tables detailing the relevant variables were generated and quality checked. The census questionnaire involved tick box responses: the researcher focussed on variables that addressed the thesis research questions; specifically including variables representing health



or wellbeing measures and demographic variables. Tables 3 and 4 show the variables used in this secondary analysis. The Statistical Package for Social Sciences (SPSS), version 22, was used for all data analyses.

**Table 3: Description of the health-related variables used in the secondary analysis of Scotland's Census (2011)**

Survey Question	Variable	Measures
How is your health in general?	General health	5 = Very good 4 = Good 3 = Fair 2 = Bad 1 = Very bad
Do you have any of the following conditions which have lasted, or are expected to last, at least 12 months?	Mental health condition	1 = Yes 0 = No
	Physical disability	1 = Yes 0 = No
	Long term illness, disease or condition	1 = Yes 0 = No
	Deafness or hearing impairment	1 = Yes 0 = No
	Blindness or vision impairment	1 = Yes 0 = No
	Developmental disorder (for example autism spectrum disorder or Asperger's syndrome)	1 = Yes 0 = No
	Number of conditions	0 1 2 3 or more
Are your day to day activities limited because of a health problem or disability which has lasted, or is expected to last, at least 12 months?	Health-related activity limitations	2 = Yes, limited a lot 1 = Yes, limited a little 0 = No

**Table 4: Description of the demographic and geographical variables used in the secondary analysis of Scotland's Census (2011)**

Survey Question	Variable	Measures
What is your sex?	Gender	1 = Female 0 = Male
Postcode	SIMD (Scottish Index of Multiple Deprivation: area deprivation)	1 = Most deprived 2 3 4 5 = Most affluent
Postcode	Rurality	1 = rural (settlement of less than 3,000 people) 2 = urban (settlement of more than 3,000 people)

## 19.2.1 Descriptive statistics: population with intellectual disabilities

### 19.2.1.1 General health

In order to address Research Question 1 (*Does transition affect health and wellbeing in young people with intellectual disabilities, and in what particular ways?*), frequency tables

of general health ratings in the population with intellectual disabilities were utilised. Bar charts were used to display the distribution of general health ratings in the population with intellectual disabilities aged 13-18 and 19-24 years in order to facilitate comparison visually.

In addition, frequency tables of each of the following conditions for the population with intellectual disabilities were created:

- Mental health condition
- Physical disability
- Long term illness, disease or condition
- Deafness or hearing impairment
- Blindness or visual impairment.

Bar charts were used to display the distribution of each of these conditions in the population with intellectual disabilities aged 13-18 and 19-24 years in order to facilitate comparison visually.

Frequency tables of health-related activity limitations in the population with intellectual disabilities were created. Bar charts were used to display the distribution of health-related activity limitations in the population with intellectual disabilities aged 13-18 and 19-24 years in order to facilitate comparison visually.

#### **19.2.1.2 Comorbidities**

Frequency tables of the number of conditions reported in the population with intellectual disabilities were created. Bar charts were used to display the distribution of the number of conditions reported in the population with intellectual disabilities aged 13-18 and 19-24 years in order to facilitate comparison visually.

Frequency tables of general health ratings in the population with both intellectual disabilities and physical disabilities were created. Bar charts were used to display the

distribution of general health ratings in the population with intellectual disabilities with and without physical disabilities in order to facilitate comparison visually.

Frequency tables of general health ratings in the population with both intellectual disabilities and mental health conditions were created. Bar charts were used to display the distribution of general health ratings in the population with intellectual disabilities with and without mental health conditions in order to facilitate comparison visually.

Frequency tables of general health ratings in the population with both intellectual disabilities and autism were created. Bar charts were used to display the distribution of general health ratings in the population with intellectual disabilities with and without autism in order to facilitate comparison visually.

### **19.2.1.3 Geographic variables**

Frequency tables of general health ratings in the population with intellectual disabilities living in the most deprived areas of Scotland (SIMD quintiles 1-2) and the most affluent areas of Scotland (SIMD quintiles 3-5) were created. Bar charts were used to display the distribution of general health ratings in the population with intellectual disabilities living in the most deprived and the most affluent areas in order to facilitate comparison visually.

Frequency tables of general health ratings in the population with intellectual disabilities living in rural and urban areas of Scotland were created. Bar charts were used to display the distribution of general health ratings in the population with intellectual disabilities living in rural areas and living in urban areas in order to facilitate comparison visually.

## **19.2.2 Univariate analyses: population with intellectual disabilities**

### **19.2.2.1 General health**

Research question 1 (*Does transition affect health and wellbeing in young people with intellectual disabilities, and in what particular ways?*) was next examined using univariate analyses. Potential associations between age group (13-18 years or 19-24 years) or gender (male or female) and each of the following variables in the population with intellectual disabilities were assessed using chi squares:

- A derived, dichotomised variable ‘poor health’ (general health rating of ‘fair’, ‘bad’ or ‘very bad’) compared to ‘good health’ (general health rating of ‘good’ or ‘very good’)
- Presence of a mental health condition
- Presence of a physical disability
- Presence of a long-term illness, disease or condition
- Presence of deafness or hearing impairment
- Presence of blindness or visual impairment
- A derived, dichotomised variable ‘health-related activity limitations’ (activities reported to be limited ‘a little’ or ‘a lot’) compared to ‘no activity limitations’ (activities reported to be ‘not limited’).

#### **19.2.2.2 Comorbidities**

In order to gain insights into who among the population with intellectual disabilities is most vulnerable to poor health, mann whitney *U* tests were used to determine differences in the number of conditions reported by individuals aged 13-18 and 19-24 years; and males and females in the population with intellectual disabilities. An intellectual disability was not included as a long-term condition.

Potential associations between ‘poor’ health and each of the following variables in the population with intellectual disabilities were assessed using chi squares:

- Presence of a physical disability
- Presence of a mental health condition
- Presence of autism.

### 19.2.2.3 Geographic variables

To examine further who among the population with intellectual disabilities is most vulnerable to poor health, potential associations between ‘poor’ health and each of the following variables in the population with intellectual disabilities were assessed using chi squares:

- A derived, dichotomised variable of ‘most deprived’ area (SIMD quintiles 1-2) compared to ‘most affluent’ area (SIMD quintiles 3-5)
- Rurality.

## 19.2.3 Independent predictors of health outcomes: population with intellectual disabilities

### 19.2.3.1 General health

Research question 1 (*Does transition affect health and wellbeing in young people with intellectual disabilities, and in what particular ways?*) was then examined using binary logistic regression for dichotomised dependant variables and cumulative odds ordinal logistic regression for ordinal dependant variables. In both cases the independent predictor variables were categorical. Odds ratios are reported for effect sizes of the relationship between predictor variables and dichotomous or ordinal outcomes (Field, 2013).

The predictor variables age group (13-18 years or 19-24 years; 13-18 years was the reference group) and gender (male or female; male was the reference group) were entered into a series of enter method binary logistic regression analyses for each of the following dichotomous dependant variables in turn. Predictor variables were included in regressions if univariate analyses revealed them to be significant at  $p < 0.05$ .

- A derived, dichotomised variable of ‘poor health’ (general health rating of ‘fair’, ‘bad’ or ‘very bad’) compared to ‘good health’ (general health rating of ‘very good’ or ‘good’). ‘Good health’ was the reference group.
- Presence of mental health conditions. No mental health condition was the reference group.
- Presence of physical disabilities. No physical disability was the reference group.

- Presence of long-term illnesses, diseases or condition. No long-term illness, disease or condition was the reference group.
- Presence of deafness or hearing impairment. No deafness or hearing impairment was the reference group.
- Presence of blindness or visual impairment. No blindness or visual impairment was the reference group.
- A derived, dichotomised variable of 'limited activities' (activities reported to be limited 'a little' or 'a lot') compared to 'activities not limited'. 'Activities not limited' was the reference group.

The assumptions of binary logistic regression include no significant outliers and no multicollinearity between predictor variables. As the data were categorical, it was not necessary to identify or remove outliers. The predictor variables entered into regression models included: age group (13-18 years or 19-24 years) and gender (male or female). In order to test for multicollinearity, a linear regression using age group and gender as predictor variables was run in order to obtain tolerance and Variance Inflation Factor (VIF) statistics. Tolerance values less than 0.1 (Menard, 1995) and VIF values greater than 10 (Myers, 1990) indicate a problem with multicollinearity.

The predictor variables age group (13-18 years or 19-24 years; 13-18 years was the reference group) and gender (male or female; male was the reference group) were entered into cumulative odds ordinal logistic regression analyses for the following ordinal dependant variable:

- Number of conditions reported.

The assumptions of ordinal logistic regression include proportional odds and no multicollinearity between predictor variables. In order to assess proportional odds, a full likelihood ratio test comparing the fit of the proportional odds model to a model with varying location parameters was conducted. In order to test for multicollinearity, a linear regression using age group and gender as predictor variables was run in order to obtain tolerance and VIF statistics.

### **19.2.3.2 Comorbidities**

In order to gain insights into who among the population with intellectual disabilities is most vulnerable to poor health, the following individual predictor variables were entered together into a backward stepwise binary logistic regression analysis for the dichotomised dependant variable ‘poor health’:

- Gender. Male was the reference group.
- Presence of physical disability. No physical disability was the reference group.
- Presence of mental health condition. No mental health condition was the reference group.
- Presence of autism. No autism was the reference group.

Due to restrictions on cell sizes within frequency tables generated by NRS, it was not possible to include age group as a predictor variable in this analysis.

In order to test for multicollinearity, a linear regression was first run in order to obtain tolerance and VIF statistics for the predictor variables.

Likelihood ratio tests determined statistical significance for each factor. A cut-off criterion of 0.05 was set for the predictors. At each step, the regressor with the smallest partial correlation was removed if it met the removal criteria and the regression model was re-run.

### **19.2.3.3 Geographic variables**

To further examine who among the population with intellectual disabilities is most vulnerable to poor health, the following individual and geographical predictor variables were entered together into a backward stepwise binary logistic regression analysis for the dichotomised dependant variable ‘poor health’:

- Gender. Male was the reference group.



- A derived, dichotomised variable of ‘most deprived’ area (SIMD quintiles 1-2) compared to ‘most affluent’ area (SIMD quintiles 3-5). ‘Most affluent’ was the reference group.
- Rurality. Rural was the reference group.

Due to restrictions on cell sizes within frequency tables generated by NRS, it was not possible to include age group as a predictor variable in this analysis.

The analyses here followed the same procedure as those outlined in Section 19.2.3.2.

#### **19.2.4 Descriptive statistics: population without intellectual disabilities**

Before answering Research Question 2 (*Is the impact of transition on health and wellbeing similar or different for young people with intellectual disabilities compared with young people without intellectual disabilities?*), descriptive statistics for the population without intellectual disabilities were generated. Frequency tables and bar charts were used to compare the variables of interest in young people without intellectual disabilities aged 13-18 and 19-24 years, following the procedure described in Section 19.2.1.

#### **19.2.5 Descriptive statistics: whole population**

In order to address Research Question 2 (*Is the impact of transition on health and wellbeing similar or different for young people with intellectual disabilities compared with young people without intellectual disabilities?*), frequency tables and bar charts were used to compare the health variables of interest in the populations with and without intellectual disabilities, following the procedure described in 19.2.1.

#### **19.2.6 Univariate analyses: whole population**

Research Question 2 (*Is the impact of transition on health and wellbeing similar or different for young people with intellectual disabilities compared with young people without intellectual disabilities?*) was next examined via univariate analyses. Potential associations between ability (intellectual disabilities or no intellectual disabilities), age group (13-18 years or 19-24 years) or gender (male or female) and each of the variables of

interest in the whole population were assessed using chi squares, following the procedure outlined in Section 19.2.2.

### **19.2.7 Independent predictors of health outcomes: whole population**

Research Question 2 (*Is the impact of transition on health and wellbeing similar or different for young people with intellectual disabilities compared with young people without intellectual disabilities?*) was finally examined using binary logistic regression for dichotomised dependant variables and cumulative odds ordinal logistic regression for ordinal dependant variables, following the procedures described in Section 19.2.3. with an additional predictor variable: ability (intellectual disabilities or no intellectual disabilities; no intellectual disabilities was the reference group).

## **20 Pilot qualitative study: focus group**

Focus groups are an ideal way to enhance participants' role in research (Hopkins, 2007). This is especially relevant for individuals with intellectual disabilities; as the systematic review identified, this population may run the risk of being excluded from research about them. A focus group study was therefore conducted to pilot the use of qualitative methodologies with young people with intellectual disabilities. Specifically, the focus group was conducted to assess whether the use of a visual aid would be helpful during interviews to facilitate communication between the researcher and participants. Vaughn et al. (1996) suggest that a group environment allows individuals to disclose information more freely, since the presence of peers contributes to greater anonymity. As such, the group was also used to discern the best way to phrase questions to ensure that they were acceptable to young people with intellectual disabilities, and sensitive to the personal nature of some of the topics covered, such as relationships and mental health. Most importantly, the focus group was used to inform the topic guide for the semi-structured interviews. The researcher explored a range of topics identified from the literature on transition in this population, and noted topics which were most salient to young people who participated in the focus group. Any additional topics covered in the focus group were also noted, to be included in the topic guide for the interviews.

## 20.1 Recruitment

The researcher approached a representative from a special education secondary school in Greater Glasgow and Clyde with information about the aims and procedure of the study. The representative agreed to take part in the study and provided the researcher with contact details of students in the S5 class, who were approaching their final year of school. The researcher sent postal invitations to the eight students in the class and followed up with a single phone call to parents.

## 20.2 Procedure

The focus group took place in a classroom at the secondary school during the school day. The duration of the focus group was around 30 minutes. The researcher explained the aims and procedure of the focus group, and sought consent again from the students. A broad topic guide was developed from a review of the literature. The guide covered aspects of transition, including school, services, relationships and health (Appendix N). The researcher guided the discussion using prompts from the topic guide, and followed up on themes identified by the students throughout the progress of the focus group. A visual aid was also used to facilitate discussion: two large coloured pieces of card depicting a sad face and a happy face were placed in the centre of the table, and during the discussion students were invited to write down or draw the points they were making on post-it notes provided by the researcher. These were placed on top of the faces depending on whether they were positive or negative points. The focus group was audio-recorded and was later transcribed by the researcher. Thematic analysis using both emic (themes arising from the participants themselves) and etic (themes based on previous literature) coding categories was conducted on the data in order to draw out relevant themes to consider in the semi-structured interviews. In principle, the analysis here was identical to that deployed in the treatment of interview recordings and transcripts (see Section 21.5). Themes that were identified through the focus group to be of particular importance for young people during transition were noted and questions exploring these themes were developed for use in the semi-structured interviews.

## **21 Semi-structured interviews with young people with intellectual disabilities and parents/carers of young people with intellectual disabilities**

### **21.1 Recruitment**

Interviews were conducted with young people with intellectual disabilities between the ages of 16 and 27 years, and parents/carers of young people with intellectual disabilities within the same age range. Initially the age group under investigation was limited to 16 to 24 years, in line with Arnett's (2000) conceptualisation of transition as a period spanning adolescence and the early 20s, and to draw on experiences of young people who were approaching leaving school, through to those who had been out of school for a number of years, and those of their parents/carers. However, during the course of data collection and analysis it became clear that crucial components of transition in the more conceptual sense of attaining independence from parents occurs later, in the mid to late 20s, for many young people with intellectual disabilities (see Chapter 7). The age range of interviewees was therefore extended, and young people/parents of young people up to the age of 35 years were invited to participate in the study, in order to capture the full range of experiences of transition. An ethical amendment, seeking to extend the age range of interviewees, was sought and approved (Appendix J-K).

Recruitment of both young people with intellectual disabilities and of parents/carers of young people with intellectual disabilities for the qualitative studies occurred in tandem.

Initially, the researcher contacted representatives from special education secondary schools and colleges in Greater Glasgow and Clyde via email to outline the aims and procedure of the study. Seven schools, and a football club for young adults with intellectual disabilities which was run by a parent at one of the schools, responded positively to the email, and the researcher sent postal invitation packs including a cover letter, information sheets and consent forms (Appendix C-H) to school administration teams who then distributed the information packs. Individuals who were interested in participating in the study were instructed to either post their completed consent forms, along with their contact details, to the researcher in a provided freepost envelope, or to contact the researcher directly via email or telephone to arrange an interview. In practice, 150 information packs were distributed through schools. Four parents/young person pairs, and two parents alone

contacted the researcher to take part in the study, either via telephone or by returning their contact details via post.

In addition, the researcher contacted a representative from the Moving On Transition Service in West Dunbartonshire, run by the voluntary organisation Share Scotland, with which ethnographic work was concurrently conducted (see Section 23). The representative sent information packs via post to 50 individuals who were involved with this service and four young person/parent pairs contacted the researcher to take part in the study. The researcher also contacted a representative from the Workmates day centre, run by a special education school in the area. Thirty invitation packs were distributed in this way, and two families, including one young person/parent pair and one parent, contacted the researcher to take part.

A further method of recruitment was pursued through the charities PAMIS (Profound and Multiple Impairment Service), Enable, who provide services to individuals with intellectual disabilities and their families, and People First, an organisation providing advocacy for individuals with intellectual disabilities. Representatives from each organisation approached the families with whom they worked to pass on the information sent by the researcher, and then contacted the researcher with contact details of those who expressed interest in the study. Four parents who were supported by PAMIS took part in the study and one young woman with intellectual disabilities who was supported by People First participated. One young woman and her mother who were supported by Enable took part in the study. In addition, Enable posted an advert describing the study and instructing interested families to contact the researcher on their Facebook page. As a result of this advert, five families, involving three parent/young person dyads and two parents, contacted the researcher to take part. The researcher also met with a representative from the 'The Life I Want' project, a social partnership run by and for individuals with intellectual disabilities. Two young men with intellectual disabilities who worked for the project took part in an interview.

Finally, information about the research and instructions for any individuals interested in taking part to contact the researcher were posted on the Scottish Learning Disabilities Observatory website (Appendix I) and on the Facebook pages of two charities supporting carers: Carers Views Count and the Princes Trust for Carers. One mother and her son contacted the researcher to participate in the study as a result of a Facebook post.

A sample of between 12 and 20 individuals has been identified as sufficient to identify robust themes in qualitative research (Lincoln & Guba, 1985). Recruitment continued until a sample of 23 parents/caregivers and 17 young people with intellectual disabilities had been reached, which had resulted in robust themes being identified in the data. In order to address Research Question 3 (*Is the impact of transition on health and wellbeing similar or different for individuals with profound and multiple intellectual disabilities compared to those with mild to moderate intellectual disabilities?*), efforts were deliberately made to recruit young people/parents of young people with a spread of abilities. The researcher also attempted to recruit a sample that was demographically representative, including males and females, and individuals from single parent families as well as those from partnerships.

## 21.2 Consent

The researcher sought to obtain consent from both young people with intellectual disabilities and their parents or caregivers, except in cases where only the young person with intellectual disabilities participated in an interview; in these instances, only the young person's consent was sought. Separate consent forms were created and distributed for young people, parents, and parents on behalf of their children, the latter for cases where the young person could not consent for themselves (Appendix F-H). Regardless of whether participants had returned signed consent forms via post, the researcher sought consent at the time of the interview. In cases where young people with intellectual disabilities were not able to provide consent for themselves, consent was sought from their nearest relative or welfare guardian (usually a parent). This approach was in keeping with The Adults with Incapacity (Scotland) Act (2000). Consent was taken to participate in the study, and specifically and separately, for tape recordings to be made of the interviews.

## 21.3 Semi-structured interviews with young people with intellectual disabilities: interview procedure

Interviews were conducted face to face in participants' homes by the researcher in all but four cases, wherein two interviews were conducted in local cafés and two were conducted at the interviewees' place of work, in view of participants' preferences. Interviews were conducted with young people either on their own or in the presence of a parent, depending on individual preferences/abilities. One young woman participated with her support worker present. Individuals with severe intellectual disabilities were supported to take part in the interview by their parents, who helped to probe their answers to the interview questions,

and offered clarification where their response was unclear. All of the young people who participated in an interview did so in conjunction with their parent/carer, with the exception of one young woman and two young men, whose parents declined to participate or were not invited due to estrangement.

Interviews were semi-structured in nature, based on a topic guide (Appendix O) developed by the researcher based on the pilot focus group study, with a view to gaining an insight into the transition experiences of young people across the domains of health, services/activities, and relationships. This semi-structured format was chosen in lieu of highly structured or informal interviews, as it was thought that this more conversational format would facilitate a more relaxed atmosphere (Cloke et al., 2014) and best enable young people to tell their own stories of transition, while ensuring that topics related to transition and health or wellbeing were covered. The researcher attempted to expand on themes identified during the interview and allowed the participants to explore any issues that they thought were of relevance. Interviews lasted between 15 minutes and 1 hour, and in all cases were completed in one session. As a result of feedback from the pilot focus group study, no visual aid was used during the interviews.

#### **21.4 Semi-structured interviews with parents/carers of young people with intellectual disabilities: interview procedure**

Interviews were conducted face to face in participants' homes by the researcher in all but two cases, wherein one interview was conducted in a local café and one took place in a university building, in view of participants' preferences. Parents' interviews took place either before or after the young people's interviews, except in cases where the parent's son/daughter was unable to take part in an interview due to severe communication impairments. This was the case for nine young people, who did not have sufficient verbal skills to take part in an interview. In these instances, parents were relied on exclusively to provide an account of their son/daughter's experience of transition.

As with the young people's interviews, parents' interviews were semi-structured in format, following a topic guide (Appendix P) informed by the issues identified through the generic and systematic literature reviews (see Chapters 1 and 2) covering health, services/supports, and issues related to independence. Interviews lasted between 30 minutes and 2 hours, and in all cases were completed in one session.

## 21.5 Analysis of interview data

The process of analysing both young people's and parents' interview data was the same. All interviews were audio-recorded and transcribed verbatim by the researcher. All participants were given pseudonyms and any identifiable information was removed.

In order to address Research Questions 1 (*Does transition affect health and wellbeing in young people with intellectual disabilities, and in what particular ways?*) and 4 (*What supports are helpful for young people with intellectual disabilities during transition?*), thematic analysis (Braun & Clarke, 2006) was conducted on the data using NVIVO qualitative analysis software (version 11). Analysis was conducted on young people's interview data and parents' interview data separately, and then the themes identified in both datasets were compared and contrasted.

One of the main functions of qualitative analysis is to make explicit the categorisations made by participants as they seek to bring order and meaning into their understanding of the world, particularly the immediacy of their own surroundings and circumstances (Dey, 1993). In order to do this analysis, transcripts were read closely and repeatedly to identify patterns in the data. Recurrent topics were identified as codes; initially codes were identified based on previous literature (etic coding categories). When all codes identified as potentially occurring in the data from previous literature had been identified, additional codes were identified based on emergent themes arising from the data (emic coding categories). This process provided a coding framework for analysis of subsequent transcripts, wherein any additional coding categories were identified. Transcripts were read a number of times and codes were re-visited and re-organised to ensure that all relevant codes had been identified and that all of the data had been coded appropriately. The concepts expressed within codes were summarised to form themes. Once this process was complete for all of the transcripts, themes that were related to each other were grouped together and themes were organised hierarchically into master themes and sub-themes, depending on how the themes were related to each other. Themes that emerged from parents' interviews and young people's interviews were compared and contrasted, in order to describe the topic as seen from different observers (Dey, 1993).

This process facilitated the piecing together of different transition narratives, in order to develop a cohesive picture of how the transition to adulthood had affected the young people involved in the study, in terms of both their physical and mental health, as well as



their overall wellbeing. A supervisor coded a sub-sample of the interview data and a workshop was held by the researcher and the supervisor, comparing codes and revealing a high degree of consistency in themes found between the researcher and the supervisor. This exercise ensured that the themes identified were solidly grounded in the data, not being in any way an artifice of the researcher's own presumptions.

In order to address research question 3 (Is the impact of transition similar or different for young people with profound and multiple intellectual disabilities compared with young people with mild to moderate intellectual disabilities?) the themes arising from each interview were grouped according to the level of intellectual disability experienced by the young person who participated/whose parent participated. This process facilitated a comparison of the themes identified from interviews with individuals/families in each disability category. Differences in the themes identified between participants in each category were identified and, where the same themes were identified by all participants, any subtle differences in the content of the themes were noted.

## **22 Measures used during the interviews**

In addition to the semi-structured interviews, standardised assessments were used to attain a measure of ability level and to identify the presence of any health issues in the sample of young people with intellectual disabilities. Measures were only completed after the semi-structured interviews so as not to disrupt the facilitation of a relaxed atmosphere within which to encourage participants to share their experiences of transition, dissuading them from concerns over providing 'right' or 'wrong' answers to the interview questions. Where possible, the researcher completed the measures with the young person, with the caregiver providing additional information where necessary. In cases where this was not possible due to communication impairments, the researcher completed the measures with the caregiver.

### **22.1 The Vineland Adaptive Behaviour Scales - II (Vineland II)**

Adaptive behaviour was measured through the Vineland Adaptive Behaviour Scales, Second Edition, Survey Interview Form (Vineland II) (Sparrow et al., 2005). The Vineland-II is the second revision of the Adaptive Behaviour Scales (ABS) (Sparrow et al., 2005) and is an individually administered measure of adaptive behaviour across the domains of communication, socialisation and daily living skills. It allows derivation of an

overall composite score and individual domain standard scores. The adaptive levels that correspond to standard scores are as follows (Sparrow et al., 2005:253):

- Mild disability (50–69, mental age equivalent 9-12 years)
- Moderate disability (35-49, mental age equivalent 6-9 years)
- Severe disability (20-34, mental age equivalent 3-6 years)
- Profound disability (<20, mental age equivalent 0-3 years).

The average mental age equivalent was identified by summing the mental age equivalent for each sub-domain score and dividing by the total number of sub-domain scores. This average mental age equivalent score was used to identify the ability level of each participant. The Vineland-II has high correlations to the previous version (Sparrow et al., 2005), which itself has high internal consistency and convergent validity, and is considered to be appropriate for use with individuals with intellectual disabilities (De Bildt et al., 2005).

## **22.2 The Strengths and Difficulties Questionnaire (SDQ)**

The existence of mental health difficulties was assessed through the SDQ. The SDQ is a behavioural screening questionnaire for children. It contains 25 items assessing problems across emotional, conduct, hyperactivity/inattention, and peer relationship domains. It also contains a prosocial domain. Each individual is assigned a score out of 40, with a score of 16-17 or over suggesting the presence of mental health difficulties. While the SDQ is designed for use with 3-16 year old children of normal development, it is suitable for use with individuals with intellectual disabilities: Emerson (2005a) conducted a secondary analysis of a nationally representative survey of children with and without intellectual disabilities in Britain, finding an acceptable level of correspondence between SDQ scores and ICD-10 diagnoses in both disabled and typically developing children. Due to the developmental age of the participants in this study, the SDQ was deemed to be a suitable assessment tool. Parent-report and self-report forms are available for the SDQ; wherever possible, the self-report form was used in this study, as only a moderate degree of correspondence between child reports and parent reports was found in the Emerson (2005a) analysis, which calls in to question the ability of third party informants to

comment on the emotions and experiences of people with intellectual disabilities. When young people were not able to complete the self-report form due to communication impairments, the parent-report form was used.

## 22.3 The EQ-5D

The EQ-5D is a standardised instrument for use as a measure of general health. A descriptive system of health outcomes across the domains of mobility, self-care, usual activities, pain/discomfort and anxiety/depression is included, resulting in a score of between 5 and 15 (with a higher score indicating poor general health) alongside a visual analogue scale of health status ‘today’, resulting in a score of between 0 and 10 (with a higher score indicating better general health).

## 23 Ethnography

In order to address Research Questions 1 (*Does transition affect health and wellbeing in young people with intellectual disabilities, and in what particular ways?*), 3 (*Is the impact of transition on health and wellbeing similar or different for young people with profound and multiple intellectual disabilities compared with young people with mild to moderate intellectual disabilities?*), and 4 (*What supports are helpful for young people with intellectual disabilities during transition?*), an ethnographic study of the Moving On Transition Service was conducted. Ethnographic work is detailed and immersive, enabling a researcher to understand how the world is seen and lived in by the participants under study (Cloke et al., 2004). Ethnography therefore involves direct and sustained social contact with individuals, recognising the “irreducibility of human experience” (Willis & Trondman, 2000:5). In order to conduct ethnography, the researcher is involved with the group under study for a lengthy period of time in order to share the experiences of the group alongside them, with the purpose being to develop a rich and complex account – and assumedly a more truthful account – of the social world being studied (Van Maanen, 2011).

This component of the research design facilitated an in-depth study of young people in a key transition space. The transition service was run by Share Scotland, a voluntary organisation, and provided services to young people with disabilities in West Dunbartonshire. Among these services was the Social Circle, a two-hour long group meeting held fortnightly in a local college, providing opportunities for young people to

meet and socialise. Between 20 and 30 young people attended the Social Circle each week, and 3-4 members of staff were also present. In addition, some family members and support workers attended to provide additional support to young people throughout the meeting.

The researcher initially gave a short presentation at a Social Circle session, introducing herself and the research, and offering young people and parents the opportunity to ask any questions about the research. She then attended seven Social Circle sessions; while the former sessions were primarily observational, as the researcher became more immersed in the group, opportunities for interaction with both members of staff and young people attending the group were possible. Throughout the course of the ethnography, the researcher became more involved with the group, both in terms of actively participating in the group along with the young people involved, for example by taking part in games and discussion tasks, and in terms of supporting individuals who required assistance to take part in group activities. This experience resulted in the researcher taking on a 'dual role' in the group as both a participant in and a facilitator of the activities involved. The researcher was therefore able to gain an 'insider' perspective (Cloke et al., 2004) on matters relating to transition in this population; she discussed with staff the implications of transition for the young people who they supported, and gained insights into the transition experiences of the young people attending the group through both interactions with them and observations of their interactions with other members of the group. These observational and immersive methods facilitated a richer, more detailed understanding of the ways in which transition affects individuals, particularly those with severe intellectual disabilities, than would have been possible using interview methods alone, which rely on more sophisticated communication abilities on the part of the young person with intellectual disabilities. Furthermore, the immersive nature of the ethnographic work, which resulted in the researcher becoming part of the Social Circle group, allowed her to engage with the topic at an emotional level, experiencing the challenges and changes associated with transition alongside the participants in the group.

Observations were noted and reflected upon in a field diary, which was updated after each session. When completing the field diary, a protocol similar to the topic guide utilised in the interviews was considered, with specific attention being paid to health, social relationships, opportunities for engagement in the community, and the use of supports and services. The field diary was then coded by hand using primarily etic coding categories, utilising themes arising from the literature, the pilot focus group, and the interview data. It

was not thought necessary to type up all of the field diary notes, which would have allowed use of NVIVO software; rather, a hand-based colour coding system sufficed.

## 24 Final remarks

The combination of qualitative and quantitative research methods was utilised to facilitate complementary in-depth and wide scale examination of how transition impacts upon health and wellbeing in young people with intellectual disabilities. Quantitative analysis of a large dataset from Scotland facilitated an examination of the health of young people with and without intellectual disabilities of transition age at a national level. The secondary analysis facilitated both comparisons of health in young people with intellectual disabilities and their same-age peers without intellectual disabilities, and of health in two age cohorts of individuals with intellectual disabilities; those aged 13-18 years who were still in school, and those aged 19-24 years who had left school. In conjunction, the semi-structured interviews and ethnographic fieldwork, the focus of which was informed by the pilot focus group study, provided the opportunity for young people with intellectual disabilities and their families to reflect on their experiences of transition and to provide narratives detailing the ways in which the transition experience affected their health and wellbeing. In this way, the crucial voices of young adults with intellectual disabilities were included in the research, whilst acknowledging that parents could offer their own critical insights into the transition experience, and might also offer richer data than would be possible from conducting interviews solely with individuals with intellectual disabilities. This research was therefore designed to provide contrasting and complementary data on transition and health and wellbeing in people with intellectual disabilities at both a macro and a micro level.

The next three chapters will explore the results from the Census (2011) analysis (Chapter 5), the interviews with young people with intellectual disabilities and ethnography (Chapter 6), and the interviews with parents/carers of young people with intellectual disabilities (Chapter 7). Chapter 8 will then integrate and discuss the findings from the separate components of the thesis.

## Chapter 5: Results from the secondary analysis of Scotland's Census (2011)

This chapter will present secondary analysis of Scotland's Census (2011). Research question 1 (*Does transition affect health and wellbeing in young people with intellectual disabilities?*) will be answered via comparisons of health outcomes in the population with intellectual disabilities who are aged 13-18 years – assumed to be still at school ('pre-transition') – with those who are aged 19-24 years – assumed to have left school ('post-transition'). Research question 2 (*Is the impact of transition on health and wellbeing similar or different for young people with intellectual disabilities compared with young people without intellectual disabilities?*) will be answered via comparisons of health outcomes during transition in the populations with and without intellectual disabilities.

### 25 The population

Of the 815,889 people aged 13-24 years who returned the Census questionnaires, 5,556 reported having intellectual disabilities. Therefore, 0.7% of the Scottish population aged 13-24 years had intellectual disabilities. The sample with intellectual disabilities comprised 3,396 males (61.1%) and 2,160 females (38.9%). The sample without intellectual disabilities comprised 407,962 males (50.3%) and 402,371 females (49.7%).

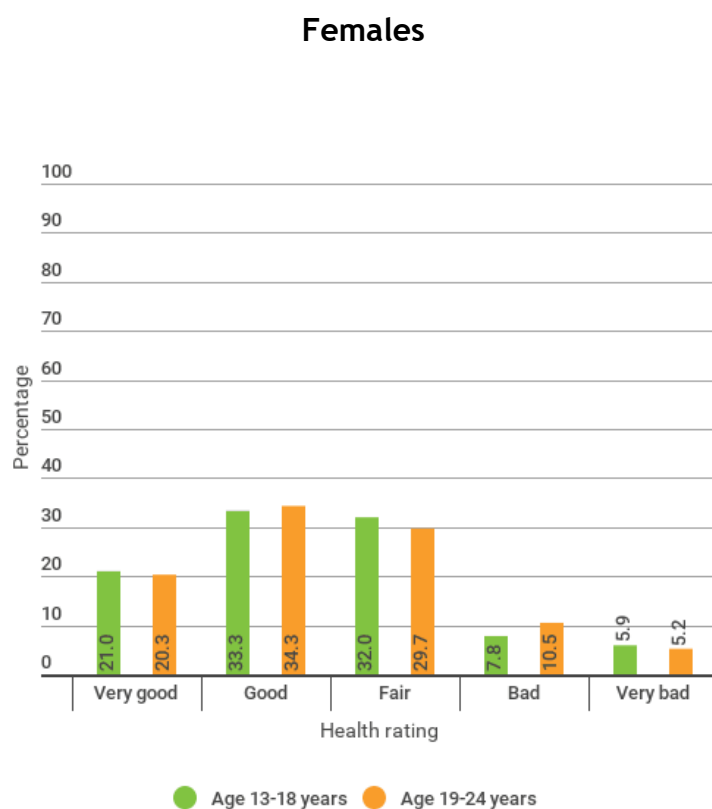
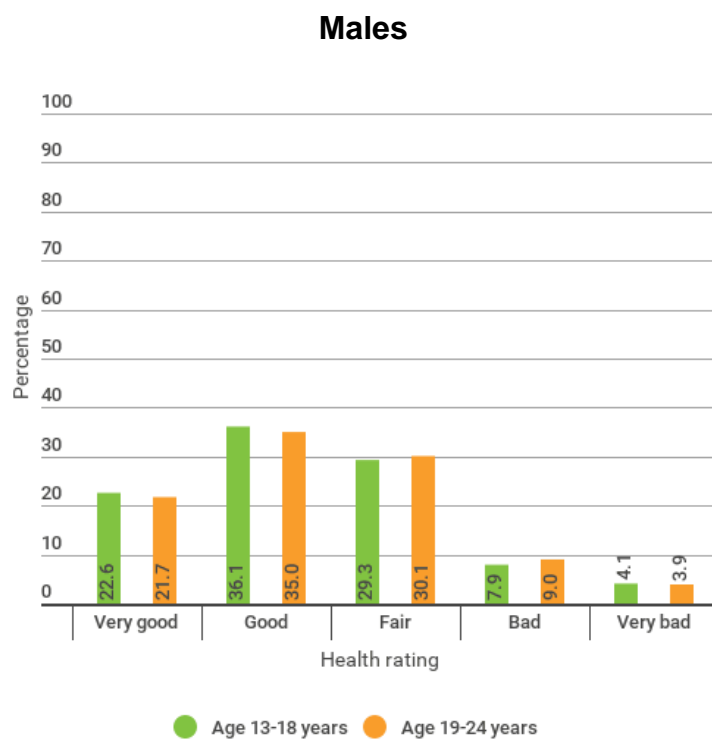
### 26 Descriptive statistics: population with intellectual disabilities

#### 26.1 General health

41.3% of males and 45.7% of females with intellectual disabilities aged 13-18 years reported 'poor health' (fair, bad or very bad health) compared to 43.0% of males and 45.4% of females aged 19-24 years (Table 5; Figure 2).

**Table 5: General health ratings in the population with intellectual disabilities**

<b>General Health</b>	<b>Males with ID aged 13-18 n = 1,740</b>	<b>Males with ID aged 19-24 n = 1,656</b>	<b>Females with ID aged 13-18 n = 1,037</b>	<b>Females with ID aged 19-24 n = 1,123</b>	<b>Total</b>
<b>Very good</b>	393 (22.6%)	360 (21.7%)	218 (21.0%)	229 (20.3%)	1,200
<b>Good</b>	629 (36.1%)	581 (35.0%)	345 (33.3%)	385 (34.3%)	1,940
<b>Fair</b>	509 (29.3%)	499 (30.1%)	332 (32.0%)	333 (29.7%)	1,673
<b>Bad</b>	137 (7.9%)	150 (9.0%)	81 (7.8%)	118 (10.5%)	486
<b>Very bad</b>	72 (4.1%)	66 (3.9%)	61 (5.9%)	58 (5.2%)	257

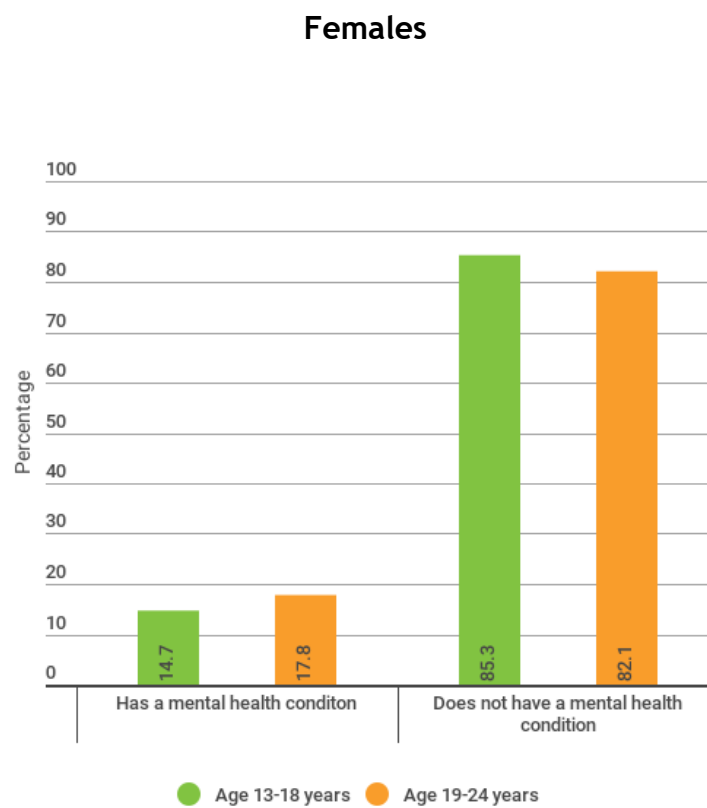
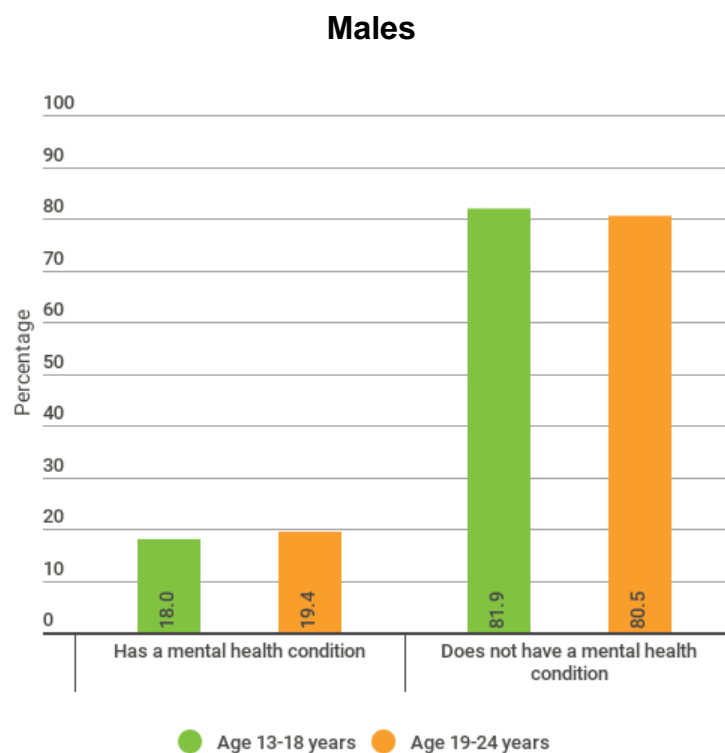
**Figure 2: General health ratings in the population with intellectual disabilities**



18.0% of males and 14.7% of females with intellectual disabilities aged 13-18 years reported the presence of a mental health condition, compared to 19.4% of males and 17.8% of females aged 19-24 years (Table 6; Figure 3).

**Table 6: Presence of mental health conditions in the population with intellectual disabilities**

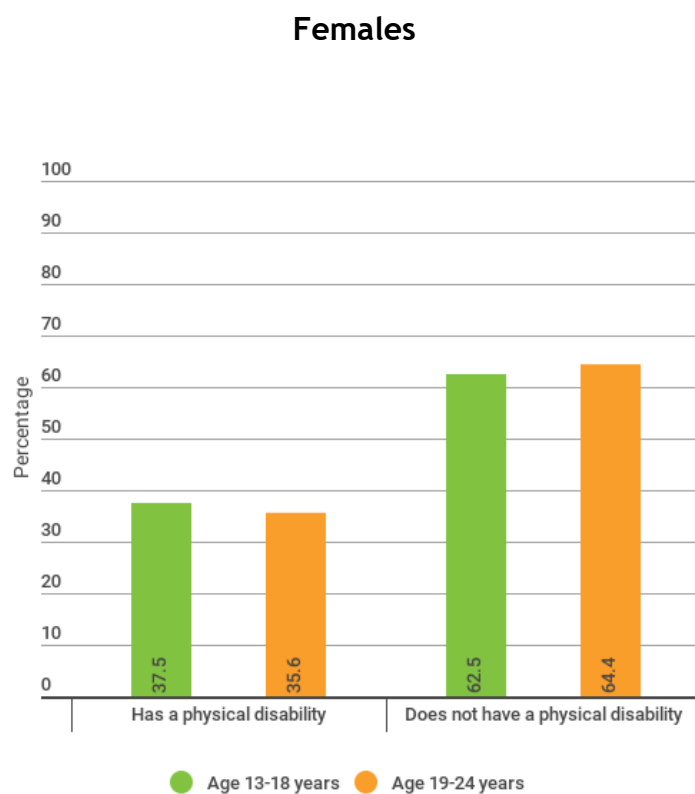
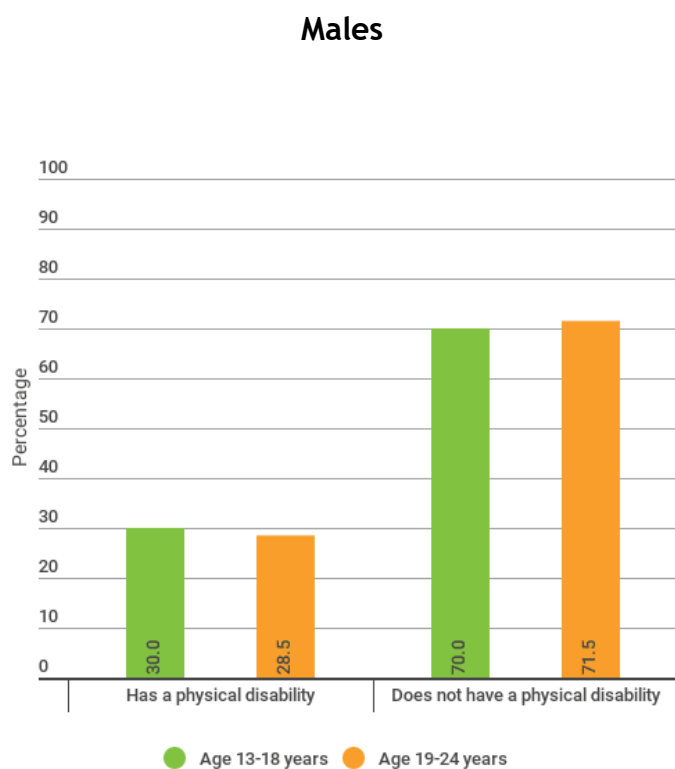
	<b>Males with ID aged 13-18</b> n = 1,740	<b>Males with ID aged 19-24</b> n = 1,656	<b>Females with ID aged 13-18</b> n = 1,037	<b>Females with ID aged 19-24</b> n = 1,123	<b>Total</b>
<b>Has a mental health condition</b>	314 (18.0%)	322 (19.4%)	152 (14.7%)	200 (17.8%)	988
<b>Does not have a mental health condition</b>	1,426 (81.9%)	1,334 (80.5%)	885 (85.3%)	923 (82.1%)	4,568

**Figure 3: Mental health conditions in the population with intellectual disabilities**

30.0% of males and 37.5% of females with intellectual disabilities aged 13-18 years reported the presence of a physical disability compared to 28.5% of males and 35.6% of females aged 19-24 years (Table 7; Figure 4).

**Table 7: Presence of physical disabilities in the population with intellectual disabilities**

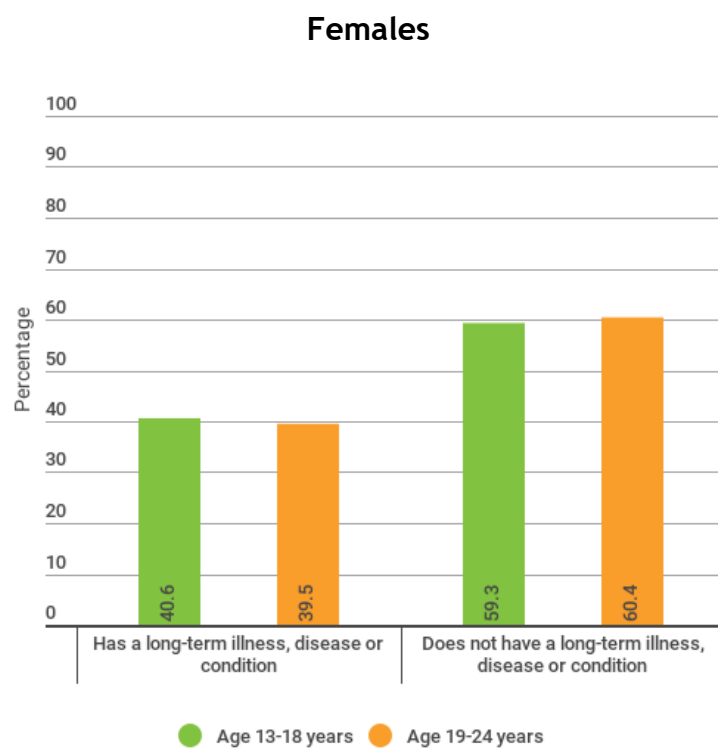
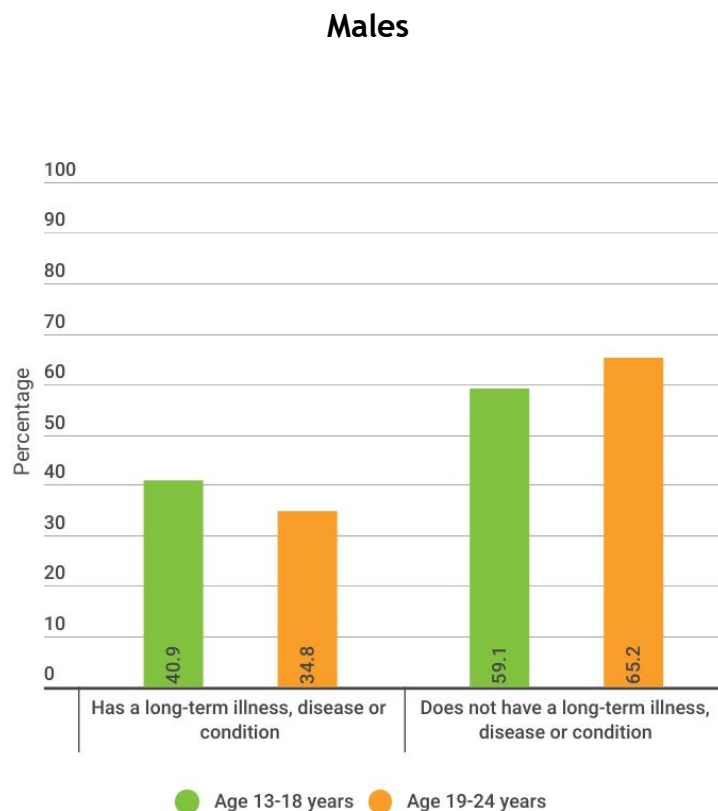
	<b>Males with ID aged 13-18</b> n = 1,740	<b>Males with ID aged 19-24</b> n = 1,656	<b>Females with ID aged 13-18</b> n = 1,037	<b>Females with ID aged 19-24</b> n = 1,123	<b>Total</b>
<b>Has a physical disability</b>	522 (30.0%)	472 (28.5%)	389 (37.5%)	400 (35.6%)	1,783
<b>Does not have a physical disability</b>	1,218 (70.0%)	1,184 (71.5%)	648 (62.5%)	723 (64.4%)	3,773

**Figure 4: Physical disabilities in the population with intellectual disabilities**

40.9% of males and 40.6% of females with intellectual disabilities aged 13-18 years reported the presence of a long-term illness, disease or condition, compared with 34.8% of males and 39.5% of females with intellectual disabilities aged 19-24 years (Table 8; Figure 5).

**Table 8: Presence of long-term illnesses, diseases or conditions in the population with intellectual disabilities**

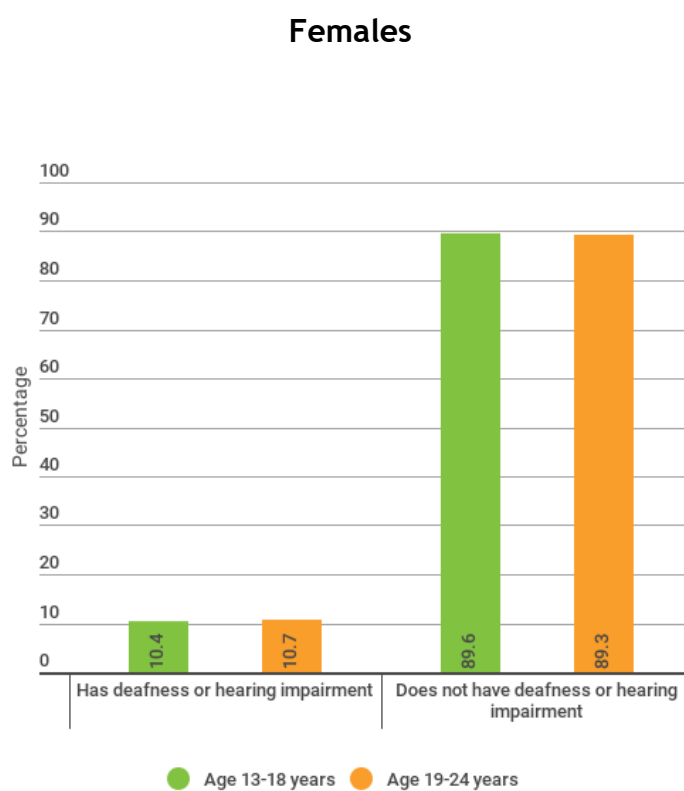
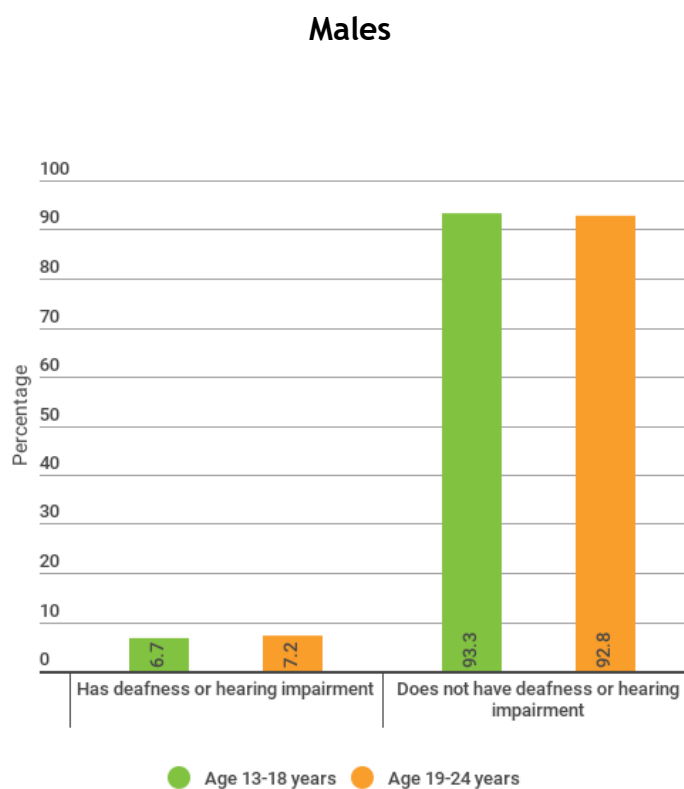
	<b>Males with ID aged 13-18</b> n = 1,740	<b>Males with ID aged 19-24</b> n = 1,656	<b>Females with ID aged 13-18</b> n = 1,037	<b>Females with ID aged 19-24</b> n = 1,123	<b>Total</b>
<b>Has a long-term illness, disease or condition</b>	711 (40.9%)	577 (34.8%)	422 (40.7%)	444 (39.5%)	2,154
<b>Does not have a long-term illness, disease or condition</b>	1,029 (59.1%)	1,079 (65.2%)	615 (59.3%)	679 (60.5%)	3,402

**Figure 5: Long-term illnesses, diseases or conditions in the population with intellectual disabilities**

6.7% of males and 10.4% of females with intellectual disabilities aged 13-18 years reported the presence of deafness or a hearing impairment compared to 7.2% of males and 10.7% of females aged 19-24 years (Table 9; Figure 6).

**Table 9: Presence of deafness or hearing impairment in the population with intellectual disabilities**

	<b>Males with ID aged 13-18</b> n = 1,740	<b>Males with ID aged 19-24</b> n = 1,656	<b>Females with ID aged 13-18</b> n = 1,037	<b>Females with ID aged 19-24</b> n = 1,123	<b>Total</b>
<b>Has deafness or hearing impairment</b>	117 (6.7%)	120 (7.2%)	108 (10.4%)	120 (10.7%)	465
<b>Does not have deafness or hearing impairment</b>	1,623 (93.3%)	1,536 (92.8%)	929 (89.6%)	1,003 (89.3%)	5,091

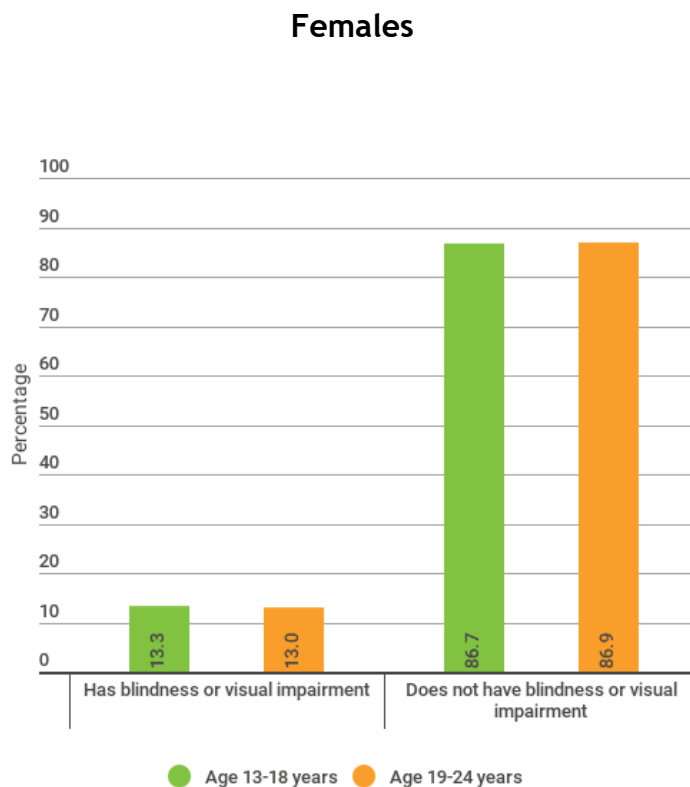
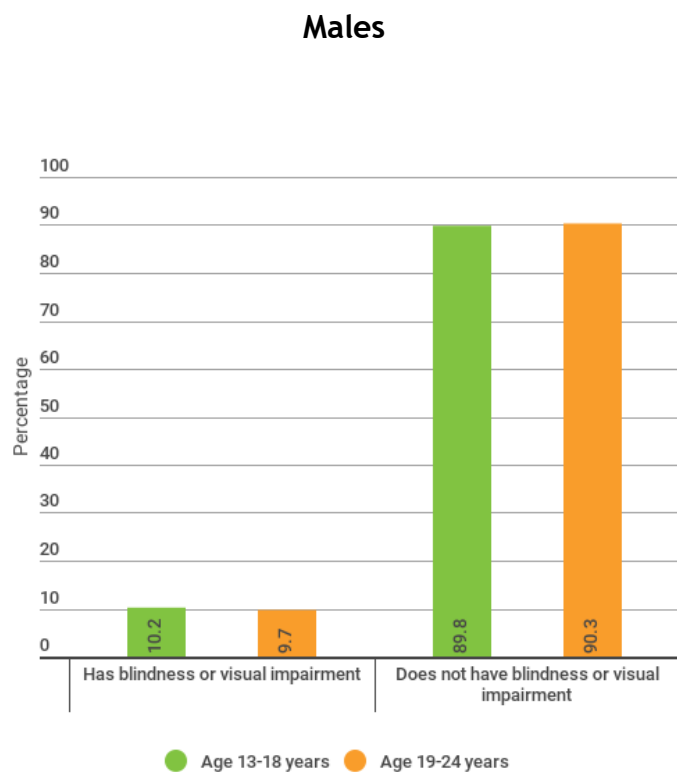
**Figure 6: Deafness or hearing impairment in the population with intellectual disabilities**



10.2% of males and 13.3% of females with intellectual disabilities aged 13-18 years reported the presence of blindness or a visual impairment compared to 9.7% of males and 13.0% of females aged 19-24 years (Table 10; Figure 7).

