

Health inequalities in people with intellectual disability

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Declaration

This thesis is all my own work and has not been submitted in substantially the same form towards the award of a degree or for any other qualification. Any sources used within this thesis have been acknowledged as references*.

Martin McMahon

21/2/2022

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This thesis is an edited version of the thesis that was submitted and examined for the Doctor of Philosophy (PhD) award. The final accepted version of the published studies in Chapter 4 (McMahon and Hatton 2021a), 5 (McMahon et al. 2020a), 6 (McMahon et al. 2021b) and 7 (McMahon et al. 2019) replace the published studies. The McMahon et al. (2022) study in chapter 9 is published in open access format and has been included in this edited version of this thesis in its published format.

* APA 7th Edition citation style is used in the introduction, background, methodology and discussion chapters. For all other chapters — containing studies — the citation and formatting style corresponds to the journal that the study was published in, or submitted to be published in.

Abstract

Background: The opportunity for people with intellectual disability to live a long and healthy life is impacted by the conditions into which they are born, grow up and live. This research provides insight into health and non-medical factors that influence health, in a comparative population of people with and without intellectual disability.

Aim: To examine the health, objective and subjective socioeconomic status of adults with and without intellectual disability in Jersey. It explores the prevalence of health problems, polypharmacy and drug-drug interactions and the relationships with objective and subjective socioeconomic status on the health of people with an intellectual disability.

Methods: An administrative population of 217 adults with, and a random stratified sample of 2,350 adults without, intellectual disability participated in this study. Proxy respondents were used where people did not have capacity to consent. The prevalence, patterns and relationships with health problems, polypharmacy, drug-drug interactions and socioeconomic status are described. Associations of these characteristics were analysed using univariate and multivariate analysis.

Findings: People with intellectual disability have poorer health than the general population which starts earlier in life. They are especially vulnerable to the negative effects of taking multiple medications. Adults with intellectual disability also occupy lower socioeconomic status and report lower levels of subjective socioeconomic status and poorer self-rated health than the general population. Higher subjective socioeconomic status and younger age were significant predictors of better self-rated health reported by the proxy intellectual disability group only, while being employed was associated with better health for all populations.

Conclusion: Significant efforts are needed to reduce the non-medical factors that influence the health inequalities experienced by adults with intellectual disability. This study underlines the poorer health and adverse impact that multiple medications may have. Equally, it highlights the atypical and lower socioeconomic position that adults with an intellectual disability experience. Further research in larger prospective comparative studies is needed to understand the relationship between subjective socioeconomic status and health in adults with intellectual disability.

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Preamble

Significant numbers of people with intellectual disability will not only die sooner than those without intellectual disability, but most will experience greater levels of ill health and deprivation throughout their lives. The findings from this research suggest that people with an intellectual disability living in Jersey:

- spend much of their adult life with multiple health problems
- have greater health needs at an earlier age than the general population
- report lower socioeconomic status
- are exposed to polypharmacy and psychotropic polypharmacy in the absence of mental illness
- are exposed to developing adverse drug reactions from drug-drug interactions
- are less well off financially
- have low levels of education
- are more likely to be unemployed
- are more likely to live in residential care settings and not to own their own home
- are not in intimate relationships

These findings suggest that something is fundamentally wrong with services, how society is organised and how it responds to the needs of people with intellectual disability. The evidence in this thesis advances the understanding and contributes to the scientific evidence of how people with intellectual disability are disproportionately impacted by many non-medical factors that influence health. The methodological approach employed where a comparative representative general population sample is used is unusual and contributes to the overall rigour of the research. This contribution provides sufficient guidance on how policy and practice could be tailored to reduce health inequalities that people with an intellectual disability experience in Jersey and elsewhere. Marmot (2017) reported that:

“Health inequalities[†] that are avoidable and are not avoided are unjust. Putting them right is a matter of social justice” (p.545)

[†] Throughout this thesis the term inequality has been employed. Health inequalities are understood as the unjust and avoidable differences in people’s health across the population and between specific population groups. While some researchers use the term ‘inequalities’ to illustrate differences between groups and ‘inequities’ to illustrate unjust differences between groups, this thesis uses ‘inequalities’ to describe unjust differences (Public Health Scotland, 2022).

Improving the circumstances in which people with an intellectual disability grow up, live, work and age, and the systems that are put in place to support their physical and mental wellbeing is critically important. The urgency of this cannot be overstated. People with an intellectual disability will continue to endure greater levels of ill health and die earlier than their peers until the non-medical factors that contribute to health inequalities are fully understood, clearly identified and addressed.

Chapter 1: Introduction

1.1. Introduction to thesis

Despite improvements in the health and wellbeing of adults with intellectual disability over the last decades, they continue to experience significant health inequalities and die at a younger age than those without intellectual disability. They are also more likely to be exposed to the social determinants that are associated with poorer health. That is to say, people with an intellectual disability are born into, grow up and live in environments that create conditions that contribute to considerable health inequalities. These conditions are broadly determined by general socioeconomic factors such as education, occupation and income. In essence, people with intellectual disability are congregated around the lower end of this socioeconomic gradient as they are more likely to have limited education, be unemployed and have reduced income. The consequence of this is poorer health that begins at a younger age, and a reduced life expectancy — somewhere in the region of 20 years.

From a personal and professional perspective, I have worked with children and adults with intellectual disability for nearly twenty years and I have seen first-hand the inequalities that people with an intellectual disability experience. Having first worked as a nurse in Ireland, I witnessed the high prevalence of ill health that this population experiences; this poor health is often amenable to good healthcare. While health surveillance and preventive healthcare are improving, there continue to be barriers to accessing and receiving good quality healthcare for this population. Additionally, from later employment as a non-medical prescriber for adults with a dual diagnosis[‡] in the Island of Jersey, I witnessed the increased medication burden that people with an intellectual disability experience. This is most commonly borne out in the high level of psychotropic medication that is prescribed for people with intellectual disability, often in the absence of any psychiatric illness. More recently,

[‡] Dual diagnosis in this instance refers to the co-occurrence of an intellectual disability and a mental illness.

my career has taken me back to Ireland on a path into health and social care regulation, an area where I now work to enable people with disabilities enjoy an ordinary life, a life free from restrictions and where their health and wellbeing is at the centre of service delivery.