**Table 10: Presence of blindness or visual impairment in the population with intellectual disabilities**

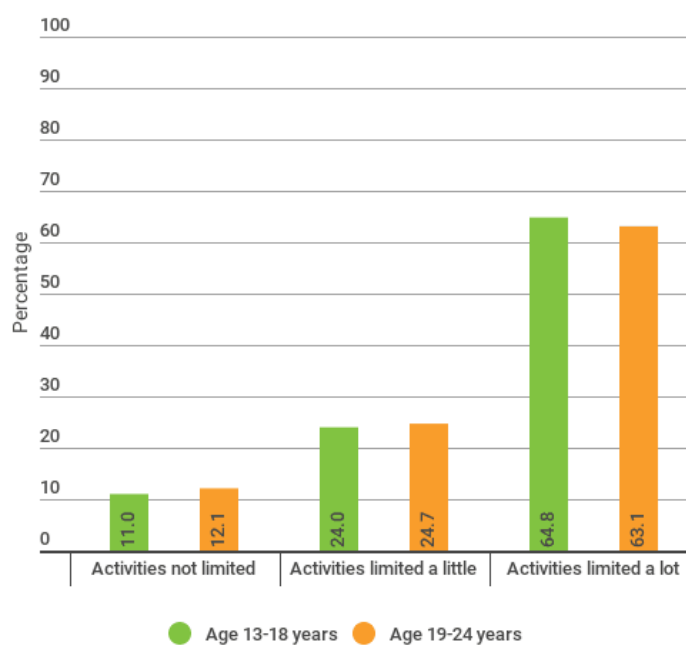
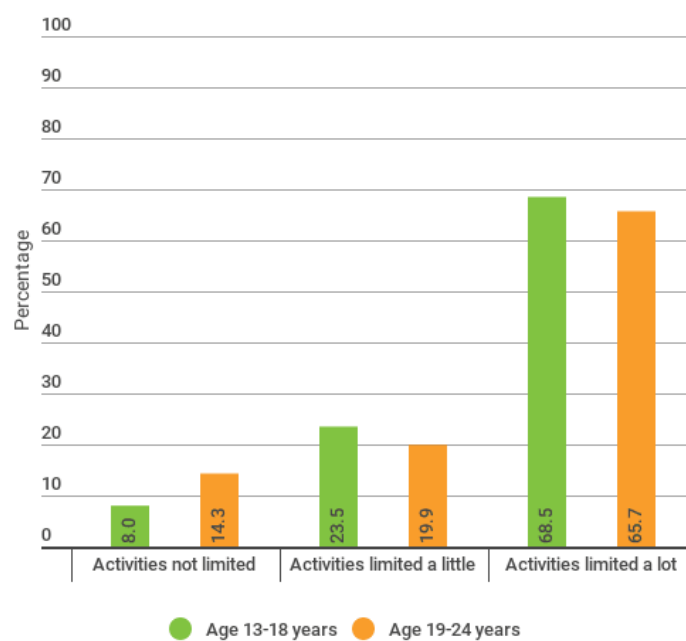
	<b>Males with ID aged 13-18</b> n = 1,740	<b>Males with ID aged 19-24</b> n = 1,656	<b>Females with ID aged 13-18</b> n = 1,037	<b>Females with ID aged 19-24</b> n = 1,123	<b>Total</b>
<b>Has blindness or visual impairment</b>	178 (10.2%)	161 (9.7%)	138 (13.3%)	146 (13.0%)	623
<b>Does not have blindness or visual impairment</b>	1,562 (89.8%)	1,495 (90.3%)	899 (86.7%)	977 (86.9%)	4,933

**Figure 7: Blindness or visual impairment in the population with intellectual disabilities**

88.8% of males and 92.0% of females with intellectual disabilities aged 13-18 years reported their activities to be limited 'a little' or 'a lot' due to health conditions, compared to 87.8% of males and 85.6% of females with intellectual disabilities aged 19-24 years (Table 11; Figure 8).

**Table 11: Health-related activity limitations in the population with intellectual disabilities**

	<b>Males with ID aged 13-18</b> n = 1,740	<b>Males with ID aged 19-24</b> n = 1,656	<b>Females with ID aged 13-18</b> n = 1,037	<b>Females with ID aged 19-24</b> n = 1,123	<b>Total</b>
<b>Activities not limited</b>	193 (11.0%)	201 (12.1%)	83 (8.0%)	161 (14.3%)	638
<b>Activities limited a little</b>	419 (24.0%)	409 (24.7%)	244 (23.5%)	224 (19.9%)	1,296
<b>Activities limited a lot</b>	1,128 (64.8%)	1,046 (63.1%)	710 (68.5%)	738 (65.7%)	3,622

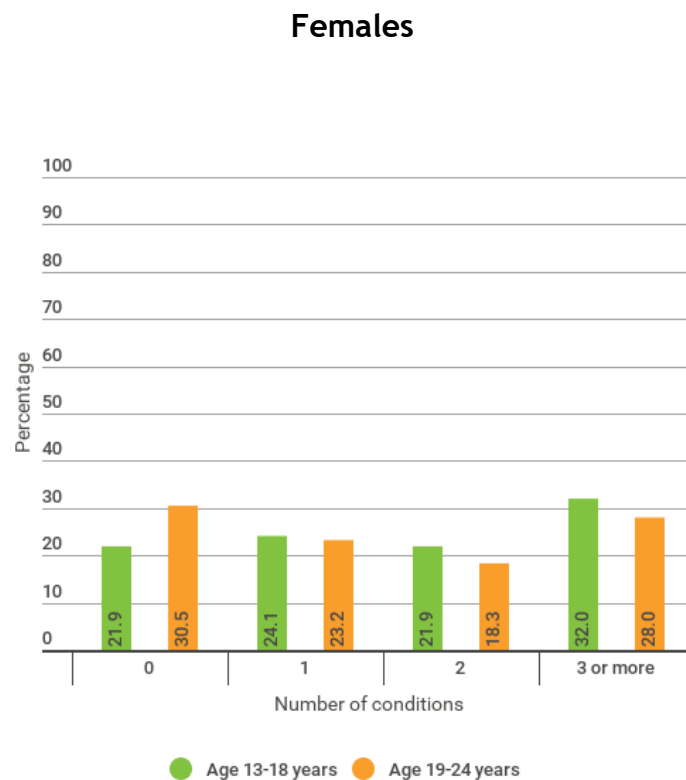
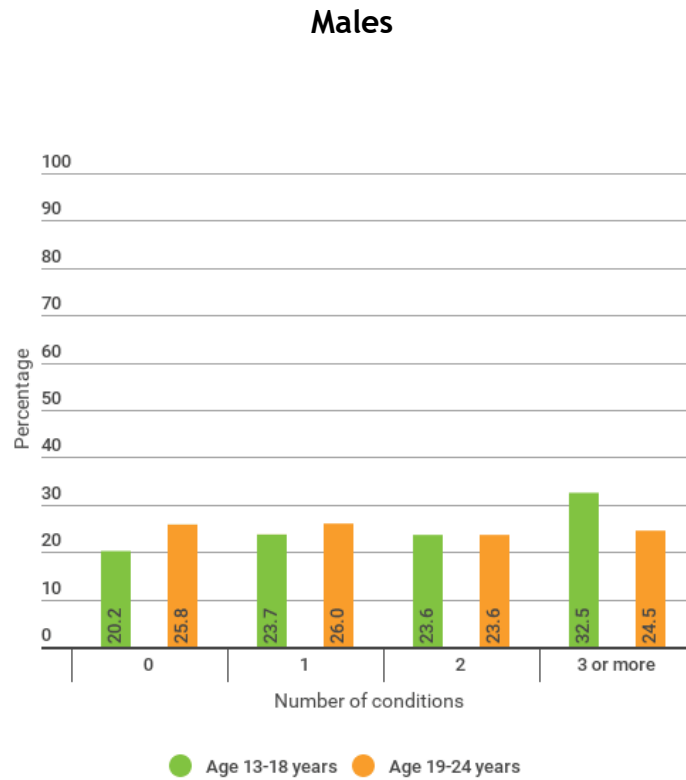
**Figure 8: Health-related activity limitations in the population with intellectual disabilities****Males****Females**

## 26.2 Comorbidities

79.8% of males and 78.0% of females with intellectual disabilities aged 13-18 years reported the presence of at least one health condition, compared to 74.1% of males and 69.5% of females with intellectual disabilities aged 19-24 years (Table 12; Figure 9).

**Table 12: Number of conditions reported in the population with intellectual disabilities**

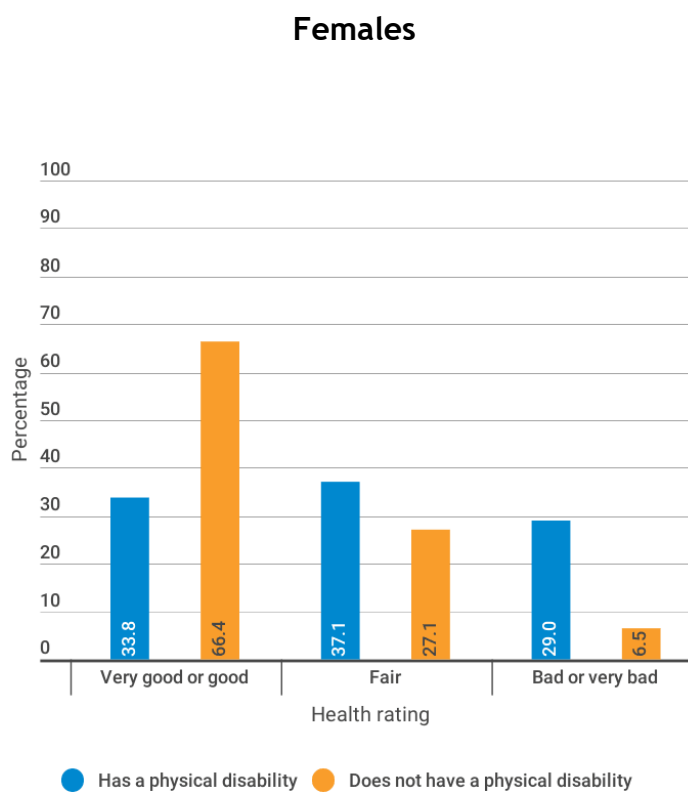
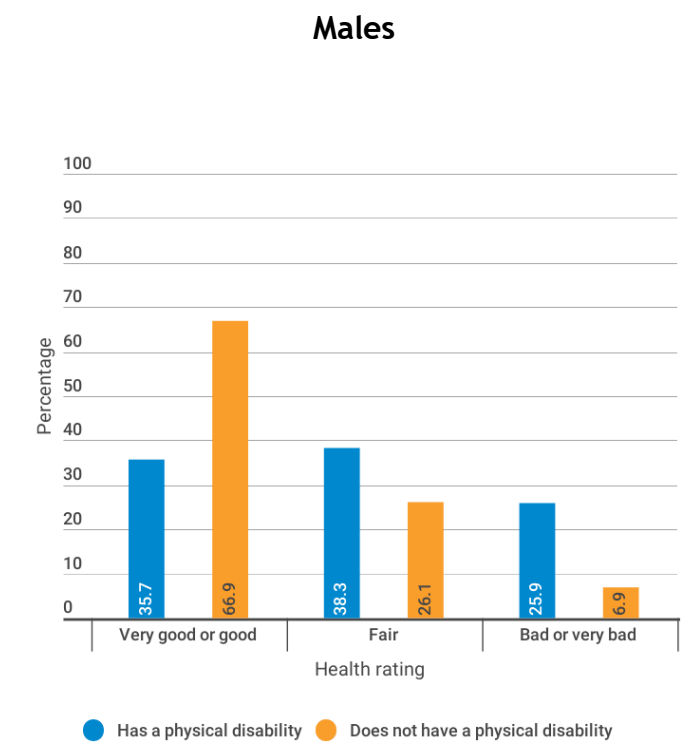
<b>Number of conditions</b>	<b>Males with ID aged 13-18</b> n = 1,740	<b>Males with ID aged 19-24</b> n = 1,656	<b>Females with ID aged 13-18</b> n = 1,037	<b>Females with ID aged 19-24</b> n = 1,123	<b>Total</b>
<b>0</b>	351 (20.2%)	427 (25.8%)	227 (21.9%)	343 (30.5%)	1,348
<b>1</b>	413 (23.7%)	432 (26.0%)	250 (24.1%)	260 (23.2%)	1,355
<b>2</b>	411 (23.6%)	391 (23.6%)	228 (21.9%)	205 (18.3%)	1,235
<b>3 or more</b>	365 (32.5%)	406 (24.5%)	332 (32.0%)	315 (28.0%)	1,618

**Figure 9: Number of conditions in the population with intellectual disabilities**

Of the 994 males and 789 females with intellectual disabilities and physical disabilities (PD), 639 males (64.2%) and 522 females (66.1%) reported 'poor' health (Table 13, Figure 10).

**Table 13: General health ratings in the population with intellectual disabilities with and without physical disabilities**

<b>General health</b>	<b>Males with ID &amp; PD aged 13-24</b> n = 994	<b>Males with ID &amp; no PD aged 13-24</b> n = 2,402	<b>Females with ID &amp; PD aged 13-24</b> n = 789	<b>Females with ID &amp; no PD aged 13-24</b> n = 1,371	<b>Total</b>
<b>Very good or good</b>	355 (35.7%)	1,608 (66.9%)	267 (33.8%)	910 (66.4%)	3,140
<b>Fair</b>	381 (38.3%)	627 (26.1%)	293 (37.1%)	372 (27.1%)	1,673
<b>Bad or very bad</b>	258 (25.9%)	167 (6.9%)	229 (29.0%)	89 (6.5%)	743

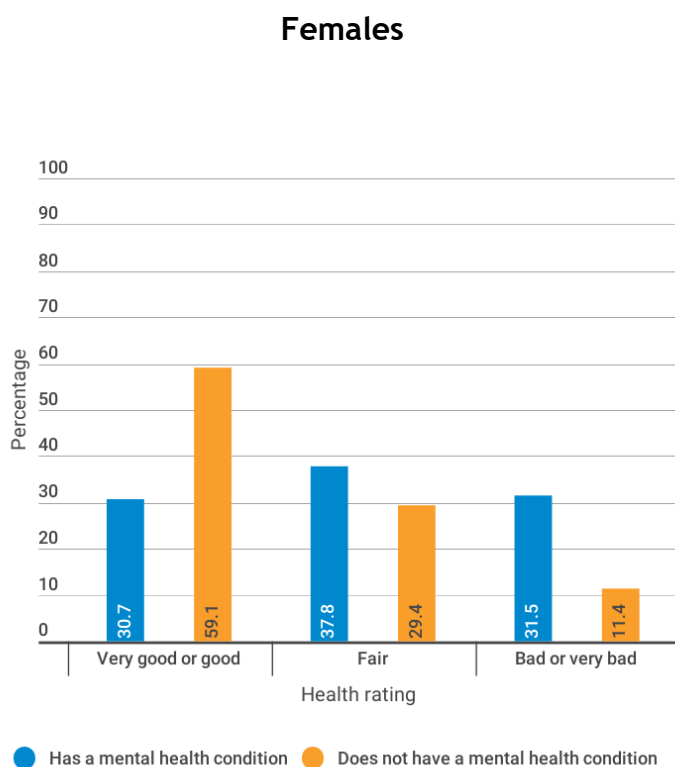
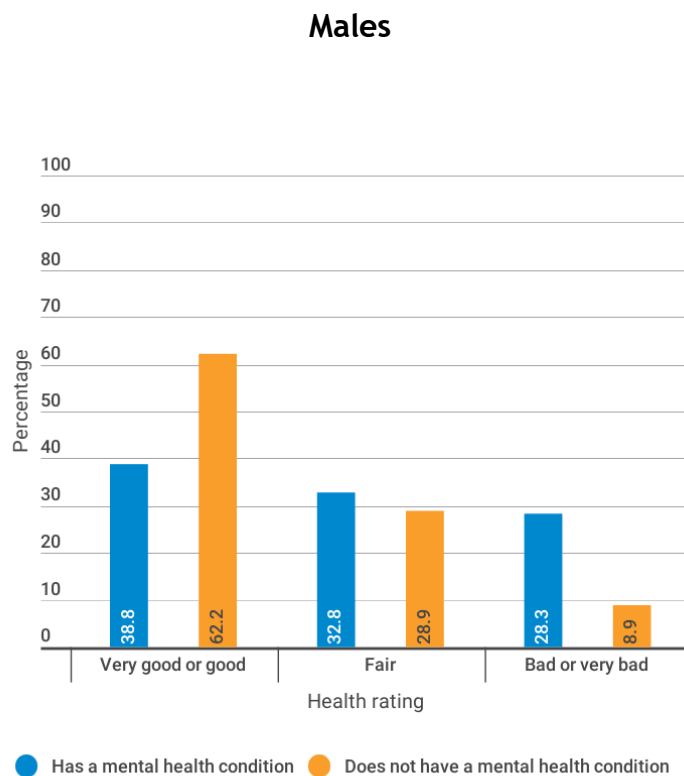
**Figure 10: General health ratings in the population with intellectual disabilities with and without physical disabilities**



Of the 636 males and 352 females with intellectual disabilities and mental health conditions (MH), 389 males (61.1%) and 244 females (69.3%) reported 'poor' health (Table 14, Figure 11).

**Table 14: General health ratings in the population with intellectual disabilities with and without mental health conditions**

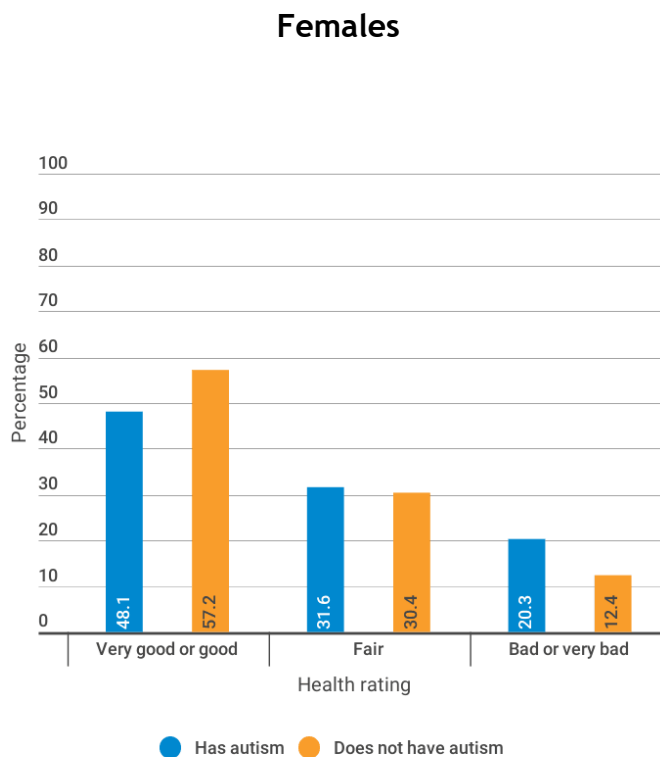
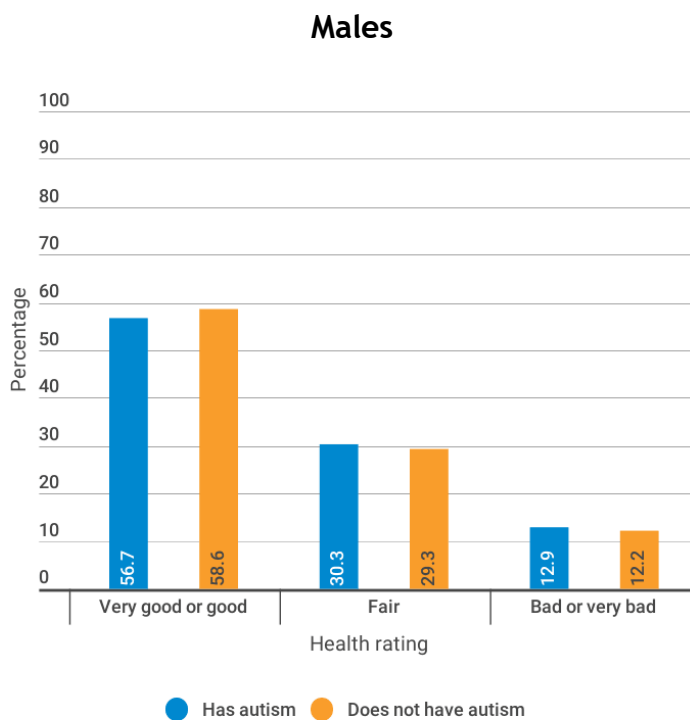
<b>General health</b>	<b>Males with ID &amp; MH aged 13-24</b> n = 636	<b>Males with ID &amp; no MH aged 13-24</b> n = 2,760	<b>Females with ID &amp; MH aged 13-24</b> n = 352	<b>Females with ID &amp; no MH aged 13-24</b> n = 1,808	<b>Total</b>
<b>Very good or good</b>	247 (38.8%)	1,716 (62.2%)	108 (30.7%)	1,069 (59.1%)	3,140
<b>Fair</b>	209 (32.8%)	799 (28.9%)	133 (37.8%)	532 (29.4%)	1,673
<b>Bad or very bad</b>	180 (28.3%)	245 (8.9%)	111 (31.5%)	207 (11.4%)	743

**Figure 11: General health ratings in the population with intellectual disabilities with and without mental health conditions**

Of the 1,386 males and 646 females with intellectual disabilities and autism (ASD), 600 males (43.2%) and 335 females (51.9%) reported 'poor' health (Table 15, Figure 12).

**Table 15: General health ratings in the population with intellectual disabilities with and without autism**

<b>General health</b>	<b>Males with ID &amp; ASD aged 13-24</b> n = 1,386	<b>Males with ID &amp; no ASD aged 13-24</b> n = 2,010	<b>Females with ID &amp; ASD aged 13-24</b> n = 646	<b>Females with ID &amp; no ASD aged 13-24</b> n = 1,514	<b>Total</b>
<b>Very good or good</b>	786 (56.7%)	1,177 (58.6%)	311 (48.1%)	866 (57.2%)	3,140
<b>Fair</b>	420 (30.3%)	588 (29.3%)	204 (31.6%)	461 (30.4%)	1,673
<b>Bad or very bad</b>	180 (12.9%)	245 (12.2%)	131 (20.3%)	187 (12.4%)	743

**Figure 12: General health ratings in the population with intellectual disabilities with and without autism**

## 26.3 Geographic variables

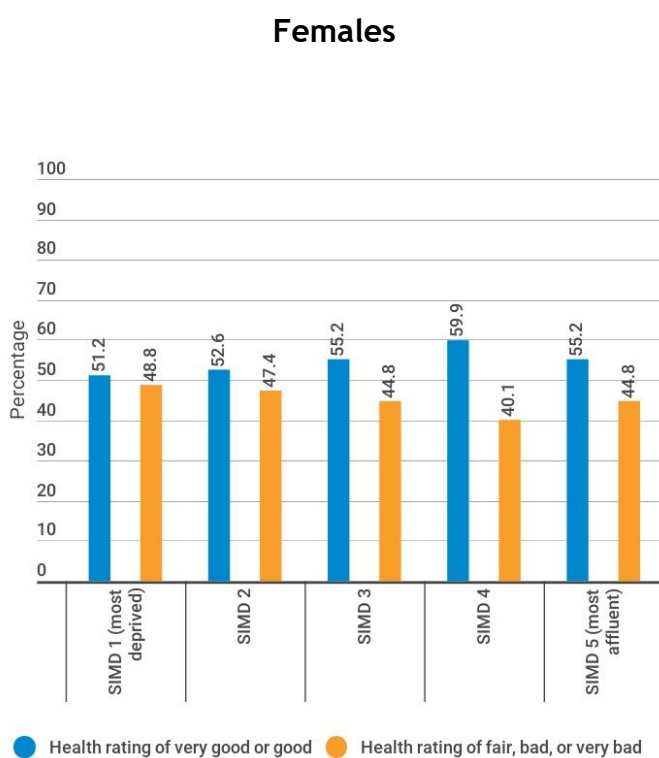
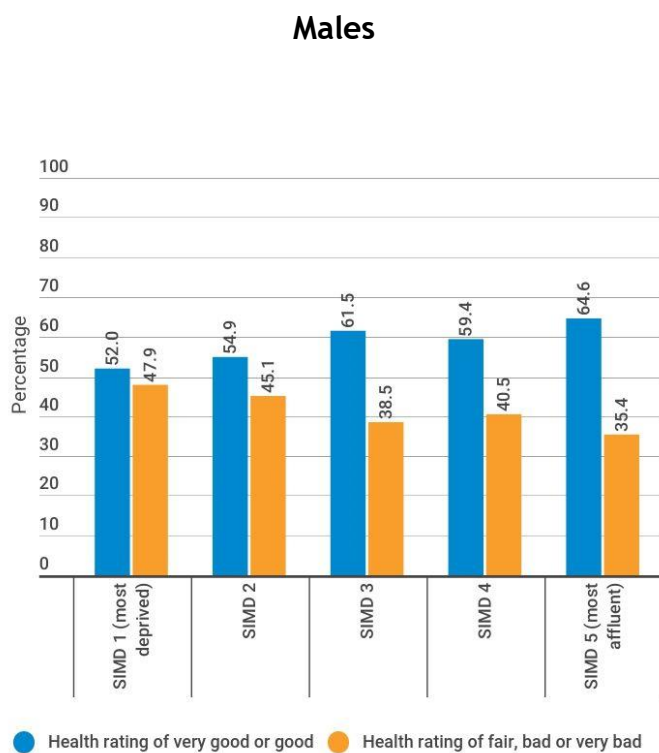
Of the 1,588 males with intellectual disabilities who lived in the most deprived (SIMD quintile 1-2) areas of Scotland, 741 (46.7%) reported 'poor' health (Table 16, Figure 13). Of the 991 females with intellectual disabilities who lived in the most deprived areas of Scotland, 447 (45.1%) reported 'poor' health (Table 17, Figure 13). Of the 1,808 males with intellectual disabilities who lived in the most affluent (SIMD quintile 3-5) areas of Scotland, 692 (38.3%) reported 'poor health' (Table 16, Figure 13). Of the 1,169 females with intellectual disabilities who lived in the most affluent areas of Scotland, 506 (43.3%) reported 'poor' health (Table 17, Figure 13).

**Table 16: General health ratings in the male population with intellectual disabilities living in the most deprived (SIMD 1) and the most affluent (SIMD 5) areas of Scotland**

General health	Males with ID aged 13-24 SIMD 1 n = 861	Males with ID aged 13-24 SIMD 2 n = 727	Males with ID aged 13-24 SIMD 3 n = 683	Males with ID aged 13-24 SIMD 4 n = 597	Males with ID aged 13-24 SIMD 5 n = 528	Total
Very good or good	448 (42.0%)	399 (54.9%)	420 (61.5%)	355 (59.4%)	341 (64.6%)	1,963
Fair, bad or very bad	413 (47.9%)	328 (45.1%)	263 (38.5%)	242 (40.5%)	187 (35.4%)	1,433

**Table 17: General health ratings in the female population with intellectual disabilities living in the most deprived (SIMD 1) and the most affluent (SIMD 5) areas of Scotland**

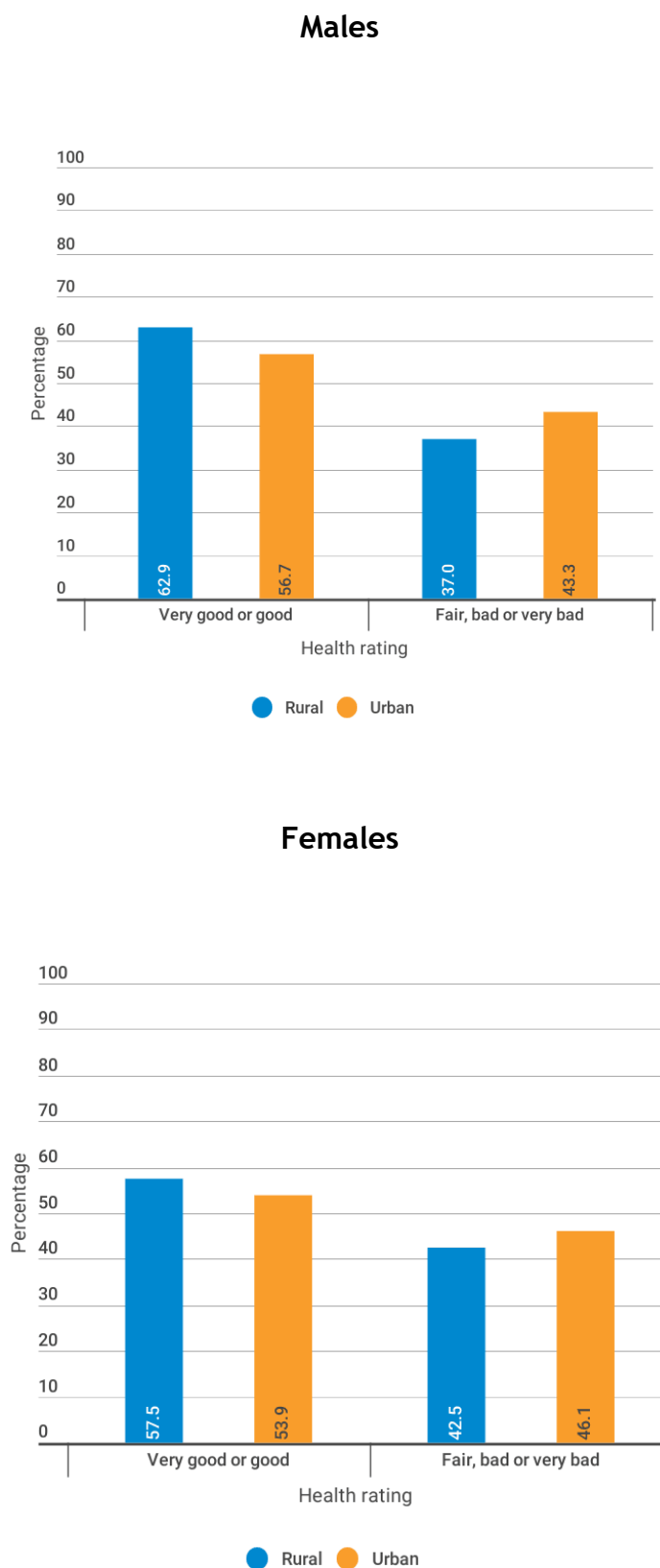
General health	Females with ID aged 13-24 SIMD 1 n = 521	Females with ID aged 13-24 SIMD 2 n = 470	Females with ID aged 13-24 SIMD 3 n = 426	Females with ID aged 13-24 SIMD 4 n = 379	Females with ID aged 13-24 SIMD 5 n = 364	Total
Very good or good	267 (51.2%)	247 (52.6%)	235 (55.2%)	227 (59.9%)	201 (55.2%)	1,177
Fair, bad or very bad	254 (48.8%)	223 (47.4%)	191 (44.8%)	152 (40.1%)	163 (44.8%)	983

**Figure 13: General health ratings in the population with intellectual disabilities living in the most deprived and the most affluent areas of Scotland**

Of the 594 males and 362 females with intellectual disabilities who reported living in rural areas, 220 (37.0%) males and 154 (42.5%) females reported 'poor' health (Table 18, Figure 14). Of the 2,802 males and 1,798 females with intellectual disabilities who reported living in urban areas, 1,213 males (43.3%) and 829 females (46.1%) reported 'poor' health (Table 18, Figure 14).

**Table 18: General health ratings in the population with intellectual disabilities living in rural areas and in urban areas**

General health	Males with ID aged 13-24 Rural n = 594	Males with ID aged 13-24 Urban n = 2,802	Females with ID aged 13-24 Rural n = 362	Females with ID aged 13-24 Urban n = 1,798	Total
<b>Very good or good</b>	374 (62.9%)	1,589 (56.7%)	208 (57.5%)	969 (53.9%)	3,140
<b>Fair, bad or very bad</b>	220 (37.0%)	1,213 (43.3%)	154 (42.5%)	829 (46.1%)	2,416

**Figure 14: General health ratings in the population with intellectual disabilities living in urban areas and rural areas**



## **27 Univariate analyses: population with intellectual disabilities**

### **27.1 'Poor' general health**

A chi-square test of association between age group and a report of 'poor' health in the population with intellectual disabilities revealed no significant association:  $\chi^2(1) = 0.710$ ,  $p = 0.400$ .

A chi-square test of association between gender and a report of 'poor' health in the population with intellectual disabilities revealed a significant association:  $\chi^2(1) = 5.895$ ,  $p = 0.015$ . Females were more likely to report poor health than were males (OR 1.144, 95% CI 1.026 – 1.275).

### **27.2 Mental health conditions**

A chi-square test of association between age group and the presence of a mental health condition in the population with intellectual disabilities revealed a significant association:  $\chi^2(1) = 25.671$ ,  $p < 0.001$ . Individuals aged 19-24 years were more likely to have a mental health condition than were individuals aged 13-18 years (OR 1.432, 95% CI 1.246 – 1.646).

A chi-square test of association between gender and the presence of a mental health condition in the population with intellectual disabilities revealed a significant association:  $\chi^2(1) = 5.339$ ,  $p = 0.021$ . Males were more likely to have a mental health condition than were females (OR 1.184, 95% CI 1.026 – 1.366).

### **27.3 Physical disabilities**

A chi-square test of association between age group and the presence of a physical disability in the population with intellectual disabilities revealed no significant association:  $\chi^2(1) = 1.298$ ,  $p = 0.255$ .

A chi-square test of association between gender and the presence of a physical disability in the population with intellectual disabilities revealed a significant association:  $\chi^2(1) = 31.914$ ,  $p < 0.001$ . Females were more likely to have a physical disability than were males (OR 1.391, 95% CI 1.240 – 1.560).

## 27.4 Long-term illnesses

A chi-square test of association between age group and the presence of a long-term illness, disease or condition in the population with intellectual disabilities revealed a significant association:  $\chi^2(1) = 9.643$ ,  $p = 0.002$ . Individuals aged 13-18 years were more likely to have a long-term illness, disease or condition than individuals aged 19-24 years (OR 1.187, 95% CI 1.065 – 1.322).

A chi-square test of association between gender and the presence of a long-term illness, disease or condition in the population with intellectual disabilities revealed no significant association:  $\chi^2(1) = 0.121$ ,  $p = 0.728$ .

## 27.5 Deafness/hearing impairment

A chi-square test of association between age group and the presence of deafness or a hearing impairment in the population with intellectual disabilities revealed no significant association:  $\chi^2(1) = 0.516$ ,  $p = 0.472$ .

A chi-square test of association between gender and the presence of deafness or a hearing impairment in the population with intellectual disabilities revealed a significant association:  $\chi^2(1) = 22.025$ ,  $p < 0.001$ . Females were more likely to have deafness or a hearing impairment than were males (OR 1.572, 95% CI 1.300 – 1.903).

## 27.6 Blindness/visual impairment

A chi-square test of association between age group and the presence of blindness or a visual impairment in the population with intellectual disabilities revealed no significant association:  $\chi^2(1) = 0.154$ ,  $p = 0.695$ .

A chi-square test of association between gender and the presence of blindness or a visual impairment in the population with intellectual disabilities revealed a significant association:  $\chi^2(1) = 13.291$ ,  $p < 0.001$ . Females were more likely to have blindness or a visual impairment than were males (OR 1.365, 95% CI 1.154 – 1.615).

## 27.7 Health-related activity limitations

A chi-square test of association between age group and the presence of health-related activity limitations in the population with intellectual disabilities revealed a significant association:  $\chi^2(1) = 13.026$ ,  $p < 0.001$ . Individuals aged 13-18 years were more likely to report that their activities were limited 'a little' or 'a lot' than were individuals aged 19-24 years (OR 1.357, 95% CI 1.149 – 1.603).

A chi-square test of association between gender and the presence of health-related activity limitations in the population with intellectual disabilities revealed no significant association:  $\chi^2(1) = 0.121$ ,  $p = 0.728$ .

## 27.8 Number of additional health conditions

A mann whitney *U* test to determine differences in the number of conditions reported by individuals aged 13-18 years and 19-24 years in the population with intellectual disabilities showed a significant difference:  $U = 3388710.500$ ,  $p < 0.001$ . Individuals aged 13-18 years (mean rank = 2753.02) reported a higher number of conditions than individuals aged 19-24 years (mean rank = 2609.40).

A mann whitney *U* test to determine differences in the number of conditions reported between males and females in the population with intellectual disabilities showed no significant difference:  $U = 3374589.500$ ,  $p = 0.151$ .

## 27.9 Comorbidities

A chi square test of association between the presence of a physical disability and having 'poor' health in the population with intellectual disabilities revealed a significant association:  $\chi^2(1) = 499.869$ ,  $p < 0.001$ . Individuals with physical disabilities were more likely to report 'poor' health than were individuals without physical disabilities (OR 3.745, 95% CI 3.326 – 4.217).

A chi square test of association between the presence of a mental health condition and having 'poor' health in the population with intellectual disabilities revealed a significant association:  $\chi^2(1) = 207.187$ ,  $p < 0.001$ . Individuals with mental health conditions were more likely to report 'poor' health than were individuals without mental health conditions (OR 2.785, 95% CI 2.414 – 3.213).

A chi square test of association between the presence of autism and having 'poor' health in the population with intellectual disabilities revealed a significant association:  $\chi^2(1) = 8.339$ ,  $p = 0.004$ . Individuals with autism were more likely to report 'poor' health than were individuals without autism (OR 1.176, 95% CI 1.053 – 1.312).

## 27.10 Geographic variables

A chi square test of association between area deprivation and having 'poor' health' in the population with intellectual disabilities revealed a significant association:  $\chi^2(1) = 27.441$ ,  $p < 0.001$ . Individuals living in the most deprived areas of Scotland (SIMD 1-2) were more likely to report 'poor' health than were individuals living in the most affluent areas of Scotland (SIMD 3-5) (OR 1.329, 95% CI 1.195 – 1.478).

A chi square test of association between rurality and having 'poor' health in the population with intellectual disabilities revealed a significant association:  $\chi^2(1) = 8.945$ ,  $p = 0.003$ . Individuals living in urban areas were more likely to report 'poor' health than were individuals living in rural areas (OR 1.242, 95% CI 1.077 – 1.432).

## 28 Independent predictors of health outcomes: population with intellectual disabilities

### 28.1 Multicollinearity between predictor variables

A series of enter binary logistic regressions was used to ascertain the independent effects of age group and gender on the health outcomes under investigation in the population with intellectual disabilities. Tests to see if the data met the assumption of collinearity indicated that multicollinearity was not a concern (Table 19) (Menard, 1995; Myers, 1990).

**Table 19: Collinearity statistics for age group and gender in the population with intellectual disabilities**

Variable	Tolerance	VIF
Age group	0.999	1.001
Gender	0.999	1.001

## 28.2 'Poor' general health

Gender was found to be significant, with being female predicting having 'poor' health (Table 20). The model explained 1.0% (Nagelkerke  $R^2$ ) of the variance in 'poor' health and correctly classified 56.5% of cases.

**Table 20: Independent predictors of poor health in the population with intellectual disabilities**

Characteristic		Odds ratio	95% confidence interval of odds
Age group	13-18 (reference)	-	-
	19-24	1.042	0.937 – 1.159
Gender	Male (reference)	-	-
	Female	1.44	1.026 – 1.275
Constant		0.730	-

## 28.3 Mental health conditions

Both predictor variables were found to be significant, with being aged 19-24 years and being male predicting having a mental health condition (Table 21). The model explained 3.0% (Nagelkerke  $R^2$ ) of the variance in mental health conditions and correctly classified 82.2% of cases.

**Table 21: Independent predictors of having a mental health condition in the population with intellectual disabilities**

Characteristic		Odds ratio	95% confidence interval of odds
Age group	13-18 (reference)	-	-
	19-24	1.153	1.005 – 1.324
Gender	Male (reference)	-	-
	Female	0.841	0.729 – 0.970
Constant		0.215	-

## 28.4 Physical disabilities

Gender was found to be significant, with being female predicting having a physical disability (Table 22). The model explained 8.0% (Nagelkerke  $R^2$ ) of the variance in poor health and correctly classified 67.9% of cases.

**Table 22: Independent predictors of having a physical disability in the population with intellectual disabilities**

Characteristic		Odds ratio	95% confidence interval of odds
Age group	13-18 (reference)	-	-
	19-24	0.927	0.828 – 1.038
Gender	Male (reference)	-	-
	Female	1.394	1.243 – 1.564
Constant	-	0.429	-

## 28.5 Long-term illnesses

Age group was found to be significant, with being aged 13-18 years predicting having a long-term illness, disease or condition (Table 23). The model explained 2.0% (Nagelkerke  $R^2$ ) of the variance in long-term illnesses, diseases and conditions and correctly classified 60.9% of cases.

**Table 23: Independent predictors of having a long-term illness, disease or condition in the population with intellectual disabilities**

Characteristic		Odds ratio	95% confidence interval of odds
Age group	13-18 (reference)	-	-
	19-24	0.865	0.776 – 0.964
Gender	Male (reference)	-	-
	Female	1.076	0.963 – 1.202
Constant	-	0.671	-

## 28.6 Deafness/hearing impairment

Gender was found to be significant, with being female predicting having deafness or a hearing impairment (Table 24). The model explained 9.1% (Nagelkerke  $R^2$ ) of the variance in deafness or hearing impairment and correctly classified 91.6% of cases.

**Table 24: Independent predictors of having deafness or hearing impairment in the population with intellectual disabilities**

Characteristic		Odds ratio	95% confidence interval of odds
Age group	13-18 (reference)	-	-
	19-24	1.057	0.874 – 1.279
Gender	Male (reference)	-	-
	Female	1.573	1.300 – 1.903
Constant	-	0.073	-

## 28.7 Blindness/visual impairment

Gender was found to be significant, with being female predicting having blindness or a visual impairment (Table 25). The model explained 5.0% (Nagelkerke  $R^2$ ) of the variance in blindness or visual impairment and correctly classified 88.8% of cases.

**Table 25: Independent predictors of having blindness or visual impairment in the population with intellectual disabilities**

Characteristic		Odds ratio	95% confidence interval of odds
Age group	13-18 (reference)	-	-
	19-24	0.958	0.810 – 1.132
Gender	Male (reference)	-	-
	Female	1.367	1.156 – 1.617
Constant	-	0.113	-

## 28.8 Health-related activity limitations

Age group was found to be significant, with being aged 13-18 years predicting reporting activities to be limited 'a little' or 'a lot' (Table 26). The model explained 8.0% (Nagelkerke  $R^2$ ) of the variance in activity limitations and correctly classified 88.5% of cases.

**Table 26: Independent predictors of having health-related activity limitations in the population with intellectual disabilities**

Characteristic		Odds ratio	95% confidence interval of odds
Age group	13-18 (reference)	-	-
	19-24	0.736	0.623 – 0.869
Gender	Male (reference)	-	-
	Female	1.041	0.878 – 1.234
Constant	-	8.928	-

## 28.9 Comorbidities

Cumulative odds ordinal logistic regression was used to ascertain the independent effects of age group and gender on the number of conditions reported in the population with intellectual disabilities. A full likelihood ratio test comparing the fit of the proportional odds model to a model with varying location parameters suggested that the assumption of proportional odds was violated,  $\chi^2(4) = 15.529$ ,  $p = 0.004$ . However, the full likelihood ratio test can identify violations of the assumption of proportional odds that do not exist

when conducting analysis on large sample sizes (Laerd, 2016). A deeper investigation of the assumption of proportional odds was undertaken by running separate binary logistic regressions on cumulative dichotomous dependent variables. The odds ratios were similar for each variable in the equation so the assumption of proportional odds was met (Table 27).

**Table 27: Odds ratios for variables in the equation**

Characteristic	Odds Ratio 1	Odds Ratio 2	Odds Ratio 3
Age group	-0.372	-0.315	-0.311
Gender	-0.177	-0.079	-0.076

Age group was found to be significant, with being aged 13-18 years predicting having a higher number of conditions (Table 28). The model statistically significantly predicted the dependent variable over and above the intercept-only model,  $\chi^2 (2) = 14.385$ ,  $p < 0.001$ .

**Table 28: Independent predictors of the number of conditions reported in the population with intellectual disabilities**

Characteristic		Odds ratio	95% confidence interval of odds
Age group	13-18 (reference)	-	-
	19-24	0.842	0.765 – 0.927
Gender	Male (reference)	-	-
	Female	1.075	0.975– 1.185

Backwards stepwise binary logistic regression with likelihood ratio test ( $p < 0.05$ ) was used to ascertain the independent effects of gender, the presence of a physical disability, the presence of a mental health condition, and the presence of autism on having 'poor' health in the population with intellectual disabilities. Tests to see if the data met the assumption of collinearity indicated that multicollinearity may be of concern, since all of the tolerance statistics were below 0.1 (Table 29) (Menard, 1995).

**Table 29: Collinearity statistics for gender, physical disability, mental health condition, and autism in the population with intellectual disabilities**

Variable	Tolerance	VIF
Gender	0.926	
		1.080
Physical disability	0.962	1.039
Mental health condition	0.965	1.036
Autism	0.901	1.110



The following model should therefore be approached with caution as it may be unreliable (Field, 2013). Physical disability and mental health condition were found to be significant, with having a mental health condition and having a physical disability independently predicting reporting 'poor' health (Table 30). The final model explained 14.2% (Nagelkerke  $R^2$ ) of the variance in 'poor' health and correctly classified 66.5% of cases.

**Table 30: Individual independent predictors of having poor health in the population with intellectual disabilities**

Characteristic		Odds ratio	95% confidence interval of odds
Gender	Male (reference)	-	-
	Female	1.082	0.964 – 1.215
Physical disability	No physical disability (reference)	-	-
	Physical disability	3.524	3.126 – 3.972
Mental health condition	No mental health condition (reference)	-	-
	Mental health condition	2.438	2.127 – 2.795
Autism	No autism (reference)	-	-
	Autism	0.970	0.863 – 1.090
Constant	-	0.424	-

## 28.10 Geographic variables

Backwards stepwise binary logistic regression with likelihood ratio test ( $p < 0.05$ ) was used to ascertain the independent effects of gender, area deprivation and rurality on having 'poor' health in the population with intellectual disabilities. Tests to see if the data met the assumption of multicollinearity indicated that multicollinearity may be of concern, since two of the tolerance statistics were below 0.1 (Table 31) (Menard, 1995).

**Table 31: Collinearity statistics for gender, area deprivation, and rurality in the population with intellectual disabilities**

Variable	Tolerance	VIF
Gender	1.000	
		1.000
Area deprivation	0.929	1.077
Rurality	0.929	1.077

The following model should therefore be approached with caution as it may be unreliable (Field, 2013). Area deprivation was found to be significant, with living in the most deprived areas of Scotland independently predicting reporting 'poor' health (Table 32). The final model explained 7.0% (Nagelkerke  $R^2$ ) of the variance in 'poor' health and correctly classified 56.5% of cases.

**Table 32: Geographic independent predictors of having poor health in the population with intellectual disabilities**

Characteristic		Odds ratio	95% confidence interval of odds
Gender	Male (reference)	-	-
	Female	1.147	1.028 – 1.279
Area deprivation	Least deprived (reference)	-	-
	Most deprived	1.299	1.163 - 1.450
Rurality	Rural (reference)	-	-
	Urban	1.131	0.976 – 1.312
Constant	-	0.582	-

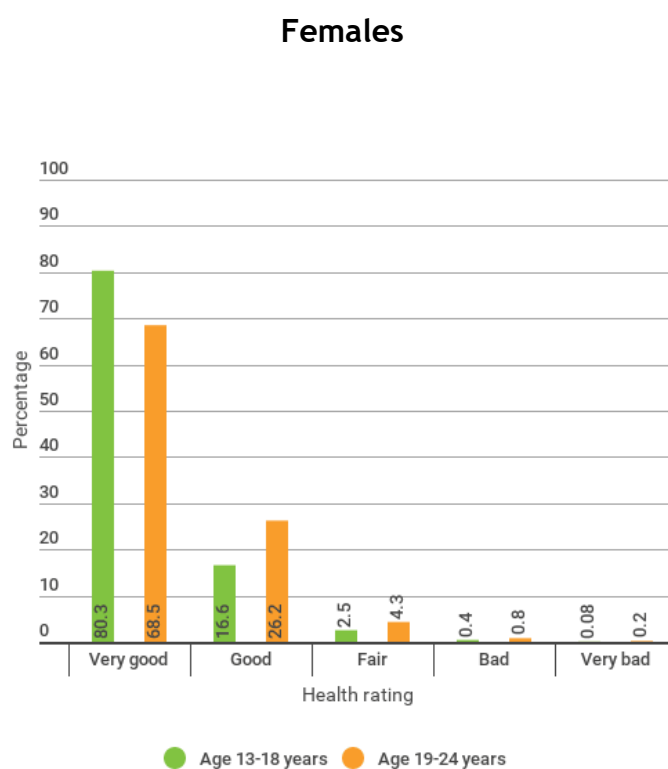
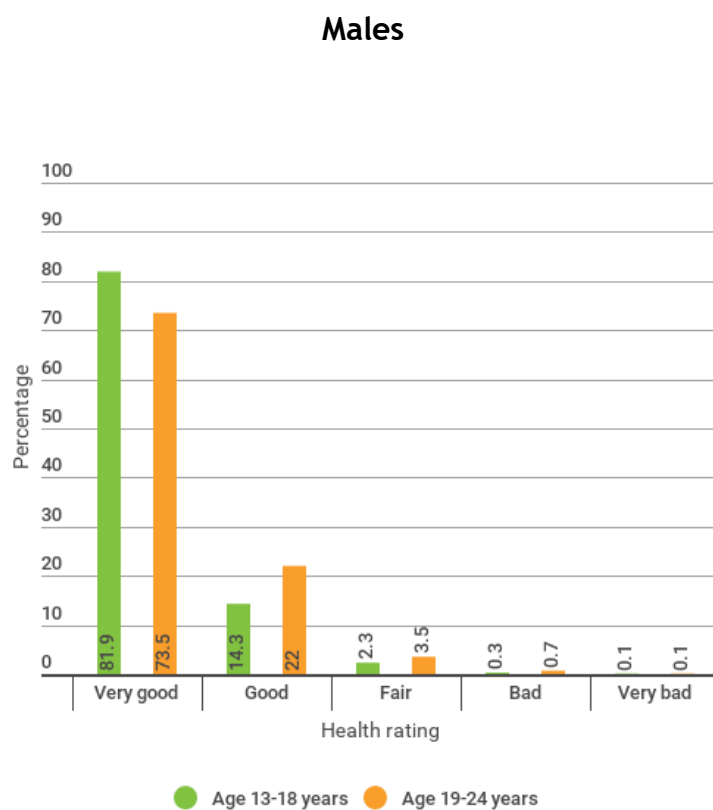
## 29 Descriptive statistics: population without intellectual disabilities

### 29.1 General health

2.7% of males and 2.9% of females without intellectual disabilities aged 13-18 years reported 'poor health' (fair, bad or very bad health) compared to 4.3% of males and 5.3% of females aged 19-24 years (Table 33, Figure 15).

**Table 33: General health ratings in the population without intellectual disabilities**

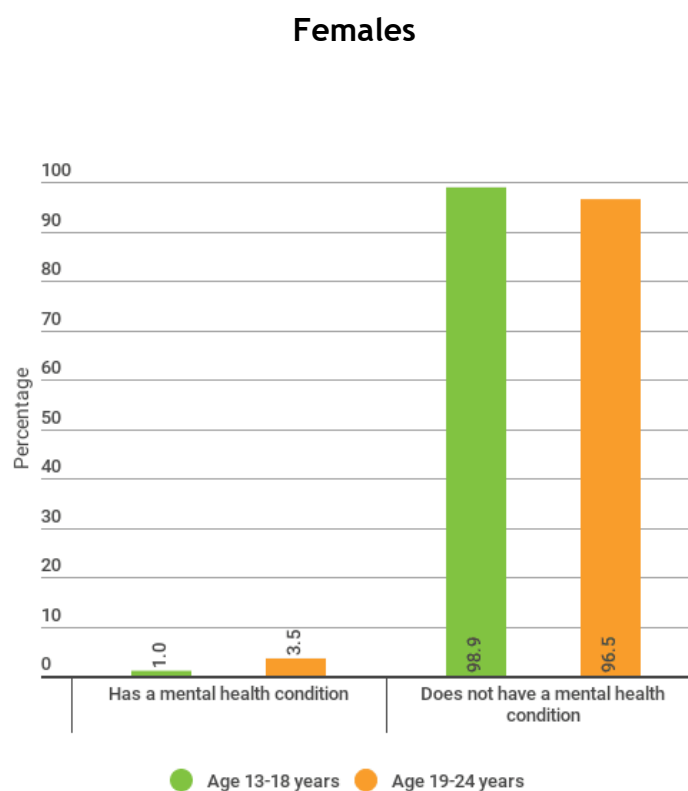
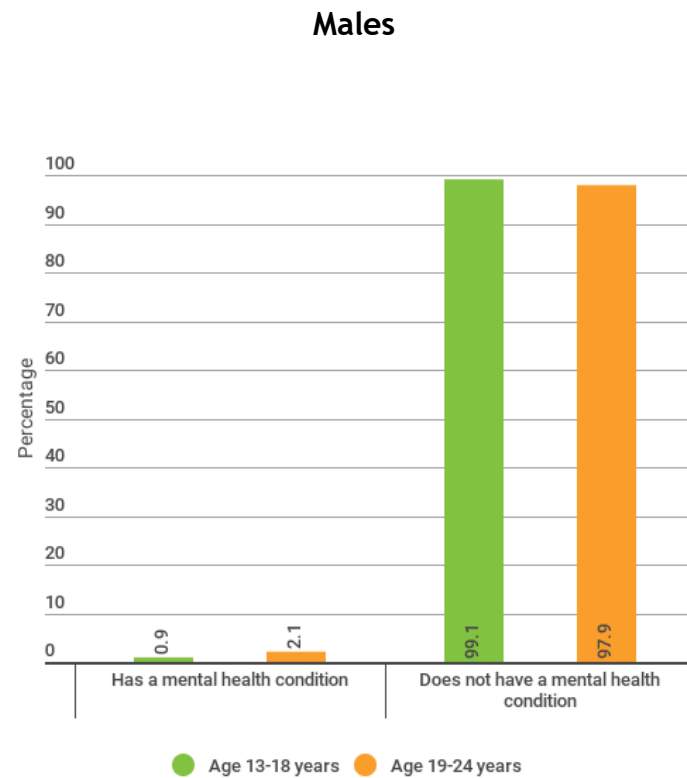
General Health	Males without ID aged 13-18 n = 191,647	Males without ID aged 19-24 n = 216,315	Females without ID aged 13-18 n = 183,373	Females without ID aged 19-24 n = 218,998	Total
<b>Very good</b>	156,912 (81.9%)	159,103 (73.5%)	147,281 (80.3%)	150,024 (68.5%)	613,320
<b>Good</b>	29,414 (14.3%)	47,727 (22.0%)	30,521 (16.6%)	57,362 (26.6%)	165,024
<b>Fair</b>	4,369 (2.3%)	7,557 (3.5%)	4,599 (2.5%)	9,513 (4.3%)	26,038
<b>Bad</b>	752 (0.3%)	1,542 (0.7%)	812 (0.4%)	1,752 (0.8%)	4,858
<b>Very bad</b>	200 (0.1%)	386 (0.1%)	160 (0.08%)	347 (0.2%)	1,093

**Figure 15: General health ratings in the population without intellectual disabilities**

0.9% of males and 1.0% of females without intellectual disabilities aged 13-18 years reported the presence of a mental health condition compared to 2.1% of males and 3.5% of females aged 19-24 years (Table 34, Figure 16).

**Table 34: Presence of mental health conditions in the population without intellectual disabilities**

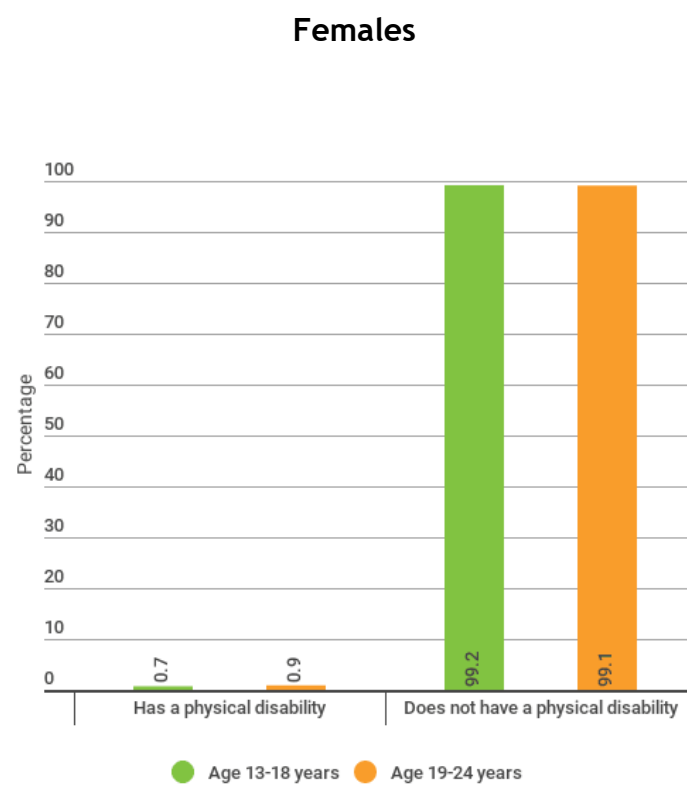
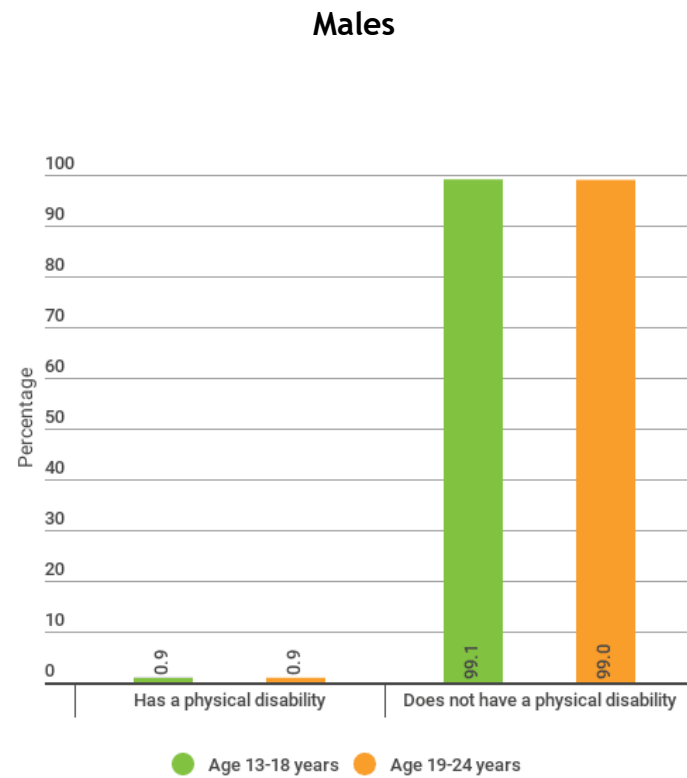
	<b>Males without ID aged 13-18</b> n = 191,647	<b>Males without ID aged 19-24</b> n = 216,315	<b>Females without ID aged 13-18</b> n = 183,373	<b>Females without ID aged 19-24</b> n = 218,998	<b>Total</b>
<b>Has a mental health condition</b>	1,805 (0.9%)	4,555 (2.1%)	1,983 (1.0%)	7,635 (3.5%)	15,978
<b>Does not have a mental health condition</b>	189,842 (99.1%)	211,760 (97.9%)	181,390 (98.9%)	211,363 (96.5%)	794,355

**Figure 16: Mental health conditions in the population without intellectual disabilities**

0.9% of males and 0.7% of females without intellectual disabilities aged 13-18 years reported the presence of a physical disability compared to 0.9% of males and 0.9% of females aged 19-24 years (Table 35, Figure 17).

**Table 35: Presence of physical disabilities in the population without intellectual disabilities**

	<b>Males without ID aged 13-18</b> n = 191,647	<b>Males without ID aged 19-24</b> n = 216,315	<b>Females without ID aged 13-18</b> n = 183,373	<b>Females without ID aged 19-24</b> n = 218,998	<b>Total</b>
<b>Has a physical disability</b>	1,631 (0.9%)	2,086 (0.9%)	1,344 (0.7%)	1,904 (0.9%)	6,965
<b>Does not have a physical disability</b>	190,016 (99.1%)	214,229 (99.0%)	182,029 (99.2%)	217,094 (99.1%)	803,368

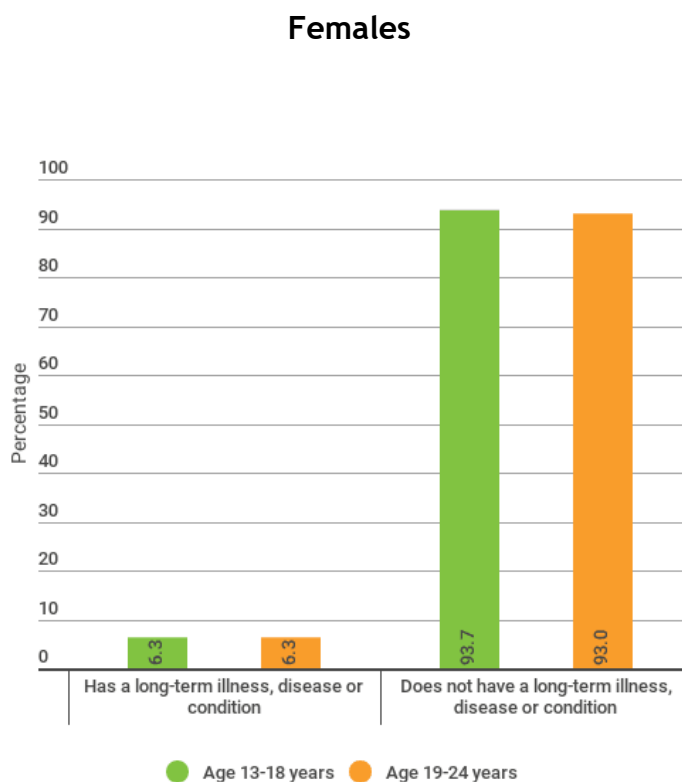
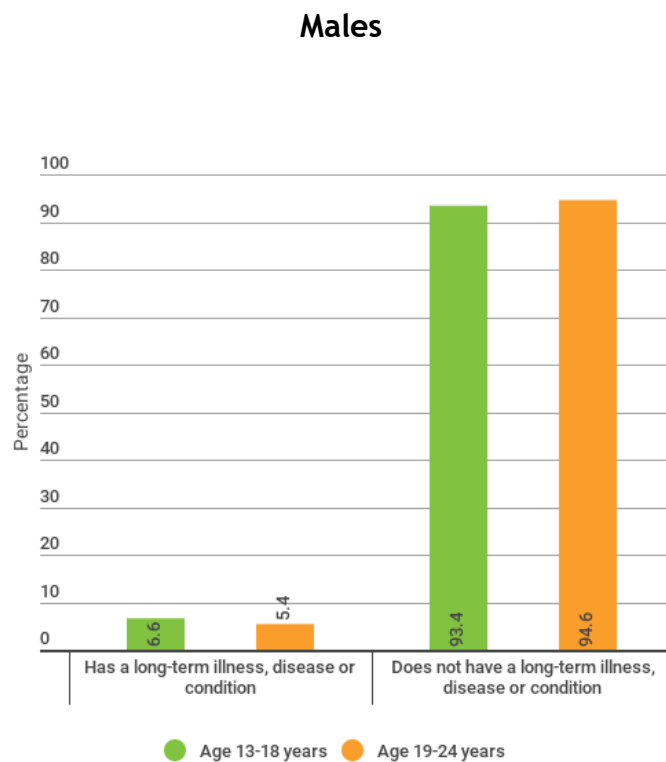
**Figure 17: Physical disabilities in the population without intellectual disabilities**

6.6% of males and 6.3% of females without intellectual disabilities aged 13-18 years reported the presence of a long-term illness, disease or condition compared to 5.4% of males and 6.9% of females aged 19-24 years (Table 36, Figure 18).

**Table 36: Presence of long-term illnesses, diseases or conditions in the population without intellectual disabilities**

	<b>Males without ID aged 13-18</b> n = 191,647	<b>Males without ID aged 19-24</b> n = 216,315	<b>Females without ID aged 13-18</b> n = 183,373	<b>Females without ID aged 19-24</b> n = 218,998	<b>Total</b>
<b>Has a long-term illness, disease or condition</b>	12,562 (6.6%)	11,739 (5.4%)	11,583 (6.3%)	15,122 (6.9%)	51,006
<b>Does not have a long-term illness, disease or condition</b>	179,085 (93.4%)	204,576 (94.6%)	171,790 (93.7%)	203,876 (93.0%)	759,327

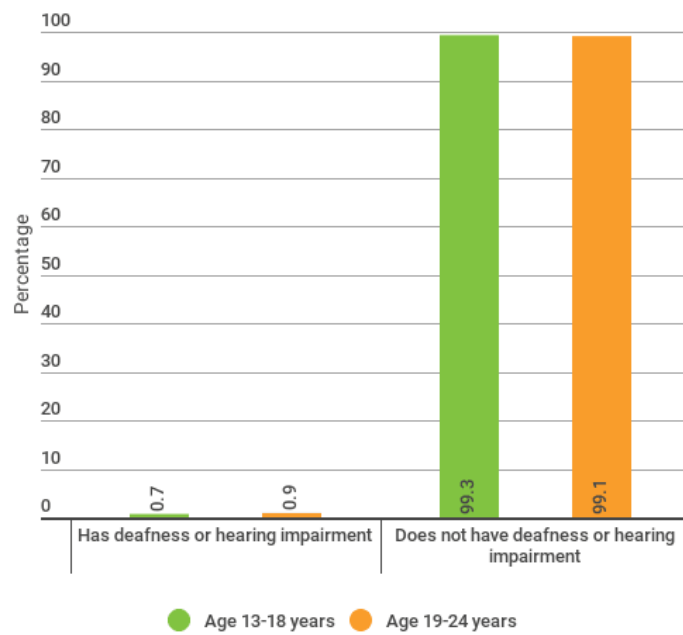
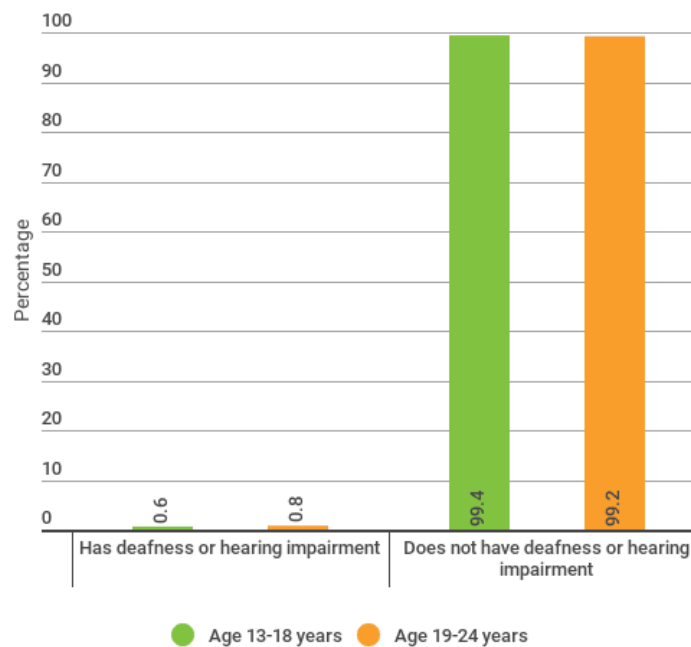


**Figure 18: Long-term illnesses, diseases or conditions in the population without intellectual disabilities**

0.7% of males and 0.6% of females in the population without intellectual disabilities aged 13-18 years reported the presence of deafness or a hearing impairment compared to 0.9% of males and 0.8% of females aged 19-24 years (Table 37, Figure 19).

**Table 37: Presence of deafness or hearing impairment in the population without intellectual disabilities**

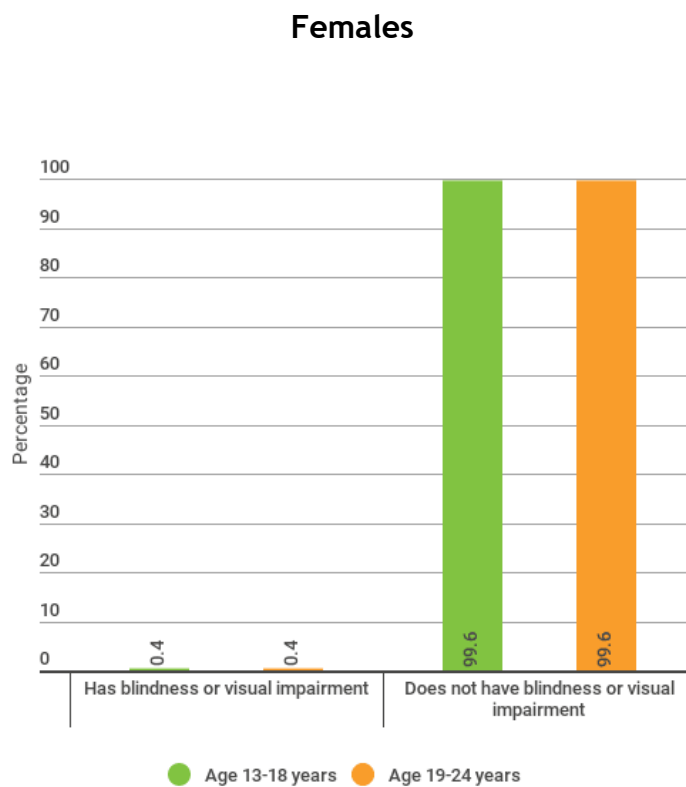
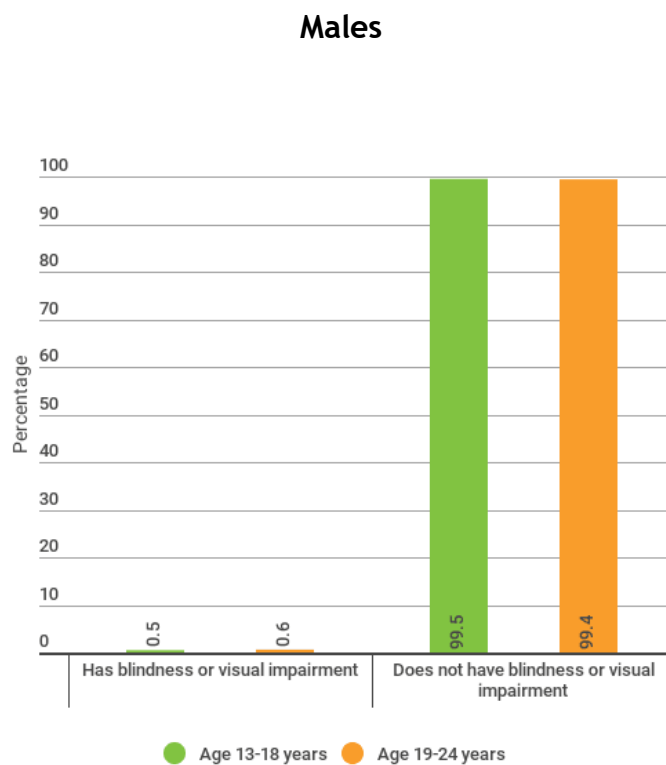
	<b>Males without ID aged 13-18</b> n = 191,647	<b>Males without ID aged 19-24</b> n = 216,315	<b>Females without ID aged 13-18</b> n = 183,373	<b>Females without ID aged 19-24</b> n = 218,998	<b>Total</b>
<b>Has deafness or hearing impairment</b>	1,351 (0.7%)	1,883 (0.9%)	1,178 (0.6%)	1,723 (0.8%)	6,135
<b>Does not have deafness or hearing impairment</b>	190,296 (99.3%)	214,432 (99.1%)	182,195 (99.4%)	217,275 (99.2%)	804,198

**Figure 29: Deafness or hearing impairment in the population without intellectual disabilities****Males****Females**

0.5% of males and 0.4% of females without intellectual disabilities aged 13-18 years reported the presence of blindness or a visual impairment compared to 0.6% of males and 0.4% of females aged 19-24 years (Table 38, Figure 20).

**Table 38: Presence of blindness or visual impairment in the population without intellectual disabilities**

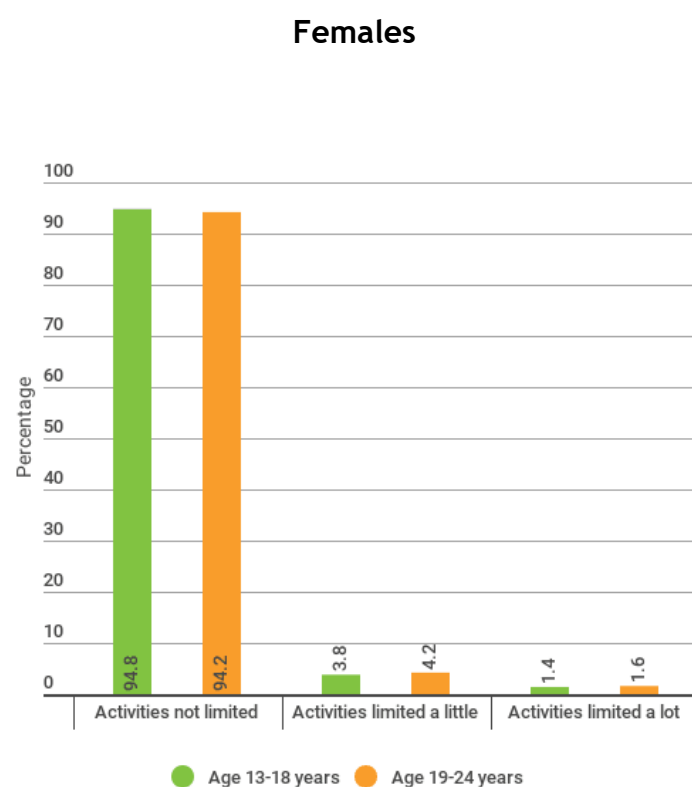
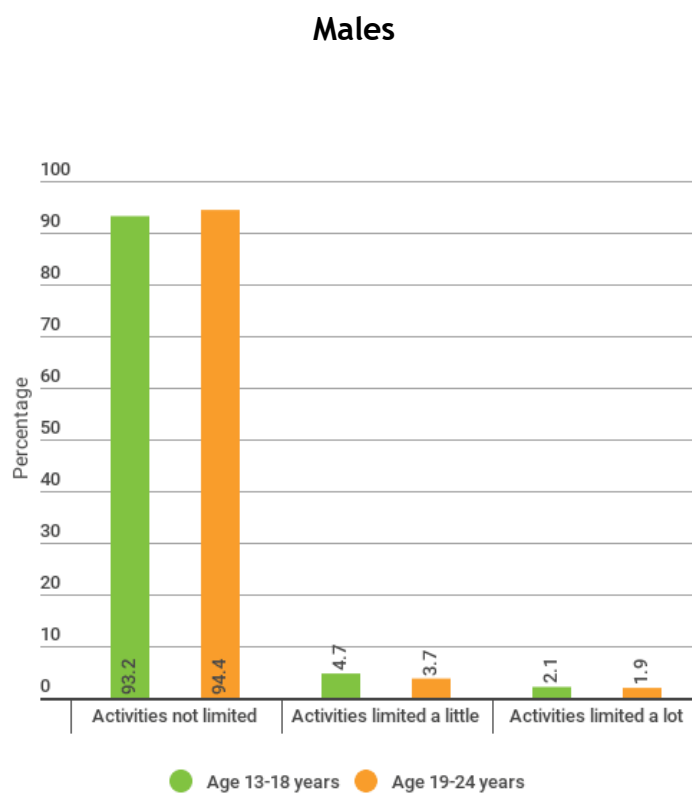
	<b>Males without ID aged 13-18</b> n = 191,647	<b>Males without ID aged 19-24</b> n = 216,315	<b>Females without ID aged 13-18</b> n = 183,373	<b>Females without ID aged 19-24</b> n = 218,998	<b>Total</b>
<b>Has blindness or visual impairment</b>	891 (0.5%)	1,335 (0.6%)	757 (0.4%)	968 (0.4%)	3,951
<b>Does not have blindness or visual impairment</b>	190,756 (99.5%)	214,980 (99.4%)	182,616 (99.6%)	218,030 (99.6%)	806,382

**Figure 20: Blindness or visual impairment in the population without intellectual disabilities**

6.8% of males and 5.2% of females without intellectual disabilities aged 13-18 years reported their activities to be limited 'a little' or 'a lot' due to health conditions, compared to 5.6% of males and 5.8% of females aged 19-24 years (Table 39, Figure 21).

**Table 39: Health-related activity limitations in the population without intellectual disabilities**

	<b>Males without ID aged 13-18</b> n = 191,647	<b>Males without ID aged 19-24</b> n = 216,315	<b>Females without ID aged 13-18</b> n = 183,373	<b>Females without ID aged 19-24</b> n = 218,998	<b>Total</b>
<b>Activities not limited</b>	178,593 (93.2%)	204,265 (94.4%)	173,893 (94.8%)	206,353 (94.2%)	763,104
<b>Activities limited a little</b>	8,988 (4.7%)	8,026 (3.7%)	6,988 (3.8%)	9,146 (4.2%)	33,148
<b>Activities limited a lot</b>	4,066 (2.1%)	4,024 (1.9%)	2,492 (1.4%)	3,499 (1.6%)	14,081

**Figure 21: Health-related activity limitations in the population without intellectual disabilities**

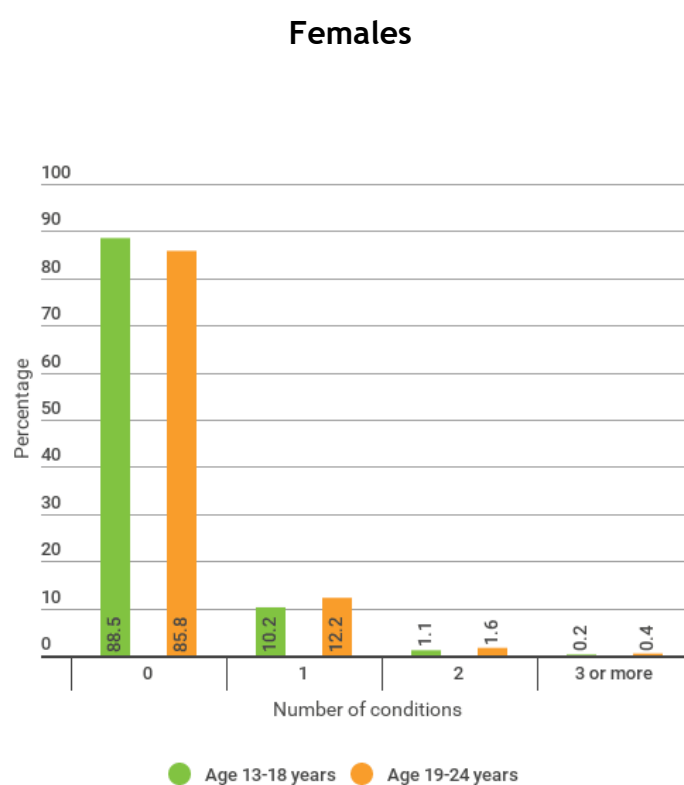
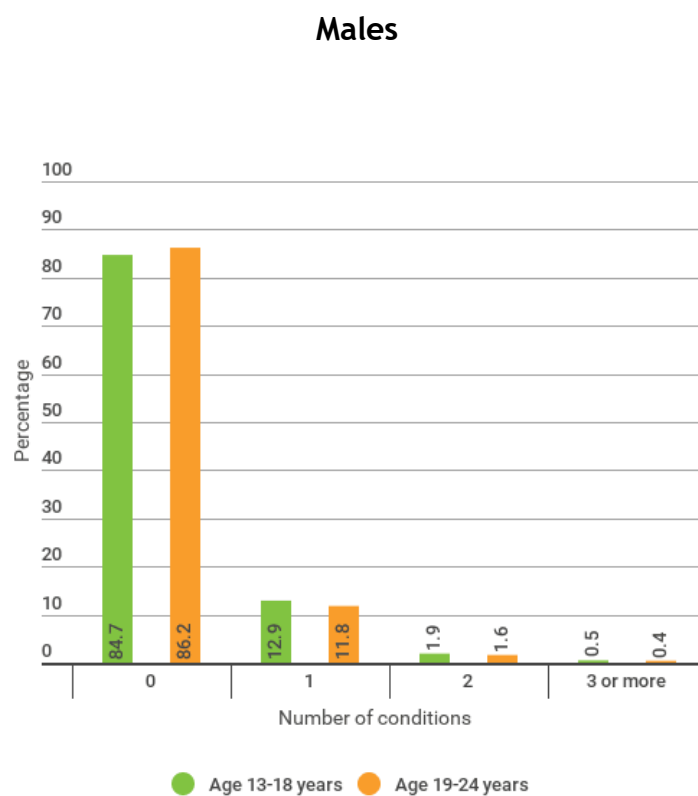
## 29.2 Comorbidities

15.3% of males and 11.5% of females without intellectual disabilities aged 13-18 years reported at least one health condition compared to 13.8% of males and 14.2% of females aged 19-24 years (Table 40, Figure 22).

**Table 40: Number of conditions in the population without intellectual disabilities**

<b>Number of conditions</b>	<b>Males without ID aged 13-18</b> n = 191,647	<b>Males without ID aged 19-24</b> n = 216,315	<b>Females without ID aged 13-18</b> n = 183,373	<b>Females without ID aged 19-24</b> n = 218,998	<b>Total</b>
<b>0</b>	162,339 (84.7%)	186,501 (86.2%)	162,229 (88.5%)	187,999 (85.8%)	699,068
<b>1</b>	24,782 (12.9%)	25,565 (11.8%)	18,642 (10.2%)	26,783 (12.2%)	95,772
<b>2</b>	3,591 (1.9%)	3,361 (1.6%)	2,019 (1.1%)	3,459 (1.6%)	12,430
<b>3 or more</b>	935 (0.5%)	888 (0.4%)	483 (0.2%)	757 (0.4%)	3,063

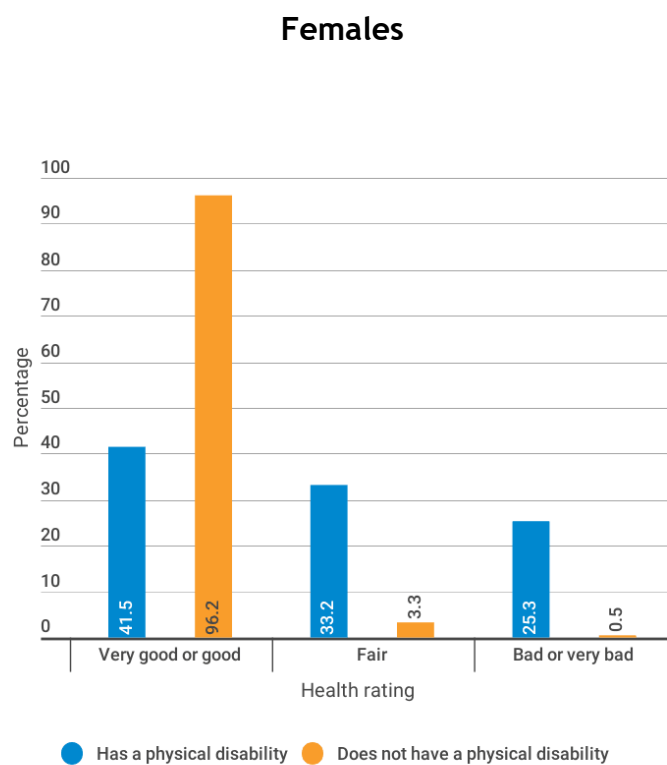
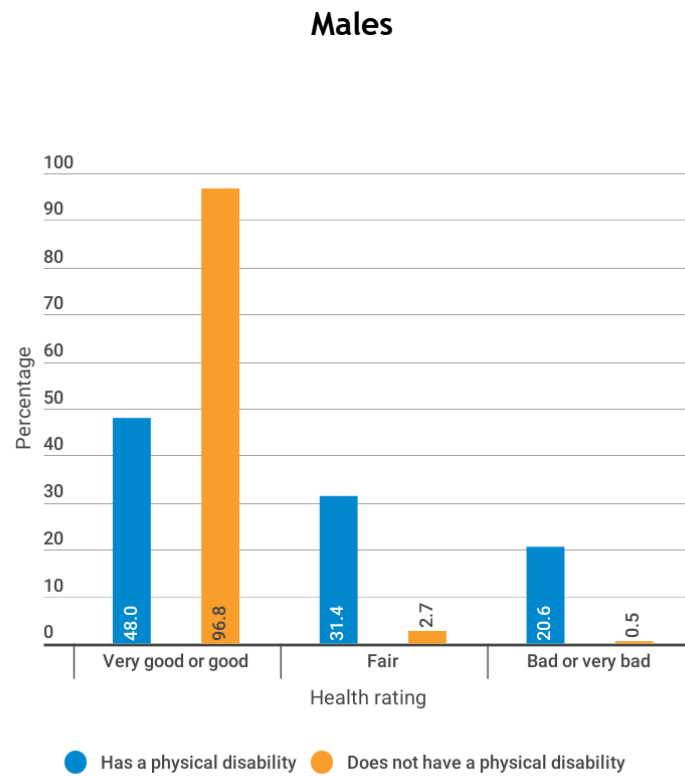


**Figure 22: Number of conditions in the population without intellectual disabilities**

Of the 3,717 males and 3,248 females without intellectual disabilities and with physical disabilities, 1,932 males (51.9%) and 1,899 females (58.5%) reported 'poor' health (Table 41, Figure 23).

**Table 41: General health ratings in the population without intellectual disabilities with and without physical disabilities**

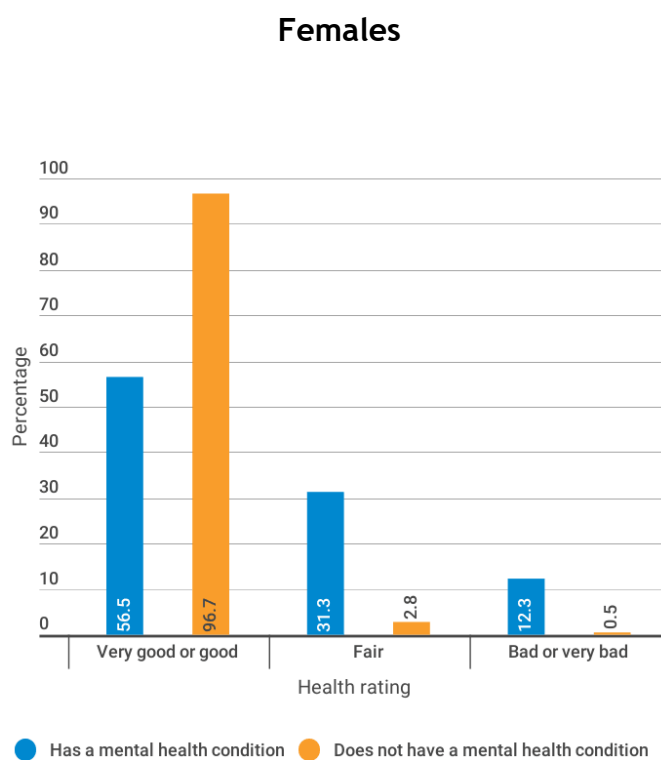
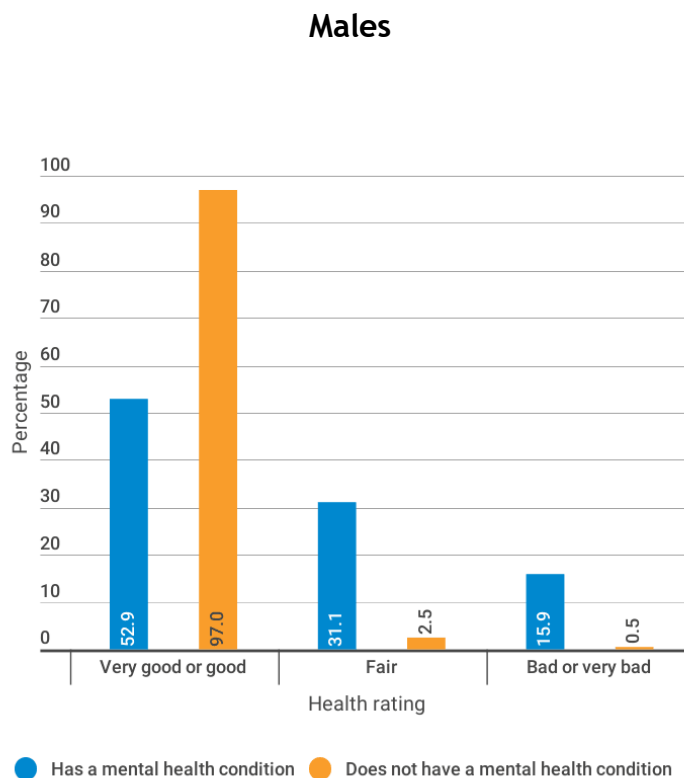
<b>General health</b>	<b>Males without ID with PD aged 13-24</b> n = 3,717	<b>Males without ID with no PD aged 13-24</b> n = 404,245	<b>Females without ID with PD aged 13-24</b> n = 3,248	<b>Females without ID with no PD aged 13-24</b> n = 399,123	<b>Total</b>
<b>Very good or good</b>	1,785 (48.0%)	391,371 (96.8%)	1,349 (41.5%)	383,839 (96.2%)	778,344
<b>Fair</b>	1,168 (31.4%)	10,758 (2.7%)	1,077 (33.2%)	13,035 (3.3%)	26,038
<b>Bad or very bad</b>	764 (20.6%)	2,116 (0.5%)	822 (25.3%)	2,249 (0.5%)	5,951

**Figure 23: General health ratings in the population without intellectual disabilities with and without physical disabilities**

Of the 6,360 males and 9,618 females without intellectual disabilities with mental health conditions, 2,992 males (47.0%) and 4,186 females (43.5%) reported 'poor' health (Table 42, Figure 24).

**Table 42: General health ratings in the population without intellectual disabilities with and without mental health conditions**

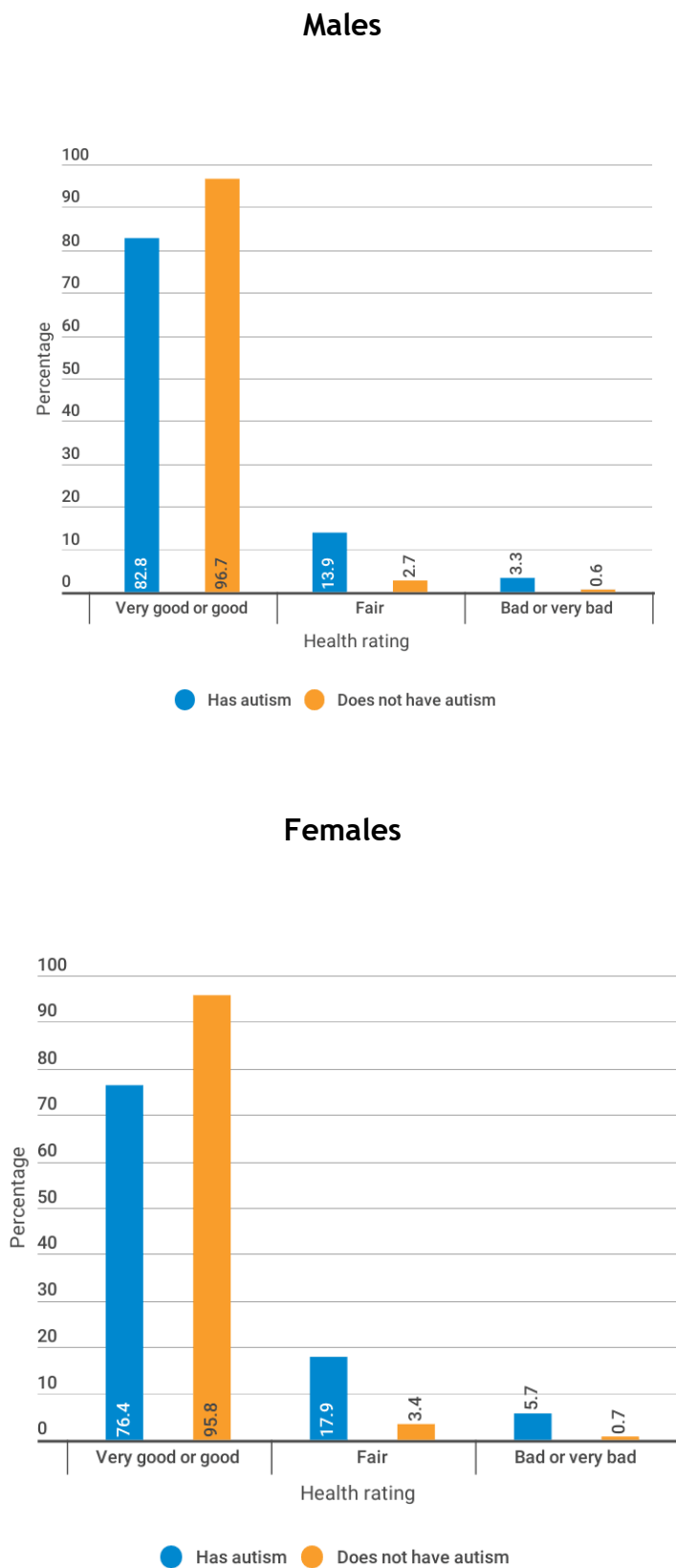
<b>General health</b>	<b>Males without ID with MH aged 13-24</b> n = 6,360	<b>Males without ID with no MH aged 13-24</b> n = 401,602	<b>Females without ID with MH aged 13-24</b> n = 9,618	<b>Females without ID with no MH aged 13-24</b> n = 392,753	<b>Total</b>
<b>Very good or good</b>	3,368 (52.9%)	389,788 (97.0%)	5,432 (56.5%)	379,756 (96.7%)	778,344
<b>Fair</b>	1,978 (31.1%)	9,948 (2.5%)	3,006 (31.3%)	11,106 (2.8%)	26,038
<b>Bad or very bad</b>	1,014 (15.9%)	1,866 (0.5%)	1,180 (12.3%)	1,891 (0.5%)	5,951

**Figure 34: General health ratings in the population without intellectual disabilities with and without mental health conditions**

Of the 8,651 males and 1,967 females without intellectual disabilities and with autism, 1,486 males (17.1%) and 464 females (23.6%) reported 'poor' health (Table 43, Figure 25).

**Table 43: General health ratings in the population without intellectual disabilities with and without autism**

<b>General health</b>	<b>Males without ID with ASD aged 13-24</b> n = 8,651	<b>Males without ID with no ASD aged 13-24</b> n = 399,311	<b>Females without ID with ASD aged 13-24</b> n = 1,967	<b>Females without ID with no ASD aged 13-24</b> n = 400,404	<b>Total</b>
<b>Very good or good</b>	7,165 (82.8%)	385,991 (96.7%)	1,503 (76.4%)	383,685 (95.8%)	778,344
<b>Fair</b>	1,204 (13.9%)	10,722 (2.7%)	352 (17.9%)	13,760 (3.4%)	26,038
<b>Bad or very bad</b>	282 (3.3%)	2,598 (0.6%)	112 (5.7%)	2,959 (0.7%)	5,951

**Figure 25: General health ratings in the population without intellectual disabilities with and without autism**

## 29.3 Geographic variables

Of the 160,844 males without intellectual disabilities who lived in the most deprived (SIMD quintiles 1-2) areas of Scotland, 8,040 (4.9%) reported 'poor' health. Of the 247,118 males without intellectual disabilities who lived in the most affluent (SIMD quintiles 3-5) areas of Scotland, 6,766 (2.7%) reported 'poor health' (Table 44, Figure 26). Of the 145,979 females without intellectual disabilities who lived in the most deprived (SIMD quintiles 1-2) areas of Scotland, 9,604 (6.6%) reported 'poor' health. Of the 237,534 females without intellectual disabilities who lived in the most affluent (SIMD quintiles 3-5) areas of Scotland, 7,579 (3.2%) reported 'poor' health (Table 45, Figure 26).

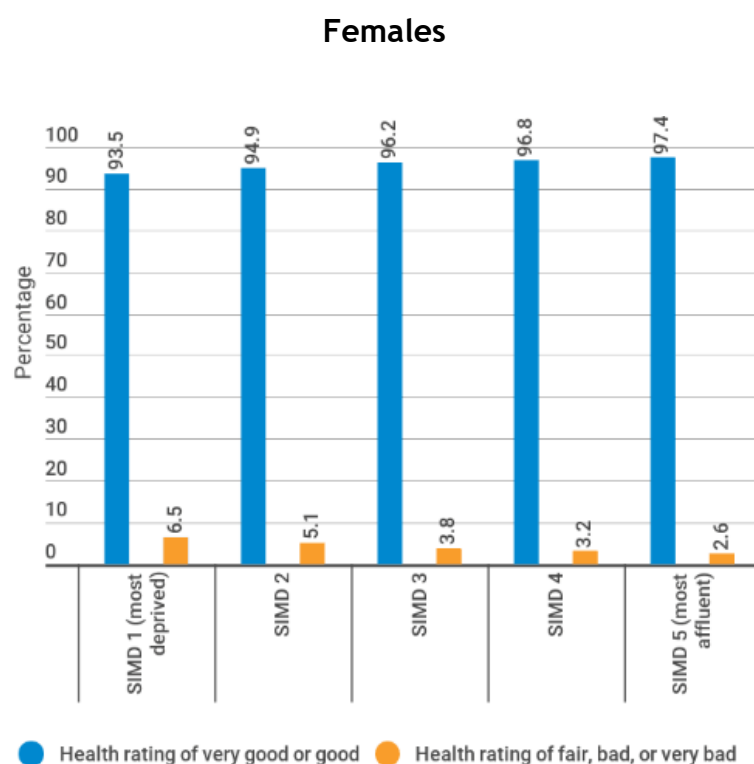
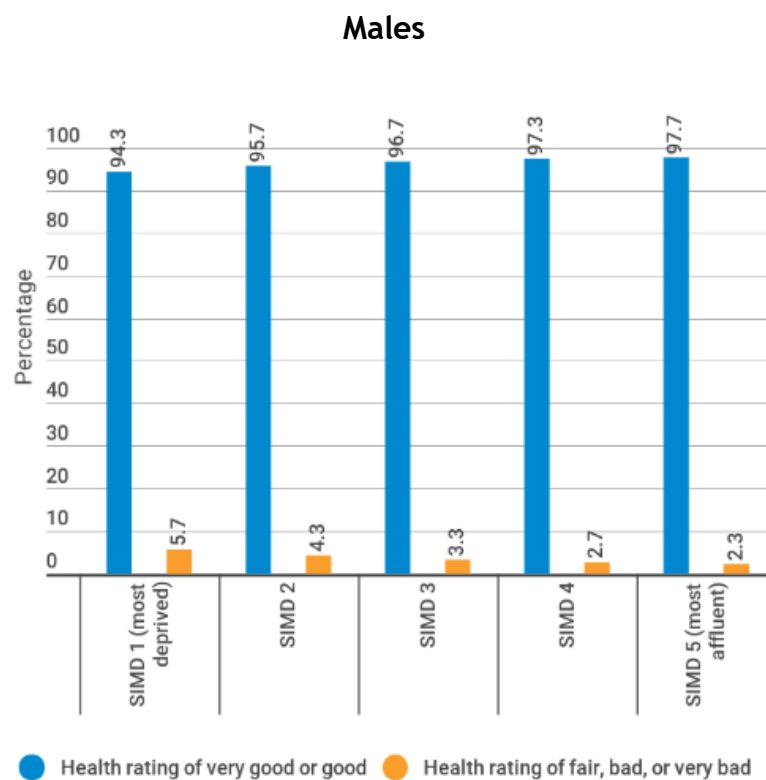
**Table 44: General health ratings in the male population without intellectual disabilities living in the most deprived (SIMD 1) and the most affluent (SIMD 5) areas of Scotland**

General health	Males without ID aged 13-24 SIMD 1 n = 80,600	Males without ID aged 13-24 SIMD 2 n = 80,244	Males without ID aged 13-24 SIMD 3 n = 81,364	Males without ID aged 13-24 SIMD 4 n = 78,404	Males without ID aged 13-24 SIMD 5 n = 87,350	Total
Very good or good	75,974 (94.3%)	76,830 (95.7%)	78,702 (96.7%)	76,284 (97.3%)	85,366 (97.7%)	393,156
Fair, bad or very bad	4,626 (5.7%)	3,414 (4.3%)	2,662 (3.3%)	2,120 (2.7%)	1,984 (2.3%)	14,806

**Table 45: General health ratings in the female population without intellectual disabilities living in the most deprived (SIMD 1) and the most affluent (SIMD 5) areas of Scotland**

General health	Females without ID aged 13-24 SIMD 1 n = 84,278	Females without ID aged 13-24 SIMD 2 n = 80,519	Females without ID aged 13-24 SIMD 3 n = 79,323	Females without ID aged 13-24 SIMD 4 n = 74,884	Females without ID aged 13-24 SIMD 5 n = 83,367	Total
Very good or good	78,788 (93.5%)	76,405 (94.9%)	76,271 (96.2%)	72,483 (96.8%)	81,241 (97.4%)	385,188
Fair, bad or very bad	5,490 (6.5%)	4,114 (5.1%)	3,052 (3.8%)	2,401 (3.2%)	2,126 (2.6%)	17,183

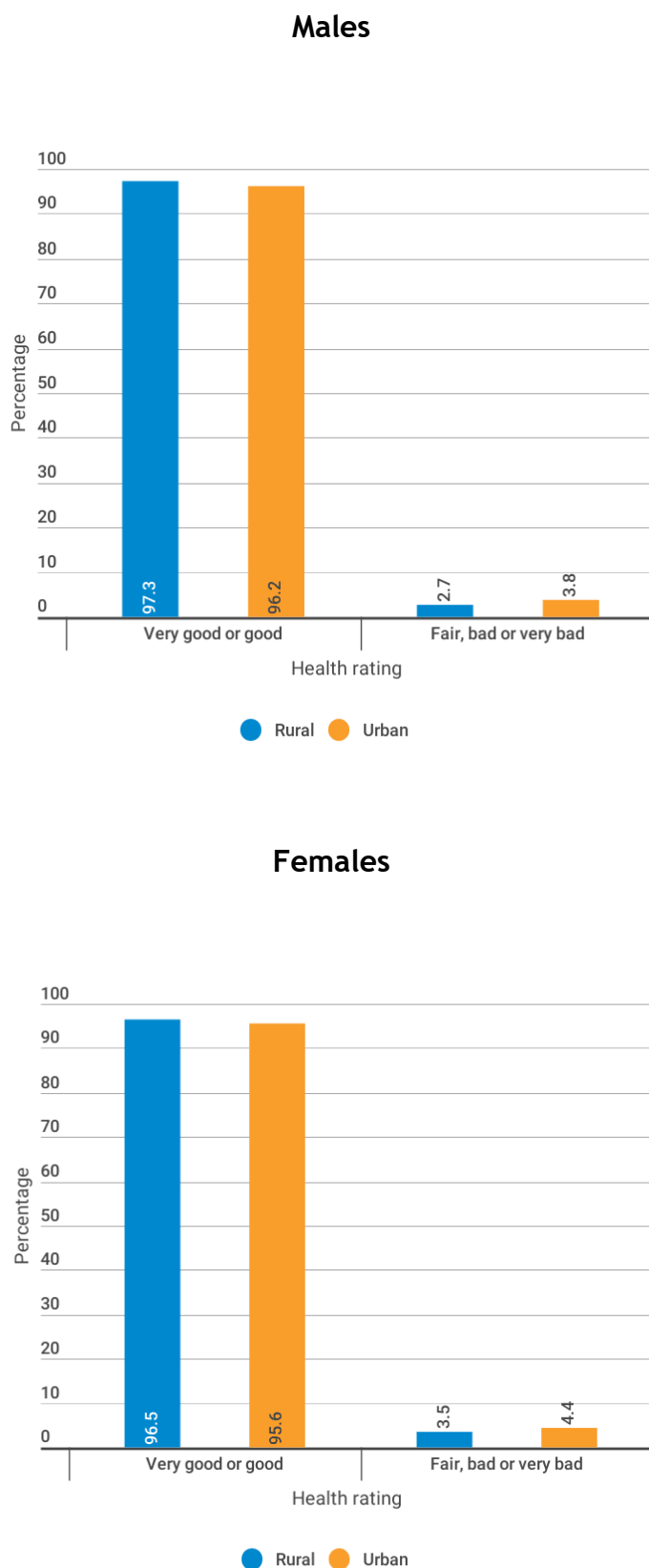


**Figure 46: General health ratings in the population without intellectual disabilities living in the most deprived and the most affluent areas of Scotland**

Of the 62,983 males and 57,409 females without intellectual disabilities who reported living in rural areas, 1,714 males (2.7%) and 2,005 females (3.5%) reported 'poor' health (Table 46, Figure 27). Of the 344,979 males and 344,962 females without intellectual disabilities who reported living in urban areas, 13,092 males (3.8%) and 15,178 females (4.4%) reported 'poor' health (Table 46, Figure 27).

**Table 46: General health ratings in the population without intellectual disabilities living in rural areas and in urban areas**

<b>General health</b>	<b>Males without ID aged 13-24 Rural</b> n = 62,983	<b>Males without ID aged 13-24 Urban</b> n = 344,979	<b>Females without ID aged 13-24 Rural</b> n = 57,409	<b>Females without ID aged 13-24 Urban</b> n = 344,962	<b>Total</b>
<b>Very good or good</b>	61,269 (97.3%)	331,887 (96.2%)	55,404 (96.5%)	329,784 (95.6%)	778,344
<b>Fair, bad or very bad</b>	1,714 (2.7%)	13,092 (3.8%)	2,005 (3.5%)	15,178 (4.4%)	31,989

**Figure 27: General health ratings in the population without intellectual disabilities living in urban areas and rural areas**

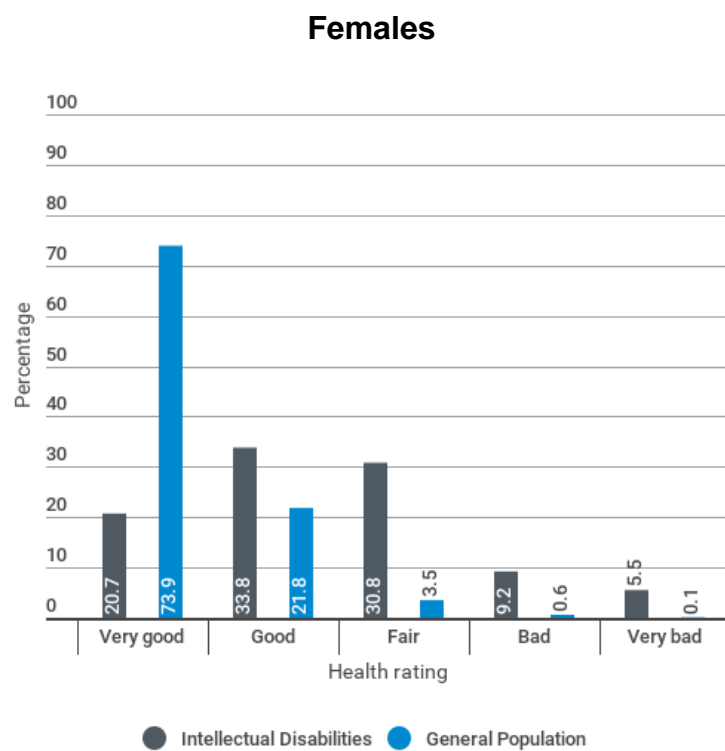
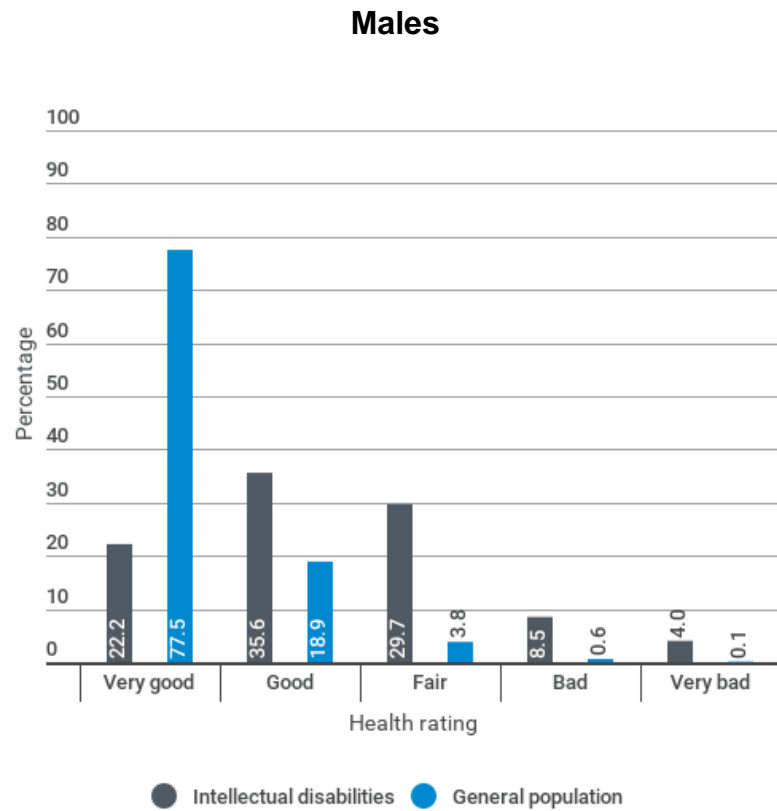
## 30 Descriptive statistics: whole population

### 30.1 General health

Across the whole population, 42.2% of males and 45.5% of females with intellectual disabilities reported 'poor health' (fair, bad or very bad health), compared with 4.5% of males and 4.2% of females without intellectual disabilities (Table 47; Figure 28).

**Table 47: General health ratings in the whole population**

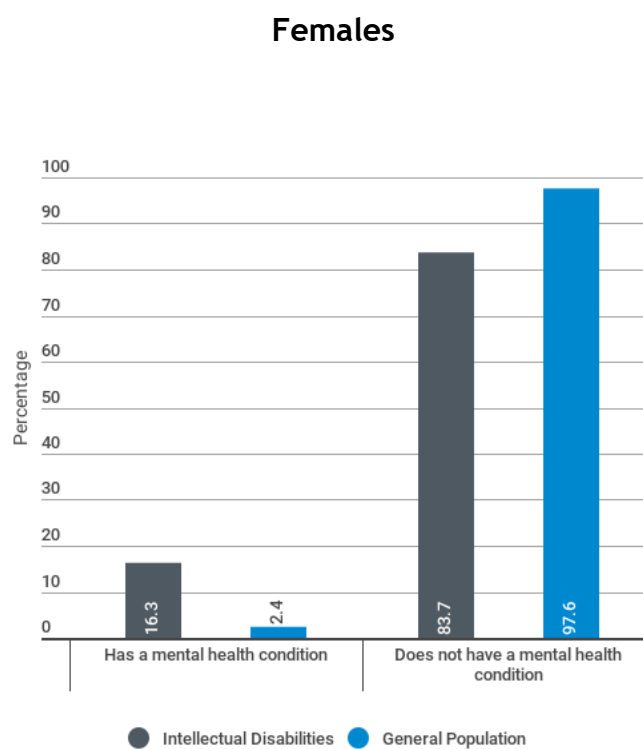
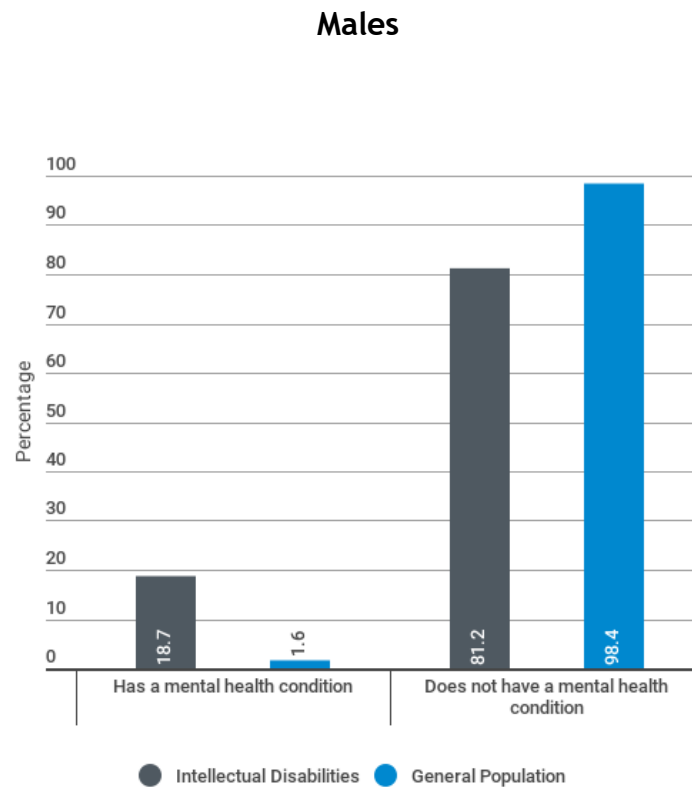
<b>General Health</b>	<b>Males with ID aged 13-24</b> n = 3,396	<b>Females with ID aged 13-24</b> n = 2,160	<b>Males without ID aged 13-24</b> n = 407,962	<b>Females without ID aged 13-24</b> n = 402,371	<b>Total</b>
<b>Very good</b>	753 (22.2%)	447 (20.7%)	316,015 (77.5%)	297,305 (73.9%)	614,520
<b>Good</b>	1,210 (35.6%)	730 (33.8%)	77,151 (18.9%)	87,883 (21.8%)	166,964
<b>Fair</b>	1,008 (29.7%)	665 (20.8%)	11,926 (3.8%)	14,112 (3.5%)	27,711
<b>Bad</b>	287 (8.5%)	199 (9.2%)	2,294 (0.6%)	2,564 (0.6%)	5,344
<b>Very bad</b>	138 (4.0%)	119 (5.5%)	586 (0.1%)	507 (0.1%)	1,350

**Figure 58: General health ratings in the whole population**

Across the whole population, 18.7% of males and 16.3% of females with intellectual disabilities reported the presence of a mental health condition, compared to 1.6% of males and 2.4% of females without intellectual disabilities (Table 48; Figure 29).

**Table 48: Presence of mental health conditions in the whole population**

	<b>Males with ID aged 13-24</b> n = 3,396	<b>Females with ID aged 13-24</b> n = 2,160	<b>Males without ID aged 13-24</b> n = 407,962	<b>Females without ID aged 13-24</b> n = 402,371	<b>Total</b>
<b>Has a mental health condition</b>	636 (18.7%)	352 (16.3%)	6,360 (1.6%)	9,618 (2.4%)	16,966
<b>Does not have a mental health condition</b>	2,760 (81.2%)	1,808 (83.7%)	401,602 (98.4%)	392,753 (97.6%)	798,923

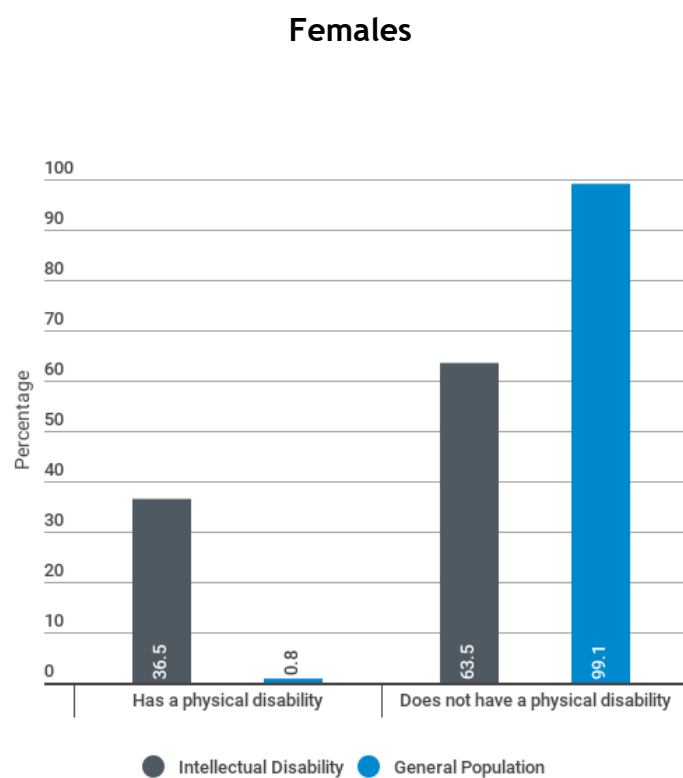
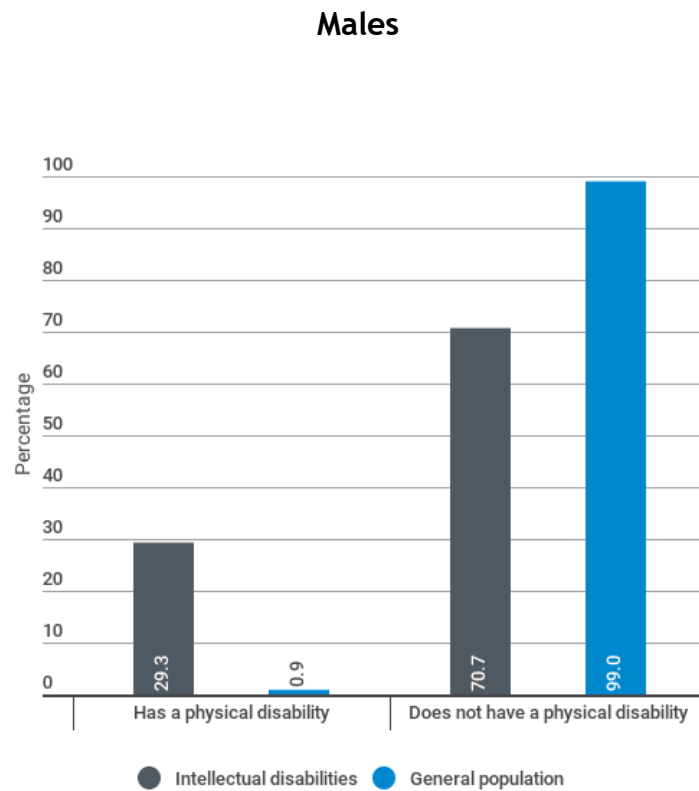
**Figure 69: Mental health conditions in the whole population**

Across the whole population, 29.3% of males and 36.5% of females with intellectual disabilities reported the presence of a physical disability, compared to 0.9% of males and 0.8% of females without intellectual disabilities (Table 49; Figure 30).