Across my career to date there has been one consistent representation of people with an intellectual disability. That is, I have consistently observed the socioeconomic deprivation that this population experience, one of the biggest contributing factors to poorer health. In this vein, I have come to realise and believe that in order for there to be greater improvements in the lives of people with intellectual disability there needs to be a resolute effort to improve the circumstances in which many of these individuals live, work and engage with their daily lives. This experience and exposure to this issue has been the motivation behind this PhD research.

1.2. A global pandemic

On the 30th January 2020, the World Health Organisation (WHO) declared the novel coronavirus (2019-nCoV) outbreak a public health emergency of international concern. Six weeks later, with over 4,000 deaths and 118,000 cases worldwide, this public health emergency was characterised as a pandemic, now known as COVID-19 (SARS-CoV-2). Now, nearly two years later, there have been over 5 million deaths and over a quarter of a billion cases of COVID-19 worldwide. The world we knew pre-2020 has changed and COVID-19 has particularly stricken the most vulnerable in society. What was meant to be the 'great equaliser' (Mein, 2020) has instead amplified and revealed the truth about how a person's position on the societal gradient influences health outcomes. In simple terms, COVID-19 has further exposed the inequalities that exist in society (Marmot et al., 2020) and this is particularly stark for individuals with intellectual disability. For example, other than age, having an intellectual disability was the strongest independent risk factor for COVID-19 mortality in a study of over 65 million adults in the USA (Gleason et al., 2021). This is a situation also borne out in England, where people with intellectual disability have significantly increased risk for hospital admission and are more than

eight times more likely to die from COVID-19 than the general population (Williamson et al., 2021). COVID-19 has amplified and exposed the inequalities that this population experience to an undeniable degree.

The findings of the studies presented in my thesis come from data that was collected pre-COVID-19. While the findings present a grim picture of the health and socioeconomic status of people with an intellectual disability, when the findings of this study are considered through the guise of a pandemic, the effects of lockdowns, unemployment, isolation, illness and mortality, they are perhaps now more augmented and impactful. Many people with an intellectual disability who contributed to this study have endured a difficult and challenging time since they participated, and some will have died. Reflecting on this makes it even more important to highlight their plight and tell their story through the published research in this thesis.

1.3. My contribution to the research

Given the significant effort that was needed to plan this study and collect the data, it is important to set out my role at the outset. I developed and identified the topic of this thesis in collaboration with Professor Chris Hatton. I wrote the research proposal and developed all the consenting and capacity processes based on previous published research. I completed the ethical approval processes and received ethical approval from Lancaster University Faculty of Health and Medicine and Jersey Health and Community Services. Regarding data collection, I disseminated the questionnaires and reminder letters to the general population, and I undertook 120 interviews with the intellectual disability population and their proxy respondents. The remainder of the interviews were completed by colleagues who were trained in the research procedures and they are duly noted in the published studies. All people who collected data were Police vetted and received training in the survey tools and had frequent research supervision to ensure reliability. I collated the data of just over 1500 general population respondents and all of the intellectual disability data. I developed the statistical databases and undertook the analysis and interpreted the

results for each study under the supervision of Professor Chris Hatton. I drafted each research study in this thesis and all listed authors in each study commented on the draft manuscript and approved each final manuscript submitted for publication. I wrote this thesis in its entirety and Professor Chris Hatton, Professor Nancy Preston and Dr Claire Hardy provided guidance, critique and critical opinion throughout the process. Appendix 1 outlines the contribution of each author for each research study included in this thesis.

1.4. Layout of thesis

This PhD concerns the health, well-being and health inequalities experienced by adults with intellectual disability who live in Jersey in the Channel Islands. This PhD thesis is presented in 'Alternative Format' and comprises six studies, of which five are published, one is due to be resubmitted for publication (an overview of each of these studies is presented towards the end of this chapter in section 2.17). Each study represents a chapter and together they tell a coherent story about the health and wellbeing, life and socioeconomic status of adults with intellectual disability who live in Jersey. Introduction and methodology chapters precedes the research studies and these chapters set out the context of this thesis, detailing the background literature and the methodology and methods employed in my thesis. A discussion chapter follows the research studies, explaining the unique contribution of this research in the context of existing international literature. Finally, this thesis concludes with a chapter that briefly summarises the research findings and sets out the implications of these conclusions along with recommendations for policy, practice and future research. A reflective account is also offered at the end of this thesis to supplement the journey that I have been on over the last few years while undertaking this research as a part-time PhD student.

1.5. Aims of thesis

This thesis aims to examine the health and health inequalities that adults with an intellectual disability experience in the Island of Jersey. More specifically, this thesis focuses on three aspects of health inequalities:

- 1) The health and wellbeing and socioeconomic position of people with and without intellectual disability who live in Jersey
- 2) The subjective socioeconomic status and health in adults with intellectual disability
- 3) The relationship between objective and health in adults with and without an intellectual disability in Jersey.

Chapter 2: Background

2.1. What is intellectual disability?

Throughout this thesis the term 'intellectual disability' is used. This is in preference to terms such as learning disability that are used in the United Kingdom (UK), mental handicap or mental retardation that have up until recently been used in other parts of the world. The terminology surrounding intellectual disability has changed over the last century in response to societal and cultural preferences. The term intellectual disability reflects the development of preferential terminology among the scientific community. Despite this, given the changing terminology there are broadly three definitions of intellectual disability that are used throughout the developed world (Schalock et al., 2019). Firstly, the International Statistical Classification of Diseases and Related Health Problems 11th revision (ICD-11) classifies intellectual disability as disorders of intellectual development categorised into mild (intellectual functioning and adaptive behavior approximately two to three standard deviations [SD] below the mean), moderate (approximately three to four SD below the mean), severe and profound (both approximately four or more SD below the mean) disorders. These classifications are identified on the normal distribution of intelligence quotient (IQ) where the IQ of the general population is 100 with a standard deviation of 15 (Figure 1).