**Table 49: Presence of physical disabilities in the whole population**

	<b>Males with ID aged 13-24</b> n = 3,396	<b>Females with ID aged 13-24</b> n = 2,160	<b>Males without ID aged 13-24</b> n = 407,962	<b>Females without ID aged 13-24</b> n = 402,371	<b>Total</b>
<b>Has a physical disability</b>	994 (29.3%)	789 (36.5%)	3,717 (0.9%)	3,248 (0.8%)	8,748
<b>Does not have a physical disability</b>	2,402 (70.7%)	1,371 (63.5%)	404,245 (99.0%)	399,123 (99.1%)	807,141

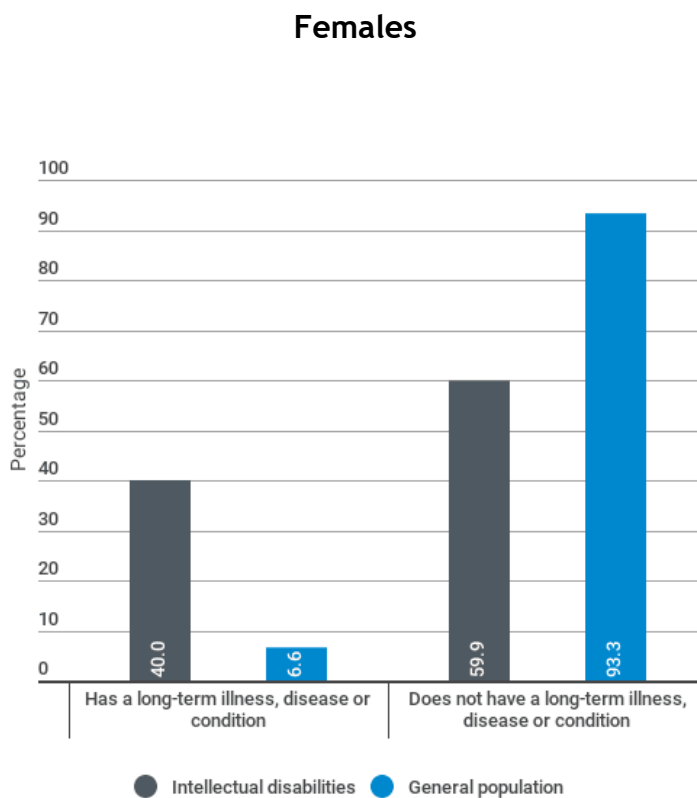
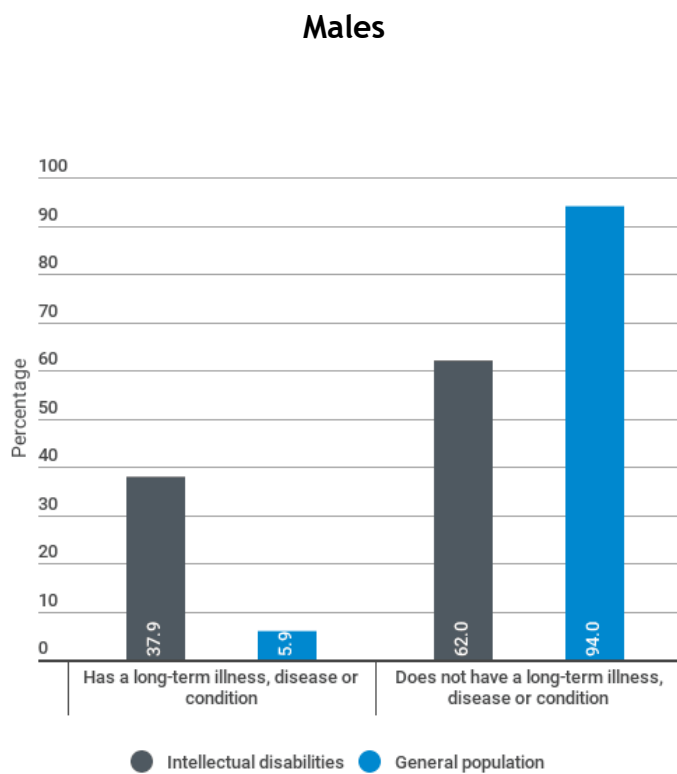


**Figure 30: Physical disabilities in the whole population**

Across the whole population, 37.9% of males and 40.0% of females with intellectual disabilities reported the presence of a long-term illness, disease or condition, compared to 5.9% of males and 6.6% of females without intellectual disabilities (Table 50; Figure 31).

**Table 50: Presence of long-term illnesses, diseases or conditions in the whole population**

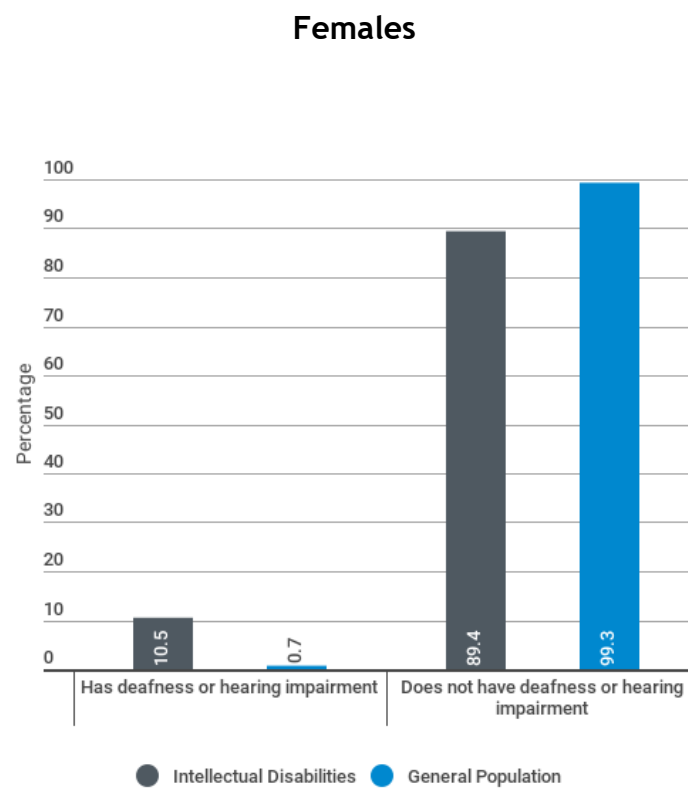
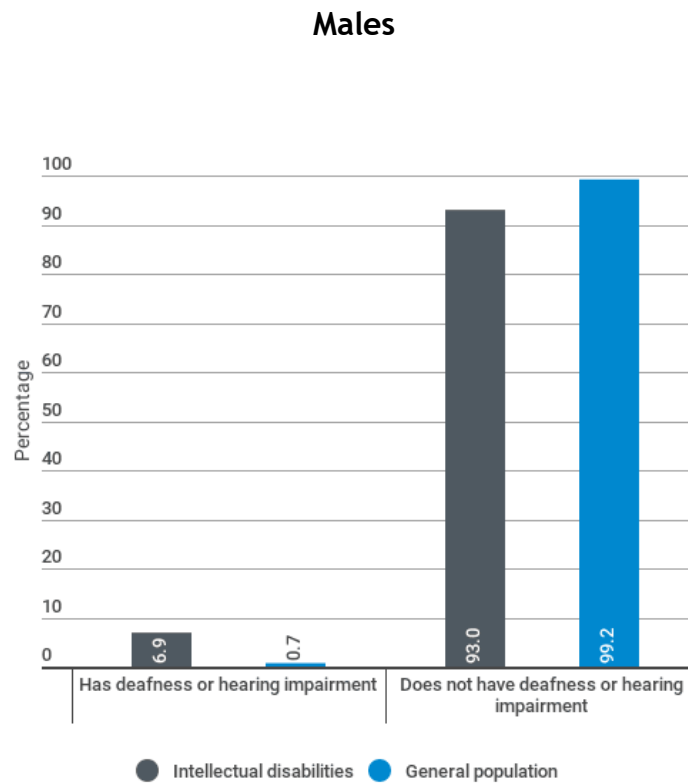
	<b>Males with ID aged 13-24</b> n = 3,396	<b>Females with ID aged 13-24</b> n = 2,160	<b>Males without ID aged 13-24</b> n = 407,962	<b>Females without ID aged 13-24</b> n = 402,371	<b>Total</b>
<b>Has a long-term illness, disease or condition</b>	1,288 (37.9%)	866 (40.0%)	24,301 (5.9%)	26,705 (6.6%)	53,160
<b>Does not have a long-term illness, disease or condition</b>	2,108 (62.0%)	1,294 (59.9%)	383,661 (94.0%)	375,666 (93.3%)	762,729

**Figure 71: Long-term illnesses, diseases or conditions in the whole population**

Across the whole population, 6.9% of males and 10.5% of females with intellectual disabilities reported the presence of deafness or a hearing impairment, compared to 0.7% of males and 0.7% of females without intellectual disabilities (Table 51; Figure 32).

**Table 51: Presence of deafness or hearing impairment in the whole population**

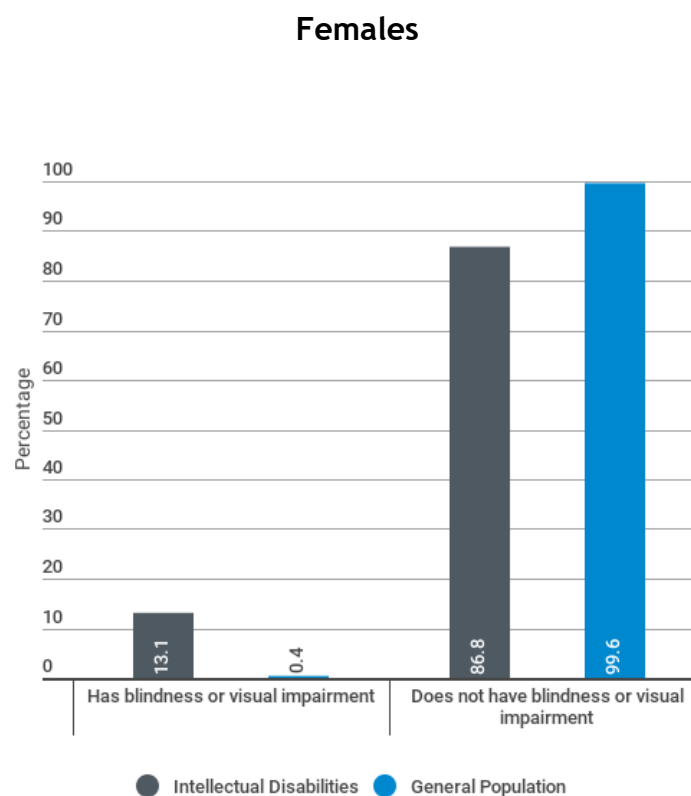
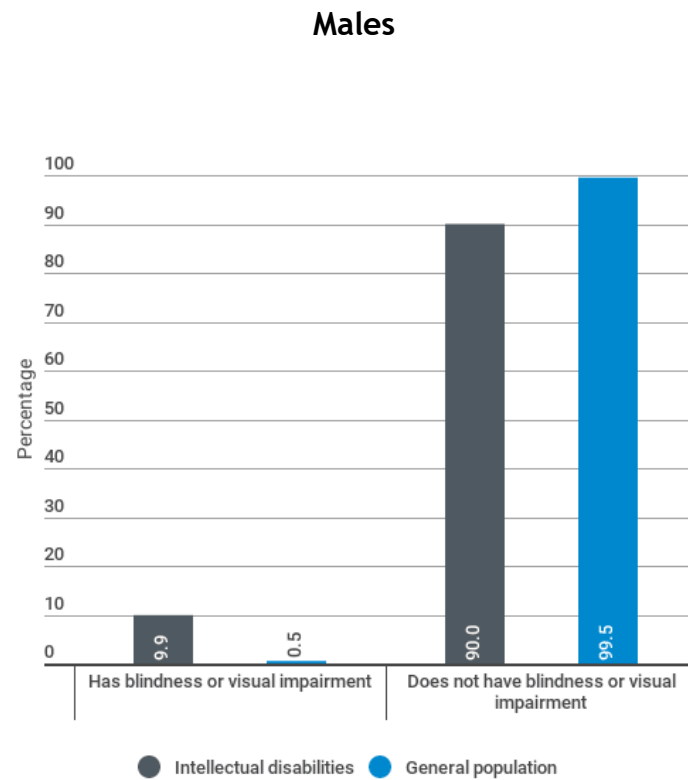
	<b>Males with ID aged 13-24</b> n = 3,396	<b>Females with ID aged 13-24</b> n = 2,160	<b>Males without ID aged 13-24</b> n = 407,962	<b>Females without ID aged 13-24</b> n = 402,371	<b>Total</b>
<b>Has deafness or hearing impairment</b>	237 (6.9%)	228 (10.5%)	3,234 (0.7%)	2,901 (0.7%)	6,600
<b>Does not have deafness or hearing impairment</b>	3,159 (93.0%)	1,932 (89.4%)	404,728 (99.2%)	399,470 (99.3%)	809,289

**Figure 82: Deafness or hearing impairment in the whole population**

Across the whole population, 9.9% of males and 13.1% of females with intellectual disabilities reported the presence of blindness or a visual impairment compared to 0.5% of males and 0.4% of females without intellectual disabilities (Table 52; Figure 33).

**Table 52: Presence of blindness or visual impairment in the whole population**

	<b>Males with ID aged 13-24</b> n = 3,396	<b>Females with ID aged 13-24</b> n = 2,160	<b>Males without ID aged 13-24</b> n = 407,962	<b>Females without ID aged 13-24</b> n = 402,371	<b>Total</b>
<b>Has blindness or visual impairment</b>	339 (9.9%)	284 (13.1%)	2,226 (0.5%)	1,725 (0.4%)	4,574
<b>Does not have blindness or visual impairment</b>	3,057 (90.0%)	1,876 (86.8%)	405,736 (99.5%)	400,646 (99.6%)	811,315

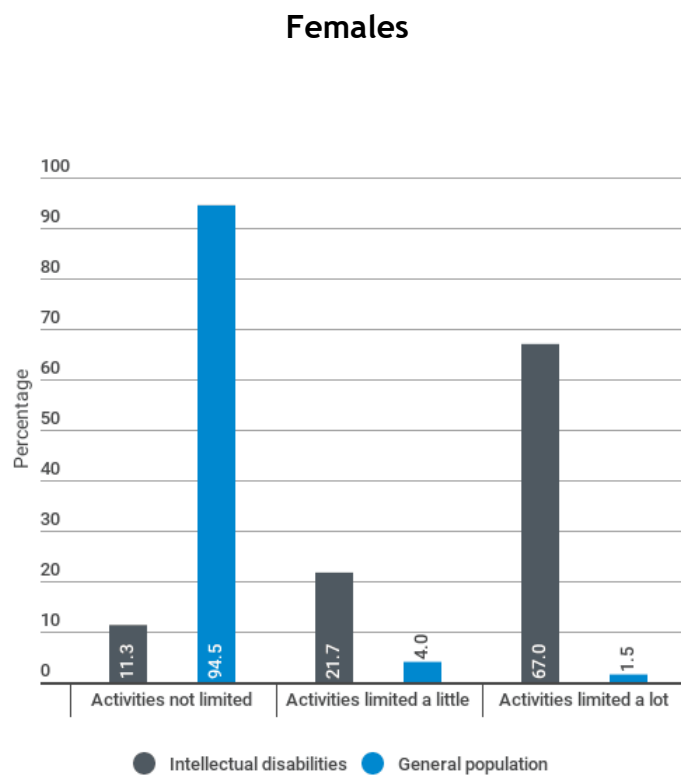
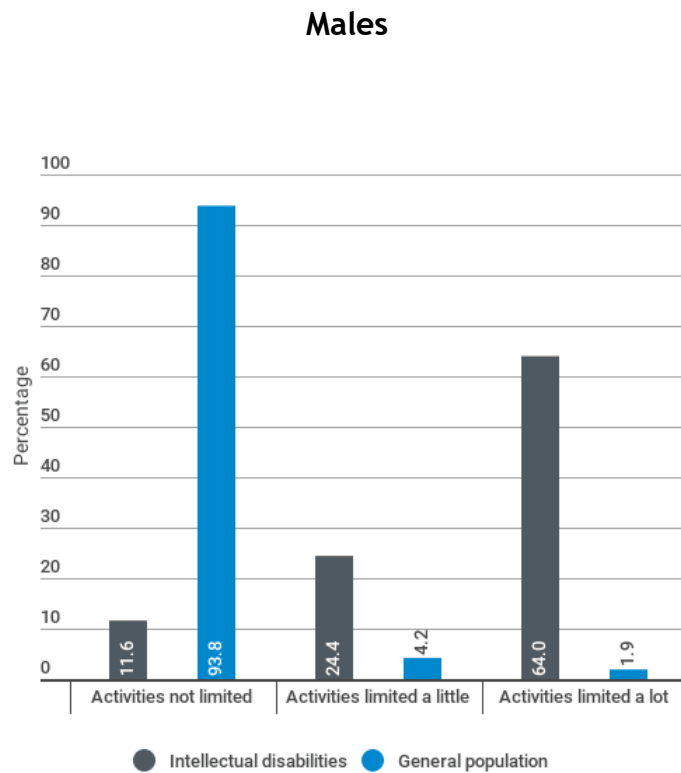
**Figure 93: Blindness or visual impairment in the whole population**

Across the whole population, 88.4% of males and 88.7% of females with intellectual disabilities reported their day to day activities to be limited 'a little' or 'a lot' due to their health conditions, compared to 6.1% of males and 5.5% of females without intellectual disabilities (Table 53; Figure 34).

**Table 53: Health-related activity limitations in the whole population**

	<b>Males with ID aged 13-24</b> n = 3,396	<b>Females with ID aged 13-24</b> n = 2,160	<b>Males without ID aged 13-24</b> n = 407,962	<b>Females without ID aged 13-24</b> n = 402,371	<b>Total</b>
<b>Activities not limited</b>	394 (11.6%)	244 (11.3%)	382,858 (93.8%)	380,246 (94.5%)	763,742
<b>Activities limited a little</b>	828 (24.4%)	468 (21.7%)	17,014 (4.2%)	16,134 (4.0%)	34,444
<b>Activities limited a lot</b>	2,174 (64.0%)	1,448 (67.0%)	8,090 (1.9%)	5,991 (1.5%)	17,703

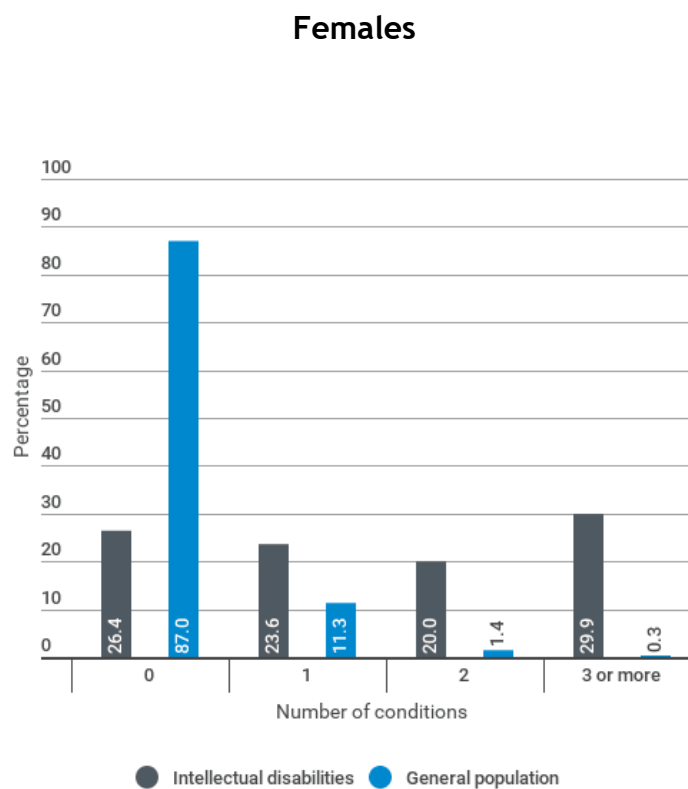
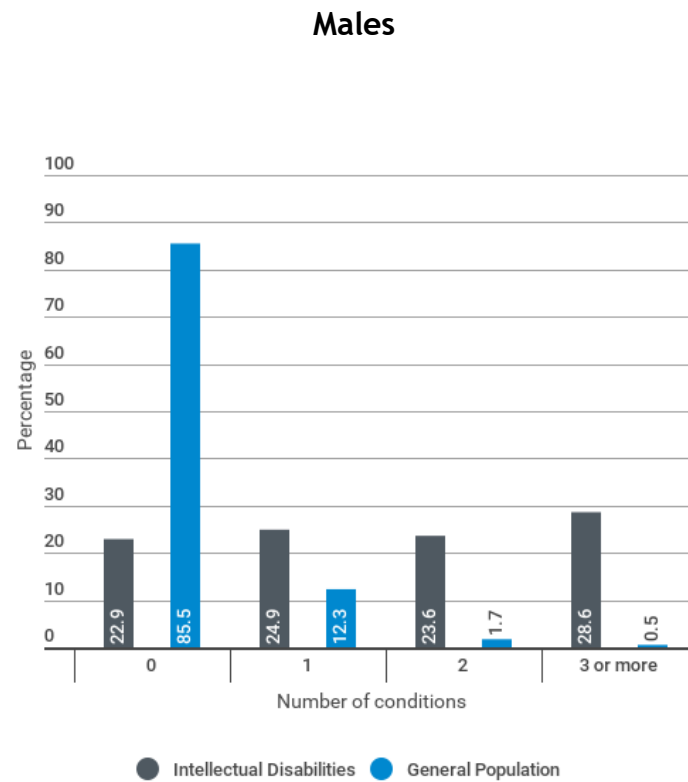


**Figure 104: Health-related activity limitations in the whole population**

Across the whole population, 85.5% of males and 87.0% of females without intellectual disabilities reported no health conditions. 77.1% of males and 73.5% of females with intellectual disabilities reported at least one health condition (Table 54; Figure 35).

**Table 54: Number of conditions in the whole population**

<b>Number of conditions</b>	<b>Males with ID aged 13-24</b> n = 3,396	<b>Females with ID aged 13-24</b> n = 2,160	<b>Males without ID aged 13-24</b> n = 407,962	<b>Females without ID aged 13-24</b> n = 402,371	<b>Total</b>
<b>0</b>	778 (22.9%)	570 (26.4%)	348,840 (85.5%)	350,228 (87.0%)	700,416
<b>1</b>	845 (24.9%)	510 (23.6%)	50,347 (12.3%)	45,425 (11.3%)	97,127
<b>2</b>	802 (23.6%)	433 (20.0%)	6,952 (1.7%)	5,478 (1.4%)	13,665
<b>3 or more</b>	971 (28.6%)	647 (29.9%)	1,823 (0.5%)	1,240 (0.3%)	4,681

**Figure 115: Number of conditions in the whole population**

## 31 Univariate analyses: whole population

### 31.1 'Poor' general health

A chi-square test of association between ability and a report of 'poor' health in the whole population revealed a significant association:  $\chi^2 (1) = 21356.008$ ,  $p < 0.001$ . Individuals with intellectual disabilities were more likely to report 'poor' health than were those without intellectual disabilities (OR 18.721, 95% CI 17.734 – 19.764).

A chi-square test of association between age group and a report of 'poor' health in the whole population revealed a significant association:  $\chi^2 (1) = 1806.431$ ,  $p < 0.001$ .

Individuals aged 19-24 years were more likely to report 'poor' health than were those aged 13-18 years (OR 1.625, 95% CI 1.588 – 1.662).

A chi-square test of association between gender and a report of 'poor' health in the whole population revealed a significant association:  $\chi^2 (1) = 150.426$ ,  $p < 0.001$ . Females were more likely to report 'poor' health than were males (OR 1.145, 95% CI 1.120 – 1.170).

### 31.2 Mental health conditions

A chi square test of association between ability and the presence of a mental health condition in the whole population revealed a significant association:  $\chi^2 (1) = 6774.541$ ,  $p < 0.001$ . Individuals with intellectual disabilities were more likely to have a mental health condition than were individuals without intellectual disabilities (OR 10.753, 95% CI 10.021 – 11.539).

A chi square test of association between age group and the presence of a mental health condition in the whole population revealed a significant association:  $\chi^2 (1) = 3141.203$ ,  $p < 0.001$ . Individuals aged 19-24 years were more likely to have a mental health condition than were individuals aged 13-18 years (OR 2.624, 95% CI 2.534 – 2.718).

A chi square test of association between gender and the presence of a mental health condition in the whole population revealed a significant association:  $\chi^2 (1) = 724.359$ ,  $p < 0.001$ . Females were more likely to have a mental health condition than were males (OR 1.546, 95% CI 1.498 – 1.597).

### 31.3 Physical disabilities

A chi square test of association between ability and the presence of a physical disability in the whole population revealed a significant association:  $\chi^2(1) = 50745.289$ ,  $p < 0.001$ . Individuals with intellectual disabilities were more likely to have a physical disability than were individuals without intellectual disabilities (OR 54.508, 95% CI 51.279 – 57.940).

A chi square test of association between age group and the presence of a physical disability in the whole population revealed a significant association:  $\chi^2(1) = 12.615$ ,  $p < 0.001$ . Individuals aged 19-24 years were more likely to have a physical disability than were individuals aged 13-18 years (OR 1.080, 95% CI 1.035 – 1.127).

A chi square test of association between gender and the presence of a physical disability in the whole population revealed a significant association:  $\chi^2(1) = 41.712$ ,  $p < 0.001$ . Males were more likely to have a physical disability than were females (OR 1.149, 95% CI 1.102 – 1.199).

### 31.4 Long-term illnesses

A chi square test of association between ability and the presence of a long-term illness, disease or condition in the whole population revealed a significant association:  $\chi^2(1) = 953.999$ ,  $p < 0.001$ . Individuals with intellectual disabilities were more likely to have a long-term illness, disease or condition than were individuals without intellectual disabilities (OR 9.426, 95% CI 8.924 – 9.956).

A chi square test of association between age group and the presence of a long-term illness, disease or condition in the whole population revealed a significant association:  $\chi^2(1) = 35.401$ ,  $p < 0.001$ . Individuals aged 13-18 years were more likely to have a long-term illness, disease or condition than were individuals aged 19-24 years (OR 1.055, 95% CI 1.036 – 1.074).

A chi square test of association between gender and the presence of a long-term illness, disease or condition in the whole population revealed a significant association:  $\chi^2(1) = 118.517$ ,  $p < 0.001$ . Females were more likely to have a long-term illness, disease or condition than were males (OR 1.103, 95% CI 1.083 – 1.122).

## 31.5 Deafness/hearing impairment

A chi square test of association between ability and the presence of deafness or a hearing impairment in the whole population revealed a significant association:  $\chi^2(1) = 3985.048$ ,  $p < 0.001$ . Individuals with intellectual disabilities were more likely to have deafness or a hearing impairment than were individuals without intellectual disabilities (OR 11.973, 95% CI 10.853 – 13.209).

A chi square test of association between age group and the presence of deafness or a hearing impairment in the whole population revealed a significant association:  $\chi^2(1) = 56.079$ ,  $p < 0.001$ . Individuals aged 19-24 years were more likely to have deafness or a hearing impairment than were individuals aged 13-18 years (OR 1.206, 95% CI 1.148 – 1.267).

A chi square test of association between gender and the presence of deafness or a hearing impairment in the whole population revealed a significant association:  $\chi^2(1) = 12.563$ ,  $p < 0.001$ . Males were more likely to have deafness or a hearing impairment than were females (OR 1.092, 95% CI 1.040 – 1.146).

## 31.6 Blindness/visual impairment

A chi square test of association between ability and the presence of blindness or a visual impairment in the whole population revealed a significant association:  $\chi^2(1) = 11386.974$ ,  $p < 0.001$ . Individuals with intellectual disabilities were more likely to have blindness or a visual impairment than were individuals without intellectual disabilities (OR 25.776, 95% CI 23.581 – 28.175).

A chi square test of association between age group and the presence of blindness or a visual impairment in the whole population revealed a significant association:  $\chi^2(1) = 20.974$ ,  $p < 0.001$ . Individuals aged 19-24 years were more likely to have blindness or a visual impairment than were individuals aged 13-18 years (OR 1.147, 95% CI 1.082 – 1.216).

A chi square test of association between gender and the presence of blindness or a visual impairment in the whole population revealed a significant association:  $\chi^2(1) = 58.936$ ,  $p <$

0.001. Males were more likely to have blindness or a visual impairment than were females (OR 1.257, 95% CI 1.186 – 1.333).

## 31.7 Health-related activity limitations

A chi square test of association between ability and the presence of health-related activity limitations in the whole population revealed a significant association:  $\chi^2(1) = 63062.596$ ,  $p < 0.001$ . Individuals with intellectual disabilities were more likely to report that their activities were limited 'a little' or 'a lot' than were individuals without intellectual disabilities (OR 124.550, 95% CI 114.630 – 135.328).

A chi square test of association between age group and the presence of health-related activity limitations in the whole population revealed a significant association:  $\chi^2(1) = 65.023$ ,  $p < 0.001$ . Individuals aged 13-18 years were more likely to report that their activities were limited 'a little' or 'a lot' than were individuals aged 19-24 years (OR 1.076, 95% CI 1.057 – 1.095).

A chi square test of association between gender and the presence of health-related activity limitations in the whole population revealed a significant association:  $\chi^2(1) = 269.760$ ,  $p < 0.001$ . Males were more likely to report that their activities were limited 'a little' or 'a lot' than were females (OR 1.161, 95% CI 1.140 – 1.181).

## 31.8 Number of additional health conditions

A mann whitney  $U$  test to determine differences in the number of conditions reported between individuals with and without intellectual disabilities in the whole population showed a significant difference:  $U = 3781238254.000$ ,  $p < 0.001$ . Individuals with intellectual disabilities (mean rank = 683346.00) reported a higher number of conditions than individuals without intellectual disabilities (mean rank = 406056.72).

A mann whitney  $U$  test to determine differences in the number of conditions reported between individuals aged 13-18 years and 19-24 years in the whole population showed a significant difference:  $U = 83076020127.000$ ,  $p < 0.001$ . Individuals aged 19-24 years (mean rank = 408677.95) reported a higher number of conditions than individuals aged 13-18 years (mean rank = 406900.26).

A mann whitney *U* test to determine differences in the number of conditions reported between males and females in the whole population showed a significant difference:  $U = 84683259162.000$ ,  $p < 0.001$ . Males (mean rank = 411542.18) reported a higher number of conditions than females (mean rank = 404287.12).

## 32 Independent predictors of health outcomes: whole population

### 32.1 Multicollinearity between predictor variables

A series of enter binary logistic regressions was used to ascertain the independent effects of ability, age group and gender on the health outcomes under investigation in the whole population. Tests to see if the data met the assumption of collinearity indicated that multicollinearity was not a concern (Table 55) (Menard, 1995; Myers, 1990).

**Table 55: Collinearity statistics for ability, age group, and gender in the whole population**

Variable	Tolerance	VIF
Ability	1.000	1.000
Age group	1.00	1.000
Gender	0.999	1.001

### 32.2 'Poor' general health

All three predictor variables were found to be significant, with having intellectual disabilities, being aged 19-24 years, and being female predicting having 'poor' health (Table 56). The model explained 42.0% (Nagelkerke  $R^2$ ) of the variance in 'poor' health and correctly classified 95.8% of cases.

**Table 56: Independent predictors of poor health in the whole population**

Characteristic		Odds ratio	95% confidence interval of odds
Ability	No intellectual disabilities (reference)	-	-
	Intellectual disabilities	19.952	18.887 – 21.076
Age group	13-18 (reference)	-	-
	19-24	1.661	1.623 – 1.699
Gender	Male (reference)	-	-
	Female	1.175	1.149 – 1.201
Constant	-	0.028	-



## 32.3 Mental health conditions

All three predictor variables were found to be significant, with having intellectual disabilities, being aged 19-24 years, and being female predicting having a mental health condition (Table 57). The model explained 45.0% (Nagelkerke  $R^2$ ) of the variance in mental health conditions and correctly classified 97.9% of cases.

**Table 57: Independent predictors of having a mental health condition in the whole population**

Characteristic		Odds ratio	95% confidence interval of odds
Ability	No intellectual disabilities (reference)	-	-
	Intellectual disabilities	12.084	11.243 – 12.986
Age group	13-18 (reference)	-	-
	19-24	2.655	2.564 – 2.750
Gender	Male (reference)	-	-
	Female	1.484	1.439 – 1.531
Constant		0.009	-

## 32.4 Physical disabilities

All three predictor variables were found to be significant, with having intellectual disabilities, being aged 19-24 years and being male predicting having a physical disability (Table 58). The model explained 10.6% (Nagelkerke  $R^2$ ) of the variance in physical disabilities and correctly classified 98.9% of cases.

**Table 58: Independent predictors of having a physical disability in the whole population**

Characteristic		Odds ratio	95% confidence interval of odds
Ability	No intellectual disabilities (reference)	-	-
	Intellectual disabilities	54.463	51.226 – 57.905
Age group	13-18 (reference)	-	-
	19-24	1.122	1.015 – 1.108
Gender	Male (reference)	-	-
	Female	0.943	0.902 – 0.985
Constant		0.008	-

## 32.5 Long-term illnesses

All three predictor variables were found to be significant, with having intellectual disabilities, being aged 13-18 years and being female predicting having a long-term illness,

disease or condition (Table 59). The model explained 16.0% (Nagelkerke  $R^2$ ) of the variance in long-term illnesses, diseases and conditions and correctly classified 93.5% of cases.

**Table 59: Independent predictors of having a long-term illness, disease or condition in the whole population**

Characteristic		Odds ratio	95% confidence interval of odds
Ability	No intellectual disabilities (reference)	-	-
	Intellectual disabilities	9.620	9.106 – 10.162
Age group	13-18 (reference)	-	-
	19-24	0.951	0.935 – 0.968
Gender	Male (reference)	-	-
	Female	1.122	1.102 – 1.142
Constant		0.065	-

## 32.6 Deafness/hearing impairment

All three predictor variables were found to be significant, with having intellectual disabilities, being aged 19-24 years and being male predicting having deafness or a hearing impairment (Table 60). The model explained 20.0% (Nagelkerke  $R^2$ ) of the variance in deafness or hearing impairment and correctly classified 99.2% of cases.

**Table 60: Independent predictors of having deafness or hearing impairment in the whole population**

Characteristic		Odds ratio	95% confidence interval of odds
Ability	No intellectual disabilities (reference)	-	-
	Intellectual disabilities	11.989	10.866 – 13.229
Age group	13-18 (reference)	-	-
	19-24	1.220	1.162 – 1.282
Gender	Male (reference)	-	-
	Female	0.938	0.894 – 0.985
Constant		0.007	-

## 32.7 Blindness/visual impairment

All three predictor variables were found to be significant, with having intellectual disabilities, being male and being aged 19-24 years predicting having blindness or a visual impairment (Table 61). The model explained 51.0% (Nagelkerke  $R^2$ ) of the variance in blindness or visual impairment and correctly classified 99.4% of cases.

**Table 61: Independent predictors of having blindness or visual impairment in the whole population**

Characteristic		Odds ratio	95% confidence interval of odds
Ability	No intellectual disabilities (reference)	-	-
	Intellectual disabilities	25.777	23.574 – 28.185
Age group	13-18 (reference)	-	-
	19-24	1.179	1.111 – 1.251
Gender	Male (reference)	-	-
	Female	0.855	0.787 – 0.886
Constant	-	0.004	-

## 32.8 Health-related activity limitations

All three predictor variables were found to be significant, with having intellectual disabilities, being aged 13-18 years and being male predicting reporting activities to be limited 'a little' or 'a lot' (Table 62). The model explained 77.0% (Nagelkerke  $R^2$ ) of the variance in activity limitations and correctly classified 94.1% of cases.

**Table 62: Independent predictors of having health-related activity limitations in the whole population**

Characteristic		Odds ratio	95% confidence interval of odds
Ability	No intellectual disabilities (reference)	-	-
	Intellectual disabilities	124.979	115.030 – 135.789
Age group	13-18 (reference)	-	-
	19-24	0.940	0.923 – 0.957
Gender	Male (reference)	-	-
	Female	0.890	0.873 – 0.906
Constant	-	0.068	-

## 32.9 Comorbidities

Cumulative odds ordinal logistic regression was used to ascertain the independent effects of ability, age group and gender on the number of conditions reported in the whole population. A full likelihood ratio test comparing the fit of the proportional odds model to a model with varying location parameters suggested that the assumption of proportional odds was violated:  $X^2(6) = 1701.007$ ,  $p < 0.001$ . However, the full likelihood ratio test can identify violations of the assumption of proportional odds that do not exist when conducting analyses on large sample sizes (Laerd, 2016). A deeper investigation of the assumption of proportional odds was undertaken by running separate binary logistic

regressions on cumulative dichotomous dependent variables. The odds ratios were not similar for each variable in the equation so the assumption of proportional odds was not met (Table 63).

**Table 63: Odds ratios for variables in the equation**

Characteristic	Odds Ratio 1	Odds Ratio 2	Odds Ratio 3
Ability	-2.968	-3.985	-4.716
Age group	-0.045	-0.035	-0.014
Gender	-0.134	-0.270	-0.362

If the assumptions of ordinal logistic regression are violated, a multinomial logistic regression can be conducted (Laerd, 2016). A multinomial logistic regression was therefore used to ascertain the independent effects of ability, age group and gender on the number of conditions reported in the whole population. As indicated previously, multicollinearity was not a concern. Having intellectual disabilities, being aged 19-24 years and being male predicted having a higher number of conditions (Table 64). The model explained 34.0% (Nagelkerke  $R^2$ ) of the variance in the number of conditions and correctly classified 85.9% of cases.

**Table 64: Independent predictors of the number of conditions reported in the whole population**

N conditions	Characteristic		Odds ratio	95% confidence interval of odds
1	Ability	No intellectual disabilities (reference)	-	-
		Intellectual disabilities	7.295	6.763 – 7.869
	Age group	13-18 (reference)	-	-
		19-24	1.045	1.031 – 1.059
	Gender	Male (reference)	-	-
		Female	0.896	0.884 – 0.908
2	Ability	No intellectual disabilities (reference)	-	-
		Intellectual disabilities	50.784	46.912 – 54.976
	Age group	13-18 (reference)	-	-
		19-24	1.040	1.005 – 1.076
	Gender	Male (reference)	-	-
		Female	0.776	0.749 – 0.803
3 or more	Ability	No intellectual disabilities (reference)	-	-
		Intellectual disabilities	236.546	217.773 – 256.939
	Age group	13-18 (reference)	-	-
		19-24	0.999	0.939 – 1.062

	Gender	Male (reference)	-	-
		Female	0.782	0.735 – 0.832

Backwards stepwise binary logistic regression with likelihood ratio test ( $p < 0.05$ ) was used to ascertain the independent effects of ability, gender, the presence of a physical disability, the presence of a mental health condition, and the presence of autism on having 'poor' health in the whole population. Tests to see if the data met the assumption of collinearity indicated that multicollinearity may be of concern, since all of the tolerance statistics were below 0.1 (Table 65) (Menard, 1995).

**Table 65: Collinearity statistics for ability, gender, physical disability, mental health condition, and autism in the whole population**

Variable	Tolerance	VIF
Ability	0.893	
		1.120
Gender	0.994	1.006
Physical disability	0.934	1.071
Mental health condition	0.977	1.024
Autism	0.936	1.069

The following model should therefore be approached with caution as it may be unreliable (Field, 2013). All of the variables were found to be significant, with having intellectual disabilities, being female, having a mental health condition, having a physical disability and having autism independently predicting reporting 'poor' health (Table 66). The final model explained 19.5% (Nagelkerke  $R^2$ ) of the variance in 'poor' health and correctly classified 95.9% of cases.

**Table 66: Individual independent predictors of having poor health in the whole population**

Characteristic		Odds ratio	95% confidence interval of odds
Ability	No intellectual disabilities (reference)	-	-
	Intellectual disabilities	3.950	3.659 – 4.263
Gender	Male (reference)	-	-
	Female	1.177	1.149 – 1.205
Physical disability	No physical disability (reference)	-	-
	Physical disability	23.509	22.371 – 24.704
Mental health condition	No mental health condition (reference)	-	-
	Mental health condition	21.403	20.674 – 22.158
Autism	No autism (reference)	-	-
	Autism	2.784	2.619 – 2.959
Constant	-	0.026	-

## 32.10 Geographic variables

Backwards stepwise binary logistic regression with likelihood ratio test ( $p < 0.05$ ) was used to ascertain the independent effects of ability, gender, area deprivation and rurality on having 'poor' health in the whole population. Tests to see if the data met the assumption of multicollinearity indicated that multicollinearity may be of concern, since three of the tolerance statistics were below 0.1 (Table 67) (Menard, 1995).

**Table 67: Collinearity statistics for ability, gender, area deprivation and rurality in the whole population**

Variable	Tolerance	VIF
Ability	1.000	
		1.000
Gender	0.999	1.001
Area deprivation	0.955	1.047
Rurality	0.955	1.047

The following model should therefore be approached with caution as it may be unreliable (Field, 2013). All of the variables were found to be significant, with having intellectual disabilities, being female, living in the most deprived areas of Scotland and living in urban areas independently predicting reporting 'poor' health (Table 68). The final model explained 47.0% (Nagelkerke  $R^2$ ) of the variance in 'poor' health and correctly classified 95.8% of cases.

**Table 68: Geographical independent predictors of having poor health in the whole population**

Characteristic		Odds ratio	95% confidence interval of odds
Ability	No intellectual disabilities (reference)	-	-
	Intellectual disabilities	19.136	18.112 – 20.217
Gender	Male (reference)	-	-
	Female	1.172	1.147 – 1.198
Area deprivation	Least deprived (reference)	-	-
	Most deprived	1.821	1.781 – 1.863
Rurality	Rural (reference)	-	-
	Urban	1.098	1.060 – 1.136
Constant	-	0.026	-

## 33 Summary

### 33.1 Independent predictors of poorer health outcomes in young people with intellectual disabilities

Across the young population with intellectual disabilities:

- Being female predicted reporting 'poor' health
- Being aged 19-24 years and being male independently predicted having a mental health condition
- Being female predicted having a physical disability
- Being aged 13-18 years predicted having a long-term illness, disease or condition
- Being female predicted having deafness or a hearing impairment
- Being female predicted having blindness or a visual impairment
- Being aged 13-18 years predicted having health-related activity limitations
- Being aged 13-18 years predicted having a higher number of additional health conditions
- Having a physical disability and having a mental health condition independently predicted reporting 'poor' health
- Living in the most deprived areas predicted reporting 'poor' health.

The results of this secondary analysis therefore indicate that, within the population with intellectual disabilities, the transition from school may be associated with poorer mental health: those young people who had left school (aged 19-24 years) were more likely to have a mental health condition than were those who were still in school (aged 13-18 years). Contrary to the hypotheses, no other health outcomes were predicted by older age, and two health outcomes (having health-related activity limitations and having a higher number of additional conditions) were actually worse in the younger group.

Analyses were conducted adjusting for gender, revealing that being female independently predicted four health outcomes, including: reporting 'poor' general health; having a physical disability; and being deaf or blind. Additionally, those young people who had physical disabilities or mental health conditions were more likely to report 'poor' general health; as were those living in the most deprived areas of Scotland. These analyses indicate who among the population with intellectual disabilities may be most vulnerable to poorer health during transition.

### **33.2 Independent predictors of poorer health outcomes in the whole young population**

Across the whole young population:

- Having intellectual disabilities, being aged 19-24 years and being female independently predicted reporting 'poor' health
- Having intellectual disabilities, being aged 19-24 years and being female independently predicted having a mental health condition
- Having intellectual disabilities, being aged 19-24 years and being male independently predicted having a physical disability
- Having intellectual disabilities, being aged 13-18 years and being female independently predicted having a long-term illness, disease or condition
- Having intellectual disabilities, being aged 19-24 years and being male independently predicted having deafness or a hearing impairment
- Having intellectual disabilities, being aged 19-24 years and being male independently predicted having blindness or a visual impairment
- Having intellectual disabilities, being aged 13-18 years and being male independently predicted having health-related activity limitations
- Having intellectual disabilities, being aged 19-24 years and being male independently predicted having a higher number of additional health conditions



- Having intellectual disabilities, being female, having a mental health condition, having a physical disability and having autism independently predicted reporting 'poor' health
- Having intellectual disabilities, being female, living in the most deprived areas and living in urban environments independently predicted reporting 'poor' health.

Within the whole population, having intellectual disabilities predicted all of the health outcomes investigated, adjusting for age group and gender. These findings reveal a substantial health inequality between young people with and without intellectual disabilities, with young people with intellectual disabilities being between 9 and 125 times more likely to report the health conditions under investigation than those without intellectual disabilities.

## **Chapter 6: Results from the focus group, ethnography, and semi-structured interviews with young people with intellectual disabilities**

This chapter will present results from the focus group (used to inform the topic guide for the semi-structured interviews), ethnography and semi-structured interviews with young people with intellectual disabilities. Research questions 1a (*Does transition to adulthood affect health and wellbeing in young people with intellectual disabilities from the perspective of young people with intellectual disabilities?*) and 4 (*What supports [formal and informal] are helpful for young people with intellectual disabilities during transition?*) will be answered via the semi-structured interviews, utilising the voices of young people themselves, and ethnography, via observations of and interactions with young people. Research question 3 (*Is the impact of transition on health and wellbeing similar or different for young people with profound and multiple intellectual disabilities compared with young people with mild to moderate intellectual disabilities?*) will be answered via the ethnography, which included young people with a range of intellectual disabilities.

### **34 Pilot focus group**

#### **34.1 Participants**

Three young people with intellectual disabilities took part in the pilot focus group. They were two young men and one young woman, aged between 16 and 17 years.

#### **34.2 Results**

The following themes were identified from the focus group, which informed the topic guide for the semi-structured interviews and framed the focus of the ethnographic field diary.

##### **34.2.1 Health**

The young people in the focus group identified healthy eating and exercise as their primary concerns about health. All three participants in the focus group perceived themselves as not eating healthily.

### **34.2.2 Responsibility**

The participants demonstrated an awareness that their responsibilities would shift as they grew older. They anticipated taking responsibility for their own lives, for example by finding a job, and for more day-to-day aspects of their own care, such as making their own packed lunch.

### **34.2.3 Uncertainty**

The young people were concerned about the uncertainty that the future held for them. College was considered to be the most likely post-school option, but the participants emphasised that they were unsure of what college would be like, and thus struggled to decide whether or not it would be suitable for them.

### **34.2.4 Something to do**

The need for ‘something to do’ to replace the school routine was reiterated numerous times; young people described pressures, particularly from their parents, to find something to do when they left school.

### **34.2.5 Growing up**

Developmental issues associated with growing up, such as menstruation, were discussed in particular by the female participant, who worried, for example, about how she might cope with menstrual cramps in the workplace.

### **34.2.6 Friends**

Friends at school (who also had intellectual disabilities) were perceived as a primary source of support with whom to discuss the uncertainties of the transition from school; young people stressed that friends were important because they were ‘in the same boat’ as themselves and so could provide better support than parents or teachers. It was acknowledged that it might become harder to pursue friendships outside of school, and young people expressed sadness at leaving their group of friends upon school exit.

### **34.2.7 Decision-making**

Parents (primarily mothers) were identified as playing a key role in making decisions about young people's lives, for example whether to go to college or to look for a job after leaving school. Two out of the three participants explained that they did not always agree with their parents' decisions, and reported dissatisfaction at being pushed towards things (such as a job) that they did not want to do.

## **35 Ethnography: participants**

Approximately 30 young people with intellectual disabilities attended the Social Circle meetings. There was an even mix of males and females, and ages ranged from 16 to 21 years. In addition, five members of staff (one male and four females) who were employed by the voluntary organisation Share Scotland facilitated the group.

## **36 Interviews: participants**

Seventeen young people with intellectual disabilities participated in the semi-structured interviews. Recruitment was stopped at this number of participants as robust themes had been identified in the data. The young people were aged between 16 and 27 years (mean = 20.5 years). They had mild ( $n = 7$ ), moderate ( $n = 4$ ), and severe ( $n = 6$ ) intellectual disabilities, assessed on the Vineland-II scale. There were six young women and 11 young men. The interview transcript of one young woman (Sarah) was excluded from the analysis because her responses to the interview questions were unintelligible. At the time of the interview, 16 young people were still living in the family home, and one young man was living with his fiancée's parents. Five young people were still in school. Among those who had left school, five were at college; three were involved in various organised work and activity placements; two were in part-time employment, and two had no form of organised daytime activity at all. Among those young people who had left school, the average number of years since school exit was 4.8. Table 69 shows the participants' pseudonyms (chosen by the researcher), gender, ability, primary daytime activity, number of years since school exit and living situation at the time of the interview. Five of the young people who participated in an interview attended the Social Circle sessions, and so were also involved in the ethnographic work. All interviewees participated in conjunction with a parent/grandparent except for one young woman and two young men, whose parents declined to participate or were not invited due to estrangement.

**Table 69: Young people with intellectual disabilities who took part in the semi-structured interviews**

Young person	Age	Gender	Level of ID	Current activity	N years since leaving school	Living situation
Arnold	25	Male	Severe	Work placements	9	Home
Celia	17	Female	Severe	Nothing	1	Home
Daniel	16	Male	Severe	School	N/A	Home
Darren	27	Male	Mild	Part-time employment	9	With fiancée's parents
James	17	Male	Severe	School	N/A	Home
Jamie	17	Male	Severe	School	N/A	Home
Jeremy	25	Male	Mild	Work placements	10	Home
Josh	26	Male	Mild	Part-time employment	6	Home
Lara	25	Female	Mild	College	10	Home
Louis	21	Male	Moderate	College	5	Home
Mike	21	Male	Mild	College	5	Home
Rosie	21	Female	Mild	Nothing	4	Home
Sam	16	Male	Moderate	School	N/A	Home
Sally	21	Female	Mild	College	5	Home
Sarah	19	Female	Severe	Work placements	2	Home
Tim	19	Male	Moderate	College	2	Home
Zena	16	Female	Moderate	College	N/A	Home

### 36.1 SDQ and EQ-5D scores

The SDQ is scored out of a total of 40. A total score of 17-40 indicates the presence of a mental health difficulty, and a total score of 14-16 indicates borderline difficulties. Sub-scores for internalising and externalising disorders are also generated out of a total of 20 each, with a higher score indicating more difficulties (no cut-offs are provided for these scores). Across the sample of young people with intellectual disabilities, seven out of 17 scored in the 'abnormal' range of the SDQ, indicating the presence of a mental health difficulty, and an additional two young people scored in the borderline range (Table 70). The mean externalising score was 8.0 out of 20, and the mean internalising score was 8.2 out of 20.

The EQ-5D provides a measure of general health out of a total of 10, with a higher score indicating better health. The mean score on the EQ-5D health rating scale was 7.5 out of 10 (Table 70). Hence, although a high proportion of young people were assessed as having mental health difficulties, the majority were rated as having reasonably good general health by either themselves or their parents.

**Table 70: SDQ and EQ5-D scores in the interview sample of young people with intellectual disabilities**

(ab) indicates 'abnormal' range of the SDQ; (b) indicates borderline range

Young person	Age	Level of ID	SDQ total score	SDQ Externalising score	SDQ Internalising score	EQ-5D Score
Arnold	25	Severe	9	8	1	9.7
Celia	17	Severe	33 (ab)	18	15	8.0
Daniel	16	Severe	27 (ab)	11	16	7.5
Darren	27	Mild	9	4	5	8.5
James	17	Severe	19 (ab)	12	7	10.0
Jamie	17	Severe	19 (ab)	9	10	3.3
Jeremy	25	Mild	14 (b)	9	5	9.0
Josh	26	Mild	12	7	5	6.0
Lara	25	Mild	21 (ab)	10	11	4.5
Louis	21	Moderate	12	8	4	8.0
Mike	21	Mild	9	2	7	9.0
Rosie	21	Mild	20 (ab)	7	13	5.0
Sally	20	Mild	12	6	6	6.6
Sam	16	Moderate	7	2	5	9.8
Sarah	19	Severe	26 (ab)	13	13	7.5
Tim	19	Mild	10	6	4	8.0
Zena	16	Moderate	16 (b)	4	12	8.0

## 37 Themes identified from the ethnography/interviews

A high degree of consistency was found in the themes identified from both the ethnographic field diary and the semi-structured interviews; while some themes were exclusively identified in the interviews, all themes identified in the ethnographic field diary were also present in the interviews (Table 71). The following sections will examine each theme in detail, inter-weaving data from both the interviews and the ethnography. Extracts from the ethnographic field diary will be italicised.

While the interviews focussed on young people's experience of transitioning from school and onwards into adulthood, and the impact of this experience on their health, additional themes that affected their wellbeing more generally were also identified. Table 71 outlines the six master themes that were identified through the coding process (see Chapter 4) and the sub-themes within them, and demonstrates the structure that this chapter will now follow.

**Table 71: Description of the master themes and sub-themes identified from the semi-structured interviews with young people with intellectual disabilities**

\*indicates themes that were also identified in the ethnographic field diary

Master theme	Sub-theme	Description
Transition from school/to adulthood	Leaving school	Interviewees' feelings regarding leaving school
	Support to transition	Support available to young people during transition from school/to adulthood
Health	Health conditions	Health conditions experienced by the interviewees and their continued impact into adulthood
	Healthy lifestyles	Opportunities for young people to engage in healthy behaviours e.g. exercise
Activity	Daytime activity*	Opportunities available for young people to participate in meaningful daytime activity following school exit
	Confidence	Positive impact of having meaningful activity following school on young people's confidence
Relationships	Socialising*	Experiences related to socialising following school exit
	Experiences of intolerance	Experiences of intolerance of disability within the community, including bullying
Support	Changing landscape of support	Changes in the support networks available to young people during transition
	Positive supports*	Examples of helpful supports during transition
Growing up	Independence*	Young people's perceptions of their increased independence (or lack thereof) in adulthood
	Responsibilities	Young people's perceptions of their increased responsibilities in adulthood

## 37.1 Transition from school/to adulthood

### 37.1.1 Leaving school

Young people throughout various stages of the transition to adulthood were interviewed, and thus a range of experiences were described and challenges and opportunities related to each stage of the process identified. Among those individuals who were approaching the transition from school, opinions on the impending exit from school differed. While some adolescents did not seem concerned about the transition: "It's alright, leaving school" (James), others described more mixed feelings, including excitement but also trepidation, largely due to fears of expectations from others to behave in a more adult fashion:

"Yeah I am looking forward to it, and a bit nervous at the same time ... [college is] different from school 'cause they treat you more as an adult ... it's basically up to you if you want to make a good effort to it." (Sam)

Among those who had already transitioned from school, most reflected that they had been simultaneously sad and excited about leaving: "[I felt] sad ... and I was excited 'cause I was going to college ... kind of mixed" (Louis). While young people reported excitement related to the new activities that they might pursue following school, such as college,

sadness was attributed to leaving behind a network of teachers and support staff that they had come to view as friends: “[I was] sad about [not] seeing the support workers ... I got on well with one, her name was Mrs Macdonald ... she's a friend now” (Mike).

### **37.1.2 Lack of support to transition**

As well as their feelings about leaving school, young people were asked to comment on the support to transition – both from school and on into adulthood – that they had received. The emerging picture of support was that it fell short of young people's needs, with a lack of continuity in staff who were responsible for supporting the transition, combined with short-term timescales, contributing to difficulties in arranging the practicalities of the transition:

“When I left school I sort of struggled to move because we had a social worker that then also left to have a baby ... so I had somebody temporary purely for transition which is not really ideal ... it was like a few weeks before the end of term that everybody came, mum ... I was there, the teachers that were involved with me, the so-called social worker ... she literally had that meeting and then left, so it was literally from the meeting all the way through [to] maybe half way through my first year of college that I had a temporary social worker.”  
(Lara)

An impression emerges here of a hurried and chaotic transition experience. In addition to this lack of support for the practicalities of leaving school, young people also commented on the deficiencies in the preparation for life in the adult world that they had received:

“In high school they mostly just taught you about writing a CV and that was about it, they never taught you about how to manage money or accounts or anything like that.” (Celia)

This lack of support to practise the skills necessary for independent living meant that many young people felt unprepared to live as an adult, and hence worried about how they would cope: “It’s impossible, I don’t know how my mum does it” (Celia). This issue will be discussed in detail later on in this chapter.

## **37.2 Health**

In order to identify whether the experience of transition had impacted on young people’s health in any way, one focus of the interviews was young people’s current health and any worries associated with their health.



### 37.2.1 Health problems

When asked if they had any current concerns about their health, most young people explained that they did not have any specific health-related worries. However, a small number of young people mentioned specific physical health issues such as colitis or epilepsy, when prompted by their parents, and their concerns about these conditions were centred on practical issues with which they would have to cope in new, adult environments: “Going to the toilet [makes me worried]” (Tim). Young people also described assuming more responsibility for managing their own care in relation to their health conditions as they grew older, for example by taking charge of their own medications: “I’ve got epilepsy ... I take medication ... I can do it by myself” (Celia). Thus, while health problems were not described by the interviewees as currently being of particular concern, it was evident that the health in the sample was generally poor, and for many young people, the careful management of long-term health conditions would be ‘background noise’ accompanying them throughout their lives: “[I’m worried about] my condition, basically if it deteriorates more than it already has” (Rosie).

### 37.2.2 Healthy lifestyles

As in the focus group, some young people identified their diet as their primary health concern: “Not eating right [worries me]” (Jamie), and some expressed desires to lose weight: “I need to lose some weight” (Josh). When asked whether they had opportunities to exercise and eat healthily, young people explained that they knew in theory how to maintain a healthy lifestyle, but acknowledged that they struggled to translate their knowledge into action: “[Healthy eating and exercise] isn’t my strong point. I know what to do but ... I find it quite hard to put what I know into practice” (Darren), suggesting that support in this respect might be beneficial during transition. The previous quote suggests that young people may be receptive to positive messages about maintaining a healthy lifestyle, and might be more able to manage their weight and engage in exercise with the appropriate support. Despite this suggestion, however, the following extract from the ethnographic field diary suggests that this may indeed be where support is inadequate:

*Schools and colleges have broken up for the Easter holidays, so today’s Social Circle is a ‘games day’. When I arrive, there is music playing and board games set out on the tables. There are also snacks available, with fizzy drinks, crisps and sweets on offer. Although today is meant to be fun, I find the lack of discussion about healthy eating in the Social Circle sessions more generally to be cause for concern. A high proportion of the young people who come to these*

*sessions are significantly overweight, and every session I have noticed people arriving with armfuls of unhealthy snacks.*

*Back to the games day, and I listen to Craig telling Mike about a club night he recently attended, organised by Dates –n- Mates<sup>1</sup>, where he reports drinking two WKDs<sup>2</sup> and a Coke. A discussion about alcohol (and smoking) ensues, and the table comment, disapprovingly, that people’s voices change when they are drunk, and sometimes people are sick. I am interested to note that these conversations have obviously been started in more structured environments – possibly at school or home – but that similar conversations about healthy diets do not seem to be happening.*

### 37.3 Activity

The most obvious difference between young people’s school and post-school environments was the daily activity in which they were engaged, and it was this component that most interviewees – both those anticipating and those reflecting on their move from school – primarily focussed on.

#### 37.3.1 Daytime activity

College – offering courses specifically for individuals with intellectual disabilities including ‘life skills’ courses as well as more conventional courses – was the most popular activity after school exit: of the 12 young people who had left school, six were currently at college; one was awaiting a place at college; and two had already been to and left college. Among the five young people who were still at school, all were planning on going to college when they left. The primary purpose of attending college seemed to be to replicate the school routine, with young people describing the college environment as similar to school:

“Nothing much has changed in my opinion, ’cause it was just still technically attending education even if it was for like three days a week ... it’s just basically attending education ... I just treat it as if I was moving school.”  
(Celia)

Moreover, college was familiar to most young people, since many schools introduced attendance at college to the school’s final year curriculum in an effort to prepare young people for the transition. Therefore, most young people had been attending college for

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<sup>1</sup> A friendships and dating agency run for people with intellectual disabilities.

<sup>2</sup> A brand of alcopop.

around one day a week during school, and were hence more comfortable with the idea of going there than with any other options: “I’d like to go to college for another five years” (Jamie). However, many, if not all, of the young people seemed to be going to college simply for the sake of it, and did not appear to be gaining much in the way of skills or qualifications:

“Even though it was all different courses, they were all at level three. So ... even though I was doing different subjects over four years it was all at the one level, so you weren’t really learning as such.” (Lara)

The older participants in the sample who had been out of school for a number of years were all engaged in either part-time employment or assisted work placements. While it must be noted that these young people may have been atypical in their ability to secure employment, work was a core component of these young people’s identities, offering a source of significant pride: “I’m going ‘look at me, I’m doing that’. Just because you’ve got a disability doesn’t mean that you can’t [work], you can do things” (Darren). However, it must be noted that not all of the interviewees had the capability to navigate a work environment independently, which limited their ability to secure employment: “It’s hard for me to keep focused on things sometimes so that’s probably why I couldn’t do a full-time job, I don’t think” (Louis).

Furthermore, some young people experienced physical disabilities in addition to their intellectual disabilities, which further limited their ability to access employment or educational environments: “I am disabled and I am in a wheelchair so ... I need to get, like, people to do my personal care” (Zena). Indeed, some young people were keenly aware of their difference relative to the non-disabled population and anticipated difficulties in identifying something appropriate to do following school exit: “Trying to find a job that fits me [might be challenging]” (Daniel).

Hence, arguably the most vulnerable young people who experienced additional impairments as well as their intellectual disabilities, including challenging behaviours and physical disabilities, struggled to access post-school spaces, and were thus left with nothing to fill their time after leaving school. In recognition of the fact that many young people had little to do following school exit, one of the key focuses of the Social Circle was to signpost young people to various activities in the community:

*At each session there is a flipchart pad detailing a list of upcoming activities in the community, such as creative activities, social events, and walking groups. At the beginning of each session, Damien<sup>3</sup> describes these activities, and draws attention to any new activities that young people mention during the course of the group. This week, Adam and Kevin tell us that they have met to play basketball and that they plan to play every week. Damien addresses the group as a whole, asking if anybody else would like to join in with weekly basketball. Meanwhile, Cathy<sup>4</sup> is describing an upcoming creative writing course. She asks everybody who is not at college full-time, who would like something else to do during the week, to raise their hands. Around a quarter of the group raise their hands and I am surprised by how many people must be struggling to fill their days.*

Despite the Social Circle's efforts to direct young people to opportunities in the community, this extract highlights the fact that a large proportion of young people had very little to do during the day following school exit, which itself had negative consequences for young people's wellbeing. For example, Celia had been expelled from various post-school placements due to challenging behaviour, and she had eventually been left with nothing to fill her day; an experience that caused her considerable frustration. She contrasted her current boredom with her busy school days, commenting:

"I'm used to spending time at school, I mean from half eight till four o' clock I've always been inside school ... now that I'm not in school I find myself absolutely bored out of my mind ... sitting in the house all day's kind of annoying in my opinion." (Celia)

### 37.3.2 Confidence

As foregrounded in the previous section, having a job, or, indeed, any form of meaningful daytime activity, had positive implications for various areas of young people's lives. Specifically, young people experienced a significant improvement in their confidence as a result of tackling new challenges and succeeding in new environments. For example, Josh described the opportunities to develop new skills with which his part-time job had provided him, which had positive effects throughout his life:

"[I have enjoyed] learning new things and getting out and meeting other people ... it has helped me with travelling 'cause I didn't really know that many places but for this job we need to travel all over Scotland so it does give you a bit more confidence when you're out travelling by yourself." (Josh)

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<sup>3</sup>Group facilitator.

<sup>4</sup>Group facilitator.

In this way, Josh was able to experience more independence outside of work due to the skills he had developed through his job. Furthermore, Darren noted the increase in confidence and improvement in his social skills that he had experienced as a result of his work, which had served as a gateway to other important facets of adulthood, such as his relationship with his fiancée:

“I’ve found it has gave me a lot more confidence ... if I didn’t have the job I don’t think I’d have met my fiancée because ... I wasn’t really going on nights out with friends ... a Friday night, or Saturday night, I was more than happy to sit in front of the TV ... now [I’m] ... going out more often with friends ... my social skills improved.” (Darren)

In this way, the progression in terms of the development of skills and confidence for those young people who were employed seemed to outweigh the benefits of college, where young people seemed to be attending for the sake of it. However, work was not the only environment that promoted an increase in young people’s confidence (and the positive experiences, contributing to more positive wellbeing in general, that increased confidence made possible), and young people described other activities that had helped them in this regard. For example, Sally explained how her participation in a drama group had helped her to develop both confidence and maturity: “I think I’ve just grown in confidence and I’ve matured a lot and like I take things more seriously” (Sally). In this way, it was environments outwith home or school, offering young people opportunities to tackle new challenges, that conferred increases in confidence, and by extension, positive wellbeing.

The participants in the focus group identified the importance of having ‘something to do’ primarily following pressures from their parents to engage in some form of activity following school exit. Nevertheless, the interviews support the importance of having something to do because of the positive implications for other areas of life arising from meaningful, enjoyable activity. It is hence important to recall that a number of young people did not have any such meaningful activity following the transition from school, and that these individuals were thus excluded from these important opportunities to experience new things in the adult world, with implications for (in many cases) a relatively lower sense of personal wellbeing.

## 37.4 Relationships

The pilot focus group identified relationships as an important topic for young people with intellectual disabilities undergoing transition, with friends with intellectual disabilities

being considered an important source of support who could empathise with the challenges associated with leaving school and growing up. It was hence considered that any difficulties associated with relationships would have implications for young people's overall wellbeing, possibly resulting in loneliness or isolation. Indeed, as with the focus group, both the interviews and ethnography revealed the importance of relationships to young people undergoing transition.

### **37.4.1 Socialising**

A large disparity in the opportunities to socialise available to the interviewees was identified. While some young people described active social lives, including age-appropriate activities such as “going to discos and parties” (Mike), others experienced fewer opportunities to socialise following school exit. For some young people, problems in making friends were related to personal factors, such as a lack of confidence. This lack of confidence was a crucial anxiety for young people, which permeated their visions of the future. For example, Rosie described her worry that she would not be able to make friends at college:

“[The main challenge for me is] just like not having the confidence to actually speak to people. So [when I first went to college] ... trying to speak to somebody that I didn't know, I would stutter, it was like I would feel like I was really stupid.” (Rosie)

Lara also experienced difficulties in making friends at college. For her, these problems occurred as a result of her placement in a mainstream college; during her interview she continually contrasted her ability to cope with some facets of mainstream education with her incapability relative to her non-disabled peers in other areas, such as socialising. Thus:

“Socialising in mainstream is very difficult, I have now done five years ... at [college] and to this day I am still sitting at the additional needs table at lunchtime with the support workers, when I'm more than able to talk. Somehow I can't seem to attract people to me and make friends. But yet I find that easier in additional support needs.” (Lara)

This poignant quote demonstrates the challenges that young people experience in navigating the social world outside of the school environment. These difficulties are multifaceted, with young people struggling to adjust to life alongside their non-disabled peers; recognising and acknowledging their own difference compared to these peers; and in

some cases coping with the fear of being stigmatised or excluded because of this difference. These issues will be returned to later in this chapter.

Indeed, while none of the sample overtly described themselves as lonely, a substantial number did not seem to have a social network beyond the family. Celia described herself as currently having “no friends”, but described the acquaintances made through a support group at school; while these people were not friends who she would see outside of school, the school environment had still provided an important opportunity to connect with her peers:

“In high school ... I was part of this kind of like support group ... and I was probably friends with maybe some of the people in the group but I wouldn’t say we were friends outside of school, just spoke to them whenever I saw them inside the building.” (Celia)

In the absence of organised activities which might facilitate opportunities to socialise with peers described in the previous section, many young people were isolated and, outside of the family, young people’s primary source of social contact was paid carers: “I also get six hours per week from support workers so that’s really just to get me out the house and a bit socialised” (Lara). Indeed, as the previous section identified, work (or additional sources of meaningful activity) was a gateway to participation in the social world: “I’ve got a lot of contacts though the job” (Darren).

Hence, again it is clear that those young people who were most vulnerable due to, for example, challenging behaviours, which prevented them from accessing organised activities, were those who were most at risk of exclusion from the social world. The following extract from the ethnographic field diary highlights this issue:

*Lauren approaches me during break time to chat about her transition from school. She explains that she has been ‘kicked out’ of her day centre for misbehaving but that she wants to get back in. I observe her throughout the rest of the sessions; she often behaves aggressively to other members of the group, and is ostracised by the other girls. I hear her tell Cathy<sup>5</sup> that she feels sad that nobody wants to be her friend, and consider that she is trapped in a vicious cycle, wherein her aggression prevents her from being able to interact positively with her peers, but that her upset at having few positive relationships prompts more aggression.*

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<sup>5</sup>Group facilitator.

In addition to challenging behaviours, young people with personal care or accessibility requirements also experience barriers to participating in some social activities. A key component of the Moving On Transition Service was the organisation of residential trips, which occurred every few months. However, some young people were excluded from participating in such crucial opportunities to socialise with their peers:

*Emma<sup>6</sup> is describing an upcoming residential trip to the Lake District. There is a clamour of excitement as the group joke about previous trips and make plans for this one. Emma stresses that this particular trip is not suitable for wheelchair users; she hastens to add that the next trip will be suitable, and those who do not go on this trip will have a place on the next. I look around the room. There are at least three people in wheelchairs who are immediately excluded from the excitement in the room.*

This exclusion extended to more routine aspects of the sessions. One of the objectives of the group was to facilitate opportunities for young people to socialise independently, and the group routinely organised activities, which they would plan in one session, and attend the following week. Again, those with additional support needs were at risk of exclusion from these events if they did not have paid support in place to facilitate their involvement:

*The staff emphasise that while they will help to choose a venue and plan bus routes with everybody, they will not accompany young people on the trip. They reiterate that anybody who requires additional support will therefore have to arrange it for themselves. While this is undoubtedly a positive step towards independence for the majority of the young people here, I am struck by how, once again, wheelchair users and those with personal care needs run the risk of being excluded from social activities if they cannot arrange for support workers to accompany them – something I know to be a challenge for many of these young people due to the limited funding allocated to their care.*

While the above extract exemplifies an extreme example of inaccessible adult environments, most of the interviewees experienced some difficulty in navigating the community independently, which caused frustration when they were prevented from organising their own opportunities to socialise:

“I did have a really good friend at school but they stayed in Paisley and of course I stay here and we both can’t drive. Until we learn how to use transport that was always a struggle.” (Lara)

Perhaps because of these difficulties experienced in meeting friends and hence maintaining friendships outside of school, when asked about their support networks, young people

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<sup>6</sup>Group facilitator.



described primarily family members: “I’ve got a lot of people, a lot of family” (Mike). Interestingly, this phenomenon can be contrasted with the views of the young people who participated in the pilot focus group, who identified friends as a key part of their lives. The fact that the participants in the pilot focus group were all still at school and therefore had ongoing contact with their classmates may account for these differences since, as this section has argued, those young people who had transitioned from school enjoyed considerably fewer opportunities to maintain friendships.

At first glance, the ethnographic work suggests that young people did enjoy a positive social environment, where friendships appeared to flourish:

*I am immediately struck by how warm and welcoming the atmosphere of the Social Circle is. The first half of the session is dominated by ‘New and Good’, wherein everybody sits in a large circle and a microphone is passed around, providing everybody with an opportunity to introduce themselves and to describe their news from the previous week. Everybody claps and choruses ‘hello’ when somebody introduces themselves, and the more popular members of the group are even cheered. Achievements, such as passing courses, are routinely congratulated, and a genuine interest is taken in everybody’s news. Young people report engaging in activities together outside of the group, such as trips to the cinema, and there is evidence of close friendships, with banter, affection and laughter passing between those present.*

However, while the Social Circle presented an opportunity for young people to socialise together, there were few opportunities for these young people to socialise outside of this specific space, and the group’s funding was withdrawn at the end of the ethnographic period of study, resulting in its termination and depriving young people of this social space altogether. In recognition of the limited opportunities to socialise beyond the group setting, a primary focus of the group was to equip young people with the skills necessary to socialise independently, and the group facilitators repeatedly encouraged young people to use the skills learned there to plan activities together outside of the group setting. Once again, however, this was only possible for those young people who were able to negotiate the community by themselves, and those who required additional support were potentially excluded.

As well as relationships with friends, romantic or intimate relationships were also identified as important for young people. A key part of growing up was considered to be involvement in an intimate relationship: many interviewees identified having their own family as one of the integral characteristics that demarcated adulthood. Some young people expressed a desire to get married and to have children, although this idea was generally

expressed in rather abstract terms: “Yeah I would quite like to get married maybe, like ‘cause like I think every girl would like to get married one day, but I just need to find that guy, I need to find that person” (Zena). For others, having a girlfriend or boyfriend was a much more concrete goal; for example, Tim identified “being single” as one of his current worries. Indeed, there was evidence at the Social Circle of young people exploring their emerging sexuality, highlighting the Social Circle to be a crucial safe space where young people could explore the numerous roles of adulthood:

*Dougal and Siobhan sit together holding hands throughout each session; this week, they have been to a restaurant together to celebrate Siobhan’s birthday. Every week Lauren announces during ‘New and Good’ that she has been kissing her boyfriend at the weekend. This week, Lauren has stayed over at her boyfriend’s house for the first time. Later, I overhear Craig telling Mike that he has been to a club night organised by Dates-n-Mates. He describes asking a girl, whose name he can’t remember, for her phone number. She didn’t give it to him. He goes on to explain that he likes girls who wear make-up; eyeliner especially.*

Social relationships, including those with friends and with romantic partners, were thus considered to be a central aspect of adulthood for the majority of the young people in the sample. In this way, the positive implications of having a social network for young people’s wellbeing is evident, with friends offering support, acceptance and fun. However, as this section has suggested, many young people – especially those who were in some respects the most vulnerable among the sample – were excluded from this important component of adulthood, and hence experienced negative wellbeing consequences as a result of this phenomenon, including significant worry about maintaining social relationships in the future: “When I done college before I got bullied so that is my biggest worry” (Rosie).

### **37.4.2 Experiences of intolerance**

As well as barriers to participating in the social world due to inaccessible environments, the interviewees did describe experiences of intolerance and even bullying, which had further excluded them from adult spaces, and undermined their confidence to participate in them in the future. For example:

“All through my life I’ve always been bullied, but like going to college and knowing that it was adults that were bullying me and not like teenagers and children. So it was like adults picking on me, calling me names and telling me that I was a baby and things like that, so it kind of put me down and made me actually leave college before the end of the course.” (Rosie)

These experiences of intolerance extended beyond educational environments and into the community at large: during Zena's interview, her mum described her daughter being refused entry on to a bus because of her wheelchair. This negative experience had undermined Zena's independence because she refused to travel by herself, fearing a similar experience: "I'd probably refuse to go ... myself ... that's how scared I am" (Zena). Perhaps because of experiences like this one, a key component of the Social Circle was 'travel training', which aimed to provide young people with the necessary skills and confidence to travel independently:

*The group is given a travel scenario (in this instance, getting the last train home at night and being bothered by a group of drunk people) and asked how they might cope with it. There is much discussion, and responses are thoughtful: somebody suggests staying on the phone to a parent or friend, but somebody else points out that somebody might steal their phone. Other suggestions include moving train carriages, or sitting by the door to facilitate a swift exit. A few people point out that they don't use public transport so this activity does not apply to them, but a surprising majority of young people have their own stories of being afraid on public transport. I am struck by how scary it must be for these young people to negotiate the adult world by themselves, and can see why some families might be tempted to prohibit their sons and daughters from travelling independently.*

Since some of the young people feared experiences of intolerance and bullying in adult environments, their opportunities to participate in the community, and hence to benefit from the positive consequences of such participation as outlined in previous sections, was indeed inhibited. The fear of an intolerant community was clearly a factor that young people routinely considered when planning for their futures, contributing to worry when they contemplated navigating unfamiliar environments: "[I'm worried about] going into my first job 'cause I don't know how I'm gonna be, like, taken ... 'cause I'm quite different from other people" (Sally).

## 37.5 Support

While professional support was not something that was identified as important during the pilot focus group, given the crucial role that professionals and paid carers play in facilitating young people's access to the adult world, and the change in support networks that may occur upon the transition from school, a key focus throughout the interviews was the support that young people had received during the transition from school and beyond.

### 37.5.1 Changing landscape of support

Throughout the transition from school, young people experienced changes in their interactions with professional networks due to changes in both funding sources and the activities in which they were engaged. Some young people could reflect on the cause of these changes and did not seem too disturbed by them: “It’s not that they’re<sup>7</sup> finished with me ... they just don’t have the money any more ... to continue doing it” (Celia). Others less able to comprehend the organisational structures within which their care was situated perceived only that the people upon whom they had relied for many years were no longer there for them: “[My occupational therapist has] left me” (James). As mentioned in previous sections, young people often considered support staff to be a crucial part of their social networks, not merely professional helpers, and expressed sadness when these important figures in their lives suddenly disappeared.

As well as experiencing changes to their networks of staff, young people also commented on differences in the type of support that was available to them after leaving school, with post-school environments perceived to be less supportive than school had been and thus falling short of their needs:

“I feel like you don’t get any help at college; you just get put in and then, if you’re struggling ... you’re on your own really. I think college should be more supportive.” (Josh)

These changes in the level of support provided to young people were attributed to differences in the availability of funding for paid support, with funding being limited when young people left school and reached ‘adulthood’. For some, this lack of funding and the ensuing withdrawal of services, while stressful, had served as a “kick up the bum” (Lara), forcing young people to become more independent and hence prompting the development of skills, such as using public transport, that would allow them to access the community better and thereby the positive consequences for wellbeing that such access afforded. Thus:

“When I went to [college], first year they provide a taxi and then that was the ... whole start of the world cutting their money. So they’re like ‘you either have to get the train or we can’t afford for you to come to college’ ... So it was either pay for the taxi which would be a fortune, or learn the train, or don’t go at all, so I had to learn with a support worker pretty quickly how you get the

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<sup>7</sup>Support worker.

train there ... At that point I wasn't really using public transport on my own at all, so in some respects that was sort of a kick up the bum.” (Lara)

While this phenomenon had actually benefited some young people, for those who did not have the capability to develop such independence, they were simply left with inadequate support in their post-school spaces, leading to feelings of vulnerability: “The first course I did ... was quite a hard course for me, the work was all going quite fast and I couldn't, like, keep up with it. I found it quite difficult” (Louis). As well as affecting individualised support, limited funding for adults with intellectual disabilities – compared to that available for children – affected young people's access to groups and activities as they transitioned to adulthood. Indeed, funding for the Social Circle was cut during the period of ethnographic study, with the researcher witnessing the distress that the withdrawal of a vital source of support and socialisation could cause for young people during transition:

*As the Social Circle will soon be ending, today is an 'evaluation' day, and everyone is asked to write or draw on post-it notes what they have enjoyed the most and the least about the Social Circle. Lydia asks me to help her with her writing. She tells me that she is sad that the Social Circle is ending. She liked “being all together” and “going on trips” most of all, highlighting two key functions (socialisation and stimulation) of this group. Lydia's sadness is echoed throughout the group; Celia explains that she likes to get out with the Social Circle because she doesn't get out of the house much otherwise. I wonder what these young people will do without this vital support network.*

As well as experiencing limitations in the availability of support when young people grew older, those with long-term health conditions requiring continued contact with health teams also had to transition between child and adult health services. Lara was the only interviewee who had experienced both children's and adult services at the time of the interview, possibly because the transition to adult services was reported to be significantly delayed: “Even though I was in my 20s, by this point they hadn't transferred me, none of my notes were in the adult services ... so I got put back into children's services” (Lara). Indeed, by continuing to receive care in children's services, young people's adult identities were perhaps undermined, and their overall transition to adulthood delayed through continued contact with services offering fewer opportunities to exercise independence and responsibility. Nevertheless, children's services appeared to be superior in catering to young people's needs, primarily through offering a more flexible style of care:

“[In adult services] everything was recorded in the notes and yet I still didn’t get the care that I needed ... Children’s were much better in the sense of the wee subtle things, the colouring in [in the waiting room], you were allowed to wander up the [corridor] ... mum could come in at any time and be with me. So it was much more flexible.” (Lara)

### 37.5.2 Positive supports

The Social Circle provided an example of a positive source of support for young people during transition. As mentioned previously, the group provided a safe space for peer support, and there were numerous additional activities, such as ‘travel training’, which aimed to produce the following formal outcomes for young people: increased confidence; increased socialisation; increased independence; increased skills; increased opportunities; and increased friendships. As the ethnographic work coincided with the ending of the Social Circle due to funding cuts, the ways in which the group had achieved these outcomes became evident during the ‘evaluation’ sessions, which were ran before the conclusion of the group:

*Many young people approach me to tell me how upset they are that the Social Circle is ending. Everybody agrees that the Social Circle has done a lot for them in terms of improving their confidence and facilitating positive experiences with peers, such as residential trips. We move into the next room to take part in the formal ‘evaluation’ of the group. When asked to pick words that describe how the Social Circle makes them feel, people choose “equal”, “supported” and “listened to”. Emma<sup>8</sup> asks what everyone is most proud of achieving at the Social Circle, and the answers include learning to read a bus timetable independently, and having the confidence to speak in front of a large group of people. There are numerous examples of young people putting into practice the skills that they have learned at the Social Circle. For example, drawing on the organisation and route planning skills he learned here, Dougal has planned a trip to a local shopping centre with some friends next week, and as a result of the ‘travel training’, Nina now goes to college independently.*

The Social Circle hence provided young people with a constant during transition; a safe space where they could engage with their peers and learn new skills that would benefit them in the adult community.

As with employment, an increase in confidence seemed to be the key thing that young people reported as a benefit from professional support: “My befriender’s helped me as well with confidence ... my befriender’s a lifesaver” (Mike). In this way, many young people required this input from professional services to experience

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<sup>8</sup>Group facilitator.

a positive transition to adulthood, both in terms of developing their own confidence and in accessing groups and activities: “[People First<sup>9</sup> have] got me involved with like different groups and stuff to try and build my confidence and they’ve helped me to fill out applications and things” (Rosie). Thus, when this professional support was limited or withdrawn, young people’s ability to access the community was limited in tandem, again inhibiting the positive consequences of community participation that they could experience.

## 37.6 Growing up

The young people in the pilot focus group described specific concerns related to ‘growing up’, such as menstruation for young women. The interviews extended the focus of ‘growing up’; encouraging young people to reflect on the meaning of adulthood for them. Some young people focussed on personal qualities of character, such as responsibility and independence: “To me I guess [adulthood] means maturity ... doing things yourself, having to do things without being told or asked ... being responsible for your actions” (Celia). Others described more traditional, practical goals, such as having a job or starting a family: “Growing up means that you go in to work, you earn money and you start a family” (Sally). Meanwhile, some young people commented on the privileges that their new ‘adult’ status afforded, such as “staying up [late]” (Arnold) and being able to choose where to go and what to do: “I ... just [do] whatever I feel like doing” (Jeremy), although the latter remarks betray a naivety about what the routines and responsibilities of adult life more commonly entail.

### 37.6.1 Independence

The pilot focus group revealed dissatisfaction among the young people who participated in terms of their opportunities to exercise independence in decision-making. Central to conceptualisations of adulthood among the young people in the interview sample was an increase in independence, to which they looked forward: “Adulthood means independence maybe? Even though I maybe can’t be independent<sup>10</sup> ... I would like to be independent” (Zena). As foregrounded in the pilot focus group, however, for some young people in the

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<sup>9</sup>Advocacy service for individuals with intellectual disabilities.

<sup>10</sup>Zena has physical disabilities that prevent her from managing her own care independently.

interview sample, this desire for independence was thwarted due to parents' reluctance to allow their children access to the community alone:

*There is a day trip to Oban arranged for tomorrow, and Cathy<sup>11</sup> discusses the final details with the group. Celia asks if her mum can accompany her on the trip, since she will not arrive home until 9pm and her mum is not happy with her getting the train alone at that time of night. In an effort to compromise between independence and safety, Cathy suggests that Celia does not need her mum to be with her all day and instead that she might just meet her at the train station in the evening.*

Indeed, as one might expect from the typically developing population, some young people railed against their parents' desires to shield them from the community, expressing instead a desire to "do [their] own thing" (Zena):

*"[I'm looking forward] to do[ing] my own thing and what I mean by that is like, this might sound bad, but even though people telling me what to do, even though I might still have that when I leave school, I might not have that as much." (Zena)*

Others, though, were not inclined or felt unable to challenge their parents' decisions in lieu of their own:

*A photographer has been invited to the session this afternoon to take pictures of the Social Circle. Emma<sup>12</sup> explains the purpose of his visit and Lydia gets noticeably agitated; we discern that she is upset because she thinks that she needs to ask her mum if it is OK before she has her picture taken. Emma tells Lydia that she can decide by herself whether or not she would like to be in a picture, but she is not convinced, and she leaves the room.*

In this way, young people's independence in both navigating the community and related decision-making was in some cases undermined. Indeed, parents' continued involvement in their children's lives may have contributed to practical impairments in young people's ability to organise activities for themselves, further inhibiting their independence, which became clear during the Social Circle:

*Damien<sup>13</sup> makes an announcement about the upcoming residential trip. He asks everybody who is attending to raise their hands. While some individuals confidently raise their hands, others look to support workers, or explain that they don't know whether they are booked on the trip or not. Despite the ethos*

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<sup>11</sup>Group facilitator.

<sup>12</sup>Group facilitator.

<sup>13</sup>Group facilitator.



*around promoting independence here, it is clear that a lot of young people still rely on parents or support workers to arrange their activities for them.*

As well as difficulties associated with parental involvement in their lives in giving permission to access activities in the community, young people's ability to experience independence was sometimes blocked due to their own position within the community which, as previous sections have discussed, was often isolated. For example, Celia poignantly contrasted her excitement at the prospect of leaving her family home with the isolation that such a move would probably entail for her, since her social network was primarily limited to her family: "I'd love to be able to move out ... it's just ... I really wouldn't have anyone to talk to apart from my mum and my sister" (Celia). Celia's independence here is potentially constrained due to her lack of a social network outside of the family, resulting in her continued reliance on her family into adulthood. This reliance on parents was a universal phenomenon; when young people were asked who they thought made decisions about their lives, as in the pilot focus group, the answer was almost always "mum", indicating that young people accepted what might be considered a high level of involvement in the lives of typically developing young people of a similar age.

Even so, some young people were indeed experiencing more independence in their lives, for example travelling independently: "Now I'm able to travel on my own and I don't actually have to rely on other people" (Rosie). These experiences were clearly a source of both enjoyment and pride for young people:

*During 'New and Good' those present are keen to describe their latest achievements on the path towards independent adulthood. Kieran is moving into his own flat next month and is planning a house-warming party. Dougal went to a local shopping centre alone for the first time this week, and Adam attended a dentist appointment by himself today. These achievements are a source of pride for those involved, and their efforts are congratulated warmly by staff and young people alike.*

Thus, while independence was identified by young people as a central aspect of adulthood, and something which many appeared to anticipate with excitement, most of the interviewees seemed unable to experience a significant level of independence, both due to their parents' reluctance to facilitate independence, and their isolation within the community in general, which itself necessitated more reliance on their parents. Again, the opportunities for success in the adult community, prompting positive personal wellbeing, were therefore circumscribed.

### 37.6.2 Responsibilities

As discussed in previous sections, some young people did not seem overly concerned about leaving school and beginning new activities. That said, they were more universally apprehensive about their ability to cope with the responsibilities of adulthood, with concerns centred on practical issues such as managing money and keeping a house: “[I’m worried about] money, having to go places by myself ... and getting up at the right time for like work and all that ... and making sure the house is clear and all that” (Jamie).

However, for most young people these ideas were considered in far-off, abstract terms, and did not appear to be of any pressing concern. There was a sense that the practicalities of adulthood, such as paying bills or finding a job, were issues that had been discussed with young people by parents or teachers, but were not activities that they identified themselves as needing to do any time soon: “Yeah I need to have my own finances but ... if I like hit 30 or 20 or something or above, I may think of like, being responsible for my own house” (Tim).

However, the interviewees did acknowledge that they would eventually have to take more responsibility for themselves in the future when their parents would no longer be able to care for them: “My mum’s not gonna be there ... for like all my life ... so I’ll need to learn to ... do things myself” (Zena). This issue was obviously not straightforward, and young people explored the difficulties involved in trying to become independent when they had been so used to relying on their families:

“I’ve always been used to relying on my mum or my dad to be doing something with me, like going to the shops or pick out clothes ... I’ve been used to that my whole life ... I’m trying to learn how to do them more myself, but it just makes it more easier if my mum or dad ... was doing it with me or for me.” (Celia)

In recognition of these difficulties, the process of assuming more responsibilities was indeed very gradual for these young people: “I’m going to learn to take on new responsibilities as I’m getting older” (Mike). This approach was comforting for young people, who for the most part seemed confident that they would eventually master some of the immediate responsibilities that they would need to shoulder: “[I struggle with] travelling independently, but with the right practice I’ll know how to do it, learn how to cope with myself” (Sam). Hence, although the interviewees did express some degree of worry over their eventual need to assume more responsibility for themselves, most were confident that they would eventually master the challenges of adulthood, and that they

would eventually transition, even if the process might take longer for them than for their peers without intellectual disabilities.

## 38 Summary

The primary purpose of the interviews and ethnography was to ascertain whether the transition from school had affected health and wellbeing in young people with intellectual disabilities. Despite the significant proportion of health issues identified in the sample, most young people were not overly concerned about their health in general. This assertion is reinforced by the EQ-5D scores; with a mean score of 7.5 out of a possible 10, it can be assumed that most young people rated their health as generally positive. Indeed, as in the focus group, worries about health were primarily related to issues associated with healthy eating, with young people often identifying a need to lose weight as their only significant health-related concern.

Mixed views in relation to the transition from school were identified, ranging from sadness at leaving behind a familiar network to excitement at the prospect of starting new activities. Support during transition was identified to be poor, with a lack of continuity in staff and short-term timescales contributing to a hurried and chaotic experience. Furthermore, changes in young people's professional support structures were also perceived negatively, with support seeming to decrease significantly upon entering 'adulthood'. The Social Circle was clearly a key source of both support and activity, serving numerous positive functions for young people. The fact that funding was cut for this crucial service exemplifies the problem that a lack of funding, potentially declining further under new fiscal regimes, poses for this population during transition.

With regards to more holistic aspects of the transition, which arguably have implications for young people's wellbeing more generally, meaningful daytime activity, and a resultant social network, were positive facets of adulthood identified to afford young people a significant boost in confidence, themselves facilitating increased independence and access to additional achievements of adult status. Those young people who were arguably the most vulnerable due to experiencing behavioural and physical challenges in tandem with their intellectual disabilities, were in some respects excluded from these positive experiences as a result of a lack of support and experiences of intolerance in the general community. Some interviewees thus experienced barriers towards experiencing independence, and hence to important aspects of adulthood. While some young people

reported a desire for more independence, they also seemed apprehensive about assuming more responsibility for themselves. The situation was complicated further by parents' reluctance to facilitate independence in their sons and daughters. Either due to fears around increased independence, or desires to achieve independence that were in some respects blocked, young people were in some ways negatively affected by this complicated situation.

As covered in the next chapter, the semi-structured interviews with parents of children with intellectual disabilities offer an interesting comparison to consider in line with this data. The next chapter will hence describe the themes identified from the semi-structured interviews with parents. The following discussion chapter will then synthesise findings across these two studies, and the secondary analysis of Scotland's Census (2011), before outlining the conclusions of this thesis.

## Chapter 7: Results from the semi-structured interviews with parents/carers of young people with intellectual disabilities

This chapter will present the results from the semi-structured interviews with parents/carers of young people with intellectual disabilities. Research questions 1b (*Does transition to adulthood affect health and wellbeing in young people with intellectual disabilities from the perspective of families/carers of young people with intellectual disabilities?*), 3 (*Is the impact of transition on health and wellbeing similar or different for young people with profound and multiple intellectual disabilities compared with young people with mild to moderate intellectual disabilities?*), and 4 (*What supports [formal and informal] are helpful for young people with intellectual disabilities during transition?*) will be answered via the semi-structured interviews with parents/carers, which covered perspectives from families of young people with a range of intellectual disabilities.

### 39 Participants

Twenty-three parents/grandparents of young people with intellectual disabilities participated in the semi-structured interviews. Recruitment was stopped at this number of participants as robust themes had been identified from the data. Nineteen mothers participated; one father; one mother and father pair; one grandmother; and one grandmother and grandfather pair. As all of the grandparents interviewed were in parental roles, all interviewees will be referred to as ‘parents’ throughout this chapter. Their children/grandchildren were aged between 16 and 26 years (mean = 19.4 years) and had mild ( $n = 4$ ), moderate ( $n = 4$ ), severe ( $n = 7$ ) and profound ( $n = 8$ ) intellectual disabilities, assessed on the Vineland-II scale. There were nine young women and 14 young men. At the time of the interview, 21 young people were still living in the family home; one was living in residential care; and one was living in an independent flat with 24-hour care. Nine young people were still in school; five were at college; five were involved in various organised work and activity placements; and four had no form of organised daytime activity at all. Among those who had left school, the average number of years since school exit was 4.4. Table 72 shows the pseudonyms (chosen by the researcher), gender, ability, current activity, number of years since school exit, and living situation at the time of the interview of the sons and daughters of the parents who participated in an interview, as well as the parent/grandparent who participated.

**Table 72: Parents of young people with intellectual disabilities who took part in the semi-structured interviews**

\*indicates young people who also took part in an interview

Young person	Age	Parent/ grandparent	Gender	Level of ID	Current activity	N years since leaving school	Living situation
Aaron	20	Mother & father	Male	Profound	Work placements	2	Home
Adrian	17	Mother	Male	Profound	School	N/A	Residential care
Arnold*	25	Mother	Male	Severe	Work placements	9	Home
Carol	17	Father	Female	Profound	School	N/A	Home
Caroline	17	Mother	Female	Profound	Nothing	0.5	Home
Celia*	17	Mother	Female	Severe	Nothing	1	Home
Daniel*	16	Mother	Male	Severe	School	N/A	Home
David	24	Mother	Male	Profound	Nothing	6	Own flat with 24 hour care
Hannah	17	Mother	Female	Profound	Nothing	0.5	Home
Jake	18	Mother	Male	Severe	School	N/A	Home
James*	17	Mother	Male	Severe	School	N/A	Home
Jamie*	17	Mother	Male	Severe	School	N/A	Home
Jeremy*	25	Mother	Male	Mild	Work placements	10	Home
Lara*	25	Mother	Female	Mild	College	10	Home
Louis*	21	Mother	Male	Moderate	College	5	Home
Mike*	21	Grandmother	Male	Mild	College	5	Home
Molly	18	Mother	Female	Profound	School	N/A	Home
Sally*	21	Grandmother & grandfather	Female	Mild	College	5	Home
Sam*	16	Mother	Male	Moderate	School	N/A	Home
Sarah*	19	Mother	Female	Severe	Work placements	2	Home
Simon	23	Mother	Male	Severe	Work placements	4	Home
Tim*	19	Mother	Male	Moderate	College	2	Home
Zena*	16	Mother	Female	Moderate	School	N/A	Home

### 39.1 SDQ and EQ-5D scores

The SDQ is scored out of 40. A total score of 17-40 indicates the presence of a mental health difficulty and a total score of 14-16 indicates borderline difficulties. Sub-scores for internalising and externalising disorders are also generated out of 20 each, with a higher score indicating more difficulties (no cut-offs are provided for these scores). Among the interviewees' children with intellectual disabilities, nine out of 23 scored in the 'abnormal' range of the SDQ, indicating the presence of a mental health difficulty (Table 73). The mean externalising score was 7.9 out of 20, and the mean internalising score was 7.5 out of 20.

The EQ-5D provides a measure of general health out of 10, with a higher score indicating better health. The mean score on the EQ-5D health rating scale was 7.6 out of 10 (Table 73). Hence, although a high proportion of young people were assessed as having mental health difficulties, the majority either rated themselves, or were rated by their parents, as having reasonably good general health.

**Table 73: SDQ and EQ-5D scores in the interviewees' children with intellectual disabilities**  
(ab) indicates 'abnormal' range of the SDQ; (b) indicates borderline range

Young person	Age	Gender	Level of ID	Total SDQ score	Externalising score	Internalising score	EQ-5D score
Aaron	20	Male	Profound	18 (ab)	7	11	10.0
Adrian	17	Male	Profound	16 (b)	8	8	7.0
Arnold	25	Male	Severe	9	8	1	9.7
Carol	17	Female	Profound	10	5	5	6.5
Caroline	17	Female	Profound	11	8	3	10.0
Celia	17	Female	Severe	33 (ab)	18	15	8.0
Daniel	16	Male	Severe	27 (ab)	11	16	7.5
David	24	Male	Profound	18 (ab)	11	7	9.0
Hannah	17	Female	Profound	25 (ab)	14	11	5.0
Jake	18	Male	Severe	9	5	4	5.0
James	17	Male	Severe	19 (ab)	12	7	10.0
Jamie	17	Male	Severe	19 (ab)	9	10	3.3
Jeremy	25	Male	Mild	14 (b)	9	5	9.0
Lara	25	Female	Mild	21 (ab)	10	11	4.5
Louis	21	Male	Moderate	12	8	4	8.0
Mike	21	Male	Mild	9	2	7	9.0
Molly	18	Female	Profound	6	4	2	7.0
Sally	21	Female	Mild	12	6	6	6.6
Sam	16	Male	Moderate	7	2	5	9.8
Sarah	19	Female	Severe	26 (ab)	13	13	7.5
Simon	23	Male	Severe	7	1	6	7.0
Tim	19	Male	Moderate	10	6	4	8.0
Zena	16	Female	Moderate	16 (b)	4	12	8.0

## 40 Themes identified from the interviews

The primary focus of the interviews was how the experience of transition from school to adulthood had impacted on young people's health and wellbeing; what supports had been effective in facilitating a smooth transition; and what obstacles had prevented a smooth transition, with particular emphasis on health and wellbeing implications. The primary reported health impact of transition for these young people with intellectual disabilities was on mental health and wellbeing, with the changes in daily activity, support networks and expectations from those around them often being viewed as having profound psychological implications for young people. A variety of themes emerged that arguably contributed to mental health difficulties and less positive wellbeing during the transition experience and

this chapter will present these themes. Some themes arose from both parents' and young people's interview data, resulting in some overlap in the codes used, yet there were subtle differences in how each group discussed the issues in question. Table 74 describes the five master themes that were identified through the coding process (see Chapter 4) and the sub-themes below them, and demonstrates the structure that this chapter will now follow.

**Table 74: Description of the master themes and sub-themes identified from the semi-structured interviews with parents of young people with intellectual disabilities**

Master theme	Sub-theme	Description
General Health	Health conditions	Health conditions experienced by the young people with intellectual disabilities
	Healthy lifestyles	Opportunities for young people to engage in healthy behaviours e.g. exercise
Mental health	Stress and anxiety	Feelings of stress and anxiety experienced by young people in response to the changes associated with transition
	Coping	Parents' perceptions of their children's ability/inability to cope with the changes associated with transitioning to adulthood
	Challenging behaviour	Behaviours e.g. self-harm, aggression that young people exhibited in response to the frustrations and anxieties of their transition experience
Something to do versus nothing to do	Something to do	Parents' perceptions of the importance of young people having meaningful daytime activity in the absence of school and the difficulties associated with achieving this
	Barriers to accessing something to do	Factors that prevented young people from accessing activities in the community following school exit
	Routine	Parents' perceptions of the importance of routine in maintaining young people's wellbeing and the struggle to adjust to new routines or the absence of any routine following school exit
	Inappropriate placements	Difficulties experienced when young people were given post-school placements that did not meet their needs
	Socialising	Challenges involved in facilitating opportunities for young people to socialise with peers in the absence of school
Support and services	Inadequate care or support	Parents' perceptions that the care or support that they/their child received during transition was inadequate
	Funding	Limited funding for support or services for young people with intellectual disabilities as contributing to difficult experiences
	Timescales	Parents' perceptions of transition planning as too short-term to be effective; delays in transition experienced as a result of inappropriate timescales
	Positive supports	Services/support that parents/young people received that were helpful and contributed to positive transition experiences
Growing up	Independence	Parents' attempts to facilitate age-appropriate independence in their adult children and the challenges associated with doing so
	Adult identities	Difficulties experienced by young people in relation to growing up and developing adult identities
	Intimate relationships	Challenges experienced in relation to young people experiencing intimate relationships



## **40.1 General health**

### **40.1.1 Health conditions**

Parents were encouraged to reflect on their child's current physical and mental health and wellbeing, and any changes that had occurred during the transition experience. As identified in the previous chapter, some young people had complex health conditions. In these cases, parents reflected on how these health conditions impacted upon their children's whole lives, and the ways in which their transition to adulthood was hindered as a result of these health problems. This issue will be discussed throughout this chapter. Among the remaining young people in the sample, it was common for their parents to report the presence of a range of health conditions, including sensory impairments and epilepsy, but, interestingly, parents often made light of these problems:

“He's got a poor bowel, his bowel doesn't work very well, but other than that he's fine. He's got a hearing impairment, he's got a visual impairment, but other than that you know his health is good.” (David's mum)

Considering the young age of the sample, it is striking that parents were not more concerned about the high incidence of health issues faced by their children, perhaps reflecting the fact that such health conditions are routine and expected for individuals with intellectual disabilities.

### **40.1.2 Healthy lifestyles**

The interviews with young people with intellectual disabilities uncovered awareness that their diets and lifestyles were not always as healthy as they could, or should, be. This finding was reiterated among parents, who described their children's days as primarily sedentary, especially when they finished school and were left with fewer activities to fill their time (a point which will be discussed in detail throughout this chapter): “She was just sitting eating, getting heavier and heavier and I thought ‘this is no good’” (Sally's gran). In this way, over-eating was often considered as occurring in response to boredom. As a significant number of the young people in the sample were overweight, this phenomenon was concerning.

Those individuals receiving support to access regular exercise or information about nutrition were reported by their parents to have a healthy lifestyle: “He's got a good exercise regime, but this is all these people that work with him who have got the sport in

his head” (Jeremy’s mum). In this way, young adults’ ability to engage with exercise and healthy eating was attributed to serendipitous links made with services that advocated such things, suggesting that, in the absence of such support, young people would not get access to, or act upon, such information. Indeed, other parents, whose children could not always cope in mainstream environments, stressed the inaccessibility of environments that offer opportunities to exercise:

“He needs more exercise but what do you do, how do you get him to do more exercise? There should be places for children or adults with a disability [to exercise] ... because he’s got a quite round ... middle, how do you get rid of that if you can’t go? ... The worst place to put [weight] on is round your middle ... does he get fatter and fatter and what happens then?” (David’s mum)

In this way, for those young adults not receiving support to engage in a healthy lifestyle, the inaccessibility of public spaces excludes them from opportunities to engage in exercise, which puts them at risk of weight gain and thus to a significant number of weight-related health issues.

This phenomenon extends to aspects of medical care, wherein the inaccessibility of public health information may render young people unable to access such information without the help of their parents:

“Lara got ... a letter to be invited for a cervical smear test. A 14-page leaflet ... of course she can’t read that. So I turned it over and said ... ‘you can phone this number if you need a different format, do you want to phone them?’ and she was horrified, she said ‘can you do that for me mum?’ ... So I phoned somebody who said ‘oh you need to phone so and so’, so I got a different number, and they then only had an email version ... so then I printed it ... it was also 14 pages ... [it] was just larger print.” (Lara’s mum)

It is hence easy to see how, without her mum’s input, Lara would have been unable to access information about cervical smear testing, and would therefore miss out on a vital component of self-care for an adult woman. Lara’s insistence that her mum request accessible information on her behalf is also noteworthy, since it echoes previous discussions of young adults’ continued reliance on their parents into adulthood (see Chapter 6), further reinforcing the necessity of providing organised support to access and act upon information about healthy lifestyles, including nutrition, exercise and medical care, for individuals with intellectual disabilities into adulthood.

## 40.2 Mental Health

### 40.2.1 Stress and anxiety

To varying degrees, most parents reported that their child had experienced increased stress or anxiety during the transition from school. In most instances, parents reported that their child was already prone to anxiety, but that the experience of transition had increased their anxiety levels. The primary factor influencing such feelings was the unknown quantities involved in leaving school and starting a new routine: “I think more anxious; I think he’s more anxious because he’s not sure himself what’s going on ... he worries constantly” (Jamie’s mum). This increased worry was primarily related to an inability to cope with ambiguity; parents stressed that school had been a “cosy blanket” (Molly’s mum): a familiar place for young people where they had felt safe and secure. Stress was therefore experienced when young people anticipated or experienced unfamiliar environments with different routines and expectations for more mature behaviour, which will be explored further throughout this chapter. Moreover, this anxiety was possibly experienced because young people did not fully comprehend the changes occurring in their lives, and problems arose as they attempted to adjust to new routines or, in some cases, to the absence of a routine, a crucial claim for this thesis:

“But that’s what [the psychiatrist] thought it was all down to was her frustration and her lack of a routine. Because she had a routine when she was at school ... I think it was the anxiety of leaving school ... [her behaviour has] definitely got a lot worse since she’s left school.” (Sarah’s mum)

Among those young people demonstrating an awareness of implications arising from leaving school, a desire to avoid contemplating the future was still apparent (see Chapter 6), and it might be argued that parents were sometimes complicit in this avoidance tactic. Adrian’s mum described how she preferred the professionals working with her son to avoid mentioning his impending transition from school until a concrete plan was put in place, in order to avoid causing him unnecessary anxiety:

“I don’t allow anyone to talk about like moving Adrian. I says ‘you don’t talk about him leaving school, don’t talk about it because we don’t know where he’s going’ ... we don’t talk about that in front of him. ‘Cause that would just make him really anxious and he is a really anxious boy as it is.” (Adrian’s mum)

The above quote exemplifies attempts made by parents to protect their children from the anxieties associated with leaving school. This phenomenon can be juxtaposed with

characteristics associated with adulthood, such as responsibility and independence, which would arguably involve handling stressful situations. Young people's emotional reactions to leaving school were hence complex. Most young people did not report overwhelming anxiety about embarking on their path to adulthood during their own interviews (see Chapter 6), and this fact may be in part due to parents' attempts to shield them from any stress that might arise. Nevertheless, some parents did report that their child felt increasingly anxious in the approach to and aftermath of school exit. Young people's ability to comprehend the implications of transition may be a key factor here, in that those who could not fully understand the implications of leaving school reacted to the changes in their lives in an anxious manner because they were confused and upset by the changes occurring around them.

It is important to note here the spectrum of anxiety experienced by young people during the transition. For some, their experience of anxiety would likely be considered clinically relevant because it interfered with their daily functioning, either through preventing them from engaging in their usual activities: "He can't go anywhere ... he can't just walk to the bottom of the street without getting anxious" (Jamie's mum), or through provoking them to engage in destructive behaviours, such as self-harm: "She's going through a very frustrated phase at the moment, mental health wise she's not doing very well ... she's been self-harming" (Lara's mum). Others' experiences might be considered to reflect negative personal wellbeing in more general terms, involving stress or sadness as opposed to clinical anxiety: "Sometimes he can get a wee bit emotional ... and he'll look as if he's going to start crying or something like that" (Sam's mum). This clarification seeks not to undermine the experiences of those whose anxieties might not be considered clinically relevant, but to acknowledge the range of experiences described by the sample.

### **40.2.2      Coping**

Despite parents widely reporting stress and anxiety in their children during transition, conflicting messages regarding their children's ability to cope with adversity were reported. Some parents highlighted their child's vulnerability in relation to the 'outside world', leading them to worry about the capacity of their children to cope with the responsibilities and expectations of adulthood:

"That's what worries me because she's nearly 18 and she hasn't got the capability ... to understand, to go into a job centre and say 'right I'm here,

what have you done about a job?’ She wouldn’t understand that.” (Celia’s mum)

Other parents were concerned about how their child would handle leaving school, something around which their entire routine had been structured for many years:

“When he leaves school, it’s such a big change for him ... and it is a scary world, even mainstream, you know leaving school and leaving all your pals behind and going to college, and as much as it feels exciting and everything for somebody in mainstream it’s still scary. So I don’t know how he’s going to cope.” (Daniel’s mum)

In this way, it was reinforced that transition is difficult for any young person, even those in “mainstream” education, but that it is much harder for those with intellectual disabilities. In contrast, others seemed optimistic about their child’s ability to cope with the changes associated with leaving school, drawing attention to their easy-going nature: “I think for Simon that was fine. He is very, very laidback and he doesn’t stress over things” (Simon’s mum). Although it may simply be the case that some young people were of a laidback disposition, allowing them to take the transition “in their stride” (Simon’s mum), this possibility may also reflect young people’s cognitive capabilities, with some parents perhaps assuming that their children would not understand the full implications of transition and therefore assuming that they – their children – would not be bothered by it.

Adequate support was regarded as crucial in supporting young people to cope with the transition from school, with appropriate planning considered the key factor in supporting a positive experience:

“I think if everything is explained to Adrian, you know and we have quite a long lead in, then he can cope with just about anything. But it’s the preparation, that’s the key.” (Adrian’s mum)

It is interesting to consider this quote in relation to the previous quote from Adrian’s mum, who discussed wanting to avoid mentioning anything to do with Adrian’s transition from school until the ambiguities had been ironed out, implying that Adrian would not be involved in this key preparation for his transition. These quotes reflect an assumption that Adrian is unable to cope with unknown quantities, but that with support he is able to cope with “just about anything”. Indeed, the general picture from the parents’ interviews overall was that young people were anticipated as being able to cope as long as they had clear expectations and a familiar routine. Thus, when those features were not in place, problems would arise, and this assumption is reflected in the data: parents reported their children

struggling when change had occurred and they did not have a clear idea of why, or of what they could expect from the future. Thus:

“It has been a hard year and I think ... part of it was I couldn’t give Sarah a plan ... if I knew what was happening, if somebody could say ‘right on this day you’re going to do blah, blah, blah’ and we could say that to Sarah ... but there wasn’t.” (Sarah’s mum)

Sarah’s mum described Sarah exhibiting challenging behaviours in the period between her exit from school and her uptake of new activities, which resulted in her being prescribed anti-psychotic medication. She attributed these behavioural difficulties to Sarah’s lack of stimulation, as her daily routine changed from the rigours of school to nothing at all over night, as will be discussed further shortly.

Difficulties in coping were also identified for young people who had been given insufficient support throughout their transition from school. For example, Louis’s mum described how Louis had been placed on a course that was too difficult for him, with which he had struggled to cope (something that Louis himself confirmed in his own interview; see Chapter 6):

“I noticed Louis coming home from college a bit, yeah [he was] a bit stressed ... he didn’t really know what he was supposed to be doing and he couldn’t keep up.” (Louis’s mum)

Hence, young people were able to cope with the changes that the transition from school created, but only if their transitions were well planned and thoroughly supported. Confirming this notion, those few parents who described experiencing a positive transition from school, characterised by an absence of delays and ample support, reported being pleasantly surprised by their child’s relatively painless adaptation to life after school:

“I would say in general the transition from school to now has been very good. Quite uneventful, and he’s coped with it very well. Whereas I thought he would struggle to cope, but really honestly he’s not struggled to cope with it.” (Aaron’s mum)

In these instances, parents remarked on being impressed by the transition planning process and the support received, and, revealingly, identified themselves as the exception to the rule, expressing awareness that for most families the experience was far from positive. Further, those positive transitions, with which young people had coped well, were often described as “soft transition[s]” (Molly’s mum), characterised by few drastic changes to

young people's roles or routines. In these instances, the transition from school was smooth, with one routine simply replacing another.

### 40.2.3 Challenging behaviour

It became clear throughout the interviews that, despite parental efforts to minimise the anxiety caused by the transition from school, some young people were struggling to cope with the changes in their lives occasioned by transition. In some cases, the stress experienced throughout this transition manifested in challenging behaviours, including self-harm and aggression. Although some parents speculated that these behaviours could be attributed to changes in the presentation of their child's underlying cause of intellectual disabilities, for example among those young people who had autism in addition to their intellectual disabilities, most attributed the behaviours, at least in part, to reactions prompted by stresses of transition, as well as by losing the dual routine and stimulation of school:

“But when she actually left [school] ... she became ... aggressive, she started swearing, she started biting furniture, which is something that she does when she's upset ... and her behaviour got worse and worse and escalated ... which probably is part to do with her autism progressing, but [the psychiatrist] think[s] the trigger was the fact that she didn't have a lot to do.” (Sarah's mum)

In this way, challenging behaviours such as those described by Sarah's mum can be regarded as a behavioural reaction to a drastic change in, or indeed loss of, routine. Challenging behaviours had also hindered young people's progression to post-school activities in other ways. For example, Celia was excluded from several courses and day services due to her behavioural problems:

“She can't do [a placement] because of her aggressiveness, she can't work with kids ... she could have had a place for a college thing to work with kids, but for the time being it's a no go ... because of the way she is.” (Celia's mum)

For Celia, this situation led to a negative cycle, wherein her behavioural problems resulted in her expulsion from various placements, leaving her with no organised daytime activity, which prompted feelings of boredom and frustration (see Chapter 6). The lack of activity experienced by Celia was a problem for a number of young people. David's mum lamented that there was “nothing out there” to engage David in the absence of school and described how his lack of stimulation had led him to engage in self-harm: “His self-harming has

actually taken over quite a lot, and I just think that's because of boredom. There's nothing for him to do" (David's mum).

For Celia and David, these problems were ongoing; for others, although challenging behaviours had been exhibited immediately following school exit and before alternative activities had been put into place, a period of relative calm had ensued once a new routine had been established and stabilised. For instance: "He was starting to get into trouble and [I was saying] 'I need help! Help!' ... But we're getting there now" (Jeremy's mum). This notion supports the idea that some of the challenging behaviours exhibited by young people could be attributed, at least in part, to the lack of stability that followed school exit. It is important to note, however, that the period of instability during which challenging behaviours were exhibited often stretched on for considerable lengths of time: "There was a long period and Sarah's behaviour wasn't great ... it was a bit rocky but we're eventually getting there now" (Sarah's mum). The "long period" described by Sarah's mum here had been almost one year; a very long time for young people to experience intense distress and for parents to have to deal with such challenging behavioural problems. This limbo period between exiting school and beginning new activities (and the challenging behaviours that often manifested during this time) served to delay both young people's transition to adult spaces and their acquisition of 'adult' characteristics, such as responsibility and independence; a point which will be returned to throughout this chapter.

## **40.3 Something to do versus nothing to do**

### **40.3.1 Something to do**

One of the key themes identified as contributing to poor mental health outcomes during transition, already anticipated in some quotes given above, was the lack of appropriate activity available for young people once they had left school. Parents contrasted the routine and stimulation of school with the apparent void that was left upon school exit:

"Outside of school there was very, very little, but he had a structured day at school and they did all different things ... you had your science, which was maybe just growing a plant, you did home economics, which was probably just helping make things ... but they were involved in everything they did. When they leave school that all disappears and they've got nothing to do." (David's mum)

The necessity of having something to do was highlighted by the majority of parents, who discussed the importance of a job or alternative activity in providing meaning and purpose



for an individual: “I want Adrian to have a job because I want him to have purpose” (Adrian’s mum). Parents stressed that staying at home was not an option for their sons and daughters, who still needed the challenge experienced at school once they had left in order to maintain their positive wellbeing. A lack of relevant opportunities available to young people on school exit was highlighted by parents, however, both in terms of paid jobs and placements specifically for young adults with intellectual disabilities. Furthermore, they worried that their sons and daughters did not always realise how few opportunities were available to them, and were concerned that they would be disappointed if their hopes for the future were not met:

“He’s all built up [that he will work] in an office ... and I’ve told him, I says ‘they’ll not keep you on’, that’s closing down anyway, the office<sup>14</sup> he’s at, he’ll not be kept on there so he’ll have to look elsewhere, he’s not thought about that.” (Mike’s gran)

Even when young people did secure a course or placement following school exit, most activities ran for only a small amount of time per week, which still left substantial periods of time during which young people were unoccupied:

“[Social work are] saying ‘oh there’s a great course in [college] for two days a week’, and I’m saying ‘well what happens to the other three days? What is she doing the other days?’” (Zena’s mum)

While most parents considered this lack of full-time placements to be detrimental to their child, some regarded it as positive because it provided their son or daughter with more opportunities to make choices about how to spend their time:

“I think the first course was four days a week and now it’s two days a week ... so there was a change to his routine where he had more time and he could decide what he wanted to do.” (Louis’s mum)

Such a positive view was of course only applicable to those young people who were sufficiently able, or who had sufficient support in place, to choose to take part in additional activities. The majority of the sample did not fall into this category, and most parents hence did report struggling to fill their son’s or daughter’s time. In addition to placements being part-time, parents commonly also reported a substantial gap between school exit and the beginning of services or placements: “She left school in June, and it was December before she got anything” (Sarah’s mum), which again left young people with lengthy

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<sup>14</sup> A work placement organised through college.

periods of time during which they had little, or no, meaningful daytime activity. This situation was problematic for young people and their families alike; as discussed previously, parents struggled to fill their child's free days in order to avoid the challenging behaviours that often manifested as a reaction to boredom or frustration, and which conversely made it even more difficult for them to engage in activities within the community:

“At the moment she's sitting in the house, she's sitting on the computer, her iPad, and that's all she's doing all day. And she's falling asleep during the day ... I feel that she's not getting motivated, and 'cause she was in a routine through school, but now ... she's not got a routine now and ... her behaviour is getting more harder because she's not doing anything.” (Hannah's mum)

A lack of funding was universally perceived as contributing to ongoing difficulties with sourcing appropriate activities for young people, and parents gave multiple examples of services or placements that had had their funding cut, leaving young people with fewer and fewer opportunities upon leaving school:

“There's not a lot about. The employment team did have, they had some little fruit and veg stalls that ran from different places ... but the funding was pulled for that so that's all gone so that wasn't something that he managed to get an opportunity to do. There is a garden centre<sup>15</sup> close by and again the funding was pulled from that about two years ago ... so again that was something he didn't have. So there's very little about, what there is has lost its funding and things are getting more and more difficult.” (Simon's mum)

In the absence of any opportunities for employment, and fewer and fewer community services, college<sup>16</sup> was regarded as the only plausible option for some young people:

“She left school and went straight into college. And that was the only sort of option if she wasn't going to get a job. That was it; there was no other organisations or anything that would be suitable.” (Sally's grandad)

This led to a situation whereby college was perceived as a stopgap for young people, as it was somewhere that they could go that would in some ways mirror the routine that they had been accustomed to at school, reinforcing the suggestion in the previous chapter that some young people attended college simply for want of any alternative activities:

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<sup>15</sup> Funded work placement specifically for people with intellectual disabilities.

<sup>16</sup> Offering funded courses specifically for people with intellectual disabilities.

“Somebody gave me a tip just saying ‘enrol her for the next 10 years in as many courses as you can’, ‘cause at least she’s staying in that [education] loop.” (Zena’s mum)

More positively, as well as providing a secure, familiar routine, college also served to maintain young people’s access to psychological support via education services; something that was crucial given the high incidence of mental health problems among the young adults with intellectual disabilities. Problems were hence experienced when young people were forced to undergo a second transition out of college, and were again faced with a disruption to their routine and a search for new activities:

“He got to the age where [college] can’t keep him anymore which is a shame because that’s the only form of counselling. And that’s when I had problems, when he left college last year for good.” (Jeremy’s mum)

### **40.3.2 Barriers to accessing ‘something to do’**

For some parents, a diagnosis was regarded as a gateway to accessing specific services that might not otherwise be available to young people. A recurring theme throughout Celia’s mum’s interview was her daughter’s lack of a specific diagnosis, which she felt would be critical in allowing her to access support and in ensuring that those around her understood the causes of her behaviour, which would in turn impact on her success in the workplace: “[Her support worker]’s always said to me ‘we need to be told something’, she has to be diagnosed with something and then she’ll get all the support.” (Celia’s mum)

Indeed, David’s mum reflected on how her son’s diagnosis of autism had been integral in allowing him to access additional services:

“There was really nothing until we got in touch with Autism<sup>17</sup>, but David wasn’t diagnosed with autism until he was 15, and then they contacted the Autistic Centre and we managed to get three days with them.” (David’s mum)

For young people with physical disabilities or complex health needs, additional barriers to work are experienced in terms of the practicalities of being in the workplace with additional support needs. Those young people who needed carers to accompany them to work in order to provide personal care or one-to-one support, or those who needed adaptations to be made to accommodate physical disabilities, experienced greater

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<sup>17</sup> The National Autistic Society.

challenges to establishing something to do after school exit. This phenomenon was attributed to the challenges of being disabled in an ‘ableist’ society:

“[The social worker’s] saying there’re jobs in charity shops, I’m looking at charity shops and I’m thinking ‘there’s not any space for walking about, never mind a wheelchair.’” (Zena’s mum)

Indeed, all of the interviewees’ sons and daughters who were engaged in daytime activity were involved in activities specifically for individuals with intellectual disabilities. This exclusion from mainstream spaces was a source of sadness for some young people, who were prohibited from accessing normative goals of adulthood, such as paid employment:

“She works in a mainstream nursery at the moment ... but she has it in her head that she’ll get a childcare qualification and they’ll let her get paid for her work ... such unrealistic expectations [have] made her very unhappy.” (Lara’s mum)

### **40.3.3 Routine**

A recurring theme throughout the interviews was the damaging effect of disruption to the school routine. School and its associated routine had dominated young people’s lives for as long as they could remember: it was “all that [they] had known” (Aaron’s mum). In this way, school was the only activity for which young people had a schema, which may go some way to explaining their desire to replicate the school routine, at least in part, by attending college. The cessation of this core part of young people’s existence was often upsetting, and contributed to considerable distress, especially when there was little to replace it, and nothing with the same degree of stimulation that school had offered. For example, Zena’s mum shared an emotive anecdote heard from a parent at a voluntary support group that she ran for parents of children with intellectual disabilities:

“From [my friend’s son] going ... primary one to seven, full time 9 till 4, going to secondary school 9 to 4, his day is now 10 to 2, two days a week ... and [my friend] said that he’s not coping very good with that ‘cause he’s not in a routine; he was crying driving past ... and not going into school.” (Zena’s mum)

A lack of routine was therefore distressing for some young people who craved the consistency that school offered. Parents reinforced the idea that for many young people with intellectual disabilities to be happy and successful, routine and hence consistency were key ingredients in their lives.