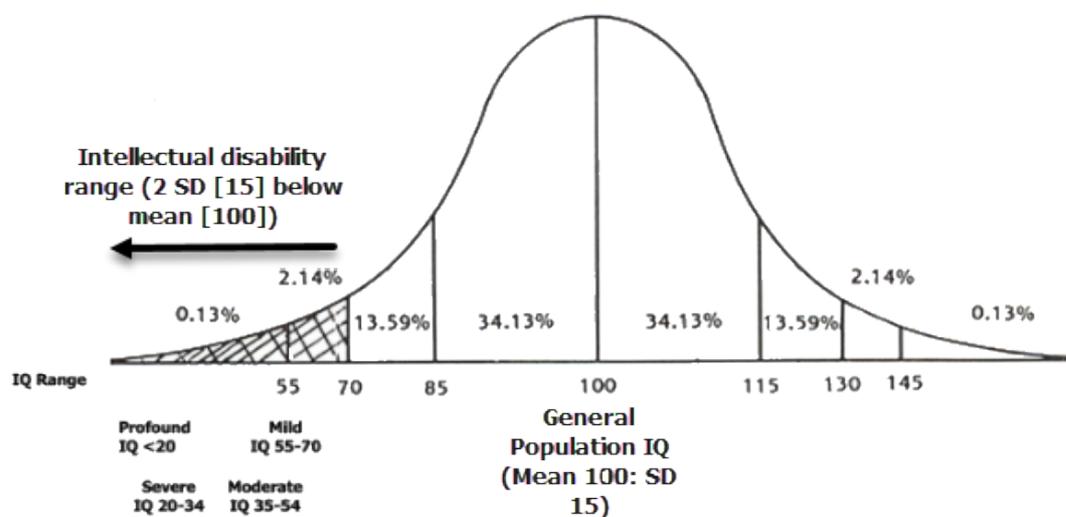


Figure 1. Severity of intellectual disability based on intellectual functioning (figure adapted from Adobe stock images)

Secondly, the American Association on Intellectual and Developmental Disabilities (AAIDD) [2008] states that, "intellectual disability is characterized by significant limitations both in intellectual functioning and adaptive behaviour as expressed in conceptual, social, and practical adaptive skill" (p.1) and thirdly, the DSM-5 by the American Psychiatric Association [APA] (APA, 2013) outlines that "intellectual disability (intellectual developmental disorder) is a disorder with onset during the developmental period that includes both intellectual and adaptive behaviour deficits in conceptual, social, and practical domains" (p. 33).

Despite the scientific conceptualisation of these definitions, and although twenty years old now, a seminal report in 2001 (Department of Health [DoH], 2001) defines intellectual disability[§] in an easily understood fashion that embodies the aforementioned scientific definitions. This is set out as:

- A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;
- A reduced ability to cope independently (impaired social functioning);
- Which started before adulthood (18 years), with a lasting effect on development (p.14).

It is also important to acknowledge another frequently used term in this area of research, that being developmental disabilities. Developmental disabilities is a term used to define a diverse group of conditions characterised by impairments in various developmental dimensions (for example, cognitive, motor, speech, vision and hearing disabilities and behavioral disorders) whereas intellectual disability is specifically focused on intellectual and adaptive functioning. In a sense, an intellectual disability may be encompassed within the spectrum of development disability but developmental disability is an umbrella term for a group of conditions characterised by impairments which includes intellectual disability. The age of onset also differs to intellectual disability and is considered before the age of 22 years

[§] Learning disability is changed to intellectual disability for coherence.

(AAIDD, 2021). Essentially, Larson et al. (2001) offers a helpful differentiation insofar as they outline that not all people with intellectual disability will have a developmental disability and not all people with a development disability will have an intellectual disability. Table 1 explains the differences further. Notwithstanding these definitions and considered with all three descriptions is that people with an intellectual disability experience deficits in intellectual and adaptive functioning that start before the age of 18 years (DoH, 2001).

Table 1. Characteristics of intellectual and developmental disability

Intellectual disability	Developmental disability
<ul style="list-style-type: none"> • Limitations in adaptive functioning 	<ul style="list-style-type: none"> • Group of conditions that lead to an impairment of • Cognitive • Communication • social and or emotional • behavioural • motor skills
<ul style="list-style-type: none"> • Limitations in intellectual functioning (IQ of 70 or lower) 	<ul style="list-style-type: none"> • Manifested before 22 years of age and likely to continue indefinitely
<ul style="list-style-type: none"> • Manifests before 18 years of age and lifelong 	<ul style="list-style-type: none"> • Examples of a developmental delay include: cerebral palsy, social emotional or behavioural delays, motor delays, speech delays

2.2. Terminology and intellectual disability

The terminology used to describe individuals with an intellectual disability has a history characterised by stigmatisation, segregation and negative connotations going back to early Egyptian, Greek and Roman societies (Roth et al., 2019). The conceptualisation and interpretation of intellectual disability has led to unfavourable or derogatory terminology being used over the years. For example, John Langdon Down's report in 1866 identified the unfavourable ethnic classification of people with Down syndrome. In this report, Down identified that a 'large number of congenital idiots are typical Mongols^{**} (Down, 1866, p.2). Other labels used throughout that

^{**} This is not the view of the author of this PhD and this example is used to outline the trajectory of terminology used to describe and categorise people with an intellectual disability.

time and into the early to mid-1900s included 'idiot, moron, feeble-minded and imbecile' (Doll, 1936; Gold, 2011). Considering these terms now elicits uncomfortable thoughts and feelings. However, terminology used at that time was reflective of the intersection of societies' understanding of health and mental health, the treatment of these individuals, legislation and beliefs at that time (Roth et al., 2019). An extract (Figure 2) from a methods section taken from a PhD thesis in this arena in 1966 outlines the use but transformation of language at this time (Primrose, 1966, p.7).