Parents often spoke about the preparation that went into most aspects of their lives, stressing that these were necessary strategies to have in place for their children, who struggled to cope with deviations from their norm: “It’s got to be like a set routine. I think if anything breaks the routine it’s gonna be stressful for him” (Jamie’s mum). From parents’ perspectives, routine was seen as key not only to maintaining young people’s wellbeing, but also to managing their behaviour:

“At the moment that’s what we’re seeing a lot of frustration around. Later on in the day she’s fed up because she would have previously had the school routine ... and now there’s just absolutely, there’s nothing.” (Caroline’s mum)

Indeed, those young people who were without any daytime activity, and therefore who had no structure to their day, were those whose parents reported the exhibition of more disruptive behaviours. In some cases, this behavioural pattern was attributed to frustration, boredom and a lack of stimulation. In others, it was attributed to a reluctance to engage in any activities at all once a lack of activity had become a normal part of everyday life. Parents feared their son or daughter “sitting on the Xbox all day” (Daniel’s mum) after school exit, and many assumed that, without the routine of school or something comparable, young people would quickly fall into the habit of doing nothing. In contrast, those young people who had gone straight from school into a placement or course experienced less anxiety during the transition, lending support to the notion that routine – and the stimulation provided by scheduled activity – are indeed key to maintaining young people’s wellbeing:

“I also found the stimulation of having so many new experiences [at college] as well balances out the fear of not having the old routine anymore. So that extra stimulation made a huge difference.” (Tim’s mum)

In this way, new activities offering appropriate stimulation, and eventually a new routine, were sufficient to combat the negative effects of the loss of the familiar school routine.

#### **40.3.4 Inappropriate placements**

A common problem identified throughout the interviews was that post-school placements<sup>18</sup> were often put in place for young people without full consideration being given to their

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<sup>18</sup>Placements for individuals with intellectual disabilities are arranged by social workers and might include a place on a course at college or a supported work/activity placement.

individual requirements. This situation led to young people being put into inappropriate placements on transition from school, which affected their wellbeing in various ways:

“[The social workers] were saying they’re wanting to put her in a cheaper place, so like [the community centre]. And you walk into [the community centre], the doors don’t lock ... so there’s not any security ... and you walk in, there’s a big café. So Hannah’s obsessed with food ... I said ‘that’s not good for Hannah’, she is obsessed with anything like that, the minute she sees food it’s like ... she’ll do everything in her power to get to it and I was like that ‘no’, I said ‘I’m not putting my daughter through that’.” (Hannah’s mum)

The above quote highlights the negative effects of austerity – resulting in a drive towards cheaper placements – on the most vulnerable individuals during transition. Indeed, among those young people who had been successful in securing a placement following school exit, many parents were dissatisfied with where their child had been placed, maybe because, for example, they had been left without adequate support, again probably reflecting a lack of funding:

“Louis was left without any support in the [college] classroom whereas at school he’d had a learning assistant with him at all times ... there was a year of Louis feeling lost and a bit anxious because he couldn’t keep up.” (Louis’s mum)

This led parents to discuss the difference between school and further education or services for young adults with intellectual disabilities; while schools often tailored their curriculum to fit the needs of the young person on an individual level, this level of individualised planning was unavailable after school exit:

“Sarah ... went through the whole school with her own curriculum; she didn’t go the national curriculum, so I don’t see why she’d stop just because she’s leaving. They personalised her education for ... 13 years ... it should be personalised before she leaves.” (Sarah’s mum)

As mentioned above, a high incidence of health issues was described in the sample of young people, with many requiring individually tailored support to be able to access a placement. Adult services were considered to offer poor support compared to school, however, which puts young people in danger of not receiving appropriate care. This problem was attributed by parents to a lack of funding and education among staff working in adult services:

“I don’t see him getting the same amount of stimulation as what he gets ... at school. The opportunities that are open ... when they’re at school, it’s not like

that once they go into adult services. The quality of training, the knowledge base of staff isn't the same as what it is in schools." (Jake's mum)

At the opposite end of the scale, a minority of parents reported that the placement in which their son or daughter had participated had been inappropriate because it was not challenging enough for them. For example, Sally's grandparents discussed their concerns regarding Sally working at a repetitive job in an environment exclusively for people with intellectual disabilities. They felt that Sally could achieve more if she were in an environment with people "not like her" (Sally's gran), but recognised that she enjoyed an environment where she could be herself without worrying about her difference relative to other people. This concern prompts important questions about the function of having something to do during the day; whether the primary purpose was for Sally to be challenged, or whether it was for her to have an enjoyable environment in which she could socialise with her peers, speaking to much larger questions about exclusion/inclusion of people with intellectual disabilities from/in mainstream environments:

"The job was very much a dead end job ... so it wasn't very challenging ... but again ... Sally likes working with people with learning difficulties and she likes working with kids she gets on well with so, you know." (Sally's grandad)

### **40.3.5 Socialising**

As identified via young people's interviews (see Chapter 6), when young people left school, they not only lost the routine and stimulation of their classes, but also their primary opportunity to socialise with their peers, since many young people could not independently arrange to meet friends in the community:

"I think when he initially left school he ... lost touch with a lot of people. It's really difficult to maintain those friendships 'cause sometimes you have no idea who the parents are. When your child's at an additional needs school, then it's a bus that picks them up ... you don't build those relationships by standing at the school gate ... so you've maybe not got phone numbers to swap." (Arnold's mum)

Work was seen as a gateway for young people to socialise in the absence of school and a way for young people to spend time with people other than their families: "I don't want him to stay in the house, sitting about ... 'cause the two of us need to get a break from each other as well, definitely" (James's mum). Parents expressed concerns about opportunities for their child to socialise after leaving school, since many opportunities to socialise that had been available for children were no longer accessible to young adults. Parents stressed

that, although the options for socialising outside of school had always been limited, their children had still enjoyed crucial opportunities to make friends at school. Furthermore, social clubs seemed to become scarcer as young people got older: “I think there are lots of groups, sports groups and things like that for children, whereas adults it’s a bit more patchy” (Louis’s mum). This presented a barrier to socialising, as young people had relied on such groups to facilitate social contacts outside of school, and relied on them even more when they were no longer at school.

Such difficulties in socialising were often attributed to young people’s vulnerability in relation to their same-aged peers without intellectual disabilities, who parents worried would ostracise them. They discussed feeling more comfortable with their children socialising with peers who also had intellectual disabilities, since these groups were perceived as more accepting of difference; again speaking to issues regarding including individuals with intellectual disabilities in mainstream environments:

“I think maybe it would be better if he went to somewhere like Motherwell college<sup>19</sup> because there’ll be other kids in his situation that he could get friendly with, whereas if he goes to a college like [his brother’s] at they might not want to be friendly with him.” (Sam’s mum)

This situation became more apparent as young people grew older. Simon’s mum explained that when they were children, those with intellectual disabilities could join in with mainstream groups, as the differences between them were either not obvious or not regarded as problematic. However, as young people grow older, these differences became more and more apparent, making it harder for young people to fit into mainstream social groups:

“Things like Brownies and Scouts ... are quite good when they’re smaller, and they fit in not too badly ... but they get that bit bigger and it doesn’t fit anymore ... The gap tends to get bigger, the bigger they get. So while you’ve maybe got a five-year-old, six-year-old with learning disabilities who fits in not too badly with a local group, by the time they get to 15, 16, it just doesn’t work.” (Simon’s mum)

This situation meant that parents tended to believe that their children needed to attend social groups that were specifically for those with intellectual disabilities, chiefly because

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<sup>19</sup> Motherwell College runs courses specifically for people with intellectual disabilities.



they were ostracised or even bullied in mainstream environments. Since fewer of these groups are available or suitable when young people grow older, they are often left isolated:

“Outside of college ... she has no friends ’cause friends either don’t want to know because, you know, Sally’s not like themselves, or they take the piss, which ... Sally doesn’t like.” (Sally’s grandad)

Even in the case of friendships involving other young people with intellectual disabilities, similar problems sometimes occur. James’s mum explained that her son’s former best friend had “grown up” and no longer wanted to spend time with James. In this way, differences in capability *between* young people with intellectual disabilities become more apparent as they become older and some become more independent, while others remain childlike: “Stephen’s<sup>20</sup> not been down for a long time ... [he] used to come ... every Sunday, but he’s grown up as well, it happens” (James’s mum).

Besides leaving school, additional movements associated with transitioning to adulthood, such as moving out of the family home, also lead to isolation in the absence of community services for people with intellectual disabilities. This was the case for David, who had moved into his own flat in his late teens due to severe challenging behaviours exhibited at home following the sudden death of his father. David was provided with 24-hour care, but his mum discussed his profound isolation in the absence of school, work or community services: “There’s nothing for him to do in the community, so he’s kind of on his own” (David’s mum). Indeed, Arnold’s mum articulated the isolation that young adults are in danger of experiencing if they are forced to rely on paid support to facilitate their contact with the wider community: “When you’re out with one person all the time ... if they don’t make an effort to build those relationships with other people who you don’t know, then how are you going to do that?” (Arnold’s mum).

As discussed in the previous chapter, barriers to socialising with peers were experienced even more profoundly for those young people who had additional health needs, including personal care needs, which meant that they could not attend social groups without having someone available to attend to their care. Due to a lack of funding for paid carers, parents were often expected to attend social groups alongside their children in order to provide care. This expectation was the case for Hannah, whose mum lamented that this scenario

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<sup>20</sup> James’s former best friend.

undermined her daughter's independence and defeated the point of Hannah going out in the first place:

“The lady phoned me and said she had a place in the Glenpark club<sup>21</sup> ... and obviously Hannah needs personal care during the clubs and that, and she says ‘well you would need to sit with her’. And I’m going like that ‘no’... I was looking for somewhere that Hannah can go and it be like a wee night out for her.” (Hannah’s mum)

As with employment spaces, young people with personal care or accessibility requirements experience barriers to participating in many social activities, resulting in limited social networks and isolation following school exit.

## 40.4 Services and support

Besides being the primary source of stimulation and routine for young people, school had often also been the primary source of support for families. Transition was therefore a stressful time for parents and young people, who were unsurprisingly apprehensive about leaving this crucial support network:

“Everything had been all supported through school, through education, even all his health issues and things, it was all dealt with through school appointments ... and that was just going to all disappear.” (Simon’s mum)

Transition between child and adult services also necessitated a change in staff, and parents reflected on the disruption that moving between services did or would cause for their child. Many families had been working with the same professionals for many years, and were concerned about having to adjust to a new team of people:

“We have a really tight team, fabulous ed[ucational] psych[ologist], fabulous ... psychiatrist through the school team, social worker: all of these things will change when he moves over to adult services. And that’s going to be a huge learning curve ... for Adrian dealing with a new team, new people in his life that don’t know him as well as the ones that he has [now].” (Adrian’s mum)

Indeed, as discussed in the previous chapter, changes in staff were disruptive to young people, who relied heavily on their support: “You get used to it and then somebody else takes over, so he finds it quite frustrating” (James’s mum).

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<sup>21</sup> A club for young adults with intellectual disabilities.

#### 40.4.1 Inadequate care or support

Parents discussed a variety of ways in which the support that they had received during and after the transition from school was inadequate. The transition from school itself was often reported to be chaotic and short-term, with insufficient support from professionals:

“I can’t remember anything in the way of review meetings until maybe a few months before she left [school] ... I’d put a fairly desperate call into social work and said ‘somebody needs to come and support this’ ... so they ... found a social worker who was just about nine months pregnant so I thought that was totally pointless.” (Lara’s mum)

As well as transitioning from school, some young people had also begun to transition between child and adult health services. Adult services were regarded as inferior to children’s services, parents perceiving there to be less support in adult services and less speciality in treating people with intellectual disabilities:

“We’ve transferred with dentist ... lovely, lovely girl ... but lacking a bit of experience with people with profound disabilities ... Jake used to attend the dentist at [the children’s hospital], he just requires that speciality ... and that speciality doesn’t exist in adult services.” (Jake’s mum)

As well as a lack of expertise in treating people with intellectual disabilities in adult services, parents reflected on the differences in organisational structures that prevented their adult children from accessing appropriate support. For example, as discussed previously, mental health support in particular is accessed via education services; and, outside of this system, there is little service provision that parents deem adequate to meet the complex needs of the population:

“She had psychological support on and off ... When she was a child that was funded by ... education ... once she became an adult they couldn’t [pay for it] ... Lara will not be referred to a service like that now ... [in adult services] you get a six week block of CBT<sup>22</sup> where a nurse has gone for a wee course. I’m sorry, Lara is very complex.” (Lara’s mum)

The inaccessibility of appropriate care had led to significant delays in seeing professionals: “It took 14 months from when ... our GP referred him for a psychologist, it took 14

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<sup>22</sup> Cognitive Behavioural Therapy: a widely used evidence-based treatment for depression and anxiety disorders.

months and then she saw him once” (Jeremy’s mum); a most concerning scenario considering the extent of mental health difficulties described in the sample.

Another inadequacy in care provision was identified in the lack of education provision for carers working with individuals with intellectual disabilities. For example, David’s mum reflected that his care provision did not meet his needs. Thus, even though David was living away from the family home, his mum still needed to take ownership of his care in order to ensure that he was appropriately stimulated rather than simply “babysat”:

“The carers I’ve got at the moment, I don’t think they forward think, they don’t think about things for him to do. Everything that he does, I basically suggested everything to do ... I’ve had to push everything.” (David’s mum)

This lack of support was often attributed to insufficient funding within adult services. Parents frequently discussed inadequacies in the budget that their child was allocated to pay for their post-school needs; often these budgets were implemented without paying sufficient attention to each young person’s individual strengths and needs:

“I think what we didn’t get was a recognition of who Louis was and what his needs were. I think there was a push to try to categorise him as being more able to save money.” (Louis’s mum)

A factor in contributing to this issue was that budgets were often put in place by social workers who parents felt did not know their child sufficiently well to recognise their needs:

“The new social worker, she’s met Hannah maybe three or four times and ... she thinks she can judge Hannah on what she sees ... she’s ... seen Hannah twice and she was going in her report ‘Hannah can do this and Hannah can do that’, and it’s not like that.” (Hannah’s mum)

Social workers were universally identified as the gatekeepers to accessing services and supports for young people both during and after the transition from school, but parents expressed frustration that there was very little evidence of tangible action being taken by them:

“I felt as though ... people who we dealt with, the social workers who we dealt with face-to-face and the educational psychologists, they all listened and everyone would nod their heads and agree at the ... meetings, but then nothing would be done after that.” (Adrian’s mum)

In this way, the support and care received by young people with intellectual disabilities routinely falls short of their needs. This phenomenon contributes to both a stressful transition from school, with young people being placed in inappropriate environments, and a situation where, if they do require service input for psychological or more general health problems, they are seemingly unable to access the necessary care.

#### **40.4.2 Funding**

As mentioned above, adult services were universally identified by the parents in this study as less well funded than child services: “All I hear is ‘there’s no money in adult services, there’s no money’” (Molly’s mum). This was a frustrating issue for parents, who juxtaposed the disparity in service provision with the fact that their children’s needs had not changed simply because they had turned 18:

“Children get more money [but] as soon as they hit adult services there’s very little going in for them ... and I think that’s wrong ’cause, although they reach 18 and they become an adult, their needs are still the same as what they were at school.” (David’s mum)

Parents expressed concerns about services in which their child was already involved being cut. These services were a vital source of activity and opportunities to socialise with peers, and parents worried about their son or daughter being “abandoned” (Celia’s mum) if these services were to finish. They reflected on how cuts to funding would impact their child’s psychological wellbeing if services were cut short or stopped altogether. Consistency was highlighted as integral to allowing young people to settle into a new post-school routine, with breaks from consistency potentially having negative implications for their overall wellbeing: “Whatever they give him it’s got to be consistent. Because if it’s not then he’ll break down as well” (Jamie’s mum). Funding was also an issue in terms of personal budgets, and many families anticipated that their allocated funds would fall short of their child’s needs:

“I’ve spoken to a few people [and] they’ve all sent their budgets<sup>23</sup> back because it’s miles short than what it should be so I’m preparing myself for that as well. No doubt it’ll be another fight.” (Carol’s dad)

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<sup>23</sup> Budgets are allocated by social workers for an individual with intellectual disabilities’ care provision (see Chapter 1).

Indeed, some individuals were not receiving adequate care as a result of funding issues. For example, Zena required carers to be present in order for her to shower, since her mum could not lift her into the shower alone. Her mum described how her limited budget meant that she was unable to employ carers to assist with Zena's shower more than twice a week; something that she worried would cause increasing difficulties when Zena started menstruating:

“You're getting social work going ‘oh there's no money for an extra shower’ ... I'm thinking she's not even took her periods yet, what's it gonna be like ... I'll need five showers on the weeks of her periods.” (Zena's mum)

Some of the parents interviewed were single parents and struggled to manage their child's care besides their other commitments; in these instances, budgets fell short if they did not cover a full-time placement for their child with intellectual disabilities during the week. However, in cases where both parents were present, budgets were also negatively impacted. For example, Aaron's parents explained that, because they were both available to take care of him, his budget was extremely limited:

“Because [Aaron's dad's] retired and I'm at home they call it a deflator<sup>24</sup>. Because we're here and Aaron's obviously in a loving caring home he's very limited with his budget and what we can do.” (Aaron's mum)

This limited budget meant that Aaron's parents spent the majority of their time taking Aaron to and from the various activities that filled his week. This situation meant that Aaron's independence was inhibited, since he spent little time away from his parents: a scenario in direct opposition with what would be expected during a ‘normal’ transition. He became accustomed to spending time primarily with his dad, and had begun to display aggressive behaviours towards his mum, again demonstrating how inadequacies in service provision can undermine a young person's independence and prompt negative consequences for their overall wellbeing:

“We have noticed a change in him; his behaviour is becoming aggressive with me.” (Aaron's mum)

“I think to be honest with you he's so used to going out with me, the routine is him and I [and] if [Aaron's mum] comes along it interferes with that routine.” (Aaron's dad)

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<sup>24</sup> Families in these circumstances are given less money because they are deemed more able to provide care for their child themselves.

Again, it is clear here how austerity measures, resulting in limited funding for services and support for individuals with intellectual disabilities and their families, had profoundly negative consequences that permeated the transition experience for young people and their families.

### **40.4.3 Timescales**

A common problem reported by parents with important implications for young people's wellbeing was the timescale on which transition planning took place. This was the case in terms of practically allocating a budget to a young person, and also in the sense of holistically preparing young people for leaving school and entering the adult world (see Chapter 6). For example:

“In all these glossy books you get it's supposed to take a year to a year and a half, transition. We've still not got a word yet and we're ... beginning of April and you're talking the end of April before we're gonna get a budget, so that leaves like two months till school leaves.” (Carol's dad)

For those young people who had profound disabilities or complex health needs, longer timescales were crucial to allow new carers to get to know the young person for whom they would be caring in order to recognise any serious health issues that might occur. For some families, budgets had been delayed, leading to lags in the transition overall, since the young people simply could not transition to a new service until their health needs were properly understood by those caring for them:

“He's not got a budget, there's no package, there's nothing sorted. The other reason is for staff to be trained in Jake's medical equipment and also to be trained in reading Jake, because Jake's non-verbal. And because of his significant health needs it takes a long time to get to know Jake, to be able to read him and then [what] you're talking about could be life or death.” (Jake's mum)

The last minute nature of transition planning had left some young people with a considerable gap between finishing school and starting their new activities. Hannah and Caroline had recently finished school, but with no alternative activities in place for them at the time of the interview. As discussed previously, both young women were exhibiting challenging behaviours as a result of the delay in putting in place new packages of routine and activity during the day. Consequently, these challenging behaviours meant that they were less able to access the community, which was arguably of further detriment to their wellbeing:

“She’s in the house and she’s looking for food, she’s in the fridge and then when you say to her ‘no’ she’s opening the fridge door and slamming it, opening it, slamming it, or she slams all the doors, and then she lies on the floor, shoes get threw off, the socks, she’ll start stripping off ... she does it outside as well.” (Hannah’s mum)

#### 40.4.4 Positive supports

During the interviews, parents were encouraged to reflect on anything that *had* been useful to them in supporting their child through the transition from school. Some parents highlighted that having somebody to advocate on their behalf had been crucial in facilitating access to services for their child: “It’s like they’ve done the talking for her; they’ll say like ‘we’ve got this lassie’ ... and they’ve done a lot of the talking” (Celia’s mum). Having somebody to advocate for their young person’s needs in this way was crucial for parents, who felt that they did not always possess the emotional resources to navigate the challenges of arranging their child’s care on their own: “If I was not able to explain myself right ... in meetings ... I’d just give her<sup>25</sup> a look and ... she could step in ... if it was getting too much for me” (Jake’s mum). This support primarily came from voluntary organisations such as PAMIS, where individual support workers offer parents a vital source of expertise:

“And just sitting down with [the support worker]; obviously, with her experience and knowledge, she was able to ... just present to me the different scenarios. You know, how we could use the budget Caroline had been allocated ... I think without having their kind of experience ... you wouldn’t know where to start.” (Caroline’s mum)

Advocacy was deemed to be crucial for parents to ensure that their voices were heard and their children’s needs were met. Parents often reiterated that the transition posed a completely novel challenge to them; they had had no idea what to expect, and in these cases individual relationships with professionals had been invaluable in guiding them towards appropriate services for their young person.

In addition, facilitating the transition gradually from when their child was still at school was discussed by parents as being crucial to a smooth experience, since young people and, indeed, parents needed time to become accustomed to the changes in support network and activities that were occurring. This approach was specifically helpful for practical activities such as getting used to travelling independently or becoming accustomed to using

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<sup>25</sup> The support worker.



community resources, such as the gym. These experiences enabled young people to familiarise themselves with new environments within the safety of the school network, and also allowed them to develop schemas for appropriate behaviour in new situations: “He didn’t get thrown in at the deep end” (Mike’s gran). However, it was also stressed that, although efforts were made by schools to facilitate these gradual transitions, efforts could fall short and parents still said that they would have appreciated a longer lead-in to the transition. This is perhaps reflective of the fact that, while schools made efforts to facilitate gradual transitions, for example by including one day per week at college in young people’s final year curriculum, transition planning timescales were still short-term and delays in putting budgets into place were common. This situation meant that the crux of the transition was rushed, and families were left with little support and little information to guide them towards positive outcomes for their children.

## **40.5 Growing up**

### **40.5.1 Independence**

The transition from school had prompted parents to contemplate their children’s emerging adulthood. As young people grew older, parents tried to adjust to providing them with more independence, including facilitating age-appropriate activities, such as going to the pub, in an effort to facilitate a ‘normal’ life for their child:

“We’ll go into a pub ... sometimes she gets a glass of wine with her meal ... but even going in and having like a soft drink, she actually quite likes being in a pub ... she actually just likes being in that environment because it’s normal.”  
(Sarah’s mum)

Parents’ efforts to facilitate ‘normal’ activities for their adult children were sometimes undermined because young people did not always behave appropriately when out in the community. For example, Jeremy’s mum explained that her son often went on trips away for the weekend; and, while she tried to facilitate this age-appropriate independence, he still fell into trouble due to his lack of understanding about appropriate behaviour in public spaces:

“[Jeremy and his friends] went [away] one weekend ... and they didn’t book into the Travel Lodge so they went to the bus depot ... and [the staff] wouldn’t let them sleep at the bus depot and they were going crazy ... Jeremy and [his friends] were so angry and they got quite aggressive.” (Jeremy’s mum)

This example illustrates the difficulties experienced by parents in relation to facilitating independence in decision-making in their adult children, thus shedding light on young people's perceptions related to their parents' involvement in their decision-making, as identified through the pilot focus group and the interviews with young people (see Chapter 6).

Leading a 'normal' life was difficult for young people for reasons beyond their intellectual disabilities. For example, those young people who were in wheelchairs or who required personal care were limited in their opportunities to experience independence since, as discussed in previous sections, parents were often expected to accompany their children to provide personal care in the absence of any funding for paid carers. Children hence had to rely on their parents to access the community, which undermined both their independence and their sense of adulthood: "It's frustrating for Louis to be so dependent on me, he doesn't like it" (Louis's mum). Indeed, some young people experienced emotional distress as a result of their own incapability compared to their same-aged peers without disabilities, which prevented them from achieving normative goals of adulthood, such as living independently:

"[She has] such unrealistic expectations and that's made her very unhappy ... she's very frustrated with her lack of independence ... she feels great pressure that ... she should be [living independently] somewhere by now." (Lara's mum)

In this way, young people's transition to adulthood was delayed due to their relative incapability in navigating the adult community (and a lack of resources that might help them to combat this issue, such as paid support workers), resulting in a much later age at which independence was facilitated than might be expected in the typically developing population, with the young people in this sample continuing to rely heavily on their parents well into their 20s.

### **40.5.2 Adult identities**

When discussing the challenges associated with facilitating more independence in their adult children, parents often called attention to their children's increasing physical size: "He's ... six foot two, he's a big tall man now" (Aaron's mum); which exacerbated problems in the community if their children behaved inappropriately: "If he's angry he's capable of hurting" (Jeremy's mum). Indeed, this disparity between young people's chronological age – and the resulting physical changes – and their developmental maturity

had caused young people in this study to encounter difficulties in the community since their mature physical appearance led to expectations for mature behaviour that they were unable to provide:

“People look at him as though he’s mature because he’s that size ... People assume that he’s going to come across as a mature person and then he says something younger.” (Jamie’s mum)

There was a perception that challenging, or indeed ‘childlike’, behaviours were more accepted by society when exhibited by children, but that once young people reached a certain age or size these behaviours were no longer tolerated. This situation sometimes caused upset within young people, as they struggled to adjust to emerging expectations for different behaviours that they did not always fully understand:

“He comes home upset now sometimes because [teachers at school] say ... ‘well you’re meant to be like an adult, looking after yourself’ ... It’s just too much pressure for them.” (Jamie’s mum)

This scenario led some parents to discuss the developmental delay experienced by their sons and daughters, describing their behaviour during their mid 20s to be reminiscent of that of a typically developing teenager:

“Even though he’s 25, it feels like ... my 14- and 12-year-old [sons] are going through puberty, it feels like he’s at a similar stage ... So kind of the moodiness and the ... losing your temper ... for nothing.” (Arnold’s mum)

This phenomenon caused problems in the community due to young people’s aforementioned adult physical presence:

“Jeremy was ... a 25-year-old acting like an adolescent, doing what 13- or 14-year-old neds<sup>26</sup> were doing and ... he was starting to get into trouble ... he was so old and so big and acting like a 14-year-old.” (Jeremy’s mum)

Indeed, this developmental delay caused parents to reflect on the various kinds of delays that their children experienced throughout the transition to adulthood, with parents of older children arguing that transition in the sense of attaining independence occurred much later in these young adults than would be expected for typically developing people because of their relative immaturity. Moreover, these parents detected here a mismatch between the organisational supports in place to cater for transition – assuming a ‘normal’ timing for

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<sup>26</sup> Informal Scottish term for a hooligan.

transition, around the age of 16 to 25 – compared with when in reality such supports are needed, when the young people in question might well be some way into their late 20s:

“She’s very much going through transition in a big way just now, much more than she did when she was 18 ... It would be cruel to do all the transition stuff and think it would be finished ... by 25.” (Lara’s mum)

Nevertheless, it was still considered important that young people be allowed access to mundane but important components of being a ‘grown up’, for example being able to buy a drink at a bar. Some of the support networks in place for young adults with intellectual disabilities prohibited such adult experiences, however, which consequently reinforced a childlike identity:

“To me a lot of it is like totally age-inappropriate, it’s like they still put things on that are for teenagers or for younger children ... [an organisation for individuals with intellectual disabilities] put dances on and until recently they wouldn’t open the bar ... they used to give everyone a can of juice and a packet of crisps.” (Arnold’s mum)

The experience of growing up is hence extremely complex for young people with intellectual disabilities, with the institutional supports available to them simultaneously forcing an organisational transition to adulthood, for which they are perhaps not yet ready, and reinforcing a childlike status by blocking their experience of normative aspects of adulthood. These conflicting messages negatively affected young people’s wellbeing in general: “She is herself very confused at the moment” (Lara’s mum).

It is important to note that the issues described here in relation to developing independence and an adult identity were experienced primarily by those with mild to severe intellectual disabilities. The meaning of adulthood for young people with profound intellectual disabilities was in practice considerably different, and during the interviews parents tended to focus on the practical aspects of their children’s transition to adult services. However, parents did still express a desire for their children to be independent of them at some point in the future, simultaneously acknowledging that their children would never be able to be wholly independent, but also referencing a desire for them to experience some aspect of a ‘normal’ transition, which in these circumstances usually entailed living in supported accommodation. Thus:

“Independent living is something that I’ve spoken about ... I think it would be a good thing for Molly at some point in her life to be living with her peers ... Molly is reliant for everything, for her total care, she needs to be kept safe ...

[but] I think she deserves to be doing her own thing, so yeah I would like that at some point in the future.” (Molly’s mum)

### 40.5.3 Intimate relationships

As described in the previous chapter, having a romantic relationship was regarded as an important aspect of adulthood by young people. Some parents were positive about their children experiencing intimate relationships, and actively encouraged such things: “The day he gets a girlfriend I will be down on my knees thanking God” (Tim’s mum). Others, however, were less positive. Through her discussion of her daughter’s experience of having a long-term boyfriend, Zena’s mum revealed an interesting ambivalence regarding her comfort with Zena engaging in a relationship. Although she reported actively encouraging Zena and her boyfriend to go on dates, she reinforced that, due to both Zena and her boyfriend being in wheelchairs, they would not be able to engage in any sort of physical relationship. Thus, it was deemed acceptable for Zena to have a relationship in the social sense, but not in the physical sense:

“Zena and Ross did have a really good relationship ... We done a lot of setting them up on a date ... Because the two of them were in wheelchairs ... they couldn’t go further than that, they can’t reach over to kiss each other so I’m OK about holding hands and I don’t think that’s, I think we should be encouraging it.” (Zena’s mum)

Zena had been prohibited from holding hands with her boyfriend in school by teachers; and, while Zena’s mum expressed outrage at this situation, perceiving it to be discriminatory, it is clear from the above quote that she too felt some discomfort at the thought of her daughter having a physical relationship.

Meanwhile, Sam’s mum highlighted a different source of discomfort in relation to her son being involved in a relationship, for she struggled with his potential vulnerability to exploitation:

“I think part of me I worry that he won’t meet somebody; my other part is he’ll meet somebody and then they’ll just mess him about and, you know, just take everything off him. Sam would just give them everything ... I don’t think he would understand that they were just taking everything off him. That is just gonna break my heart, honestly.” (Sam’s mum)

She went on to confirm that she would feel happier for Sam to be in a relationship with somebody “of the same level”; perhaps somebody he might meet through the additional support needs base that he attended at school, rather than from the mainstream school.

Hence, it was deemed acceptable for Sam to enjoy a romantic relationship, but only with somebody who also had a disability, since it was assumed that a more equal relationship in terms of cognitive ability would protect him from exploitation. In contrast, other parents seemed not to have contemplated the idea of their child engaging in a romantic relationship at all, and seemed slightly perturbed when they were asked to think about it: “I don’t know how I feel about that actually ... It’s never been something that I could imagine, Adrian having a girlfriend” (Adrian’s mum).

As with opportunities to socialise and to work, those young people who required additional support to access the community experienced more limitations in their ability to experience intimate relationships; a situation that was further complicated by a broader societal discomfort about adults with disabilities expressing any sort of sexual identity:

“I think ’cause he can’t go out without support it’s really difficult. Like he’s got a girlfriend ... but then it’s how do you manage them meeting outside [of their work placement]? ... A lot of people are dead against adults with disabilities having relationships, which is sad.” (Arnold’s mum).

In this way, young people with intellectual disabilities were again potentially excluded from this important facet of adulthood, putting them at further risk of isolation, or loneliness, and potential loss or constriction of wellbeing.

## 41 Summary

The primary purpose of the interviews with parents was to ascertain whether, and in what ways, the transition from school had affected health and wellbeing in young people with intellectual disabilities. Parents of children with mild to profound intellectual disabilities at various stages of the transition to adulthood took part in interviews, uncovering perspectives from a broad range of people. Parents were strikingly unconcerned about their young adults’ health during transition, despite the high incidence of health conditions otherwise reported. This lack of concern with health is further evidenced by the EQ-5D scores; with a mean score of 7.6 out of a possible 10 (with a higher score indicating better health), it can be assumed that most young people or parents rated their health as generally positive.

However, transition was reported to affect mental health and wellbeing in a negative manner, and nine out of the 23 young people whose parents participated in interviews scored in the ‘abnormal’ range of the SDQ, indicating the presence of a mental health

difficulty. Given the profound changes that transition precipitates, the fact that transition was reported to be an anxious period, challenging to wellbeing, is perhaps not surprising. Parents acknowledged that their sons and daughters were already prone to anxiety, but specific challenges related to the transition from school were described as exacerbating mental health difficulties. Furthermore, among those families who had stabilised a new routine for their young person, reports of anxiety ‘calming down’ were common, suggesting that the transition itself was, at least in part, a causal factor.

A lack of stimulating activity was identified as perhaps the most important factor that contributed to anxiety during this period, with young people experiencing profound changes in their routines, and often having little or no activity in place of school for significant periods. This situation negatively affected young people’s acquisition of the skills necessary to navigate the community, and their opportunities to socialise with peers, which in turn had negative consequences for their mental health and overall wellbeing. Delays in transition planning and inadequate services were crucial in contributing to this lack of activity for young people.

The transition to adulthood was significantly delayed for these young people with intellectual disabilities. Delays were caused both by organisational factors (wherein slow progress in allocating budgets caused delays between finishing school and starting new activities, which often prompted challenging behaviours, themselves limiting young people’s ability to access the community) and by young people’s own incapability in navigating the community by themselves (and a lack of organised support to combat this issue). This situation means that many facets of transition continue into, and indeed may not even begin for these young people until, the 20s. Despite this phenomenon, the organisational structures in place to support the transition follow a more ‘normal’ model, expecting to have the transition completed by the early 20s. This complicated situation had negative consequences for the overall wellbeing of the young people included in this sample, with those with milder intellectual disabilities experiencing frustration at their perceived inability to achieve normative goals of adulthood. Furthermore, parents’ understandable desires to protect their children from harm in the adult world might sometimes cross over to overprotection and a reluctance to allow young people to exercise independence in decision-making, which in itself may cause emotional distress for young people; something that was suggested by some of the young people who participated in both the pilot focus group and the interviews.

A secondary research question was whether the experience of transition is similar or different for individuals with multiple and profound intellectual disabilities, compared to those with mild to moderate intellectual disabilities. The interviews revealed some important differences in terms of the meaning of transition for these individuals; while for those with mild to moderate intellectual disabilities opportunities for increased independence from parents were being facilitated, for those with profound and multiple disabilities transition was focussed more on the practicalities of the movement from school to adult services. Further, for those individuals who experienced comorbid health conditions, the transition was further complicated by logistical problems experienced in accessing appropriate care in order to facilitate community involvement. Additionally, as identified through the young people's interviews, through this data it is clear again how those young people who were wheelchair users or who required personal care to access the community were most vulnerable to exclusion from adult environments, resulting in the poorest outcomes for these individuals. This situation can to some degree be attributed to the lack of available funding for services and support for individuals with intellectual disabilities resulting from austerity.

The next chapter will synthesise findings from the interviews with parents with findings from the interviews/ethnography with young people with intellectual disabilities. The results from these qualitative studies will also be compared to the results of the secondary analysis of Scotland's Census (2011), as reported in Chapter 5, in order to capture both broad and deep insights into the thesis research questions. The principal findings from the qualitative and quantitative components of this thesis will be compared with existing literature, and the strengths and limitations of the studies in this thesis highlighted. Finally, the implications of this work for policy and practice will be explored, and suggestions for future research identified, before outlining the conclusions of this thesis.



## Chapter 8: Discussion

This chapter will synthesise and interpret the main findings from the quantitative (Chapter 5) and qualitative (Chapters 6 and 7) studies, comparing and contrasting the data from both, as well as considering the findings from these studies in the context of previous literature. The methodological strengths and limitations of the studies will then be discussed, before the implications of this work for policy and practice are addressed. Finally, possible avenues for future research will be explored.

### 42 Principal findings

The following section will describe and interpret the principal findings from both the secondary analysis of Scotland's Census (2011) and the qualitative studies, including the ethnography and the interviews with young people with intellectual disabilities and parents of those young people, as they relate to each of the research questions outlined earlier in this thesis (see Chapter 3).

#### 42.1 Does transition affect health and wellbeing in young people with intellectual disabilities, and in what particular ways?

##### 42.1.1 General health

The secondary analysis of Scotland's Census (2011) included comparisons of two age groups of individuals with intellectual disabilities: those aged 13-18 years (who were likely to still be in school) and those aged 19-24 years (who were likely to have left school). General health did not seem to be worse in the older age group in the population with intellectual disabilities; in some respects general health actually appeared worse in the younger age group: being aged 13-18 years independently predicted both having a higher number of health conditions and reporting health-related activity limitations. It is possible that the most disabled young people with intellectual disabilities fail to reach adult years, as long-term conditions are, by definition, long-term, so one would not otherwise expect to see a reduction with age. Hence, those with the worst health may be under-represented in the older age cohort. Indeed, within the Census (2011) data, the population with intellectual disabilities is younger overall than the population without intellectual disabilities (Scottish Learning Disabilities Observatory, 2016).

As well as comparing between age cohorts, the secondary analysis utilised logistic regressions in order to characterise the population with intellectual disabilities with the worst health during transition. Females were found to have worse physical health than males, being more likely to report 'poor' general health; to have a physical disability; and to be deaf or blind. With regards to geographical factors, individuals with intellectual disabilities living in the most deprived areas of Scotland, and those living in urban environments, were more likely to report 'poor' general health than were those living in the least deprived areas or in rural environments, suggesting that the proportion of the population with intellectual disabilities living in these environments may be the most vulnerable to poor general health during transition. It is noteworthy that, given the young age of the population under investigation within this analysis, the majority of young people are likely to have been residing in their parental home, and so the use of postcodes to identify area deprivation is likely to provide a purer measure of deprivation than might be the case for adults with intellectual disabilities, who may be living in communal establishments in more affluent areas (a point which will be discussed later on in this chapter).

Despite the high prevalence of health conditions identified through the Census (2011) analysis (see Section 42.2), one of the key findings from the qualitative studies was the lack of concern over health that young people with intellectual disabilities and their parents alike demonstrated. The mean score on the EQ-5D rating scale was 7.6, where 10 was the highest score. This quantitative finding reinforces the qualitative data which suggest that young people and their parents rated their general health as relatively good. However, it was clear that young people did experience a high incidence of health problems, which they did report having to consider in the context of transition, when they moved to new environments where they would have to continue to manage their conditions, for example in managing symptoms or taking medications. The fact that parents and young people did not report significant concern over their general health during transition may reflect the fact that health problems in the population with intellectual disabilities are both anticipated and routine, and hence not considered notable in an interview setting.

A need to lose weight was the primary general health concern reported by young people with intellectual disabilities. Parents also described concern over their children's post-school weight gain, with a lack of activity contributing to a more sedentary post-school lifestyle, and the inaccessibility of mainstream environments, such as gyms, preventing some young people with intellectual disabilities from exercising. This phenomenon may

reflect a gap in the post-school support provided to adults with intellectual disabilities in terms of maintaining a healthy lifestyle; given the wide-ranging health implications of obesity, tackling this particular dearth of support may go some way towards tackling the health inequality experienced by the population with intellectual disabilities.

### **42.1.2 Mental health**

Within the Census (2011) analysis, having a mental health condition was the only variable to be independently predicted by older age in the population with intellectual disabilities, suggesting that the experience of transition may have negative effects on mental health. Furthermore, having a mental health condition, alongside having a physical disability, independently predicted reporting 'poor' health in the population with intellectual disabilities. This apparent exacerbation of mental ill-health over the period of transition may therefore contribute considerably to overall negative wellbeing.

Reinforcing the notion that transition may impact negatively on mental health, and in contrast to the qualitative findings around general health, transition was strongly identified as having a detrimental effect on mental health throughout the interviews, with parents reporting their sons and daughters to be feeling anxious throughout the transition from school, largely due to: a lack of opportunities for meaningful daytime activity; complex issues surrounding facilitating and achieving independence; and a lack of professional support during the transition period. As discussed in Chapter 7, the negative experiences of young people with intellectual disabilities ranged from significant mental ill-health, causing impairments to functioning and limiting young people's ability to access the community, to more general emotional distress and negative wellbeing. Of the 26 young people who participated in an interview, or whose parents participated, 10 scored in the 'abnormal' range of the SDQ, indicating the presence of a mental health difficulty, and a further 3 scored in the borderline range. This quantitative measure of mental ill-health supports the qualitative findings surrounding the negative implications of transition for mental health.

Previous research has demonstrated that mental health in the population with intellectual disabilities is poor in childhood and adolescence (see Chapter 1, Table 1), and the results described here may simply reflect the fact that mental health is poor throughout the life course in this population. However, almost all of the parents interviewed described their sons and daughters experiencing elevated anxiety during the initial transition from school,

and outlined specific aspects of the transition experience (e.g. a lack of routine or uncertainty about the future) that they considered to be a significant cause of the anxiety. Furthermore, those who had stabilised a new routine reported these problems ‘calming down’, suggesting that the mental health difficulties were a reaction to the specific circumstances of transition; in particular, the disruption in routine caused by school exit. Alternatively, it may be the case that the existing mental health issues experienced by the sample prior to the transition period became more problematic when families experienced a decrease in the level of support received during the transition from school in to adult services. Indeed, in the majority of cases mental health problems experienced by young adults were attributed to the organisational factors associated with transition, including inadequate support and a lack of appropriate daytime activity. Additionally, a smaller number of interviewees attributed their son’s or daughter’s mental health difficulties to the frustration experienced as a result of their own perceived delays in ‘growing up’ and developing adult roles.

On a related note, parents of older children described their adult sons and daughters as experiencing developmental delay whereby their ability to regulate their emotions and to make rational decisions was impaired in the same way that their typically developing children’s had been when they were in their mid teens and were experiencing puberty. Some of the anxiety experienced by the young adults in the samples may hence be attributed to the social challenges associated with growing up, but at a significantly later age than would be expected in the typically developing population. Furthermore, this issue may be exacerbated by the contradictory circumstances in which young people find themselves, with some organisational aspects of transition encouraging them to be ‘adults’, yet others treating them as children.

As discussed throughout this thesis, one of the key components of a conceptual model of transition to adulthood is the development of independence and the assumption of adult roles, incorporating practical elements of adulthood, such as living independently. Through the qualitative interviews, parents reported struggling to facilitate independence in their sons and daughters, primarily due to concerns over their vulnerability in adult contexts. In some instances, this situation had exacerbated mental health difficulties in young adults who felt frustrated at their lack of autonomy and perceived incapability relative to their peers. Moreover, young people’s ongoing reliance on their parents had led to anxieties surrounding the prospect of coping independently in the adult world.

## **42.2 Is the impact of transition on health and wellbeing similar or different for people with intellectual disabilities compared with people without intellectual disabilities?**

The secondary analysis of Scotland's Census (2011) included age- and sex-matched comparisons of the populations with and without intellectual disabilities during transition. It indicated that, across the transition period under investigation, young people with intellectual disabilities have worse health than young people without intellectual disabilities. Adjusting for age and gender, those with intellectual disabilities were between 9.6 and 125.0 times more likely than individuals without intellectual disabilities to: report 'poor health'; to have a mental health condition, a physical disability, deafness, blindness; to report the presence of a long-term illness, disease or condition; and to report that their activities were limited due to health conditions or disabilities. Individuals with intellectual disabilities also reported a significantly higher number of conditions than did individuals without intellectual disabilities. This poor health evidenced in people with intellectual disabilities is concerning given the young age group, one which in the general population experienced good health. The population with intellectual disabilities is therefore considerably more vulnerable to poor health during transition than the population without intellectual disabilities.

The views expressed by parents and young people in the qualitative interviews regarding transition to adulthood can also be compared with those that might be expected from individuals without intellectual disabilities. Many of the issues that contributed to anxiety or emotional distress in young people during transition, such as frustration related to a lack of independence, might conceivably be similar for young people without intellectual disabilities. As discussed in Chapter 1, Bynner (2005) suggests that modernity has enforced a period of prolonged transition in the general population, wherein young adults extend their education and continue to live in the parental home for much longer than would have been the norm in previous decades. Hence, many of the concerns expressed by young people with intellectual disabilities may simply represent the concerns of any modern young person undergoing transition. Nevertheless, it must be acknowledged that young people with intellectual disabilities face substantial difficulties in navigating a wider community that is not always accepting of difference, and further that they must do so with the cognitive competencies of younger children (Zeitlin 1985). Moreover, many young people with intellectual disabilities require paid support to access the community, and

therefore face barriers to accessing activities when the required support is not available, which, as was identified in the qualitative interviews, is often the case. For most typically developing young people, this issue is not something that they would need to consider in the context of transition.

As foregrounded in the previous section, it was common throughout the qualitative interviews for parents to remark that the developmental delay experienced by their children with intellectual disabilities resulted in them displaying behaviours associated with puberty, such as getting into trouble due to oppositional behaviour or struggling to regulate their emotions, in their mid 20s. In this way, they described their children with intellectual disabilities as behaving like children in their early teens when they were actually in their 20s. In line with these delayed developmental changes, opportunities to develop independence from families, for example through moving out of the family home, were only just beginning to be considered by those young adults at a later stage of transition, when they were in their mid to late 20s. In this way, the transition was indeed in some ways delayed for young people with intellectual disabilities, so often the same things that would occur for young people in the typically developing population during transition did happen for young people with intellectual disabilities, but at a significantly later age.

### **42.3 Is the impact of transition on health and wellbeing similar or different for people with profound and multiple intellectual disabilities compared with people with mild to moderate intellectual disabilities?**

The qualitative interviews included young people with mild to severe intellectual disabilities, and parents of young people with mild to profound intellectual disabilities, offering important insights into how the experience of transition may differ in relation to different abilities. The meaning of transition and, indeed, adulthood for individuals with profound intellectual disabilities compared to those with mild to severe intellectual disabilities was found to be fundamentally different. For parents of individuals with profound intellectual disabilities, the transition was primarily organisational; parents described the changes in service provision and activity that their children experienced as they moved from school to adult services; and, while some parents did express a desire for their adult children to have some degree of independence, for example by living outside of the family home, there was a recognition that their children would never be able to be completely independent. In this way, transition for those with profound intellectual

disabilities appeared to be more symbolic, since these young people were not able to exercise independence in decision-making, and hence were not able to experience many characteristics normally associated with ‘adulthood’.

The transition experience was in some ways more difficult for individuals with mild intellectual disabilities, for these individuals were able to reflect on their difference compared to their non-disabled peers, and therefore often had to contend with fears of experiencing stigma and exclusion in the wider community. These young people were vulnerable to mental ill-health in response to frustration associated with being unable to exercise the degree of independence that they would like; a complex issue that was associated with parents’ own fears about their children’s vulnerability in the adult world, which often resulted in arguably, if understandably, overprotective parenting styles.

In other ways, however, the transition was more difficult for young people with severe or profound intellectual disabilities. Those who required personal care in order to access activities in the community (who were often, but not exclusively, those with severe or profound intellectual disabilities), struggled more to access the community independently of their parents because of a lack of funding for paid carers. As discussed previously, a lack of activity was perhaps the most important factor contributing to emotional distress and mental ill-health, and those who were unable to access the community were most vulnerable to these negative consequences of inactivity.

## **42.4 What supports (formal and informal) are helpful for people with intellectual disabilities during transition?**

The qualitative studies sought to uncover families’ experiences of both transition from school and transition between child and adult health services. In doing so, evidence relating to how the support received during transition had been ineffective was gathered, as well as some examples of supports and services that had been helpful.

### **42.4.1 Inadequacies in support**

While few of the young people interviewed had ongoing contact with health teams, among those who did have such contact the transition to adult health services had been significantly delayed, or had not yet occurred at all. Parents cited a lack of specialism in working with people with intellectual disabilities in adult services as the reason behind this phenomenon, with adult services seeming to work in a less person-centred way.

Furthermore, children's services were described by interviewees as providing more flexible, family-oriented care than adult services, which was regarded as more appropriate in meeting the needs of young adults with intellectual disabilities. In this way, when individuals with intellectual disabilities *did* receive treatment via adult health teams, their experiences were less than adequate.

A crucial area in which families were under-supported was in mental health; families frequently lamented the lack of mental health support that their son or daughter received, especially among those who were no longer in education, since mental health support in particular was reported to be provided via education services. Within the qualitative studies reported here, mental health issues were purported to affect young adults' ability to access the general community, which had further negative implications for their overall wellbeing. Given this detrimental effect of mental health problems on other transition outcomes, and the high prevalence of mental health issues identified in the population with intellectual disabilities via the Census (2011) analysis, this lack of provision of mental health services is concerning.

The move from school was characterised throughout the qualitative studies by a lack of continuity, with the professionals responsible for supporting the transition, such as social workers, changing frequently, and with delays in implementing funding for activities beyond school resulting in significant gaps between school exit and the uptake of new activities. These factors combined to produce uncertain, confusing experiences for families, with significantly delayed organisational transitions. Social workers, identified to be the gatekeepers to accessing services for children and adults with intellectual disabilities, changed frequently and were largely characterised as unhelpful, with the key difficulty for parents described as a lack of transparency and information provision during the transition period. This issue may be related to structural problems faced by social work in the context of austerity, with social workers being in short supply and hence overburdened with cases, as well as circumscribed in what they can usefully do for the young people in their care. This situation ultimately resulted in a failure to access resources and care for young people in a timely fashion, which negatively affected their wellbeing in various ways; particularly in excluding them from participating in the community.

Among the qualitative samples described here, the most important factor that contributed to mental health difficulties for young adults during transition was a lack of daytime activity to replace the school routine. Parents attributed this phenomenon to delays



experienced in accessing funding for their children to take part in activities beyond school – such as college courses or work placements – and, for those who required support to access such activities, in delays to obtaining funding for paid carers to facilitate their children's participation in these activities. Hence, these delays in accessing services and support had both contributed to and exacerbated mental health problems for young people; a situation that was further compounded when young adults did not receive timely support for their mental health difficulties if and when it was required. In contrast, those young people who *were* involved in meaningful daytime activity reported significant increases in their confidence and social skills, since they afforded to these individuals valuable opportunities to access varied adult roles.

#### **42.4.2      Helpful supports**

There were some helpful aspects of support identified throughout the interviews, and one of the key positive supports identified by families was having a professional who could act as an independent advocate for the young person with intellectual disabilities and their family. These advocates were identified from a variety of sources, including third sector organisations, social services and healthcare teams. Thus, it did not seem to matter the source of the support; rather, it was simply having somebody available to offer expertise and to make suggestions about services during the transition that was most helpful.

The ethnographic study of the Social Circle run by the Moving On Transition Service offered insights into the type of support that was helpful to young people with intellectual disabilities undergoing transition. The specific focus of this service was to facilitate increased community participation for young adults through providing opportunities for social interaction; signposting to relevant clubs and activities; and providing training in the skills required to navigate the community independently, such as using public transport. Specifically, the necessity of a safe space for young adults with intellectual disabilities to socialise in the absence of school and often of any other organised activities was highlighted during the course of the ethnography. As discussed previously, young people often feared stigma or exclusion from mainstream environments, and many parents reinforced the importance of their children enjoying a supportive environment specifically for people with intellectual disabilities, which could potentially serve as a stepping stone to socialising elsewhere. Indeed, support and training in specific skills, such as independent travel, were crucial in providing young adults with the tools with which to be able to socialise independently; something that was repeatedly identified as important by young

people and parents alike in both the ethnographic and interview samples. The fact that the service ended due to funding issues at the end of the ethnographic period exemplifies a problem identified by almost all of the parents interviewed: a lack of funding for young adults with intellectual disabilities resulting in a lack of adequate support to access activities within the community.

## **43 Principal findings in the context of previous research**

The following section will consider the findings from the studies described in this thesis in the context of previous research.

### **43.1 Findings from the systematic literature review**

The systematic review of the literature (see Chapter 2) identified a dearth of evidence on the impact of transition to adulthood on general health in the population with intellectual disabilities. The studies described in this thesis have begun to address this gap in the literature, providing evidence that mental health may be negatively impacted by the experience of transition. Despite a high incidence of health issues, young people and parents did not report significant concern over the young person's general health in the qualitative interviews. This finding is consistent with the overall findings of the systematic review, wherein parents rated their transition-aged sons' and daughters' wellbeing in general as being positive, yet distinct health problems, including obesity, were also identified, alongside interpersonal problems, both of which were reckoned to have a substantial impact on young people's mental health and wellbeing.

These particular problems identified in the systematic review were also identified through the qualitative interviews. Firstly, obesity was highlighted to be of particular concern, with Rimmer et al. (2010) reporting parents of adolescents with intellectual disabilities to be 2-3 times more likely to report obesity and related secondary conditions (e.g. diabetes or depression) than parents of typically developing adolescents. The findings from the qualitative studies reinforce the notion that transition may be associated with increased weight gain, as young people experience increases in sedentary behaviour due to inaccessible mainstream environments in which to exercise and a lack of daytime activity in general. Secondly, interpersonal conflict was identified to be problematic during transition, with young people worrying about making friends (Larkin et al., 2012;

Rurangirwa et al., 2006), being bullied; and experiencing anxiety as a result of these problems (Forte et al., 2011; Young et al., 2016). The qualitative findings discussed here echo these results, and indicate that socialising, particularly in mainstream environments, may be difficult for some young people with intellectual disabilities, with experiences of bullying contributing to anxieties around future social relationships. Furthermore, a lack of 'safe' spaces designed specifically for young adults with intellectual disabilities (such as the Social Circle) may exacerbate these problems.

The findings of the systematic review in relation to mental health are mixed in comparison to the findings of this thesis. One article examined psychiatric morbidity before and after young people with intellectual disabilities had left school (Hepper & Garralda, 2001), and while a high frequency of emotional and behavioural difficulties in the sample overall was found, no increase in mental health difficulties was identified 6 months after school exit. Contrary to these findings, the Census (2011) analysis and the qualitative studies described here demonstrated an increase in mental health difficulties during transition. It is possible that the baseline mental health difficulties captured by Hepper and Garralda (2001) themselves reflect mental ill-health associated with the transition from school, since the baseline measure was taken during the final term before school exit and, as the qualitative studies indicate, young people may experience anxiety at the prospect of leaving school, which may continue until a new routine is stabilised.

Another article found that young people with intellectual disabilities were significantly more anxious than young people without intellectual disabilities, and that the content of their worries was largely related to bullying and decision-making (Young et al., 2016). These findings are concordant with the findings of this thesis, wherein the population with intellectual disabilities was found to be more likely to report the presence of a mental health condition than the population without intellectual disabilities through the Census (2011) analysis, and young people were found to express anxiety associated with previous experiences of bullying and their ability to exercise independence through the qualitative interviews and ethnography.

## 43.2 Findings from the literature in general

### 43.2.1 General health

Health during transition was found, through the Census (2011) analysis, to be considerably worse for the population with intellectual disabilities compared to the population without intellectual disabilities. This finding is consistent with previous literature, which has identified that rates of chronic health conditions are higher in children with intellectual disabilities than in the typically developing population (e.g. Oeseburg et al., 2011; see Chapter 1). However, during the qualitative interviews young people's general health was reported to be good, despite the high incidence of health problems experienced.

These findings from the Census (2011) analysis and the qualitative studies therefore appear contradictory, and may reflect differences in the methods of data collection. Poor health in those with intellectual disabilities may be both anticipated and routine, and therefore not considered worthy of comment in an interview setting; particularly when the interview was described as specifically about transition, since parents (and young people) may disregard the importance of health during the transition period when practical issues are of more immediate concern. Indeed, Henninger and Lounds Taylor (2014) investigated US parents' (n = 198) perspectives on successful transitions to adulthood for individuals with intellectual disabilities via an internet survey including an open-ended question on transition to adulthood. Although both psychological health, incorporating happiness, self-confidence and feeling challenged, and physical health, including being in good physical health and being safe from harm, were identified as important components of adulthood, these themes were some of the least frequently identified, with only 11.6% of participants mentioning psychological health and a mere 9.1% mentioning physical health. This finding contrasts with more practical concerns that were mentioned more frequently, such as having an occupational or functional role in society (65.2%) and living apart from the parent or caregiver (44.4%). Hence, despite parents acknowledging the importance of physical and psychological health in their adult sons and daughters, this matter may not be immediately considered in the context of transition, a period of time when other more logistical issues take precedence. In contrast, parents may be more likely to identify their child as having poor health in the context of a demographic questionnaire, which may encourage them to think in broader terms about the lives of their children. These seemingly contradictory findings underscore the value of triangulating data from different research methodologies in order to develop insights into a given topic (Olsen, 2004).

The Census (2011) analysis also indicated that general health may in some respects be worse for the younger population with intellectual disabilities (those who were still in school). As suggested previously, this phenomenon may reflect the fact that those individuals with the most severe health problems do not reach adult years. Indeed, a systematic review of studies examining mortality in the population with intellectual disabilities found that children with severe and profound intellectual disabilities had lower life expectancy compared to children with mild intellectual disabilities (O’Leary et al., 2017). It may also be the case that general health in the population with intellectual disabilities is poor from early childhood and does not worsen significantly during transition, although this suggestion is not supported by the qualitative findings, which suggest that some aspects of health (e.g. obesity) are negatively affected by transition.

#### **43.2.1.1 Gender differences**

Females with intellectual disabilities were found to have worse health than males via the Census (2011) analysis, being more likely to report ‘poor’ general health, and to have physical disabilities and sensory impairments than males. Previous research has also demonstrated that females with intellectual disabilities may have worse health than males. For example, the National Longitudinal Transition Study-2 (NLTS-2) (2003), a longitudinal study following 862 individuals with intellectual disabilities through their transition to adulthood in the USA, found a similar disparity in the health of young men and women: 12.2% of parents rated their daughters’ health as ‘fair’ or ‘poor’ at the second wave of data collection, when young people were aged 14-18 years, compared to 7.5% of parents of sons. At the fifth and final wave of data collection, when young people were aged 21-25 years, 17.4% of parents rated their daughters’ health as ‘fair’ or ‘poor’, compared to 13.9% of parents of sons.

#### **43.2.1.2 Geographical differences**

The Census (2011) population with intellectual disabilities who were living in deprived areas had worse health than those living in affluent areas of Scotland. Previous findings on the association between area deprivation and health in the population with intellectual disabilities are mixed. Emerson et al. (2010) conducted a secondary analysis of an Australian population-based cohort of 4,337 children aged 4-7 years. Controlling for socioeconomic disadvantage significantly reduced but did not eliminate group differences in the prevalence of mental health conditions between children with intellectual disabilities and children without intellectual disabilities, leading the authors to conclude that

socioeconomic disadvantage may explain some of the variability in prevalence of mental health conditions in each population.

Opposite findings on the relation between neighbourhood deprivation and health in adults with intellectual disabilities have been found. In a Scottish population of adults with intellectual disabilities ( $n = 8,014$ ) Cooper et al. (2015) found no association between area deprivation and multi-morbidity; and in another Scottish population ( $n = 1,023$ ) Cooper et al. (2011) found no association between area deprivation and access to primary healthcare services, hypothesised to contribute to health inequalities. It may therefore be the case that socioeconomic disadvantage confers some effects on health in *children* with intellectual disabilities, and the results of the Census (2011) analysis described in this thesis suggest that these effects may continue during transition to adulthood. Research has demonstrated that children with intellectual disabilities are more likely than those without intellectual disabilities to be living in sociodemographic deprivation in the UK (Emerson et al., 2005), the USA (Fijura & Yamaki, 2000) and Australia (Leonard et al., 2005), indicating that a large proportion of the young population with intellectual disabilities may be vulnerable to the negative effects of area deprivation on health suggested by these analyses.

However, the measures used to identify neighbourhood deprivation in the studies described may account for the disparity in findings between children and adults. In the Census (2011) analysis described here, and in the Cooper et al. (2011; 2015) inquiries, postcode was used to determine neighbourhood deprivation (with the Scottish Index of Multiple Deprivation being used in the Census (2011) analysis, and the Carstairs Index being used in the Cooper et al. (2011; 2015) studies). For adults in particular, an individual's postcode may be influenced by a number of factors. For example, organisations providing 'congregate' type residential care to individuals with intellectual disabilities may often be situated in affluent areas, and an adult with intellectual disabilities is more likely to be placed in residential care than a child. Thus, postcode may be a more accurate indicator of socioeconomic disadvantage in children with intellectual disabilities, who are likely to live in the family home. It is important that future research continue to tease apart the relationship between area deprivation and health in the population with intellectual disabilities.

Living in an urban environment predicted 'poor' general health over and above area deprivation in the population with intellectual disabilities included in the Census (2011) analysis. This disparity in health between urban and rural areas in the population with intellectual disabilities is consistent with previous literature. Interviews and case record

reviews of adults with intellectual disabilities living in rural areas of Scotland ( $n = 39$ ) and urban areas of Scotland ( $n = 633$ ) revealed that those from rural areas were significantly more likely to have regular daytime activities than those from urban areas (Nicholson & Cooper, 2013). Additionally, participants living in rural areas were living in significantly less deprived areas than those living in urban areas (Nicholson & Cooper, 2013), and those living in rural areas had significantly more contact with both primary and secondary healthcare services (Nicholson & Cooper, 2011). In this way, those living in rural areas may experience better opportunities, and have greater access to healthcare, than those living in urban environments, potentially resulting in better health in rural environments.

#### **43.2.1.3 Lifestyle risk factors**

A key finding from the qualitative studies was that transition from school had led to young people experiencing increasingly sedentary lifestyles and often gaining weight as a result. This problem has been recognised recently in the literature, with Mitchell et al. (2016) suggesting that the transition from school may be a specific risk period for negative lifestyle behaviours and weight gain in the population with intellectual disabilities. Indeed, a qualitative study involving semi-structured interviews with parents of young adults with profound intellectual disabilities ( $n = 14$ ) aged 18 to 26 years in Quebec highlighted young adults' significant weight gain after leaving school, which parents attributed to the lack of organised activities available to their adult children after school exit (Gauthier-Boudreault et al., 2017).

Furthermore, the poorer health identified in females with intellectual disabilities identified through the Census (2011) analysis may be partially explained by differences in lifestyle factors contributing to weight gain. Emerson (2005b) analysed data from an audit of supported accommodation for adults with intellectual disabilities ( $n = 1,542$ ) in England, and found that women were at higher risk of physical inactivity and obesity than males. Specifically, 100% of females of 'transition' age (16-24 years) who were capable of physical activity were physically inactive, compared to 83% of males. Since obesity is associated with numerous comorbidities, this finding may account for a large degree of the health inequality identified between females and males in the population with intellectual disabilities.

### 43.2.2 Mental health

The qualitative interviews revealed that transition to adulthood had had a negative impact on young people's mental health, with difficulties ranging from clinically significant anxiety, conferring significant functional impairments for young people, to more general emotional distress and negative wellbeing. Furthermore, the Census (2011) analysis indicated that young people with intellectual disabilities aged 19-24 years (who had transitioned from school) were significantly more likely to report the presence of a mental health condition than those aged 13-18 years (who were still in school). One of the primary manifestations of mental health problems in the interview samples that had significant consequences for their daily lives was challenging behaviours, including self-harm and aggression, which parents almost universally attributed to a lack of activity following school exit. These findings are echoed elsewhere: a qualitative study involving semi-structured interviews with parents of young adults with profound intellectual disabilities ( $n = 14$ ) aged 18 to 26 years in Quebec described how a lack of post-school stimulation had contributed to significant behavioural difficulties in young adults, which parents attributed to boredom (Gauthier-Boudreault et al., 2017).

This finding supports the assertion that behavioural difficulties were a manifestation of frustration or anxiety related to a lack of meaningful activity following transition from school, and further support for this notion can also be found elsewhere. A longitudinal study combining data from the Western Australian Down syndrome 'Needs Opinion Wishes' study and the Australian Child to Adult Development study, involving 789 individuals with intellectual disabilities between the ages of 8 and 27 years, investigated the prevalence of challenging behaviours via the Development and Behaviour Checklist (DBC). Scores on the disruptive, communication disturbance, anxiety and self-absorbed subscales of the DBC declined with age (Foley et al., 2016), suggesting a general overall improvement of challenging behaviours over time, thus reinforcing the argument presented in this thesis that challenging behaviours were in some respects a manifestation of the anxiety associated with leaving school; and that, once new routines were stabilised, these behaviours began to recede.

However, in the Foley et al. (2016) inquiry, depressive scores did not improve with age, and abnormal social relating behaviours (including avoiding eye contact and being a loner) increased for individuals with intellectual disabilities other than Down syndrome and remained consistent for those with Down syndrome over time (Foley et al., 2016),



suggesting that some characteristics related to poor mental health remain relatively stable into adulthood in this population. Indeed, Hughes-McCormack et al. (2017) conducted another secondary analysis of Scotland's Census (2011), finding the prevalence of mental ill-health in the population with intellectual disabilities to be 20.8% for those aged 25-34 years and 24.0% for those aged 35-44 years. These findings demonstrate an increase in the prevalence of mental health conditions from the 18.8% prevalence found in individuals with intellectual disabilities aged 19-24 years in the analysis of the Census (2011) described here, contradicting the hypothesis that mental health difficulties may improve following the initial transition period, and once new routines have been stabilised. Indeed, it is important to note that the parents interviewed, including those whose children were in their mid 20s, did still emphasise the need for better mental health provision for adults with intellectual disabilities, highlighting the fact that mental health conditions are still prevalent in the population with intellectual disabilities overall, and that the provision of services specifically for adults with intellectual disabilities and mental health conditions remains inadequate.

#### **43.2.2.1 Community participation and independence**

As suggested in the previous section, a lack of opportunity for meaningful daytime activities was identified in both qualitative studies described in this thesis, and this issue was considered to contribute significantly to the mental health difficulties and negative wellbeing experienced by young people during transition. These findings, related to a lack of meaningful activity following school exit, are consistent with previous literature, which has highlighted a lack of post-school community participation among the population with intellectual disabilities (e.g. Gray et al., 2014; Van Naarden Braun et al., 2006; Verdonshot et al., 2009a; see Chapter 1). The qualitative studies in this thesis have extended these findings by highlighting the impact that such a lack of activity can have on young people's mental health and wellbeing; young people were often frustrated when their school routine disappeared and there was little else to replace it. Furthermore, a lack of opportunities for meaningful activity led to isolation and fewer friendships, consistent with previous literature (e.g. Small et al., 2013; see Chapter 1).

Importantly, those young adults in the samples who were in the latter stages of the transition had eventually been included in some form of activity, such as work placements or college courses for young adults with intellectual disabilities, but organising such activities had not been straightforward. As discussed in the previous section, most parents

reported delays in finding a place or in obtaining funding to pay for the support that their son or daughter needed to access activities. This finding adds to the evidence base surrounding the lack of support available to the population with intellectual disabilities to encourage their active participation in the community. For example, Eisenman et al. (2009) conducted semi-structured interviews with family members of 45 young adults with intellectual disabilities who were either currently enrolled in or had graduated from transition programmes for individuals aged 18-21 years. Although an average of 5.02 community activities per student was identified, with all young adults engaging in at least one community activity each week, support for those young adults who required it was provided by family or friends in 82% of cases. Additionally, opportunities to interact with peers were limited to activities specially designed for people with intellectual disabilities, whereas families expressed a desire for their sons and daughters to have a wider network of friends and activities.

These findings echo those identified from the qualitative studies, but with one important difference: in Eisenman et al.'s (2009) inquiry, families primarily reported that they were mostly satisfied with their young adult's current community and social participation, while in the samples interviewed for this thesis young people and their parents largely reported dissatisfaction with either the choice of activities open to them or with the support provided for them to access such activities. Specifically, parents were dissatisfied with a situation that required them to accompany their son or daughter to the activities that filled their time, since this phenomenon effectively undermined their child's independence and sense of adult status. Eisenman et al.'s (2009) study is constrained by limited representation of the experiences of those young adults who had graduated from the transition programmes more than two years prior to the study, which may account for the discrepancy in findings, since those who had been without the support provided by the transition programme for a longer period of time may have begun to experience dissatisfaction with the services that were available to their children.

Problems in accessing the community also stemmed from young people's difficulties related to obtaining independence from their parents. These difficulties concerned both the practical problems associated with a lack of support to access activities where required, and parents' fears related to their adult children's vulnerability in the community, resulting in a reluctance to facilitate independence, and sometimes overprotection. Similar issues in relation to facilitating independence in the young population with intellectual disabilities have been described in the literature. For example, Isaacson et al. (2014) conducted

qualitative case studies with two Australian young men with intellectual disabilities aged 21 and 25 years who were undergoing the transition to individual supported living. The parents here had concerns about their sons' vulnerability in the adult world and found it difficult to reduce their guidance as a result. A lack of continuity from service providers, with one family reporting having three local area co-ordinators<sup>27</sup> in less than five years, exacerbated parents' concerns and contributed to their difficulties in 'letting go'.

Coincident with the descriptions from participants in this thesis, gaining independence was hence a gradual process for both men.

It is intuitive that enjoying active participation in the community and experiencing personal autonomy are important components of adulthood, with positive consequences for wellbeing: in a study involving individual and group discussions with young adults with Down syndrome (n = 12), Scott et al. (2013) identified enjoying meaningful relationships and active participation in the community, as well having control over their own lives, as themes contributing to a 'good life' for young people. However, from these studies it is evident that despite the organisational structures providing services to young people with intellectual disabilities ideologically supporting their right to self-determination (see Chapter 1), in practice there are few opportunities for young people to exercise control over their lives due to the limited support available to them, as well as parents' possible overprotection as a result of their concerns related to young people's vulnerability in the community.

#### **43.2.2.2 Delayed transitions**

These issues related to developing independence were closely related to parents' perceptions regarding their children's developmental delay, which had served significantly to delay some aspects of the transition to adulthood, since young people were not able to adopt 'adult' responsibilities until a later age than would be the norm for the typically developing population. Indeed, many parents reported their child's behaviour in their 20s to be reminiscent of a typically developing teenager. This phenomenon had negative implications for young people's mental health and wellbeing, since many experienced frustration at their perceived lack of independence. Furthermore, the situation was exacerbated by the wider community, which conversely often exerted pressure on young

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<sup>27</sup>Local area co-ordinators are in place in some areas of Scotland and Australia (Hall & McGarrol, 2013) and are semi-independent practitioners whose role is to facilitate social care and support and to organise opportunities for people with intellectual disabilities within local communities (see Chapter 1)

people to behave in a more adult fashion, causing significant distress either because young people did not understand these expectations for mature behaviour, experiencing difficulties in the community as a result, or because they *did* understand these expectations but perceived themselves as unable to fulfil them. While authors have previously suggested that the transition to adulthood may be delayed, or even prevented from happening at all (e.g. Hudson, 2006; see Chapter 1), this phenomenon has been attributed to organisational delays in the transition to adulthood, rather than to organic factors related to the development of young people with intellectual disabilities, and the social implications of such a phenomenon.

Organisational aspects of transition were also reported to be delayed in the interview samples. For example, young people reported continuing to be seen in children's health services well into their 20s. This finding mirrors data available on hospital admissions within Glasgow: the 2011 NHS Learning Disability Health Needs Assessment for Greater Glasgow and Clyde reported 69 adults with intellectual disabilities as old as 25 receiving treatment at a children's hospital between April 2003 and April 2008, supporting the notion that adults with intellectual disabilities continue to be seen by paediatric teams. This phenomenon is perhaps due to a lack of specialisation in adult health teams; both parents and young adults in the qualitative studies commented on inadequacies in the care environment within adult health services, contrasting it with their positive experiences in children's services, where flexibility was seen as contributing to more appropriate care experiences for individuals with intellectual disabilities: a point which will be discussed further in the following section.

It is important to note that the social aspects of a delayed transition to adulthood, including young people continuing to rely on parents well into their 20s, may also occur in the typically developing population. However, it is reasonable to assume that the organisational aspects of transition that caused delays, for example the allocation of funds to access post-school activities, would not be experienced by the typically developing population.

### **43.2.3 Services and support**

Consistent with previous qualitative literature (e.g. Murphy et al., 2011; Beresford, 2004; Hetherington et al., 2010; Hudson, 2006; see Chapter 1), the organisational aspects of the transition from school were reported by both parents and young people in the qualitative

studies to be chaotic, with a lack of continuity and poor information provision resulting in stressful experiences. As mentioned previously, those who required support to access the community were particularly at risk of not being engaged in meaningful activity, since there was little provision for paid support. Furthermore, parents perceived there to be less capability to work with individuals with intellectual disabilities among staff in adult services. Consistent with this finding, in a qualitative study involving 14 parents of young adults with profound intellectual disabilities aged 18-26 years, Gauthier-Boudreault et al. (2017) found that parents highlighted a lack of competence in working with individuals with profound intellectual disabilities across post-school resources, leading to reluctance among parents to use these services at all.

As well as a lack of specialism in working with individuals with intellectual disabilities, parents in the qualitative study perceived there to be less support available to adults with intellectual disabilities once they transitioned to adult services. This issue was related to austerity measures, resulting in less funding available to support young adults with intellectual disabilities. The closure of the Social Circle, offering an inclusive space for young adults with intellectual disabilities, provides a concrete example of how austerity measures, as well as changing ideologies of care for the population with intellectual disabilities – resulting in a move away from activities specifically for those with intellectual disabilities towards social inclusion of individuals with intellectual disabilities in mainstream communities – negatively impacted young people, since they experienced intolerance and even bullying in social spaces out with those specifically catering for individuals with intellectual disabilities.

A lack of formal supports following transition from school have also been reported elsewhere. For example, a longitudinal study involving mail surveys and telephone follow-ups across 2 years with parents ( $n = 209$ ) of young adults with intellectual disabilities aged 16-21 years in Ontario found that use of formal supports (including GPs, respite services, day programmes and professional helpers) dropped after leaving school. Importantly, parents did not perceive formal supports to be helpful either before or after leaving school, but significantly more parents reported being highly distressed after their children had transitioned from school (McKenzie et al., 2017), suggesting that the lack of formal supports available post-school had negative consequences for family wellbeing.

Within the qualitative studies described in this thesis, mental health support in particular was considered insufficient for young people's needs, with parents reporting significant

difficulties in accessing mental health services for their adult sons and daughters once they had transitioned from education. This finding reinforces findings from previous studies. For example, using postal questionnaires, Bhaumik et al. (2011) assessed the physical and mental health problems and service uses of 79 UK individuals with intellectual disabilities aged 16-19 years. On average, the teenagers surveyed used five different services, but parents reported that they needed an average of four more services, suggesting a significant unmet health need.

One helpful feature of support during transition was reported by parents in the qualitative study to be having a professional who could act as an advocate for the young person's needs. This finding mirrors previous research: a cross-sectional study involving semi-structured interviews ( $n = 41$ ) with young people with special health care needs – including intellectual disabilities – aged 16-25 years, their families and healthcare providers in the USA, found that a 'transition advocate', someone who could assist with the transition from paediatric to adult health services and help the young person to navigate health and community services, was essential for a successful transition (Okumura et al., 2015). Thus, formally putting into place transition advocates (such as local area co-ordinators) to support families during the transition from school may help to support families in the future.

## **44 Methodological considerations**

### **44.1 Secondary analysis of Scotland's Census (2011)**

#### **44.1.1 Strengths**

The Census (2011) provides data from a countrywide population of individuals with and without intellectual disabilities. A completion rate of around 94% is estimated (National Records of Scotland, 2013), lending confidence to the notion that this dataset captures the majority of the population of Scotland. Furthermore, the 2011 Census provided a clear question to distinguish individuals with intellectual disabilities from other populations, differentiating intellectual disabilities from learning difficulties (such as dyslexia). The data therefore provide an excellent estimation of the number of individuals with intellectual disabilities living in Scotland, and hence provides a whole country population.

### 44.1.2 Limitations

The Census questionnaire instructed that the questionnaire be completed by the householder or joint householder (the person with responsibility for paying bills in the household). It is hence likely that a significant percentage of the data on individuals with intellectual disabilities were provided by proxies, such as parents, which may have led to under-reporting of some health conditions, as some conditions may not be recognised by parents or carers. However, it is not possible to establish whether, and in which instances, this under-reporting was the case. Furthermore, it is not possible to identify the ability level of individuals within the population with intellectual disabilities from the Census (2011) dataset. Different ability levels may be associated with different health trends, but this hypothesis cannot be tested via the Census (2011) data.

The analyses of Scotland's Census (2011) presented here reflect static cross-sectional comparisons of two age groups of young people with intellectual disabilities, which comprise limitations to the conclusions that can be drawn in two ways. Firstly, the analysis presents only associations between transition and health, and causation cannot be established. Secondly, the age groups were identified to reflect the age at which young people in Scotland leave school (between 16 and 19 years) and it was assumed that the majority of those aged 13-18 years would still be in school, with those aged 19-24 years having transitioned from school. However, among the qualitative interview samples, some young people had left school at the minimum age of 16, highlighting the potential for some of those included in the younger age group to have in fact transitioned from school. As such, the analyses may not represent a clean comparison of individuals before and after the transition from school, and therefore the prevalence of mental health conditions in the population who have left school may in fact be higher than that concluded from the analysis.

Finally, there were some restrictions on the data provided to the researcher enforced by the custodian of the data, the National Records of Scotland (NRS), which impacted the analyses that could be performed. Due to restrictions enforced by NRS with regards to cell sizes in frequency tables – enforced to avoid compromising the anonymity of respondents – it was not possible to enter the geographical variables into the same regression analyses as the other putative predictors, thus limiting the conclusions that can be drawn from these analyses.

## 44.2 Qualitative studies

### 44.2.1 Reflections on conducting qualitative research with young people with intellectual disabilities and their families

The topic guides for the interviews were developed based on the systematic review of the literature on transition and health in the population with intellectual disabilities (see Chapter 2) and also on the pilot focus group study (see Chapter 6). It is important to note that the participants who took part in the focus group were at the beginning of their transition to adulthood, and were considerably younger than many of the young adults who took part in the interviews. As such, it is possible that the interview topic guide failed to include some issues that were of particular relevance to the older participants. However, the semi-structured nature of the interviews allowed participants to identify additional issues that were of particular relevance to them, and allowed the researcher to develop upon any themes that arose during the course of the interview.

The response rate for the interview studies was low, which may reflect the stressful nature of the transition period, during which families may be too busy to participate in research. As the samples were self-selected, it may be the case that those individuals with particularly negative or particularly positive transition experiences felt compelled to take part in the research, resulting in an unrepresentative sample. In relation to this issue, although the researcher sought to identify participants with intellectual disabilities up to the age of 35 years in order to describe a broad spectrum of experiences, the oldest individual who agreed to participate in an interview was 27 years old. It is important to note that, while these studies reflect only views from a relatively small number of people, they are substantial in their depth; the interviews involved sustained encounters where detailed insights into families' experiences of transition were gained, often from multiple informants (i.e. from both the young person with intellectual disabilities and their parent).

As a result of the limitations in the existing literature on transition and health in the population with intellectual disabilities (see Chapter 2), specifically, the limited inclusion of the 'voice' of individuals with intellectual disabilities, the qualitative studies aimed to include, as far as possible, young people with intellectual disabilities. All young people who were able to respond to interview questions were thus included in interviews, resulting in the inclusion of individuals with mild, moderate and severe intellectual disabilities, the latter participating in interviews with the support of their parents, who helped to probe young people's answers and offered clarification to the researcher when the young



person's responses were unclear. Even so, the methodological challenges associated with conducting interviews with individuals with intellectual disabilities, including requiring the support of parents to help individuals with intellectual disabilities to respond to interview questions, cannot but lead to some limitations to the resulting data.

Regardless of whether individuals with intellectual disabilities required their parents' support to take part in the interview, in an effort to ensure that all participants were comfortable with the interview procedure, the researcher gave parents the choice as to whether to remain present during their son's or daughter's interview. Of the 17 young people who participated in an interview, 10 did so in the presence of a parent. While this phenomenon was in some cases a necessity, the presence of parents during the interviews sometimes served to undermine the narratives from individuals with intellectual disabilities. For instance, parents often interrupted or contradicted their children, and young people often relied on their parents to answer the interview questions for them, even when they were capable of responding by themselves, an observation which corresponds with previous literature identifying an ongoing reliance on parents among young adults with intellectual disabilities (e.g. Rehm et al., 2012; see Chapter 1). This phenomenon may jeopardise the findings from the qualitative studies, since the actual views of young people may not have been accurately conveyed, especially in cases where parents helped to structure their son's or daughter's responses to questions. However, given that the participants in the pilot focus group rejected the use of visual aids to guide the interview procedure, it was decided that, while not optimal, the support of parents was the best method by which to obtain the views of individuals with severe intellectual disabilities. In addition, it was considered important ethically that parents be present for their son's or daughter's interview if they felt that it was appropriate, regardless of ability level.

The counter-argument to this limitation is that the researcher witnessed first-hand, and hence gained an intimate perspective on, the difficulties related to increasing independence in young adults with intellectual disabilities as navigated by families during the transition period: throughout the interviews, she both saw and heard the tensions between young people's wishes for their present and future lives and their parents' concerns, which arguably facilitated a deeper understanding of the emotional complexities of this period for families than would have been possible without such observations. Nevertheless, future research might consider providing independent support, such as a support worker, to allow individuals with intellectual disabilities to take part in research so as to limit potential biases associated with the presence of parents during interview procedures, although it

must be acknowledged that the presence of support workers might bring about a separate set of tensions.

Additionally, the interview procedure precluded the participation of individuals with profound intellectual disabilities and/or severe communication impairments; in these cases, parents were relied upon to provide an account of the young person's transition experience. Despite this limitation, individuals with mild to severe intellectual disabilities participated in interviews and offered crucial insights into their own experiences – perhaps more so than might be expected – highlighting the important contributions that individuals with intellectual disabilities can and should make to research.

The ethnography presented another opportunity for individuals with intellectual disabilities – including those with severe intellectual disabilities – to communicate their experience of transition, which may go some way to alleviating the limitations described above. The observational nature of the ethnography offered insights into the challenges experienced by young people undergoing transition. In this way, the researcher was able to observe interactions between members of the group with intellectual disabilities and between them and members of staff, which shed light on experiences of transition for individuals with intellectual disabilities that they may not have been able to communicate in an interview setting. Furthermore, the ethnographic sample was not self-selected, which may reduce sample biases associated with self-selecting to participate in research.

Nevertheless, the ethnographic sample is still only representative of a select group of people from one geographical location who attended one service for young people with intellectual disabilities, and therefore the findings cannot easily be generalised to the population with intellectual disabilities at large. That said, it is important to note here that all of the themes identified from the ethnographic field diary were also identified through the analysis of the interview transcripts, lending support to the notion that this research has identified, with some accuracy, the challenges experienced by young people with intellectual disabilities during transition. Furthermore, the interview samples and ethnographic sample included individuals with a spread of abilities, and both males and females, resulting in what is arguably a representative sample of the population with intellectual disabilities.

The experience of conducting qualitative work with young people with intellectual disabilities undergoing transition and their families proved to be an emotional one, with the

researcher witnessing first-hand the difficulties associated with the transition experience throughout the interviews and ethnography. The majority of the interviews with young people and/or parents were conducted in participants' homes, meaning that the researcher was included in the family environment for the duration of the interview, witnessing interactions between young people and their families and developing insights into the changing nature of these relationships – and the tensions involved in this phenomenon – during transition. Furthermore, the immersive nature of the ethnographic work meant that the researcher came to know the young people and the staff involved in the Social Circle, and therefore experienced genuine sadness at the cessation of the group alongside the group members. Thus, in-depth insights into the transition experience were generated, facilitating the development of a thorough understanding of how the life changes associated with transition impact upon young people and their families. Such an understanding is of great importance when considering the implications of this work for policy and practice.

It is also important to reflect upon how participants in the qualitative work responded to the researcher. For instance, the young people included in the ethnographic sample began to regard the researcher as part of the Social Circle group as the ethnography progressed and the work became more immersive. As discussed in Chapter 6, some of the participants in the interview sample were also included in the ethnographic sample, and the researcher observed a difference in how these young people responded to her in interview settings compared to those who did not have experience of interacting with her prior to the interview. In this way, those young people who had already interacted at length with the researcher through the ethnographic work prior to the interview adopted a more relaxed, informal interaction style throughout the interview, and therefore perhaps provided more personal insights into their transition experience than did those who encountered the researcher for the first time at the interview. This phenomenon also worked the other way round; i.e. those young people who took part in an interview were often more likely to approach the researcher to talk about their experiences in subsequent Social Circle sessions. This phenomenon highlights the interpersonal, reflective aspect of qualitative research, which necessarily involves interaction and, in the case of the research topic of this thesis, the disclosing of personal and sometimes painful narratives. Here the advantages of repeated encounters between interviewer and interviewee are brought to attention, in that such experiences bring about a degree of familiarity which may help to put research participants at ease, thus potentially facilitating both a more enjoyable participation experience and the collection of richer data.

## **45 Implications for policy and practice**

The qualitative interviews and ethnography offered crucial insights into how the support experienced by families during transition had been helpful and/or inadequate, thus providing directions for improving support in the future. The improvements to policy and practice for which the data presented in this thesis arguably call will be outlined through this section.

### **45.1 A focus on health during transition**

The studies in this thesis have highlighted the high incidence of physical and mental health problems experienced by young people with intellectual disabilities undergoing transition. The data presented have also identified the need for support for adults with intellectual disabilities to engage in exercise and healthy eating, in order to limit the damaging effects of obesity on both physical and mental health. Transition to adulthood is a crucial juncture at which important messages about healthy lifestyles could be instilled in young adults in order to protect against preventable health issues – such as obesity – in the future.

Preventing individuals on the cusp of adulthood from engaging in negative lifestyle behaviours leading to weight gain, with the multitude of health problems that obesity can precipitate, might go a significant way to reducing the health inequality currently experienced by adults with intellectual disabilities. Many young people interviewed for this thesis recognised the need to eat healthily and to exercise, suggesting that this population might be a receptive audience to positive messages about healthy behaviours.

Support must also be in place to facilitate young people's access to health promotion activities, such as cancer screening, in preparation for a future context where parents may no longer be able to provide a significant degree of support to access health services. With the appropriate support, young adults with intellectual disabilities might go on to lead much healthier adult lives.

Additionally, the parents interviewed for the qualitative study highlighted a need for better access to mental health support for their adult children with intellectual disabilities; especially once they have left an educational environment which itself confers access to support. Given the prevalence of mental ill-health in this population identified via the Census (2011) data, and the anxieties experienced by young people in connection with the

transition from school, accessible and comprehensive mental health support is necessary to ensure positive outcomes through to adulthood for this population.

## **45.2 Lengthening timescales**

Transition planning was universally reported by parents, and by some young people, as occurring too late in a young person's school career. Planning for transition hence needs to begin earlier in order to accommodate common delays in accessing funding for post-school placements. The process of transitioning to adulthood was also identified to continue well into the 20s for young people with intellectual disabilities; spanning further than the timescales for which current practices offer support. Support to access important facets of adulthood, such as living away from the parental home, must therefore continue beyond the immediate transition from school into the late 20s. Increasing support in this way might go some way towards alleviating the emotional distress experienced by young people in attempting to navigate the complexities of transitioning to adulthood without the appropriate support.

## **45.3 The importance of advocacy**

As discussed earlier in this chapter, the most frequently cited positive source of support during transition was advocacy, with parents specifically valuing the expertise that somebody with experience of navigating the necessary systems during transition could convey to them. Importantly, these advocates were identified from a range of different professional backgrounds, suggesting that the most helpful factor in the relationship was having somebody with the appropriate knowledge to 'fight' for the needs of the young person on the parents' behalf. With this in mind, the introduction of independent 'transition advocates', possessing appropriate knowledge of social work systems and the services and supports available to individuals with intellectual disabilities, might offer significant help to families undergoing transition. The introduction of such a role might serve to widen the accessibility of knowledge surrounding transition and available services and supports, and in so doing to calm some of the animosity experienced between families and professionals facilitating transition planning, and hence contributing to more positive experiences overall.

## **45.4 Daytime activity**

Insufficient and inappropriate daytime activity was perhaps the most important factor contributing to anxiety for young people with intellectual disabilities during transition. The importance of new routines and challenges outside of the home environment was stressed, with those young people who enjoyed such opportunities experiencing substantial benefits, including increased confidence, which contributed to a broader social network and more independence in the wider community. Increasing the post-school opportunities available for young adults with intellectual disabilities would hence potentially address many of the broader wellbeing problems identified throughout this thesis by offering opportunities for young adults to engage in physical activity and to socialise outside of the home, while also offering a new post-school routine.

## **45.5 The need for more funding**

It is clear from the qualitative data that funding for services and support for adults with intellectual disabilities is currently inadequate. The ethnographic work demonstrated that the Moving On Transition Service was a key source of support for young adults with intellectual disabilities, serving to facilitate independence and to create opportunities for young people to socialise. The fact that funding for this service was cut at the end of the period of study is indicative of the landscape in this area, with parents throughout the interviews describing cuts to services for adults with intellectual disabilities as a result of austerity. In relation to this point, funding for social groups for individuals with intellectual disabilities to continue to support individuals into adulthood is necessary, given that the data here suggest that transition, in the sense of achieving adult roles, continues well into the 20s. Transition groups with an upper age limit of the early 20s may therefore be insufficient, and funding would ideally be directed towards providing age-appropriate support and activities for those in their mid 20s and beyond.

Furthermore, the lack of post-school activities available for young adults with intellectual disabilities was attributed to a lack of activities in general (as a result of limited funding) and a lack of funding for paid support for those individuals who required one-to-one care in order to access activities. For some young adults, complete independence may never be a realistic option, and in these cases support outside of the immediate family must be available for adults to access the community without the support of their parents, in order to progress to age-appropriate adult roles. Directing more funding both to services and

activities for adults with intellectual disabilities, and to paid care allowing individuals to access such activities, might go a significant way to limiting the damaging implications of transition for young people's wellbeing more generally.

## 45.6 Current transition frameworks

In 2017, the Association for Real Change (ARC) Scotland in collaboration with the Scottish Transitions Forum (see Chapter 1) released the *Principles of Good Transitions 3*, a framework for practitioners to follow when supporting individuals with additional support needs, including intellectual disabilities, transitioning from school. The document outlined the following principles:

1. Planning and decision-making should be carried out in a person-centred way;
2. Support should be co-ordinated across all services;
3. Planning should start early and continue up to age 25;
4. Young people should get the support they need;
5. Young people, parents and carers must have access to the information they need;
6. Families and carers need support;
7. A continued focus on transitions across Scotland.

While neither ARC Scotland, nor the Scottish Transitions Forum, are policy makers, this document offers insights into the current issues considered to be a priority for policy change in this area. Furthermore, the Scottish Government's *Experiences of Transitions to Adult Years and Adult Services* report (2017) recommends that the *Principles of Good Transitions 3* be adopted as a standard approach to transition across both voluntary and statutory services. The data presented in this thesis certainly support the need for such principles, which parallel the necessary improvements to the handling of transition in Scotland outlined by parents and young people throughout the qualitative interviews. However, while these principles represent positive steps towards achieving good transition outcomes for this population, there remain gaps in the guidelines that should be addressed

in order to ensure that the apparently negative health and wellbeing impact of transition is alleviated.

### **45.6.1 A focus on health during transition**

The above document calls for coordination of support across health, social and educational supports under Principle 2: *Support should be co-ordinated across all services*. Apart from this brief mention, however, a focus on health is absent from these principles. Given the high incidence of both physical and mental health issues in the population with intellectual disabilities, improving the health of young adults during transition should arguably be a standalone principle. Nevertheless, health does not seem to be a priority for care providers during transition, and this situation should arguably change in order to reduce the health inequality experienced by the population with intellectual disabilities.

### **45.6.2 Transition planning timescales**

The need for transition planning to begin earlier is recognised in Principle 3: *Planning should start early and continue until the age of 25*. The qualitative studies here identified that transition to adulthood in the sense of attaining adult roles, such as living away from the family home, continues well into the 20s. Support for accessing these important facets of adulthood must therefore continue beyond the immediate transition from school, and may need to extend beyond the age of 25.

### **45.6.3 The importance of advocacy**

Principles 4: *Young people should get the support they need*; 5: *Young people, parents and carers must have access to the information they need*, and 6: *Families and carers need support* all recognise that information provision and support for families during transition are currently inadequate. Implementing specific transition advocates might serve to fulfil all of these principles, and the data presented through the qualitative studies suggest that families would find such advocacy acceptable and helpful. Given their current role in co-ordinating services and providing information to families, and their position within local geographical areas, local area co-ordinators are well situated to adopt the role of transition advocate.



### **45.6.4 The need for more funding**

In order to address the majority of the issues described throughout this section, and to implement the principles outlined in the *Principles of Good Transitions 3* policy document, more funding would ideally be directed towards support for young adults with intellectual disabilities in transition, and towards activities for young adults with intellectual disabilities in general.

## **46 Theoretical implications**

As mentioned previously in this thesis, interdependence may lie at the heart of the way in which individuals with intellectual disabilities interact with others. The qualitative data presented in this thesis suggests that this assertion holds true during the transition process, wherein young people must rely on others to learn the skills necessary for adulthood; in some cases for a much longer duration than would be typical for individuals without intellectual disabilities. This phenomenon can be related to Vygotsky's (1978) theory of 'scaffolding', which regards interaction with others as an effective way of developing skills. Vygotsky posited that, so long as individuals rest within the zone of proximal development – the difference between what an individual cannot do without help, and what they cannot do at all – for a particular task, a skill that would be too difficult for them to master on their own can be mastered with the appropriate guidance or encouragement from a more knowledgeable other, i.e. a parent or more able peer. Once the individual masters the task with the benefit of this scaffolding from others, the scaffolding can be removed and the individual will be able to complete the task without help. A key difficulty for young people with intellectual disabilities undergoing transition, which contributed to considerable anxiety, was the development of skills necessary for independence in adulthood, ranging from picking out clothes to handling money. This phenomenon underscores the importance of scaffolding young people with intellectual disabilities into adulthood in order to facilitate the learning of key skills, thereby reducing anxiety at the prospect of tackling such skills alone, if sufficient supported learning has not taken place.

## **47 Clinical implications**

This thesis has identified that transition to adulthood may be associated with negative health outcomes for young people with intellectual disabilities, including obesity and mental health difficulties. As such, there are some important clinical implications that arise

from this work. Firstly, health care providers working with young people with intellectual disabilities undergoing transition should ensure that attention is paid to a young person's weight, and that any weight gain is dealt with effectively. This could take the form of both health education in the first instance and intervention if necessary. Preventative measures, such as health education on the importance of maintaining a healthy diet and exercise, should be in place for young people undergoing transition, potentially obviating the need for future intervention. However, if required, successful interventions for weight management in this population have been evidenced in the literature. For example, a recent randomised controlled trial (Harris et al., 2017) examining the utility of a multi-component weight management programme, including an energy deficit diet as well as physical activity and behaviour change components, for adults with intellectual disabilities and obesity ( $n = 50$ ) found that the intervention was both feasible and acceptable for adults with intellectual disabilities, with 50% of participants achieving clinically significant weight loss. Clinicians should consider adopting such an intervention if necessary during the transition to adulthood, so that possible consequences of obesity into adulthood are minimised.

Secondly, clinicians working with young people undergoing transition should be aware of the possible mental health implications of the transition experience. Problems should be identified early to ensure the best therapeutic outcomes, and evidence-based interventions should be used to tackle any mental health issues. A recent randomised controlled trial (Jahoda et al., 2017) compared a behavioural activation intervention with guided self-help intervention for clinically significant depression for adults with mild to moderate intellectual disabilities ( $n = 141$ ), finding that both interventions were effective. Either of these interventions could potentially help young people with intellectual disabilities experiencing low mood as a result of difficulties associated with transition.

Randomised controlled trials represent the gold standard for evidence in healthcare research. These examples demonstrate that evidence of good practice for interventions in the areas of clinical significance described in this thesis does exist, and clinicians must be mindful of this evidence and put it into practice so that the possible negative health implications of transition can be limited.

## **48 Future research**

### **48.1 The need to include older individuals with intellectual disabilities in research on transition**

Initially, the transition period was conceptualised by the researcher to occur between the ages of 16 and 24 years, in line with previous literature (e.g. Arnett, 2000) and reflecting the age span over which young people in Scotland leave school (age 16-19 years). However, throughout the qualitative studies it became clear that, at least in the population with intellectual disabilities, the transition period may be longer, spanning into the late 20s, with specific aspects of attaining adulthood not occurring until the latter end of that period. The age range of young participants for the interview samples was therefore extended, and individuals up to the age of 35 years were invited to take part. The older adults with intellectual disabilities who were thus included in the sample confirmed the hypothesis that some aspects of transition, for example moving to independent living, continue well into adulthood. It must be acknowledged that a limited number of young adults in their 20s were interviewed, though, and so young adults falling into this age bracket represent a population requiring more study. The literature on transition in the population with intellectual disabilities reviewed throughout this thesis tends to focus on individuals in the late teens and early 20s. Future research should include individuals at this later stage of transition to adulthood, since they represent an under-studied population who may be experiencing similar difficulties to those at the earlier stages of transition. In particular, young adults undergoing the transition from college represent a population warranting further investigation. The transition from college may be similar in nature to the transition from school, since it is reasonable to assume that comparable changes to routine and daily activity might occur. Moreover, given that parents in the qualitative study described here stressed the lack of mental health support available to their children after transition from education, it is possible that young people who have left college are especially vulnerable to mental health difficulties.

### **48.2 The need for longitudinal data**

The data presented in this thesis are cross-sectional in nature. Data from the qualitative studies demonstrate that transition to adulthood is a lengthy process in this population, spanning decades. As such, a longitudinal study following a representative sample of individuals with mild to profound intellectual disabilities is required in order to examine

how health and wellbeing is affected throughout the whole course of transition. The National Longitudinal Transition Study-2 (NLTS-2) (2003) in the USA (see Chapter 2) is an example of such a study; it followed individuals with a range of additional support needs (n with intellectual disabilities = 862) for almost ten years through their transition from high school, with data collected at five time points, beginning when young people were aged 13-16 years and ending when they were aged 21-25 years. Although no general population comparison group was included in this study, it still offers an opportunity to analyse changes in health status in a large sample of people with intellectual disabilities throughout this period. As yet, there has been no such published analysis from this dataset on the population with intellectual disabilities. However, as the qualitative studies presented in this thesis have demonstrated, the age range included in the NLTS-2 may not capture the full picture of transition in this population. Additionally, distinctions between those with mild, moderate, severe and profound intellectual disabilities are not made in this dataset. Finally, due to restrictions enforced by the custodian of the data, this data is only available to researchers in the USA; and, since service provision differs substantially between the UK and USA, any conclusions drawn through analysis of this data could not easily be generalised to a UK population. Further longitudinal studies following a representative UK population with mild to profound intellectual disabilities from school into their 20s and 30s is hence still required.

## **49 Contribution to the literature**

As outlined at the beginning of this thesis, previous research has identified numerous poor transition outcomes for the population with intellectual disabilities, including with respect to employment, community participation and independent living (see Chapter 1). As the systematic review identified (see Chapter 2), health and wellbeing outcomes during transition have received less attention in the literature. Through both qualitative and quantitative methodologies, this thesis has presented data suggesting that health in the population with intellectual disabilities is poor during this crucial life stage and substantially worse in the young population with intellectual disabilities compared to the young population without intellectual disabilities. The quantitative component of this thesis involved analysis of a population wide dataset including 5,556 young people with intellectual disabilities: the largest-to-date study involving comparisons of health in the populations with and without intellectual disabilities during transition.

Transition from school was identified through the Census (2011) analysis to be associated with poorer mental health in the population with intellectual disabilities. The qualitative studies involving both young people with intellectual disabilities and their parents elucidated the factors that may contribute to this emotional distress, demonstrating how the poor transition outcomes described in previous literature, such as a lack of community involvement, combined with inadequacies in the structural aspects of care and support provided to families during transition, may aversively affect mental health, as well as wellbeing more generally. These findings are a significant contribution to the literature in that the consequences of poor transition outcomes for young people's mental health and emotional wellbeing have been outlined, and thus crucial areas in which policy and practice must be improved have been identified.

As identified in the systematic review (see Chapter 2), much of the research on transition in the population with intellectual disabilities has relied on parents' reports of their children's experiences, or on reports from those with mild or moderate intellectual disabilities. The interviews with young people described in this thesis included individuals with mild to severe intellectual disabilities. While it must be acknowledged that relying on parents to support their son or daughter with severe intellectual disabilities to take part in interviews may in some cases bias the content of young people's responses, this study is novel in its attempt to include individuals with severe intellectual disabilities in qualitative research. Importantly, it has drawn attention to the significant contribution that individuals with severe intellectual disabilities can indeed make to research, with the appropriate support.

The qualitative studies were also novel in their inclusion of individuals with intellectual disabilities up to the age of 27 in research about transition to adulthood – although, as previously noted, only a limited number of young adults in their mid to late 20s were included. As discussed earlier, previous research on transition has tended to focus on young people in their late teens to early 20s, and this research has demonstrated that the process of transition in the conceptual sense of attaining independence and developing adult roles continues well into the 20s and perhaps beyond. Possible avenues for future research into the continued transition experiences of the older population with intellectual disabilities have hence been uncovered.

Overall, this thesis has demonstrated that health in the young population with intellectual disabilities undergoing transition to adulthood is poor, and that crucial components of both

the organisational transition from school and to adult services, as well as of the holistic transition to adulthood, may have negative consequences for young people's mental health and emotional wellbeing.

The following final chapter will outline the conclusions of this thesis.

## Chapter 9: Conclusion

This thesis aimed to explore the impact of transition to adulthood on health and wellbeing in young people with intellectual disabilities. A systematic review of the literature (see Chapter 2) revealed a number of specific health and wellbeing concerns for this population during transition, including obesity and interpersonal conflict. However, a significant gap in the literature regarding the general health and wellbeing implications of transition was found. Through a mixed methods design – utilising secondary analysis of Scotland’s Census (2011) (Chapter 5), qualitative interviews with both young people with intellectual disabilities (Chapter 6) and their parents (Chapter 7), and ethnography of a transition service for young people with intellectual disabilities (Chapter 6) – this thesis began to address this gap in the literature.

The findings indicate that general health in the population with intellectual disabilities undergoing transition to adulthood is poor, and significantly worse than in the typically developing population. Furthermore, transition to adulthood may have negative consequences for mental health and wellbeing in the population with intellectual disabilities. This phenomenon may be attributed: to a lack of meaningful activity following school exit; to inadequate support for navigating the complexities of transitioning from school to adult services, and in accessing post-school environments; and to the contradictions experienced by young people with intellectual disabilities as they reach adult years, including, often simultaneously, infantilisation and pressures to ‘grow up’. Additionally, a lack of post-school activity, causing boredom and a sedentary lifestyle, may also contribute to weight gain – and the numerous negative health ramifications of obesity – in young people, as well as the psychological implications of inactivity.

These findings suggest a number of implications for policy and practice. First, there is a need to focus on health during transition to adulthood in order to ensure that young people engage in healthy lifestyle behaviours into adulthood. Secondly, transition planning must begin earlier in a young person’s school career, and continue into the late 20s; hence extending beyond current timescales. Thirdly, transition advocates – a role which could potentially be adopted by local area co-ordinators – might offer crucial support and advice to families undergoing this stressful experience. Fourthly, significantly more funding would ideally be directed towards activities and social spaces for adults with intellectual disabilities following school exit, as well as to support their accessing such opportunities,

in order to alleviate the negative consequences of having little or no meaningful daytime activity for both health and wellbeing.

The use of quantitative and qualitative methodologies has facilitated both broad and deep understanding of the current research topic. The Census (2011) analysis involved a whole country population, within which the population with intellectual disabilities was clearly distinguished. The qualitative interviews and ethnography involved sustained encounters with individuals with intellectual disabilities and their families, during which the researcher gained an intimate perspective on the difficulties experienced by these individuals during transition. Despite these strengths, however, there are some limitations to the studies which must be considered. All three studies described in this thesis were cross-sectional in nature, and no causal pathways can be established without following the same individuals over time. The Census (2011) data may represent proxy-reports of health conditions, and may therefore under-estimate the true incidence of health problems in the population with intellectual disabilities. Additionally, the qualitative studies and ethnography only represent the views of individuals within one geographical area of Scotland, limiting the generalisability of the findings to other localities that are dissimilar in character.

In order to examine further the impact of transition to adulthood on health and wellbeing in this population, future work should include a longitudinal study following individuals with intellectual disabilities throughout the course of transition. This period of time is a crucial experience for any young person, and a better understanding of how the experience impacts on health and wellbeing should lead to better support, ultimately resulting in individuals with intellectual disabilities leading healthier adult lives.



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## 50 Appendix A: Ethical approval



21<sup>st</sup> December 2015

Dear Genevieve Young-Southward, Chris Philo, Sally-Ann Cooper

### MVLS College Ethics Committee

**Project Title:** The impact of transition on health and wellbeing in young people with learning disabilities: Main study

**Project No:** 200150032

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, subject to the following conditions:

- Project end date: August 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](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

A handwritten signature in blue ink, appearing to read 'A Rankin'.

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## 50.1 Appendix B: Protocol

### The Impact of Transition on Health and Wellbeing in Young People with Learning Disabilities: Protocol

#### Background

A learning disability is a reduced intellectual ability and difficulty with everyday tasks, such as socialising or managing money, with onset before adulthood. Transition is conceptualised in different ways throughout the literature; however, broadly it refers to the move from childhood to adulthood; specifically, leaving school and entering the workplace, developing increased independence and adopting adult roles.

Transition is a huge change in a young person's life, and the 'normal' conceptualisation of transition, i.e. leaving school and starting work, is queered by all sorts of people for different reasons, for example, gender, ethnicity, or socioeconomic status. However, the transition experience may be especially complicated by the presence of a learning disability. Baron et al. (1999, in Worth, 2009) describe society as 'ableist', wherein people with disabilities are constructed as vulnerable and unable to independently negotiate adulthood; they are thus set apart from the mainstream population. Due to this 'othering', people with learning disabilities may encounter barriers to experiencing life in the way that those without disabilities do, and can be regarded as being 'outside the participatory mainstream' (Philo & Metzel: 2005:77).

Due to these social characteristics, transition can be a complex process for people with learning disabilities. Hudson (2006) describes how people with learning disabilities' transition experiences are characterised by longer duration and attenuated experiences compared to the general population. Indeed, poorer transition outcomes for people with learning disabilities, compared to those without disabilities, have been documented in terms of social relationships (Stevenson et al., 1997), independent living (Sitlington & Frank, 1993) and vocational activity (Luftig & Muthert, 2005). This disparity may be due to neighbourhood, economic and social factors that situate people with learning disabilities as different and vulnerable, as well as cognitive differences. In this way, transition for people with learning disabilities can be slowed down or even prevented from happening altogether. Intuitively, young people with profound and multiple learning disabilities may fare worse than young people with more mild and moderate disabilities, due to both cognitive differences and increased attributions of difference and vulnerability.

Even without these complications, transition in itself can be a disruptive and stressful experience. Young people with learning disabilities have the added complication of moving between child and adult health and social services, and Reiss et al. (2005) indicate that poor planning and differing philosophies between services can contribute to difficult moves. Leaving school also constitutes a huge change in a young person's daily routine, and multiple reports highlight the lack of options available to young people with learning disabilities upon leaving school (e.g. Stevenson et al, 1997; Cooney, 2002). This issue may translate into few post-school options for productive activity or socialising, which may trigger isolation, anxiety or depression.

These wellbeing issues may be further exacerbated by problems encountered in negotiating new adult roles within families and social networks; many parents of young people with learning disabilities report struggling to adjust to their child's increasing independence, particularly with regards to sensitive – but important – issues such as sex and relationships (e.g. Pownall, et al., 2011).

Child services and special education schools often provide a high level of support to young people with learning disabilities and their families, e.g. in the form of family oriented services or functional skills programmes. Leaving behind this support may result in lifestyle risk factors, such as poor diet or lack of exercise, beginning to take effect, or in health problems going unnoticed or untreated. People with learning disabilities generally experience poorer health than those without disabilities (Tracy & McDonald, 2015), and the upheaval caused by transition, combined with this lack of support following leaving school and moving to adult services, may make this time a risk period for health status.

The Pupil Census, Scotland (2014) indicates that 4,521 young people with learning disabilities are in secondary school, and will therefore be approaching transition, indicating that this is a large-scale problem. A wealth of information exists on vocational and social transition outcomes for young people with learning disabilities; however, health and wellbeing remains a relatively unexplored domain for this population following transition.

A recently conducted systematic review found limited evidence on the impact of transition on health and wellbeing in young people with learning disabilities; a rigorous literature search revealed only 16 articles and 1 published dataset that met the inclusion criteria (age of participants was between 13 and 24 years old; data for participants with learning disabilities was reported separately; both transition and health or wellbeing were included; article was written in English), and the articles reviewed yielded mixed and often contradictory results. Interpersonal problems and sexual relationships were a key issue for young people with learning disabilities undergoing transition, alongside obesity and related secondary conditions e.g. depression or diabetes. Quality of life was reported as positive in a number of studies; however, these articles based their findings on reports from parents rather than young people themselves. Finally, challenging behaviours, while prevalent in this population and continuing into adulthood, did not seem to worsen following transition. This systematic review offers a starting point in uncovering the impact of transition on health and wellbeing; however, there are still crucial gaps in the literature. Therefore, a thorough investigation, utilising both quantitative and qualitative methods, is indicated.

### **Aim**

To investigate whether and how transition impacts health and wellbeing in young people with learning disabilities, and what supports a healthy transition.

### **Questions**

1. Does transition impact health and wellbeing in young people with learning disabilities, and in what particular ways? (e.g. mental health, physical health)
  - a) From the perspectives of young people with learning disabilities?
  - b) From the perspectives of families of young people with learning disabilities?

2. What supports (formal and informal) are helpful for young people with learning disabilities in transition?
3. Is the impact of transition on health and wellbeing similar or different for young people with profound and multiple learning disabilities compared with young people with milder learning disabilities?
4. Is the impact of transition on health and wellbeing similar or different for young people with learning disabilities compared with young people without learning disabilities?

### **Hypotheses**

1. Transition has a negative impact on mental and physical health in young people with learning disabilities
  - a) Transition has a negative impact on mental health and physical health in young people with learning disabilities from the perspectives of young people with learning disabilities.
  - b) Transition has a negative impact on mental and physical health in young people with learning disabilities from the perspectives of families of young people with learning disabilities.
2. Informal supports (family, friends) are important for young people with learning disabilities in transition. Cohesive, coordinated formal supports are helpful for young people with learning disabilities in transition.
3. The impact of transition on health and wellbeing is different (more detrimental) for young people with profound and multiple learning disabilities compared with young people with milder learning disabilities.
4. The impact of transition on health and wellbeing is different (more detrimental) for young people with learning disabilities compared with young people without learning disabilities.

### **Methods**

#### *Design*

A mixed methods approach, utilising both qualitative and quantitative approaches, including secondary analysis of existing data, will be utilised.

#### *Participants and their recruitment*

Opportunistic/snowball sampling from schools, colleges and charities in Scotland will be utilised. Up to 25 young people with a learning disability in the transition period (age 16 – 24) will be purposively sampled with regards to level of ability and gender from educational institutions e.g. schools and further education colleges, and charities e.g. PAMIS and Enable, to take part in semi-structured interviews. In order to access a spread of experiences, young people who are still at school and who have left school, will be invited to take part. Parents or families of participating young people with learning disabilities will also be invited to take part in semi-structured interviews.

Young people with learning disabilities who attend the social groups held by the Moving On Transition Service in West Dunbartonshire, as well as members of staff working at the service, will also be included in an ethnography that will be conducted over a period of 8 weeks.

#### *Participants within existing datasets*

Members of the Scottish population with learning disability who returned the national Census 2011 forms will also be included (age 13-24 n = 5,556). The Census 2011 is a census questionnaire, developed from methodology developed by the Office of National Statistics, administered to the population of Scotland in order to provide an accurate picture of their household circumstances on 27<sup>th</sup> March 2011. Topics included education, ethnicity, identity, language and religion, health, housing and accommodation, labour market, population and households, and transport.

### **Research Plan**

#### **1. Does transition impact health and wellbeing in young people with learning disabilities?**

##### *Qualitative Interview*

Young participants with learning disabilities will be invited to take part in a semi-structured interview, approximately 1 hour long (or two or more interviews of shorter duration, depending on individual preferences) which will aim to investigate their transition experience and the impact or anticipated impact it has had on their health and wellbeing.

##### **a) Does transition impact health and wellbeing in young people with learning disabilities from the perspectives of young people with learning disabilities?**

Semi-structured interviews with young people with learning disabilities will discuss the young person's perspectives on their transition experience and their health and wellbeing. Interviews will be audio-recorded, with participants' consent, and will be transcribed and analysed using thematic analysis.

##### **b) Does transition impact health and wellbeing in young people with learning disabilities from the perspectives of families of young people with learning disabilities?**

Semi-structured interviews, approximately 1 hour long, with parents/families of young people with learning disabilities will discuss their perspectives on their child's transition experience and their child's health and wellbeing. Interviews will be audio-recorded, with participants' consent, transcribed, and analysed using thematic analysis.

##### *Ethnography*

Ethnography at The Moving On Transition Service, which holds social groups once a fortnight for young people with learning disabilities undergoing transition, will also be conducted to explore the ways in which the transition experience affects young people with learning disabilities. Field notes from this will be written up and analysed using thematic analysis.

### *Questionnaires*

The following questionnaires will be completed at interview:

- Strengths and Difficulties Questionnaire (SDQ) – a behavioural screening questionnaire for under-16s. This measures psychological attributes including emotional symptoms, conduct problems, hyperactivity/inattention, peer relationship problems and pro-social behaviour and could identify the presence of challenging behaviours or emotional difficulties. Given the lower developmental age (as opposed to chronological age) of people with learning disabilities, this will be used for all participants.
- EQ-5D – measures health outcomes. A descriptive system assesses problems with mobility, self-care, usual activities, pain/discomfort, and anxiety/depression.
- Vineland Adaptive Behaviour Scale – assesses adaptive behaviours across five domains: communication, daily living skills, socialisation, motor skills, and maladaptive behaviours. This will indicate the severity of the young person's disability.

### *Secondary Analysis*

Secondary analysis of the Census (2011) data will examine whether self-reported general health, mental health, physical disability, or presence of long term illnesses, diseases or conditions, deafness or blindness in young people with learning disabilities (age 13-24) in Scotland differed across the transition period.

#### **2. What supports (formal and informal) are helpful for young people with learning disabilities in transition?**

### *Qualitative Interview*

Semi-structured interviews with young people with learning disabilities will discuss sources and types of support that they have found helpful. Semi-structured interviews with families of young people with learning disabilities will discuss sources and types of support available and what has been helpful for their child. Interviews will be audio-recorded, with participants' consent, transcribed, and analysed using thematic analysis.

### *Ethnography*

Ethnographic work will take place with an organisation dedicated to providing support for young people undergoing transition (Moving On Transition Service). The researcher will observe the ways in which this service provides support and which elements of this service are especially helpful. Field notes will be analysed using thematic analysis.

### *Secondary Analysis*

Secondary analysis of the Census (2011) will assess what factors contribute to good health during transition; the association between general health measures in young people with



learning disabilities undergoing transition and the following factors will be assessed using logistic regression: gender, deprivation, rurality, mental health, physical disability.

- 3. Is the impact of transition on health and wellbeing similar or different for young people with profound and multiple learning disabilities and young people with milder disabilities?**

#### *Qualitative Interview*

Where possible, semi-structured interviews with young people with learning disabilities will be conducted across the full spectrum of disability to ascertain whether there are significant differences in emergent themes. For those with communication impairments, visual aids e.g. Talking Mats will be utilised. Interviews with parents of young people with profound and multiple learning disabilities and young people with mild/moderate disabilities will offer a source of comparison. Interviews will be audio-recorded with participants' consent, transcribed, and analysed using framework analysis. Visual aids e.g. Talking Mats images will be included in the analysis.

- 4. Is the impact of transition on health and wellbeing similar or different for young people with learning disabilities compared with young people without learning disabilities?**

#### *Qualitative Interview*

Where applicable, interviews with parents of young people with learning disabilities will include the opportunity for parents to reflect on differences between transition and its implications for health and wellbeing in their child with learning disabilities and in any siblings without learning disabilities.

#### *Secondary Analysis*

Secondary analysis of the Census (2011) data will examine differences across the transition period in self-reported general health in young people with learning disabilities compared to age-matched young people without disabilities. General health measures of young people with learning disabilities and young people without learning disabilities will be compared.

#### **Ethical issues and consent**

Approval will be sought from University College of Medical Veterinary and Life Sciences Ethics Committee. There may be an issue in terms of capacity for informed consent in some adults with a learning disability. In order to provide informed consent, participants need to understand the nature and implications of the research and their involvement in it. Accessible information will be provided to all participants and the researcher will check their understanding verbally.

In cases where an individual is unable to give their own consent, The Adults with Incapacity (Scotland) Act will be followed. This requires consent to be taken from the person's nearest

relative or welfare guardian/attorney. Consent will be taken to participate in the study, and specifically and separately, for tape recordings to be made of interviews. Consent will also be requested to re-contact participants entering transition in 5 years' time, to invite their participation in a follow up project.

Acquiescence can be an issue when working with this population so the researcher will ensure that consent is maintained throughout research procedures in order to avoid any sense of coercion. In some instances, e.g. ethnographic work, establishing trust and rapport with participants will be crucial; however, we need to be aware of not creating expectations of a friendship that will be maintained beyond the research context. This can be a specific problem when working with this population, as the literature suggests that individuals with learning disabilities have few social contacts outside their family or professional networks. With this in mind, the terms of engagement in the research and boundaries will be established and maintained. As the interviews will be in-depth and of a sensitive nature, we need to ensure that we are not being intrusive. This is also the case in the instance of ethnographic work, where repeated contact will be necessary.

The interview topic guide will be developed to ensure it is not burdensome, and the test-instruments have been selected mindful of the time they will take to complete. Asking about mental health can be a sensitive issue, and if there is any suggestions whatsoever that a participant is becoming stressed or worried about questions, or is becoming fatigued, the interview will be stopped. The student who will conduct the interviews has experience working with young people with learning disabilities.

Approval for analysis of the Census (2011) is already in place for the Scottish Learning Disabilities Observatory.

### **Risks & Benefits**

Risks to participants in this study are minimal. However, interviews may potentially invoke anxiety in young people or their families regarding the young person's future. The burden of interviews is also placed on young people and their families. Despite these risks, there are potentially a number of benefits of this study, which constitutes an exploration of an important topic that has as yet been unexplored; the results of which will be widely disseminated. This study will also give young people with learning disabilities the opportunity to be involved in research, which will give them a voice on a crucial topic and may allow them to develop self-confidence and self-advocacy skills. It will hopefully be an enjoyable experience to express their opinions and feel that they are valued as experts in this area, and they may enjoy the interaction with the researcher.

### **Data**

Data will include transcriptions from interviews, possibly visual aids e.g. Talking Mats images, ethnographic field notes, questionnaire data and secondary data from the Census (2011).

## *Analysis*

### Qualitative data

Qualitative data (from interviews and ethnography) will be transcribed and analysed using NVIVO software. Data will be analysed using thematic analysis, wherein the coding framework is developed based on issues identified from the literature and further issues that emerge throughout the course of data analysis. Data will be coded according to this framework in order to group data into emergent themes. Recurrent, related or contradictory themes will be identified in an attempt to make generalisations and answer the research questions. A second researcher will analyse a sample of the data to check coding agreement.