Methods

Practically, all the female patients in Lennox Castle Hospital at 31st December, 1964 have been medically examined by me as well as about 25% of the male patients - including all the children.

The old terminology of Feeble-minded, Imbecile and Idiot has been retained as this is still the one used in the hospital records, and it makes comparison with other surveys possible.

A record card, as shown in the Appendix, was printed in three colours - black for Feeble-minded, green for Imbecile, and red for Idiot. The appropriate card was then filled in for each patient (in alphabetical order) from the hospital records, first of all for the former patients in Lennox Castle, and then for the in-patients for each hospital. The cards were then grouped by sexes into three classes of mental defectives - Feeble-minded - Imbecile and Idiot - and those for former patients were subdivided according to method of dismissal. (Tables X, XII and XIV). This gave 40 possible groups of former patients (but 6 had no patients), and 18 of in-patients (but 3 had no patients). Schedules of each group of cards were prepared, and then each schedule was analysed so that the year of birth, year of admission, duration of stay, year of discharge etc. could be found and grouped as desired. Deaths.....^{††}

Figure 2. An extract from Primrose (1966, p.7) detailing the language previously used to describe people with an intellectual disability

^{††} Courier font is purposely used to visualise the typewriter font used in Primrose's (1966) thesis.

While the trajectory of language has changed, we are now at a stage where “intellectual disability” is broadly accepted as preferred terminology, particularly within the scientific community. Another strand to this debate concerns how people with an intellectual disability view their own social identity, especially as society labels this population as they have differences in what is viewed as ‘normal intelligence’. In a review of the literature, Beart et al. (2005) consistently found that many people were unaware of their intellectual disability label. While different reasons are offered why people with an intellectual disability are unaware of their social identity (such as the required level of cognitive development to recognise social categorisations and that many people with an intellectual disability are protected and information is filtered) (Dorozenko et al., 2015), it cannot be escaped that the terminology is complex and changeable. For example, from a personal perspective the terminology within my career has undergone significant changes. I started my nurse training as a mental handicap nurse in 2002, which then changed to learning disability nursing in 2005 and I graduated as an intellectual disability nurse in 2006.

It is through this lens that I have no doubt that in my lifetime, I will look back on the current terminology and that too will arouse uncomfortable feelings. Nonetheless, it is important to highlight that diagnostic labels are intended, or are initially intended to serve as a communication mechanism that identifies a set of symptoms or needs associated with a label. However, when they become stigmatising within themselves they lose their intended meaning and therefore the conceptualisation and understanding of the needs of people with an intellectual disability should be from a needs based perspective (Gates & Mafuba, 2014; Mac Domhnaill et al., 2020).

2.3. Prevalence of intellectual disability

Intellectual disability is a neurodevelopmental disorder recognised and reported across the world. There is difficulty determining the true prevalence of intellectual disability due to the diverse terminology used, the overreliance on proxy reporting within administrative data sets and the inability of health systems to accurately

identify people with intellectual disability more broadly (Emerson & Glover, 2012; Fujiura et al., 2010; McConkey et al., 2019; McKenzie et al., 2016). Despite this, Harris (2006) identified that the prevalence of intellectual disability varies from 1 to 3% worldwide. More recently, a Dutch study (Cuypers et al., 2021) linked administrative population data and estimated a 1.45% intellectual disability prevalence in the adult population. Similar findings have been reported in a highly regarded meta-analysis from Maulik et al. (2011). They identified a pooled prevalence rate of 9.2 per 1000 people suggesting that around 1% of the population have an intellectual disability. Of concern, they identified that this is two to three times higher in low and middle income countries. While these two studies are largely coherent and aligned, Maulik et al. (2011) warns that the diagnostic instruments and disability measurements used in developed countries can lead to lower estimates, whereas the simple psychological assessment used in low to middle income countries can lead to over estimates and therefore such estimates should be interpreted with a significant degree of caution.

2.4. Aetiology of intellectual disability

There is no single cause of intellectual disability, but it begins within the first eighteen years of life. The causes are highly heterogeneous and include various risk factors (Harris, 2006) such as poverty, genetic problems, complications during pregnancy or at birth, exposure to toxins or disease, malnutrition, behavioural, educational and the timing of [the] exposure (for example exposure during the prenatal, perinatal or postnatal periods) (AAIDD, 2021). In recent years the advancement of biological sciences has increased diagnostic capability. For example, Kochinke et al. (2016) have provided a curated database of 746 currently known genetic mutations that are associated with intellectual disability manifestation and associated clinical features, and many more await detection (Vissers et al., 2016). This can be seen as an important consideration as it facilitates pre-emptive health screening if clinical presentations or diseases are associated with specific syndromes (Prasher & Janicki, 2018). Genetic causes are considered to be present in a quarter to half of cases, with the incidence increasing in proportion with increased severity of intellectual disability (Kaufman et al., 2010). Down syndrome is the most

common genetic cause of intellectual disability that occurs in every 1/700 live births (Parker et al., 2010) while Fragile X syndrome is the most common inherited known cause of intellectual disability that occurs in every 1/5000 males (Coffee et al., 2009). However, despite this being the case, it is important to highlight that in the majority of instances, the cause of intellectual disability is unknown and international reports suggest that the cause may not be known in up to 60% of cases (Daily et al., 2000; Rauch et al., 2006). Although it has been identified that in cases where the intellectual disability is more severe (Daily et al., 2000; Harris, 2006), there is more of a chance of identifying the cause, it is important that the identification of a causative factor *per se* is not the 'holy grail'. Rather the identification of genetic and non-genetic aetiologies is important for the diagnosis of conditions that may need treatment such as inborn errors of metabolism (for example phenylketonuria or Maple Syrup Urine Disease) (Boat & Wu, 2015). Consequently, the identification of a person's support needs should be based on a thorough assessment of their needs from an adaptive and social functioning and adaptability lens.

2.5. Gender/sex, ethnicity and intellectual disability

The experience of living with an intellectual disability intersects with both gender and ethnicity. Since the 1930s it has been reported that intellectual disability is more common in males than females (Slater, 1938). In this seminal study, the first of its kind, it was determined that the ratio of males to females with intellectual disability was 1.25:1. One possible explanation for the increased prevalence in males is the common association of intellectual disability and syndromes that are linked to the X chromosome; for example Fragile X syndrome (Raymond, 2006). In broad terms it is now accepted intellectual disability is around 30% more common in males (Baird & Sadovnick, 1985; Cuyper et al., 2021; Raymond, 2006). In the intellectual disability arena it is accepted that women with intellectual disability are considered more vulnerable to greater inequalities than their male intellectual disability peers. For example, a recent review has identified that women with intellectual disability die earlier than men with intellectual disability (O'Leary et al., 2018) and they are exposed to a greater range of gender associated health inequalities than their male counterparts. One example of this inequality is that women with intellectual disability

are less likely to access screening for breast and cervical cancers (Plourde et al., 2018; Reidy et al., 2014). Nevertheless, the evidence base in this area is lacking and it is critically important for future research to consider how gender impacts the lives of people with intellectual disabilities (Robertson et al., 2021).

The prevalence of intellectual disability and association with ethnicity is not fully known. McGrother et al. (2002) identified that South Asian and white populations have similar prevalence rates of intellectual disability in a UK study, while a 2010 paediatric study (Emerson, 2010) identified that minority ethnic status was, in general, associated with lower rates of identification of intellectual and developmental disabilities. However, Emerson (2010) did identify higher rates of identification of less severe forms of intellectual disability among Gypsy/Romany and Traveller children of Irish heritage. A more recent systematic review in the USA (Anderson et al., 2019) was inconclusive and found that in three out of eight studies that considered ethnicity and prevalence rates of intellectual disability, lower prevalence rates of intellectual disability were reported for White children than for Black children. Five studies identified no difference. It is therefore reasonable to broadly conclude that people from different ethnic backgrounds have similar prevalence rates of intellectual disability. However, the changing distribution of ethnicity needs to be considered from a changing population perspective; it is now estimated that for UK population projections for 2012 to 2030, a quarter of new entrants to adult social care for people with intellectual disabilities will belong to minority ethnic communities (Emerson et al., 2012b).

2.6. Health of people with intellectual disability

There is consistent evidence highlighting that people with intellectual disability are, in general, more likely to have poorer health than people without intellectual disability (Cooper et al., 2015; Emerson & Hatton, 2014; Emerson et al., 2016; Emerson et al., 2012b; Hughes-McCormack et al., 2018; Kinnear et al., 2018; Liao et al., 2021; Turner & Moss, 1996). They are less likely to have their health needs met (Baxter et al., 2006), and they face significant health disadvantages compared to the general population (Trollor et al., 2016). Disadvantages such as socioeconomic

status (Emerson & Hatton, 2014), barriers in accessing health care (Michael & Richardson, 2008), the absence of preventive health screening (Ouellette-Kuntz et al., 2015), having unrecognised and therefore unmet health needs (Lennox et al., 2011), being excluded from health promotion activities (Taggart & Cousins, 2014), being exposed to negative staff attitudes and behaviours (Ali et al., 2013), being excluded from consultations (Ward et al., 2010) and experiencing language and communication issues (Whittle et al., 2018) mean that people with intellectual disability experience high levels of unnoticed and unmanaged health needs (Weise et al., 2017) despite having a complex health profile. Alongside this, another factor that has been reported is the concept of diagnostic overshadowing (Jopp & Keys, 2001). Diagnostic overshadowing is where a person's health needs or clinical presentation coming from their physical or mental health problems are mistakenly attributed to the individual's intellectual disability – the consequence of this can cause delayed diagnosis and treatment (Ali et al., 2013). These differences in health are avoidable, unfair and systematic and thereby constitute health inequalities (Emerson & Hatton, 2014; Marmot, 2005a), which are ultimately expressed with increased morbidity, a reduced healthy life expectancy and increased mortality (Emerson & Hatton, 2014).

In addition to these inequalities, over the last few decades, a number of studies have documented the occurrence of certain diseases in this population. For example, two of the most common disorders found in this population, mental illness (Cooper et al., 2007) and epilepsy (Robertson et al., 2015), have significantly higher rates in people with intellectual disability than without intellectual disability (Emerson et al., 2011). Mental illness is reported to range from around 23% to 40% in adults with intellectual disability (Cooper et al., 2007; Hughes-McCormack et al., 2017) while epilepsy is reported range from 9% to 51.8% (Beavis et al., 2007; Bowley & Kerr, 2000; Liao et al., 2021; McCarron et al., 2014; Robertson et al., 2015).

In a comprehensive review paper, Emerson et al. (2011) examined the prevalence of ill health in this population from a broad perspective. They identified that people with an intellectual disability are more likely to carry a higher risk of certain types of gastrointestinal cancer, possibly because of conditions typical in adults with

intellectual disability, such as gallstones or oesophageal reflux (Hogg & Tuffrey-Wijne, 2008). Equally, people with Down syndrome have a high incidence of congenital heart deficits (Brookes & Alberman, 1996) and heart disease is now one of the leading causes of death in this population more broadly (Landes et al., 2021a), a phenomenon that is thought to increase given the longer lives that people with intellectual disability are now living. Moreover, respiratory disease is reported as being highly prevalent in this population at childhood (Proesmans, 2016) and throughout life (Glover & Ayub, 2010), often associated with or caused by dysphagia (difficulties in eating, drinking or swallowing) (Robertson et al., 2018). Emerson and colleagues (2011) also cited challenging behaviour, dementia, physical impairments, oral health, sensory impairments, diabetes, constipation, endocrine disorders, osteoporosis and injuries, accidents and falls as being highly prevalent in this population. Similar results have been reported in a more up-to-date systematic review (Liao et al., 2021) suggesting that they have been relatively stable over the last decade.