### Questionnaires

Questionnaire data (SDQ, EQ-5D) will examine the existence of health or wellbeing problems in the sample. Scores on the Vineland Adaptive Scale will give an indication of the severity of the young person's disability.

### Census 2011

The Census 2011 secondary analysis will examine differences in self-reported general health, mental health, physical disability, presence of long term illness disease or condition, deafness, and blindness in young people with learning disabilities aged 13-24 across Scotland, compared to age- and gender-matched young people without disabilities.

Differences in general health in young people with learning disabilities across the transition period (between those who are still in school and those who have left school) will also be compared.

The association between general health measures in young people with learning disabilities and the following factors will be assessed using logistic regression: gender, deprivation, mental health, rurality, physical disability.

## *Storage*

Data (e.g. interview transcriptions, field notes, questionnaire data) will be stored in a locked filing cabinet at the University of Glasgow, to which only the research team will have access. Recordings will be destroyed on completion of the study and transcripts will be archived for 10 years.

Transcriptions will be anonymised i.e. all participants will be given pseudonyms so they cannot be identified in any quotations. Questionnaire data will also be anonymised, with data being identified through a number rather than through participants' names.

## *Governance*

The Data Protection Act and Adults with Incapacity (Scotland) Act will be adhered to throughout.

## **Dissemination**

The findings from this study will be disseminated through a variety of ways, including a PhD thesis, publications in scientific journals and at scientific conferences, social media, e.g. Facebook,

Twitter, and newsletters to charities, special education schools and further education colleges. Results will also be disseminated back to study participants in an accessible format.

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## 50.2 Appendix C: Cover letter

Department of Mental Health and Wellbeing  
University of Glasgow  
1<sup>st</sup> Floor, Admin Building  
Gartnavel Royal Hospital  
1055 Great Western Rd  
Glasgow G12XH

26/01/16

Dear Parent/Guardian

I am a PhD student at the University of Glasgow, working on a project examining the impact of transition on health in young people with learning disabilities. The aim of the research is to examine whether transition – incorporating the move from school to work, from child to adult services, and from childhood to adulthood – impacts health and wellbeing in young people with learning disabilities, and in what particular ways. We need more research in this area to inform future care, supports and policies.

I am writing to invite you and your child to participate in a research study. I would like to conduct some interviews with young people and parents, during which we will discuss the experience of transition and the ways in which it may have affected health and wellbeing.

Please find enclosed information about the study and consent forms for you to sign. If you would like to participate in the study, please return your signed consent forms and contact details to me in the freepost envelope provided, and I will contact you to arrange a suitable time to conduct the interview. Alternatively, please feel free to contact me using the contact details provided.

Yours sincerely,

Genevieve Young-Southward

Email: [g.young-southward.1@research.gla.ac.uk](mailto:g.young-southward.1@research.gla.ac.uk)

Phone: 07786627968

## 50.3 Appendix D: Accessible information sheet for young people



### PARTICIPANT INFORMATION SHEET

#### **The impact of transition on health and wellbeing in young people with learning disabilities: Interviews**

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 that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

#### **What is the purpose of the study?**

Leaving school is a big change in a person's life, and it can affect them in many different ways. One of these effects may be on health. We are interested in the ways in which leaving school and entering adulthood impacts health. We need more information about this so that we can improve support that is available when a person leaves school. We would like to ask you some questions about your experience of leaving school and becoming an adult.



#### **Why have I been chosen?**

This research is focussed on young people with learning disabilities undergoing transition. Therefore, you have been chosen due to your age and disability status.

#### **Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part, you may keep this information sheet, and will be asked to sign and return a consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason.

**What will happen to me if I take part?**

You will be interviewed by a researcher about your experience of leaving school, and your thoughts and feelings about the future. The discussion will be audio-recorded so that the researcher can remember what you talked about. You will also fill in three questionnaires, which measure aspects of your health, wellbeing and functioning, with the researcher.

**What do I have to do?**

There are no prior restrictions involved in taking part in this study.

**What are the possible disadvantages and risks of taking part?**

There are no risks involved in taking part in this study. You will have to give up the time to take part.

**What are the possible benefits of taking part?**

There are no direct benefits from taking part in this study. However, you may benefit from talking to the researcher about issues surrounding transition, for example you may find the experience enjoyable and it might give you the opportunity to develop self-confidence. The information that is collected during this study will give us a better understanding of what matters to young people with learning disabilities during the transition period.

**Will my taking part in this study be kept confidential?**

All information which is collected about you, or responses that you provide, during the course of the research will be kept strictly confidential. Any written information about you will not include your name or any personal information so that you cannot be recognised from it. Please note that assurances on confidentiality will be strictly adhered to unless there is the unlikely event of evidence of serious harm, or risk of serious harm, being uncovered. In such cases the University may be obliged to contact relevant statutory bodies/agencies.

**What will happen to the results of the research study?**

The information obtained from the interview will be written up as part of my PhD thesis. You will not be identified in any report or publication. I will tell you what the study found out.

**Who is organising and funding the research?**

This research is funded by an NHS scholarship and is being conducted 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**

Genevieve Young-Southward: PhD candidate.

[G.young-southward.1@research.gla.ac.uk](mailto:G.young-southward.1@research.gla.ac.uk)

07786627968



Thank you very much for considering participating in this study.



## 50.4 Appendix E: Information sheet for parents/carers



### INFORMATION FOR PARENTS

#### **The impact of transition on health and wellbeing in young people with learning disabilities: Interviews**

You and your son/daughter are being invited to take part in a research study. Before you decide whether you will take part 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 that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

#### **What is the purpose of the study?**

Following transition from school to adulthood, outcomes for young people with learning disabilities may be poorer compared to those without disabilities. Across all ages, individuals with learning disabilities experience poorer health status than the non-disabled population, and transition may be a time of vulnerability due to the upheaval in life circumstances and change in support networks that occur. My PhD project aims to examine the impact of transition on health and wellbeing in young people with learning disabilities. More evidence is needed in order to accurately inform future care, supports, and policy. The purpose of this study is to run interviews with young people and their families in order to gain some insight into the ways in which the transition period may have an impact on health and wellbeing. Information obtained from these interviews will be written up as part of my PhD thesis.

#### **Why have we been chosen?**

This research is focussed on young people with learning disabilities undergoing transition. Therefore, you and your son/daughter have been chosen due to your son/daughter's age and disability status.

**Do we have to take part?**

It is up to you and your son/daughter to decide whether or not to take part. If you do decide to take part, you may keep this information sheet, and will be asked to sign and return a consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason.

**What will happen to us if we take part?**

You and your son/daughter will be interviewed, either together or separately, depending on your preference, by a researcher. The interview will last approximately one hour long and will include questions about you and your son/daughter's experiences during the transition period, and how they may have affected your son/daughter's health and wellbeing. The interviews will be recorded so they can be considered in detail following the interviews.

**What do I have to do?**

There are no prior restrictions involved in taking part in this study.

**What are the possible disadvantages and risks of taking part?**

There are no risks involved in taking part in this study. You and your son/daughter will have to give up the time to take part. You will be reminded that you or your son/daughter may terminate the interview at any time.

**What are the possible benefits of taking part?**

There are no direct benefits from taking part in this study. However, you and your son/daughter may benefit from talking to the researcher about issues surrounding transition, for example your son/daughter may find the experience enjoyable and it might improve their confidence and self-advocacy skills. The information that is collected during this study will give us a better understanding of what matters to young people with learning disabilities and their families during the transition period.

**Will our taking part in this study be kept confidential?**

All information which is collected about you or your son/daughter, or responses that you provide, during the course of the research will be kept strictly confidential. Any written information about you or your son/daughter will not include your names or any personal information so that you cannot be recognised from it. Please note that assurances on confidentiality will be strictly adhered to unless there is the unlikely event of evidence of serious harm, or risk of serious harm, being uncovered. In such cases the University may be obliged to contact relevant statutory bodies/agencies.

**What will happen to the results of the research study?**

The information obtained from the interviews will be written up as part of my PhD thesis. You or your son/daughter will not be identified in any report or publication. I will tell you what the study found out.

**Who is organising and funding the research?**

This research is funded by an NHS scholarship and is being conducted 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**

Genevieve Young-Southward: PhD candidate.

[G.young-southward.1@research.gla.ac.uk](mailto:G.young-southward.1@research.gla.ac.uk)

07786627968



Thank you very much for considering participating in this study.

## 50.5 Appendix F: Consent form for young people



University of Glasgow | College of Medical,  
Veterinary & Life Sciences

Project Number: 63527/1

Subject Identification Number for this trial:

### YOUNG PERSON CONSENT FORM

The impact of transition on health and wellbeing in young people with learning disabilities

#### Name of Researcher(s):

Genevieve Young-Southward: PhD candidate

Professor Sally-Ann Cooper: Professor of Learning Disabilities

Professor Christopher Philo: Professor of Geography

#### Please initial box

I confirm that I have read and understand the information sheet dated 17/11/15 (version 1.4) 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 study.

☐

I agree that the interview can be tape recorded.

☐

I agree to be contacted in the future to take part in a follow-up project.

☐

_____	_____	_____
Name	Date	Signature
_____	_____	_____
Name of Person taking consent	Date	Signature
(if different from researcher)		
_____	_____	_____
Researcher	Date	Signature

## 50.6 Appendix G: Consent form for parents/carers



University of Glasgow | College of Medical,  
Veterinary & Life Sciences

Project Number: 63527/1

Subject Identification Number for this trial:

### PARENT CONSENT FORM

#### The impact of transition on health and wellbeing in young people with learning disabilities

##### Name of Researcher(s):

Genevieve Young-Southward: PhD candidate

Professor Sally-Ann Cooper: Professor of Learning Disabilities

Professor Christopher Philo: Professor of Geography

##### Please initial box

I confirm that I have read and understand the information sheet dated 17/11/15  
(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 study.

☐

I agree that the interview can be tape recorded.

☐

_____	_____	_____
Name	Date	Signature
_____	_____	_____
Name of Person taking consent	Date	Signature
(if different from researcher)		
_____	_____	_____
Researcher	Date	Signature

## 50.7 Appendix H: Consent form for parents on behalf of young people



**University of Glasgow** | College of Medical,  
Veterinary & Life Sciences

Project Number: 63527/1

Subject Identification Number:

### CONSENT FORM FOR PARENTS/GUARDIANS

#### The impact of transition on health and wellbeing in young people with learning disabilities

##### Name of Researcher(s):

Genevieve Young-Southward: PhD candidate

Professor Sally-Ann Cooper: Professor of Learning Disabilities

Professor Christopher Philo: Professor of Geography

I confirm that my

child..... is not able to  
consent to take part in the study for him/her-self and that I am his/her

parent

[ ]

guardian

[ ]

#### Please initial box

I confirm that I have read and understand the information sheet dated 17/11/15  
(version 1.1) for the above study and have had the opportunity to ask questions.

☐

I understand that my child's participation is voluntary and that they are free to  
withdraw at any time, without giving any reason.

☐

I agree for my child to take part in the above study.

☐

I agree that the interview can be tape recorded.

☐

I agree for my child to be contacted in the future to participate in a  
follow-up project.

☐

_____	_____	_____
Name	Date	Signature
_____	_____	_____
Name of Person taking consent	Date	Signature
(if different from researcher)		
_____	_____	_____
Researcher	Date	Signature

## 50.8 Appendix I: Example advert

### **Invitation to take part in research: Transition and health in young adults with learning disabilities**

I am conducting a study on how transition from school affects health and wellbeing into adulthood in young adults with learning disabilities.

I am looking to interview young adults with learning disabilities aged 25-35 years, and their families, about the experience of leaving school, and what they have been doing since leaving school.

The interview will last around one hour and will take place at home.

If you would like to hear more information about the study, or to arrange an interview, please contact me via email: [g.young-southward.1@research.gla.ac.uk](mailto:g.young-southward.1@research.gla.ac.uk) or through the Scottish Learning Disabilities website: <https://www.sldo.ac.uk/contact/>

With thanks, Genevieve Young-Southward (PhD candidate)

## 50.9 Appendix J: Ethical amendment

**Describe the design of the study and methods to be used. Include sample size and the calculation used to determine this. Statistical advice should be obtained if in doubt.**

A mixed methods study will be conducted.


Up to 20 young people with learning disabilities aged 25-35 will be invited to take part in semi-structured interviews designed to explore their transition experience and the impact it has had on their health and wellbeing. Young people's parents will also be invited to take part in a similar separate interview. Interviews will be audio-recorded, with participants' consent, transcribed, and analysed using framework analysis.



## 50.10 Appendix K: Approval of ethical amendment

**Re: Ethics amendment**

MVLS Ethics Admin

 You replied to this message on 09/01/2017 11:33.

Sent: Wed 09/11/2016 15:52

To: Genevieve Young-Southward; MVLS Ethics Admin

---

Hi Genevieve

The committee has confirmed that your amendment request below is fine and can be approved. You can consider this email as approval, but if you require a letter from the committee instead, I'll have one made for you.

Regards

Neil

## 50.11 Appendix L: CASP checklist



### 10 questions to help you make sense of qualitative research

#### How to use this appraisal tool

Three broad issues need to be considered when appraising a qualitative study:

- Are the results of the study valid? (Section A)
- What are the results? (Section B)
- Will the results help locally? (Section C)

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is "yes", it is worth proceeding with the remaining questions.

There is some degree of overlap between the questions, you are asked to record a "yes", "no" or "can't tell" to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

These checklists were designed to be used as educational pedagogic tools, as part of a workshop setting, therefore we do not suggest a scoring system. The core CASP checklists (randomised controlled trial & systematic review) were based on JAMA 'Users' guides to the medical literature 1994 (adapted from Guyatt GH, Sackett DL, and Cook DJ), and piloted with health care practitioners.

For each new checklist a group of experts were assembled to develop and pilot the checklist and the workshop format with which it would be used. Over the years overall adjustments have been made to the format, but a recent survey of checklist users reiterated that the basic format continues to be useful and appropriate.

**Referencing: we recommend using the Harvard style citation, i.e.:**

Critical Appraisal Skills Programme (2017). CASP (insert name of checklist i.e. Qualitative Research) Checklist. [online] Available at: *URL*. Accessed: *Date Accessed*.

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## Screening Questions

1. Was there a clear statement of the aims of the research?

☐ Yes ☐ Can't tell ☐ No

HINT: Consider

- What was the goal of the research?
- Why it was thought important?
- Its relevance

2. Is a qualitative methodology appropriate?

☐ Yes ☐ Can't tell ☐ No

HINT: Consider

- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal?

## Is it worth continuing?



### Detailed questions

3. Was the research design appropriate to address the aims of the research?

☐ Yes ☐ Can't tell ☐ No

HINT: Consider

- If the researcher has justified the research design (E.g. have they discussed how they decided which method to use)?

**4. Was the recruitment strategy appropriate to the aims of the research?** ☐ Yes ☐ Can't tell ☐ No

HINT: Consider

- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

**5. Was the data collected in a way that addressed the research issue?** ☐ Yes ☐ Can't tell ☐ No

HINT: Consider

- If the setting for data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, or did they use a topic guide)?
- If methods were modified during the study. If so, has the researcher explained how and why?
- If the form of data is clear (e.g. tape recordings, video material, notes etc)
- If the researcher has discussed saturation of data

**6. Has the relationship between researcher and participants been adequately considered?** ☐ Yes ☐ Can't tell ☐ No

HINT: Consider

- If the researcher critically examined their own role, potential bias and influence during
  - (a) Formulation of the research questions
  - (b) Data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

**7. Have ethical issues been taken into consideration?**☐ Yes☐ Can't tell☐ No

HINT: Consider

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

**8. Was the data analysis sufficiently rigorous?**☐ Yes☐ Can't tell☐ No

HINT: Consider

- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

**9. Is there a clear statement of findings?**☐ Yes☐ Can't tell☐ No

HINT: Consider

- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researchers arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question


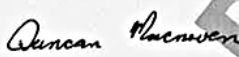




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**10. How valuable is the research?**

HINT: Consider

- If the researcher discusses the contribution the study makes to existing knowledge or understanding e.g. do they consider the findings in relation to current practice or policy?, or relevant research-based literature?
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

## 50.12 Appendix M: Census questionnaire

Household Questionnaire			
 <b>Scotland's Census 2011</b> Shaping our future		<b>27 March 2011</b>	
Official Use	CD	ED	Line Number
		If there is a <b>mistake</b> in the printed address, please write your correct address below  House name / number  Street / Town / City  Postcode	
<b>Why the census matters</b>  The census is the official count of every person and household in Scotland. It is held every 10 years and helps to plan our future public services.  Please fill in this questionnaire on, or around, Sunday 27 March. Please include everyone at this address. It shouldn't take long and you can fill it in online.  As a householder, you have a legal duty to fill in this questionnaire. If you don't, or if you supply false information, you may be fined up to £1,000.  Your personal information is protected by law and we will keep it confidential for 100 years.  Thank you for helping to shape Scotland's future.   Duncan Macniven <b>Registrar General for Scotland</b>		<b>Please fill in this questionnaire:</b>  <div>  <b>online at</b>  <a href="http://www.scotlandscensus.gov.uk">www.scotlandscensus.gov.uk</a> </div>  Enter the Internet Questionnaire Access Code:  <div> <input type="text"/> <input type="text"/> <input type="text"/> </div>  You can fill in this questionnaire online in English or Gaelic.  <b>Or</b>  Fill in this paper version and post it back using the pre-paid envelope provided.	
<b>Need help?</b>  <div>  <a href="http://www.scotlandscensus.gov.uk">www.scotlandscensus.gov.uk</a> </div> <div>  <b>Helpline 0300 123 1702</b> </div> <div>  <b>Textphone 18001 0300 123 1703</b> </div>		<b>Declaration</b> I have filled in this questionnaire fully and accurately, as far as I know.  Signature(s) <input type="text"/>  Date <input type="text"/>	

## Important guidance - before you start

### Who should fill in this questionnaire?

The **householder or joint householder** is responsible for filling in this questionnaire for their household.

The **householder or joint householder** is the person who lives, or is present, at this address who:

- owns or rents (or jointly owns or rents) the accommodation; and / or
- is responsible (or jointly responsible) for paying the household bills and expenses.

A **household** is:

- one person living alone; or
- a group of people (not necessarily related) living at the same address who share cooking facilities and share a living room or sitting room or dining area.

If there is more than one household at this address, please see the section below.

### Will you need extra questionnaires?

- If there are more than 5 people in this household, either fill in the questionnaire online for the whole household or fill in this questionnaire and ask us for a **Continuation Questionnaire**.
- If any member of this household aged 16 or over does not want to reveal their information to others in the household, you can ask us for an **Individual Questionnaire** with an envelope. Remember to include these people in the answers to household questions H1 to H13 on this questionnaire, but leave the individual questions 1 to 38 blank for them.
- If there is more than one household at this address, you need to ask for one or more extra **Household Questionnaires**.

You can ask for extra questionnaires online at [www.scotlandscensus.gov.uk](http://www.scotlandscensus.gov.uk) or by calling 0300 123 1702.

### How to fill in this questionnaire

This questionnaire will be scanned by a computer. To make sure we record your answers correctly, follow the instructions below.

Please:

- use black or blue ink
- tick your answers within the box like this: ☒
- print your answers, in English, within the box like this: SMITH Use capital letters - one per box
- correct any mistakes like this: ■ or SMITH
- continue on to the next line (if possible) like this, if a word will not fit on to one line: 130 LADYWELL CRES  
CENT

**DO NOT** draw a line through questions or pages. The computer may mistake this for an answer.



## Extra guidance for household questions H1 to H5 (on page 4)

### Children with parents who live apart

Children with parents who live apart must be included on the questionnaire at the address where they **spend the most time**, in household questions H1 to H3 and H13, and individual questions 1 to 38.

If they are staying at their other address on the night of 27 March 2011, they must also be included on the questionnaire at that other address in household questions H4 and H5, and the continuation of H5 on the back page.

If they spend their time equally between two addresses, they must only be included in household questions H1 to H3 and H13, and individual questions 1 to 38, at the address where they are staying on the night of 27 March 2011.

### Students and schoolchildren who live away from home during term-time

All students and schoolchildren who live away from home during term-time must be included on a questionnaire at **both** their home and term-time addresses.

- At their home address they must be included in household questions H1 to H3 and H13, and individual questions 1 to 6.
- At their term-time address they must be included in household questions H1 to H3 and H13, and individual questions 1 to 38.

### People from outside the UK

People from outside the UK whose total length of stay in the UK will be **6 months or more** must be included on the questionnaire at the address where they usually stay in the UK. They must be included in household questions H1 to H3 and H13, and individual questions 1 to 38.

If their total length of stay is **less than 6 months**, they must be included on the questionnaire at the address where they usually stay in the UK in household questions H4 and H5, and the continuation of H5 on the back page.

### Households away on 27 March 2011

If this address is unoccupied on the night of 27 March 2011 because the whole household is away, the questionnaire must be filled in as soon as possible when they return.

If nobody lives in the property, please complete household questions H6 to H9 only.

### People with more than one UK address

People with more than one address in the UK need to be included on a questionnaire at their permanent or family home address.

- At their **permanent or family home address** they must be included on the questionnaire in household questions H1 to H3 and H13, and individual questions 1 to 38.
- If they are staying at their **second address** on the night of 27 March 2011 they must also be included on the questionnaire at that second address, but only in household questions H4 and H5, and the continuation of H5 on the back page.
- If they **do not** have a permanent or family home address they must be included on the questionnaire at the address where they spend the most time, in household questions H1 to H3 and H13, and individual questions 1 to 38.

### People temporarily away from home

If someone is temporarily away on the night of 27 March 2011 and this is their **permanent or family home**, include them in household questions H1 to H3 and H13 and individual questions 1 to 38. This includes people who are:

- staying, or expecting to stay, in a residential establishment such as a hospital, care home or hostel, for **less than 6 months**
- living away from home while working, on holiday or travelling (unless outside the UK for 12 months or more)
- members of the Armed Forces
- staying at their second address
- visiting friends or relatives; or
- in prison on remand (for any length of time), or **sentenced to less than 6 months** in prison

Do not include anyone who is:

- staying, or expecting to stay, in a residential establishment for **6 months or more**; or
- in prison, convicted and **sentenced to 6 months or more**, or who is waiting to be sentenced

These people will be included at their establishment.

## Household questions - people

## 1 Who usually lives here?

If you need more advice about who to include, see the extra guidance on page 3 or contact us.

◆ Tick all that apply.

- ☐ Me, this is my permanent or family home
- ☐ Family members including partners, children and babies born on or before 27 March 2011
- ☐ Students and / or schoolchildren who live away from home during term-time
- ☐ Housemates / flatmates or lodgers
- ☐ People who work away from home within the UK, or are members of the Armed Forces, **if this is their permanent or family home**
- ☐ People staying temporarily who usually live in the UK but do not have another UK address
- ☐ People who usually live outside the UK who are staying in the UK for **6 months or more**
- ☐ People temporarily away from home on the night of 27 March 2011

## 2 Counting everyone you included in question 1, how many people usually live here?

## 3 Starting with the householder(s), list the names of the people counted in question 1, including children and babies.

	First name	Last name
Person 1		
Person 2		
Person 3		
Person 4		
Person 5		

If there are more than 5 people in this household, either fill in the questionnaire online for the whole household or contact the Helpline on 0300 123 1702 to ask for a Continuation Questionnaire.

## 4 Is there anyone staying at this address on the night of 27 March 2011 whose permanent or family home is elsewhere?

◆ Do not include anyone counted in question 1.

◆ Tick all that apply.

- ☐ People staying here because it is their second address, for example, for work or a holiday home. Their permanent or family home is elsewhere.
- ☐ People who usually live somewhere else in the UK, for example, boy / girlfriends, friends, relatives
- ☐ People who usually live outside the UK who are staying in the UK for less than 6 months
- ☐ People here on holiday
- ☐ No-one else is staying at this address on the night of 27 March 2011 → Go to 5

5 Counting **only** the people you included in question 4, how many people are staying at this address on the night of 27 March 2011 whose permanent or family home is elsewhere?

→ Details for these people must be recorded on the back page.

If there are **only** people staying at this address on the night of 27 March 2011 whose permanent or family home is elsewhere, please make sure you answer questions 11 to 14 on page 5 and questions 15 to 18 on the back page.

## Household questions - accommodation

H6 What type of accommodation is this?

A whole house or bungalow that is:

- ☐ detached
- ☐ semi-detached
- ☐ terraced (including end-terrace)

A flat, maisonette, or apartment that is:

- ☐ in a tenement or purpose-built block of flats (including '4-in-a-block')
- ☐ part of a converted or shared house (including bed-sits)
- ☐ in a commercial building (for example, in an office building, hotel or over a shop)

A mobile or temporary structure:

- ☐ a caravan or other mobile or temporary structure

H7 Is this household's accommodation self-contained?

- ◆ This means that all the rooms, including the kitchen, bathroom and toilet, are behind a door that only this household can use.
- ☐ Yes, all the rooms are behind a door that only this household can use
- ☐ No

H8 How many rooms are available for use only by this household?

◆ Do NOT count:

- bathrooms
- toilets
- halls or landings
- rooms that can only be used for storage such as cupboards.

◆ Count all other rooms, for example:

- kitchens
- living rooms
- utility rooms
- bedrooms
- studies
- conservatories.

◆ If two rooms have been converted into one, count them as one room.

 Number of rooms

H9 What type of central heating does this accommodation have?

◆ If the central heating is available, please tick the box whether or not you use it.

◆ Central heating is a central system that generates heat for multiple rooms.

- ☐ No central heating
- ☐ Gas
- ☐ Electric (including storage heaters)
- ☐ Oil
- ☐ Solid fuel
- ☐ Other central heating, please write in

H10 Does your household own or rent this accommodation?

◆ Tick one box only.

☐ Owns outright → Go to **Q10**☐ Owns with a mortgage or loan → Go to **Q11**☐ Part owns and part rents (shared ownership)☐ Rents (with or without housing benefit)☐ Lives here rent free

H11 Who is your landlord?

- ☐ Council (Local Authority)
- ☐ Housing Association / Registered Social Landlord
- ☐ Private landlord or letting agency
- ☐ Employer of a household member
- ☐ Relative or friend of a household member
- ☐ Other

H12 In total, how many cars or vans are owned, or are available for use, by members of this household?

◆ Include any company car(s) or van(s) available for private use.

- ☐ None
- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4 or more, please write in number

Page !

• • • • •

HQ 05

## household questions - relationships

## 13 How are the members of this household related to each other?

- ♦ Tick a box to show the relationship of each person listed in question H3 (on page 4) to each of the other members of this household. Remember to include household members who are filling in an Individual Questionnaire.
- ♦ Use the same order you used in question H3 - you may find it helpful to write the name(s) of the household member(s) in the space provided. Remember to include children and babies.
- ♦ If there are more than 5 people in this household, contact the Helpline on 0300 123 1702 to ask for a Continuation Questionnaire.

This example shows how to provide relationship information for Robert Smith, who is Person 1, his wife (Mary) and their three children (Alison, Steven and James).

Name of Person 1	Name of Person 2	Name of Person 3
ROBERT SMITH	MARY SMITH	ALISON SMITH
Relationship of Person 1 to Person:	Relationship of Person 2 to Person:	Relationship of Person 3 to Persons:
	1	1 2
Husband or wife	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Same-sex civil partner	<input type="checkbox"/>	<input type="checkbox"/>
Partner	<input type="checkbox"/>	<input type="checkbox"/>
Son or daughter	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Step-child	<input type="checkbox"/>	<input type="checkbox"/>
Brother or sister	<input type="checkbox"/>	<input type="checkbox"/>

NAME OF PERSON 1  
PLEASE USE THE SAME ORDER AS QUESTION H3

Name of Person 1	Name of Person 2	Name of Person 3
Relationship of Person 1 to Person:	Relationship of Person 2 to Person:	Relationship of Person 3 to Persons:
	1	1 2
Husband or wife	<input type="checkbox"/>	<input type="checkbox"/>
Same-sex civil partner	<input type="checkbox"/>	<input type="checkbox"/>
Partner	<input type="checkbox"/>	<input type="checkbox"/>
Son or daughter	<input type="checkbox"/>	<input type="checkbox"/>
Step-child	<input type="checkbox"/>	<input type="checkbox"/>
Brother or sister	<input type="checkbox"/>	<input type="checkbox"/>
Step-brother or step-sister	<input type="checkbox"/>	<input type="checkbox"/>
Mother or father	<input type="checkbox"/>	<input type="checkbox"/>
Step-mother or step-father	<input type="checkbox"/>	<input type="checkbox"/>
Grandchild	<input type="checkbox"/>	<input type="checkbox"/>
Grandparent	<input type="checkbox"/>	<input type="checkbox"/>
Other relation	<input type="checkbox"/>	<input type="checkbox"/>
Unrelated (including foster child)	<input type="checkbox"/>	<input type="checkbox"/>

NAME OF PERSON 1  
PLEASE USE THE SAME ORDER AS QUESTION H3

Name of Person 4		Name of Person 5	
STEVEN SMITH		JAMES SMITH	
Relationship of Person 4 to Persons:		Relationship of Person 5 to Persons:	
	1 2 3		1 2 3 4
Husband or wife	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Husband or wife	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Same-sex civil partner	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Same-sex civil partner	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Partner	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Partner	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Son or daughter	<input checked="" type="checkbox"/> <input checked="" type="checkbox"/> <input type="checkbox"/>	Son or daughter	<input checked="" type="checkbox"/> <input checked="" type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Step-child	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Step-child	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Brother or sister	<input type="checkbox"/> <input type="checkbox"/> <input checked="" type="checkbox"/>	Brother or sister	<input type="checkbox"/> <input type="checkbox"/> <input checked="" type="checkbox"/> <input checked="" type="checkbox"/>

Name of Person 4		Name of Person 5	
Relationship of Person 4 to Persons:		Relationship of Person 5 to Persons:	
	1 2 3		1 2 3 4
Husband or wife	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Husband or wife	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Same-sex civil partner	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Same-sex civil partner	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Partner	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Partner	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Son or daughter	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Son or daughter	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Step-child	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Step-child	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Brother or sister	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Brother or sister	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Step-brother or step-sister	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Step-brother or step-sister	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Mother or father	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Mother or father	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Step-mother or step-father	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Step-mother or step-father	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Grandchild	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Grandchild	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Grandparent	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Grandparent	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Other relation	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Other relation	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Unrelated (including foster child)	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Unrelated (including foster child)	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>



**Person 1 - Individual questions continued**

**12** How do you usually travel to your main place of work or study (including school)?

◆ Tick one box only.

◆ Tick the box for the longest part, by distance, of your usual journey to work or study.

- ☐ Driving a car or van
- ☐ Passenger in a car or van
- ☐ On foot
- ☐ Bus, minibus or coach
- ☐ Train
- ☐ Underground, subway, metro, light rail or tram
- ☐ Taxi
- ☐ Bicycle
- ☐ Motorcycle, scooter or moped
- ☐ Other

**13** What religion, religious denomination or body do you belong to?

◆ This question is voluntary.

- ☐ None
- ☐ Church of Scotland
- ☐ Roman Catholic
- ☐ Other Christian, please write in below
- ☐ Muslim
- ☐ Buddhist
- ☐ Sikh
- ☐ Jewish
- ☐ Hindu
- ☐ Another religion or body, please write in

**14** What do you feel is your national identity?

◆ Tick **ALL** that apply.

- ☐ Scottish
- ☐ English
- ☐ Welsh
- ☐ Northern Irish
- ☐ British
- ☐ Other, please write in

**15** What is your ethnic group?

◆ Choose **ONE** section from A to F, then tick **ONE** box which **best describes** your ethnic group or background

**A White**

- ☐ Scottish
- ☐ Other British
- ☐ Irish
- ☐ Gypsy / Traveller
- ☐ Polish
- ☐ Other white ethnic group, please write in

**B Mixed or multiple ethnic groups**

- ☐ Any mixed or multiple ethnic groups, please write in

**C Asian, Asian Scottish or Asian British**

- ☐ Pakistani, Pakistani Scottish or Pakistani British
- ☐ Indian, Indian Scottish or Indian British
- ☐ Bangladeshi, Bangladeshi Scottish or Bangladeshi British
- ☐ Chinese, Chinese Scottish or Chinese British
- ☐ Other, please write in

**D African**

- ☐ African, African Scottish or African British
- ☐ Other, please write in

**E Caribbean or Black**

- ☐ Caribbean, Caribbean Scottish or Caribbean British
- ☐ Black, Black Scottish or Black British
- ☐ Other, please write in

**F Other ethnic group**

- ☐ Arab, Arab Scottish or Arab British
- ☐ Other, please write in

Person 1 - Individual questions continued

6 Which of these can you do?

◆ Tick all that apply.

	English	Scottish Gaelic	Scots
Understand	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Speak	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Read	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Write	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

☐ None of these

7 How well can you speak English?

Very well	Well	Not well	Not at all
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

8 Do you use a language other than English at home?

◆ Tick all that apply.

- ☐ No, English only
- ☐ Yes, British Sign Language
- ☐ Yes, other - please write in

9 How is your health in general?

Very good	Good	Fair	Bad	Very bad
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

10 Do you have any of the following conditions which have lasted, or are expected to last, at least 12 months?

◆ Tick all that apply.

- ☐ Deafness or partial hearing loss
- ☐ Blindness or partial sight loss
- ☐ Learning disability (for example, Down's Syndrome)
- ☐ Learning difficulty (for example, dyslexia)
- ☐ Developmental disorder (for example, Autistic Spectrum Disorder or Asperger's Syndrome)
- ☐ Physical disability
- ☐ Mental health condition
- ☐ Long-term illness, disease or condition
- ☐ Other condition, please write in

☐ No condition

21 Are your day-to-day activities limited because of a health problem or disability which has lasted, or is expected to last, at least 12 months?

◆ Include problems related to old age.

- ☐ Yes, limited a lot
- ☐ Yes, limited a little
- ☐ No

22 If you are aged 16 or over → Go to 23

If you are aged 15 or under → Go to 38

23 Which of these qualifications do you have?

◆ Tick all that apply.

- ☐ O Grade, Standard Grade, Access 3 Cluster, Intermediate 1 or 2, GCSE, CSE, Senior Certificate or equivalent
- ☐ SCE Higher Grade, Higher, Advanced Higher, CSYS, A Level, AS Level, Advanced Senior Certificate or equivalent
- ☐ GSVQ Foundation or Intermediate, SVQ level 1 or 2, SCOTVEC Module, City and Guilds Craft or equivalent
- ☐ GSVQ Advanced, SVQ level 3, ONC, OND, SCOTVEC National Diploma, City and Guilds Advanced Craft or equivalent
- ☐ HNC, HND, SVQ level 4 or equivalent
- ☐ Degree, Postgraduate qualifications, Masters, PhD, SVQ level 5 or equivalent
- ☐ Professional qualifications (for example, teaching, nursing, accountancy)
- ☐ Other school qualifications not already mentioned (including foreign qualifications)
- ☐ Other post-school but pre-Higher Education qualifications not already mentioned (including foreign qualifications)
- ☐ Other Higher Education qualifications not already mentioned (including foreign qualifications)
- ☐ No qualifications

24 Last week were you:

◆ Tick all that apply.

◆ Include any paid work, including casual or temporary work, even if only for one hour.

- ☐ working as an employee? → Go to 33
- ☐ on a Government sponsored training scheme? → Go to 39
- ☐ self-employed or freelance? → Go to 24
- ☐ working paid or unpaid for your own or your family's business? → Go to 36
- ☐ away from work ill, on maternity leave, on holiday or temporarily laid off? → Go to 30
- ☐ doing any other kind of paid work? → Go to 33
- ☐ none of the above

Person 1 - Individual questions continued	
<p><b>25</b> Were you actively looking for any kind of paid work during the last 4 weeks?</p> <p><input type="checkbox"/> Yes <input type="checkbox"/> No</p>	<p><b>33</b> Briefly describe what you do (did) in your main job.</p>
<p><b>26</b> If a job had been available last week, could you have started it within 2 weeks?</p> <p><input type="checkbox"/> Yes <input type="checkbox"/> No</p>	
<p><b>27</b> Last week, were you waiting to start a job already obtained?</p> <p><input type="checkbox"/> Yes <input type="checkbox"/> No</p>	<p><b>34</b> Do (did) you supervise any employees?</p> <p>◆ Supervision involves overseeing the work of other employees on a day-to-day basis.</p> <p><input type="checkbox"/> Yes <input type="checkbox"/> No</p>
<p><b>28</b> Last week were you:</p> <p>◆ Tick all that apply.</p> <p><input type="checkbox"/> retired (whether receiving a pension or not)?</p> <p><input type="checkbox"/> a student?</p> <p><input type="checkbox"/> looking after home or family?</p> <p><input type="checkbox"/> long-term sick or disabled?</p> <p><input type="checkbox"/> other</p>	<p><b>35</b> How many hours (to the nearest full hour) a week d (did) you usually work in your main job?</p> <p>◆ Include paid and unpaid overtime.</p> <p>Number of hours worked in a typical week</p>
<p><b>29</b> Have you ever worked?</p> <p><input type="checkbox"/> Yes, please write in the year you last worked</p> <p>→ Go to 30</p> <p><input type="checkbox"/> No, have never worked → Go to 38</p>	<p><b>36</b> At your workplace, what is (was) the main activity of your employer or business?</p> <p>◆ For example, ARMED FORCES, PRIMARY EDUCATION, REPAIRING CARS, CONTRACT CATERING, COMPUTER SERVICING, DOCTOR'S SURGERY.</p> <p>◆ If you are (were) a civil servant, please write GOVERNMENT.</p> <p>◆ If you are (were) a local government officer, please write LOCAL GOVERNMENT and give the name of your department within the local authority.</p>
<p><b>30</b> Answer the remaining questions for your main job or, if not working, your last main job.</p> <p>◆ Your main job is the job in which you usually work (worked) the most hours.</p>	
<p><b>31</b> In your main job, are (were) you:</p> <p><input type="checkbox"/> an employee?</p> <p><input type="checkbox"/> self-employed or freelance without employees?</p> <p><input type="checkbox"/> self-employed with employees?</p>	<p><b>37</b> In your main job, what is (was) the name of the organisation you work (worked) for?</p> <p>◆ If you are (were) self-employed in your own organisation, please write in the business name.</p>
<p><b>32</b> What is (was) your full and specific job title?</p> <p>◆ For example, PRIMARY SCHOOL TEACHER, CAR MECHANIC, DISTRICT NURSE, STRUCTURAL ENGINEER.</p> <p>◆ Do not state your grade or pay band.</p>	<p><input type="checkbox"/> No organisation, for example, self-employed, freelance, or work (worked) for a private individual.</p>
	<p><b>38</b> There are no more questions for Person 1.</p> <p>◆ If there are no more people in your household, please leave the following pages blank. Otherwise go to questions for Person 2.</p> <p>◆ If you included anyone at question 1, remember to record their details on the back page.</p> <p>◆ Remember to sign the declaration on page 1.</p>



## Person 2 - Individual questions

What is your name? (Person 2 at 13 on page 4)

First name

Last name

What is your sex?

☐ Male
 ☐ Female

What is your date of birth?

Day Month Year

On the 27 March 2011, what is your legal marital or same-sex civil partnership status?

- |  |  |
|--|--|
| <input type="checkbox"/> Never married and never registered a same-sex civil partnership | <input type="checkbox"/> In a registered same-sex civil partnership                              |
| <input type="checkbox"/> Married   | <input type="checkbox"/> Separated, but still legally in a same-sex civil partnership            |
| <input type="checkbox"/> Separated, but still legally married                            | <input type="checkbox"/> Formerly in a same-sex civil partnership which is now legally dissolved |
| <input type="checkbox"/> Divorced  | <input type="checkbox"/> Surviving partner from a same-sex civil partnership                     |
| <input type="checkbox"/> Widowed   |  |

Are you a schoolchild or student in full-time education?

- ☐
- Yes
- 
- ☐
- No → Go to 2

During term-time, do you live:

- ☐
- at the address on the front of this questionnaire?
- 
- ☐
- at another address? → Go to 38

What is your country of birth?

- ☐
- Scotland → Go to 8
- 
- ☐
- England → Go to 9
- 
- ☐
- Wales → Go to 9
- 
- ☐
- Northern Ireland → Go to 10
- 
- ☐
- Republic of Ireland
- 
- ☐
- Elsewhere, please write in the current name of the country

If you were not born in the United Kingdom, when did you most recently arrive to live here?

♦ Do not count short visits away from the UK.

Month Year

9 Do you look after, or give any help or support to family members, friends, neighbours or others because of either:

- long-term physical / mental ill-health / disability; or
  - problems related to old age?
- ♦ Do not count anything you do as part of your paid employment.

- ☐
- No
- 
- ☐
- Yes, 1 - 19 hours a week
- 
- ☐
- Yes, 20 - 34 hours a week
- 
- ☐
- Yes, 35 - 49 hours a week
- 
- ☐
- Yes, 50 or more hours a week

10 One year ago, what was your usual address?

♦ If you had no usual address one year ago, state the address where you were staying.

- ☐
- Same as Person 1
- 
- ☐
- The address on the front of this questionnaire
- 
- Student term-time / boarding school address in the UK, please write in below
- 
- Another address in the UK, please write in

Postcode

- ☐
- Outside the UK, please write in country

11 What address do you travel to for your main job or course of study (including school)?

♦ Answer for the place where you spend the most time.  
 ♦ If you report to a depot, please write in the depot address.

- ☐
- Not currently working or studying → Go to 1
- 
- ☐
- Work or study mainly at, or from, home → Go to 13
- 
- ☐
- No fixed place
- 
- ☐
- Work on an offshore installation - please use the address panel below to write in where you travel offshore from, for example "ABERDEEN HARBOUR"
- 
- ☐
- The address below, please write in

Postcode

## Person 2 - Individual questions continued

**12** How do you usually travel to your main place of work or study (including school)?

◆ Tick one box only.

◆ Tick the box for the longest part, by distance, of your usual journey to work or study.

- ☐ Driving a car or van
- ☐ Passenger in a car or van
- ☐ On foot
- ☐ Bus, minibus or coach
- ☐ Train
- ☐ Underground, subway, metro, light rail or tram
- ☐ Taxi
- ☐ Bicycle
- ☐ Motorcycle, scooter or moped
- ☐ Other

**13** What religion, religious denomination or body do you belong to?

◆ This question is voluntary.

- ☐ None
- ☐ Church of Scotland
- ☐ Roman Catholic
- ☐ Other Christian, please write in below
- ☐ Muslim
- ☐ Buddhist
- ☐ Sikh
- ☐ Jewish
- ☐ Hindu
- ☐ Another religion or body, please write in

**14** What do you feel is your national identity?

◆ Tick ALL that apply.

- ☐ Scottish
- ☐ English
- ☐ Welsh
- ☐ Northern Irish
- ☐ British
- ☐ Other, please write in

**15** What is your ethnic group?

◆ Choose ONE section from A to F, then tick ONE box which best describes your ethnic group or background

**A White**

- ☐ Scottish
- ☐ Other British
- ☐ Irish
- ☐ Gypsy / Traveller
- ☐ Polish
- ☐ Other white ethnic group, please write in

**B Mixed or multiple ethnic groups**

- ☐ Any mixed or multiple ethnic groups, please write in

**C Asian, Asian Scottish or Asian British**

- ☐ Pakistani, Pakistani Scottish or Pakistani British
- ☐ Indian, Indian Scottish or Indian British
- ☐ Bangladeshi, Bangladeshi Scottish or Bangladeshi British
- ☐ Chinese, Chinese Scottish or Chinese British
- ☐ Other, please write in

**D African**

- ☐ African, African Scottish or African British
- ☐ Other, please write in

**E Caribbean or Black**

- ☐ Caribbean, Caribbean Scottish or Caribbean British
- ☐ Black, Black Scottish or Black British
- ☐ Other, please write in

**F Other ethnic group**

- ☐ Arab, Arab Scottish or Arab British
- ☐ Other, please write in

## Person 2 - Individual questions continued

6 Which of these can you do?

♦ Tick all that apply.

	English	Scottish Gaelic	Scots
Understand	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Speak	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Read	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Write	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

☐ None of these

How well can you speak English?

Very well    Well    Not well    Not at all

☐    ☐    ☐    ☐

Do you use a language other than English at home?

♦ Tick all that apply.

- ☐ No, English only
- ☐ Yes, British Sign Language
- ☐ Yes, other - please write in

How is your health in general?

Very good    Good    Fair    Bad    Very bad

☐    ☐    ☐    ☐    ☐

Do you have any of the following conditions which have lasted, or are expected to last, at least 12 months?

♦ Tick all that apply.

- ☐ Deafness or partial hearing loss
- ☐ Blindness or partial sight loss
- ☐ Learning disability (for example, Down's Syndrome)
- ☐ Learning difficulty (for example, dyslexia)
- ☐ Developmental disorder (for example, Autistic Spectrum Disorder or Asperger's Syndrome)
- ☐ Physical disability
- ☐ Mental health condition
- ☐ Long-term illness, disease or condition
- ☐ Other condition, please write in

☐ No condition

21 Are your day-to-day activities limited because of a health problem or disability which has lasted, or is expected to last, at least 12 months?

♦ Include problems related to old age.

- ☐ Yes, limited a lot
- ☐ Yes, limited a little
- ☐ No

22 If you are aged 16 or over → Go to 23

If you are aged 15 or under → Go to 38

23 Which of these qualifications do you have?

♦ Tick all that apply.

- ☐ O Grade, Standard Grade, Access 3 Cluster, Intermediate 1 or 2, GCSE, CSE, Senior Certificate or equivalent
- ☐ SCE Higher Grade, Higher, Advanced Higher, CSYS, A Level, AS Level, Advanced Senior Certificate or equivalent
- ☐ GSVQ Foundation or Intermediate, SVQ level 1 or 2, SCOTVEC Module, City and Guilds Craft or equivalent
- ☐ GSVQ Advanced, SVQ level 3, ONC, OND, SCOTVEC National Diploma, City and Guilds Advanced Craft or equivalent
- ☐ HNC, HND, SVQ level 4 or equivalent
- ☐ Degree, Postgraduate qualifications, Masters, PhD, SVQ level 5 or equivalent
- ☐ Professional qualifications (for example, teaching, nursing, accountancy)
- ☐ Other school qualifications not already mentioned (including foreign qualifications)
- ☐ Other post-school but pre-Higher Education qualifications not already mentioned (including foreign qualifications)
- ☐ Other Higher Education qualifications not already mentioned (including foreign qualifications)
- ☐ No qualifications

24 Last week were you:

♦ Tick all that apply.

♦ Include any paid work, including casual or temporary work, even if only for one hour.

- ☐ working as an employee? → Go to 36
- ☐ on a Government sponsored training scheme? → Go to 36
- ☐ self-employed or freelance? → Go to 36
- ☐ working paid or unpaid for your own or your family's business? → Go to 36
- ☐ away from work ill, on maternity leave, on holiday or temporarily laid off? → Go to 36
- ☐ doing any other kind of paid work? → Go to 36
- ☐ none of the above

## Person 2 - Individual questions continued

25 Were you actively looking for any kind of paid work during the last 4 weeks?

☐ Yes ☐ No

26 If a job had been available last week, could you have started it within 2 weeks?

☐ Yes ☐ No

27 Last week, were you waiting to start a job already obtained?

☐ Yes ☐ No

28 Last week were you:

◆ Tick all that apply.

☐ retired (whether receiving a pension or not)?

☐ a student?

☐ looking after home or family?

☐ long-term sick or disabled?

☐ other

29 Have you ever worked?

☐ Yes, please write in the year you last worked

→ Go to 30

☐ No, have never worked → Go to 38

30 Answer the remaining questions for your main job or, if not working, your last main job.

◆ Your main job is the job in which you usually work (worked) the most hours.

31 In your main job, are (were) you:

☐ an employee?

☐ self-employed or freelance without employees?

☐ self-employed with employees?

32 What is (was) your full and specific job title?

◆ For example, PRIMARY SCHOOL TEACHER, CAR MECHANIC, DISTRICT NURSE, STRUCTURAL ENGINEER.

◆ Do not state your grade or pay band.

33 Briefly describe what you do (did) in your main job.

34 Do (did) you supervise any employees?

◆ Supervision involves overseeing the work of other employees on a day-to-day basis.

☐ Yes ☐ No

35 How many hours (to the nearest full hour) a week d (did) you usually work in your main job?

◆ Include paid and unpaid overtime.

Number of hours worked in a typical week

36 At your workplace, what is (was) the main activity or your employer or business?

◆ For example, ARMED FORCES, PRIMARY EDUCATION, REPAIRING CARS, CONTRACT CATERING, COMPUTER SERVICING, DOCTOR'S SURGERY.

◆ If you are (were) a civil servant, please write GOVERNMENT.

◆ If you are (were) a local government officer, please write LOCAL GOVERNMENT and give the name of your department within the local authority.

37 In your main job, what is (was) the name of the organisation you work (worked) for?

◆ If you are (were) self-employed in your own organisation, please write in the business name.

☐ No organisation, for example, self-employed, freelance, or work (worked) for a private individual.

38 There are no more questions for Person 2.

◆ If there are no more people in your household, please leave the following pages blank. Otherwise go to questions for Person 3.

◆ If you included anyone at question 10, remember to record their details on the back page.

◆ Remember to sign the declaration on page 1.

## 50.13 Appendix N: Focus group topic guide

### Focus Group Schedule

General Purpose Statement: To explore the perspectives of young people with learning disabilities regarding how transitioning from school might impact their health and wellbeing.

#### Themes:

- Leaving school
- What's next – choice, opportunities, limitations
- Social relationships – family, friends, staff
- Health and wellbeing

As this research is specifically focused on the impact of transition on health and wellbeing, the theme of health and wellbeing will be allocated more time, if necessary at the expense of the theme of social relationships.

#### Prompts:

##### School:

- What will leaving school mean to you?
- What will you miss?
- What won't you miss?

##### What's next:

- What will the next step be for you?
- What are you most looking forward to about that?
- What will be the challenges of that? E.g. activities, competencies, relationships
- Who might help you with those challenges? Who might you talk to about these concerns?

##### Social:

- Who supports you now? Who are the important people in your life?
- Might that change in the future?

Half way point here. No break planned but if participants/helpers indicate that one would be beneficial a break can take place here.

##### Health:

- Who helps you to be healthy now?
- Will that change? Who might it be in the future?
- How is your health?
- Do you have any worries about your health?
- Might your health needs change in the future?
- Who might you talk to about that change?
- Do you get organised exercise now?
- Do you think this might be harder in the future?
- What choices do you make now about what to eat?
- Might that change in the future?

## 50.14 Appendix O: Topic guide for semi-structured interviews with young people

### Interview Topic Guide: Young People

#### *School/Work*

- What will leaving school or growing up mean to you? Are you an adult?
- What would you like to do when you leave school? Will there be any challenges associated with that?
- What might your days be like when you leave school? How might they change?
- What hopes/fears do you have about the future? E.g. what you will do, who you will see.
- What new activities might arise for you in adulthood? What new responsibilities?

#### *Services*

- Do you think child services are different to adult services?
- Who is helpful in supporting you if you need help?

#### *Health & Wellbeing*

- Is there anything to do with your health that you are worried about?
- How do you feel about leaving school/growing up? Is there anything you are excited about? Is there anything you are scared or worried about?
- Have there been any changes in your life recently? Have they affected how you feel?
- Do you get opportunities to do exercise/eat healthily?
- Do you get opportunities to do exercise/eat healthily?

#### *Family*

- Who are the important people in your life?
- Who do you turn to for support just now? Do you think that might change in the future?
- How does your experience of growing up compare with that of your brothers or sisters? (If applicable)
- Who makes decisions about your life?

*Note questions will vary slightly depending on if young person is still at school or if has already left, but the content will be the same*

## 50.15 Appendix P: Topic guide for semi-structured interview with parents/carers

### Interview Topic Guide: Parents

#### *School/Work*

- How do you feel about your child leaving school? How do you think your child feels?
- What is your child planning to do when they leave school? Do you think there will be any challenges associated with that?
- What might change for your child in terms of their everyday routine? E.g. where they go, who they meet
- What opportunities might open up for your child as they transition to adulthood? What possibilities might close down?

#### *Services*

- What formal assistance have you received during the transition process? E.g. from teachers, GP, social services. What have you not received?
- How did you and your child experience the transition between child and adult services?
- How do adult services compare to child services?
- Who/what has been effective in supporting you and your child throughout transition?

#### *Health & Wellbeing*

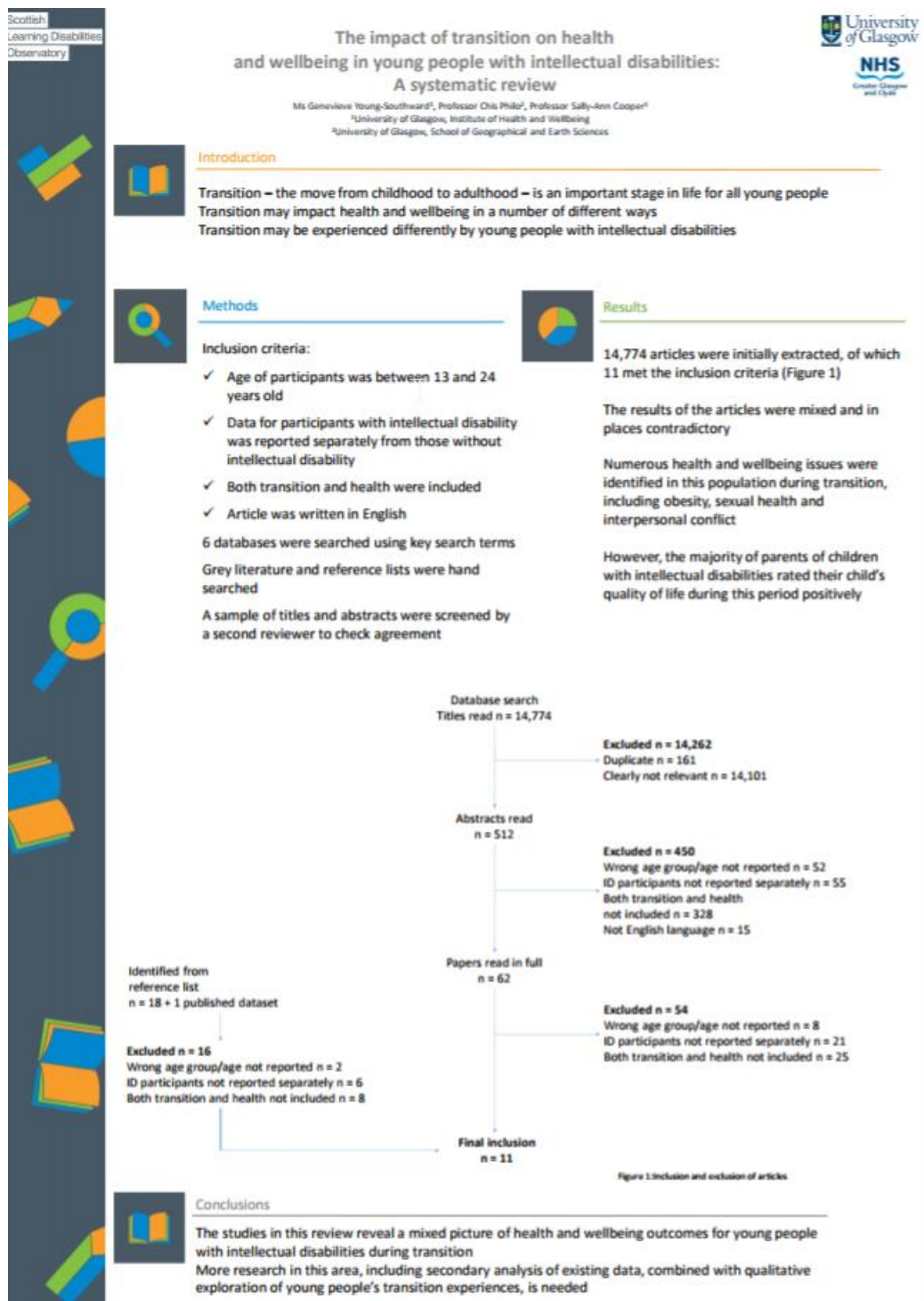
- Have you noticed any change in your child's mood or behaviour during the transition experience?
- Does your child express worries about their future?
- Does your child have any current health concerns?
- Do they get opportunities for organised exercise/healthy eating?

#### *Family*

- How do you feel about facilitating increased independence in your child? E.g. adult relationships, sex
- What hopes/fears do you have for your child in terms of friendships/relationships?
- Is there anything that you find challenging in parenting your child in terms of development or behaviour? Has this led to changes in your parenting style?
- Has your relationship with your child changed recently? How?
- How does your child's transition experience compare to your other children's experience? (if applicable)

*Note questions will vary slightly depending on if young person is still at school or if has already left, but the content will be the same*

## 50.20 Appendix U: Scientific posters





## The impact of transition to adulthood on health and wellbeing in young people with intellectual disabilities: A qualitative study

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### Introduction

Transition refers to the movement from childhood to adulthood, including leaving school, and moving from child to adult health and social services. While poor outcomes for the population with intellectual disabilities across the domains of social relationships, independent living, and community involvement are well documented, there is a lack of evidence related to the impact that transition may have on health and wellbeing in this population



### Research Questions

1. Does transition to adulthood affect health and wellbeing in young people with intellectual disabilities, and in what particular ways?
2. What supports (formal and informal) are helpful for families during transition?



### Design

Qualitative study allowing young people with intellectual disabilities and their parents/caregivers to reflect on their own experiences of transition



### Methods

Semi-structured interviews were conducted with young people with intellectual disabilities between the ages of 16 and 24 years (n = 11) and their parents/caregivers (n = 20), recruited from special education schools and charities providing services to young adults with intellectual disabilities

The interview topic guide was informed by a pilot focus group study and covered: leaving school and child services; health; support; and relationships

Interviews were audio-recorded and transcribed verbatim. Transcripts were analysed using thematic analysis, using a combination of *a priori* and *de novo* coding categories



### Results

The primary impact of transition was on mental health, with young people feeling stressed and anxious during transition. This was largely attributed to a lack of opportunities for meaningful activity following school exit; a lack of support during the transition; and difficulties related to 'growing up' and developing independence from parents

Master Theme	Sub-theme	Supporting Quote
Mental Health	Anxiety/Stress	"Sometimes he can get a wee bit emotional ... and he'll look as if he's going to start crying ... he really doesn't want to talk about [leaving school]" (Sally's mum)
	Challenging behaviours	"Her anger, her mood swings and things like that, that really worried me, that's got worse [after leaving school]" (Sally's mum)
Something to do	Lack of post-school activity	"We quite wanted [Sally] there but it's very hard there ... there's nothing out there" (Sally's dad)
	Mental health implications of having 'nothing to do'	"Because it ... it's a struggle because she doesn't have any outlet at the moment ... it's like 'what are you doing today?' ... and there's nothing, there's nothing" (Sally's mum)
Services and Supports	Inadequate post-school support	"[Sally] has been getting the same amount of education [after school] as what he gets ... at school ... the quality of teaching, the knowledge base of staff isn't the same as what it is at school" (Sally's mum)
	Poor transition planning	"We all these glossy books you get it's supposed to take a year to a year and a half, transition, but we still not get a word yet and we're ... beginning of April and you're talking the end of April before we've even got a budget so that leaves like two months till school leaves" (Sally's dad)
	Lack of funding	"It's clear it [there's] no money in adult services, there's no money" (Sally's mum)
Growing Up	Stigma	"[She worried about] going into my first job 'cause I don't know how it's going to be, like, what ... it's a quite different from other people" (Sally)
	Independence vs interdependence	"Just the worry that you've got from things like cooking meals ... you don't know what she's doing, how well she's doing outside ... it's like when you've got her by the hand when she's small and you can do things for her" (Sally's grandma)



### Conclusions

Transition to adulthood may have a negative effect on mental health in the population with intellectual disabilities

The transition from school must be better supported, including support to access meaningful activity following school exit, in order to ease anxiety during this difficult period