The incidence of morbidity is perhaps best illustrated in the recent Learning Disability Mortality Review Programme (LeDeR) annual report which summarised the deaths of children and adults with intellectual disability in England notified to LeDeR (LeDeR, 2021). Their findings suggested that of those who died, on average almost half (46%) of adults had 7 to 10 chronic health conditions when they died thereby illustrating the significant health needs this population experiences. It must be noted however that while the LeDeR programme offers detailed insights into the deaths of people with intellectual disabilities in England, the programme is not compulsory. As a result, the analysis does not have complete coverage of all deaths of people with intellectual disabilities in England and the results should be considered through this pretext.

On another level, one of the main consequences of having and living with illness is the need to take medications. As highlighted above, two of the most prevalent conditions in this population are mental health disorders and epilepsy. These disorders are associated with prescribing profiles in the form of mono and poly

prescribing patterns. This is well corroborated as psychotropic and anticonvulsant medications are the most commonly prescribed classes of medication in this population (Bowring, Totsika, Hastings, Toogood, & McMahon, 2017a; Doan et al., 2013; Holden & Gitlesen, 2004; O'Dwyer et al., 2016). Despite there being significant concern over their extensive use, and overuse, the practice of prescribing psychotropic^{††} drugs in this population since the 1970s (Branford et al., 2019) (typically first generation antipsychotic drugs in the earlier years), has continued. While the prescription of such drugs may be appropriate in certain circumstances, the burden and overuse of psychotropic medication has been well highlighted across many studies (Bowring et al., 2017a; de Kuijper et al., 2010; Tsiouris et al., 2013) and the negative side effects of such treatment, which are difficult to correct, identified (Matson & Mahan, 2010; Sheehan et al., 2017).

The use of such medication is often used in a fashion referred to as 'off label', meaning that they are prescribed for an indication other than that identified on their licence. A typical example of this comes from a large UK study by Sheehan et al. (2015) who identified that more people were treated with psychotropic drugs than the proportion with recorded mental illness. This suggests that such medications are prescribed for other indications such as challenging behaviour in an 'off label' manner. Similar studies have replicated this finding (Bowring et al., 2017a; Doan et al., 2013) and in general terms the use of such medication in this way, particularly antipsychotic drugs, is thought to suppress behaviour in general given the pharmacokinetic and pharmacodynamic properties of these drugs as opposed to any psychiatric psychopathology (Matson & Neal, 2009; Tyrer et al., 2014). The National Institute for Health and Care Excellence (NICE) guideline (NG11) (2015) for the prevention of and interventions for people with learning disabilities whose behaviour challenges, identifies that antipsychotic medication should only be used when:

1. psychological or other interventions alone do not produce change within an agreed time or,

^{††} A psychotropic drug is a drug that affects behaviour, mood, thoughts, or perception.

2. treatment for any coexisting mental or physical health problem has not led to a reduction in the behaviour or
3. the risk to the person or others is very severe (for example, because of violence, aggression or self-injury).

(NICE, 2015, p.36)

Nonetheless, the evidence in this area suggests that this is not always the case (Bowring et al., 2017a; Sheehan et al., 2015). An example of this was exposed in the Winterbourne View scandal, which publicised and brought national and international attention to the abuse of residents at a specialist inpatient facility in Bristol, England (DoH, 2012). The enquiry that followed raised significant concerns about the use of psychotropic drugs and in particular antipsychotic drugs and antidepressants in this population. Since 2015, the National Health Service (NHS) has been supporting movements to decrease the prescribing of psychotropic drugs for people with intellectual disabilities through the STOMP/STAMP programme (Branford et al., 2019; NHS, 2017). Overall, while it could be argued that the health of people with an intellectual disability is improving insofar as life expectancy has increased over the last few decades (Coppus, 2013), people with intellectual disability still have significant and often greater health needs than the general population. There is currently an imbalance in the health of people with intellectual disability compared to those without intellectual disability; this imbalance is often the result of the health inequalities faced by this population, and this is also borne out in mortality studies identified below.

2.7. Mortality and intellectual disability

It is well documented that people with intellectual disability have higher all-cause mortality rates and that they die earlier in comparison to the general population (Dieckmann et al., 2015; Glover et al., 2017; Landes et al., 2021a; Lauer and McCallion, 2015). A recent systematic review by O'Leary et al. (2018) identified that death was earlier for people with intellectual disability by approximately 20 years, with this gap widening to 28 years for people with Down syndrome and people with more severe intellectual disability (O'Leary et al., 2018). While this is a very

concerning figure, it is important to acknowledge that due to the heterogeneity of intellectual disability, the use of age as a differentiation or estimate to identify the 'age-of-death' disparity can conceal discrete differences that may exist in this population (Heslop et al., 2015; Dieckmann et al., 2015). For example, Landes et al. (2019) recently highlighted that research in this area has not fully accounted for possible differences in age at death between disability types and therefore call for the heterogeneity among disability types to be considered in order to ensure reliable estimates. This is particularly true for individuals who may have a severe or profound intellectual disability as they have a high incidence of mortality. This was recognised in two longitudinal studies (Hogg et al., 2007; Janicki et al., 1999) who reinforced this point further.

Their results suggest that the longevity of adults with intellectual disability, whose aetiology is not attributable to organic causes, is progressively increasing, and identify that while people with an intellectual disability do die younger than their peers, many adults with intellectual disability do also live as long as their age peers in the general population (Dieckmann et al., 2015). This is an important consideration that needs to be kept in mind when considering the published evidence, especially as many community dwelling adults with intellectual disability may not be identified as such by health or social care services and therefore are unaccounted for in the published research. Studies outlined in Table 2 reinforce this concept. For example, while there is a trend in increased life expectancy over the last century, some studies (Doyle et al., 2021) report nearly a ten year difference in the mean age of death in comparison to other studies (Heslop et al., 2013; Heslop et al., 2014; Landes et al., 2021b; Lauer and McCallion, 2015). The primary difference is that the Doyle et al. study uses data from a database that records persons known to specialist intellectual disability services; therefore, it excludes persons who are not known to services or who do not want to receive services. This is likely to include people with greater health and social care needs and this may impact on the findings.

Table 2. Age at death for people with intellectual disability from 1931-2021 from selected studies

Study	Country	Year(s) of study	Number of deaths	Study setting	Age at death for people with intellectual disability (years)	
					Male	Females
Carter and Jancar (1983)	England	1931-1935	124	Stoke Park hospital group	14.9 (mean)	22.0 (mean)
Carter and Jancar (1983)	England	1951-1955	144	Stoke Park hospital group	29.2 (mean)	36.3 (mean)
Primrose (1966)	Scotland	1939-1964	764	Lennox Castle and Associated Hospitals	38.5 (mean)	39.6 (mean)
Richards and Sylvester (1969)	England	1961-1965	-	St. Lawrence's Hospital, Caterham, Surrey	45.7 (mean)	52.6 (mean)
Carter and Jancar (1983)	England	1976-1980	151	Stoke Park hospital group	58.3 (Mean)	59.8 (mean)
Puri et al. (1995)	England	1981-1990	325	Leavesden Hospital	65.4 (mean)	71.7 (mean)
McLoughlin (1988)	England	1983-1987	92	Prudhoe Hospital	62.3 (mean)	66.2 (mean)
Bittles et al. (2002) [±]	Australia	1969-2000	8,724	Disability Services Commission of Western Australia	66.7 (median)	71.5 (median)
Lavin et al. (2006) [§]	Ireland	1996-2001	1,120	National Intellectual Disability Database	49.5 (median)	49.5 (median)
Heslop et al. (2014)*	England and Wales	2010-2012	247	Five primary care trusts in the south west of England	65 (median)	63 (median)
Emerson et al. (2014) ⁺	England	1980-2012	1,313	Sheffield Case Register	60 (median)	60 (median)
Landes et al. (2021a) [♦]	USA	2005-2017	22,512	National Vital Statistics System Multiple Cause-of-Death Mortality files	61.1 (mean)	61.1 (mean)
Doyle et al. (2021)	Ireland	2009-2016	4,006	National Intellectual Disability Database	52.1 (mean)	55.9 (mean)

[±] Median life expectancies of 74.0, 67.6, and 58.6 years for people with mild, moderate, and severe levels of intellectual disability. [§] There was no difference observed in lifespan between men and women. The mean age of death for people with an intellectual disability was 48.88 for people with a mild intellectual disability, 51.16 for people with a moderate intellectual disability, 44.53 for people with a severe intellectual disability and 29.37 for those with a profound intellectual disability. *In this study, people with a profound intellectual disability had a median age of death of 46. For those with a severe intellectual disability the median age of death was 59, the median age of death for those with a moderate intellectual disability was 65 and it was 67.5 for those with a mild intellectual disability. + Over a 33 year period, this study identified an increase in life expectancy from 51 years to approximately 60 years – no analysis of gender stratification was reported on ♦ Age differences in sex were not significant. Mean age of death for persons with mild/moderate intellectual disability was 63.62 and for people with a severe to profound intellectual disability was 57.17.

Notwithstanding this, it is equally correct to infer that people with intellectual disability do die earlier than their non-disabled peers (Florio and Trollor, 2015; Hosking et al., 2016; Heslop and Glover, 2015; McCarron et al., 2015), and while people with an intellectual disability are living longer, the 'age-of-death' gap is not progressively reducing, a significant inequality.

One of the most significant investigations in this area came from the Confidential Inquiry into premature deaths of people with intellectual disabilities in England (Heslop et al., 2013). This inquiry examined the deaths of people with intellectual disabilities aged four years and older who had been registered with a GP in one of five Primary Care Trust areas of southwest England, who died between June 1, 2010, and May 31, 2012. The findings identified that 247 individuals died during this period and had a median age of death of 64 years. Male individuals with intellectual disabilities died on average 13 years earlier than the population of England and Wales (median age at death 65 years [IQR 52–75] *vs* 78 years), and female individuals died on average 20 years earlier (63 years [54–75] *vs* 83 years), a trend also observed in a Canadian (Ouellette-Kuntz et al, 2015) and Australian study (Florio and Trollor, 2015). This inquiry also reported on the most common underlying causes of death, identifying these as: heart and circulatory disorders (21%); cancer (20%); nervous system (16%); respiratory disorders (15%); congenital and chromosomal (7%); digestive system (5%); external causes (4%); endocrine, nutritional and metabolic (3%); and mental and behavioural disorders (2%). Both this inquiry and a more recent study from Scotland (Cooper et al., 2020) highlighted that many deaths in this population are amenable to good quality healthcare, a commonly held opinion (Hosking et al., 2016).

Regarding risk factors in relation to mortality, the evidence is broadly consistent. Ouellette-Kuntz et al. (2015) identified that "Down syndrome, cerebral palsy, blindness/low vision, technological dependence/medical fragility, wheelchair dependence, mobility impairment without wheelchair dependence, and epilepsy were associated with increased risk of mortality" (Ouellette-Kuntz et al., 2015, p.431). Similarly, Hosking et al. (2016) identified that those with Down syndrome, high

levels of support needs, those living in supported living and having a diagnosis of epilepsy had a very high relative risk of death in comparison with controls without intellectual disability. Another Irish study by McMahon et al. (2021c) found that congregated settings (where 10 or more people live together or on a campus based setting) were associated with higher rates of mortality (IRR 2.57 (95% CI 1.79-3.68) after adjustment for bed number, nurse:resident nurse ratio and service age provision (children or adults). While other recent evidence (LeDeR, 2021) has suggested that there are improvements in this area, significant inequalities still exist. Such inequalities have been highlighted with COVID-19 where the rates of deaths in people with an intellectual disability is more than those of others. More specifically, in the UK, individuals with intellectual disability were disproportionately represented in mortality statistics where they had a threefold incidence of mortality from COVID-19 in comparison to the general population, with a greater difference in younger age groups (BMJ Best Practice, 2021), a situation also observed in other countries (Turk et al., 2020). Therefore, mortality is a particularly telling example of health inequalities experienced by people with intellectual disability.

The aforementioned mortality statistics portray a disturbing picture regarding death and intellectual disability. In a population known to health services and identified in the research, mortality rates are consistently higher in people with intellectual disability than the general population more broadly and this is a significant indicator of health inequalities (Mackenbach, 2006).

2.8. Health and health inequalities

Before exploring the concept of health inequalities it is necessary to define what is meant by "health". Firstly, it is important to note that the conceptualisation of health has evolved over time. In 1948 the World Health Organisation (WHO) originally defined health as '... a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity' (p.1). They added that the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition (WHO, 1947). In 1947 this was a significant move towards the concept of

health moving from a purely biological or medical perspective and encompassing physiological, psychological and social factors, and this has remained as the international standard since. In 1986, further additions were made insofar as the WHO identified that health is a “resource for everyday life, not the objective of living. Health is a positive concept emphasising social and personal resources, as well as physical capacities.” (WHO [para.3], 2021). There has been some criticism over the years of the definition of health from a WHO perspective as it is seen as static and utopian (Huber et al., 2011). In the context of disability, the WHO definition would mean that people who have a disability would also be classified as having poor health (Krahn et al., 2021). Recognising this, in 2001, the International Classification of Functioning, Disability and Health - known more commonly as the ICF Framework (WHO, 2002) - classified disability as distinct from health, meaning that while disability is an umbrella term that refers to impairments, activity limitations, and participation restrictions, health in and of itself relates to health conditions, environmental factors, and personal factors that may influence disability. Essentially, this differentiated health and disability.

Another significant criticism of the terminology used by the WHO is that the use of ‘complete’ in the definition of health marginalises society and essentially it “would leave most of us unhealthy most of the time” (Smith, 2008). Over the years, researchers have grappled with operationalising health, although no new definition has yet been adopted. Influential commentary from Huber et al. (2011) states that health should be viewed as “the ability to adapt and to self-manage in the face of social, physical and emotional challenges” (p.3) and in more recent work they have attempted to make this definition measurable and report that bodily functions, mental functions and perception, existential health, quality of life, social and societal participation, and daily functioning are categorised into six dimensions of health (Huber et al., 2016).

Considering this, Krahn et al. (2021) has considered the definition of health from a disability perspective and report that it requires adaptation, influenced by social, personal and environmental elements. They set out that “health is the dynamic

balance of physical, mental, social, and existential well-being in adapting to conditions of life and the environment” (p.1). This definition has, as a fundamental factor, the concept of adaptation to life circumstances at its core. This adaptation is reported to be important when considering a dynamic view of health.

Regarding the measurement of health, there are four broad approaches, these are: (1) mortality and life expectancy; (2) self-reported general health status; (3) the prevalence of disease or illness, and (4) wellbeing, functioning and disability (Emerson & Hatton, 2014). These approaches are frequently used when measuring the health of people with intellectual disability and underpin the available evidence in this area of research (for examples of these approaches see Fujiura et al., 2012; Hosking et al., 2016; Reppermund et al., 2019; Van Schrojenstein Lantman-de Valk et al., 1997).

Irrespective of the difficulties of defining health as a definition or as a concept, health can be observed as an interaction between a person’s environment, their lifestyle and behaviours and their genetics (Committee on Assessing Interactions Among Social Behavioral and Genetic Factors in Health, 2006). It is from this viewpoint that health inequalities arise. Health inequalities are unfair and avoidable differences in health across the population, and between different groups within society (NHS, 2021). In terms of terminology, McCartney et al. (2019) provide a broad overview regarding the differences in terminology that exists and how this may be construed differently. For example, in North America, health inequalities may not necessarily mean that differences between groups are unfair, and in such instances where they are unfair or unjust, differences in the term health inequity may be used. Moreover, McCarthy et al. (2019) contend that inequity is a term not used in Europe and adds further confusion regarding terminology where the use of health disparity is used, which has also been defined as simple differences between groups.

Nevertheless, regardless of terminology, health inequalities are largely preventable (Marmot, 2005a; Marmot & Bell, 2012) and they are not randomly distributed across

the population (Graham, 2009); rather they are concentrated on groups of people who have lower levels of education, are of lower occupational class and have lower levels of income (Marmot, 2005a; Marmot & Bell, 2012). In addition to this, certain characteristics, such as age, race, sexual orientation and disability are associated with health inequalities, where you live and being in a vulnerable group are all associated with health inequalities (NHS, 2021). The consequences of certain characteristics means that the opportunity to live a long and healthy life is profoundly unequal (Graham, 2009) and this is often the case regarding people with an intellectual disability.

2.9. A framework for understanding health inequalities faced by people with an intellectual disability

A significant body of evidence over the last few years has documented the association between social factors and health (Adler & Stewart, 2010; WHO, 2008; Dignan, 2001; Marmot et al., 1991). Essentially, these factors known as social determinants of health are the non-medical factors that influence health outcomes. This is a complex area that is shaped by both internal and external factors and the interplay between these. For people with an intellectual disability this is a very important consideration given the often atypical way of life for many of these individuals. For example, many live in residential or congregated settings and they generally occupy low socioeconomic positions on the societal gradient. In Emerson et al's (2011) work in this area they cite five broad classes of determinants that people with an intellectual disability face and these are largely aligned to the seminal work of the Dahlgren and Whitehead 'rainbow model' of health determinants (Dahlgren & Whitehead, 1991) (Figure 3 is adapted from Dahlgren & Whitehead 1991). This rainbow model maps the relationship between the individual, their environment and health and considers the broad social and economic circumstances that determine the quality of health of a population.

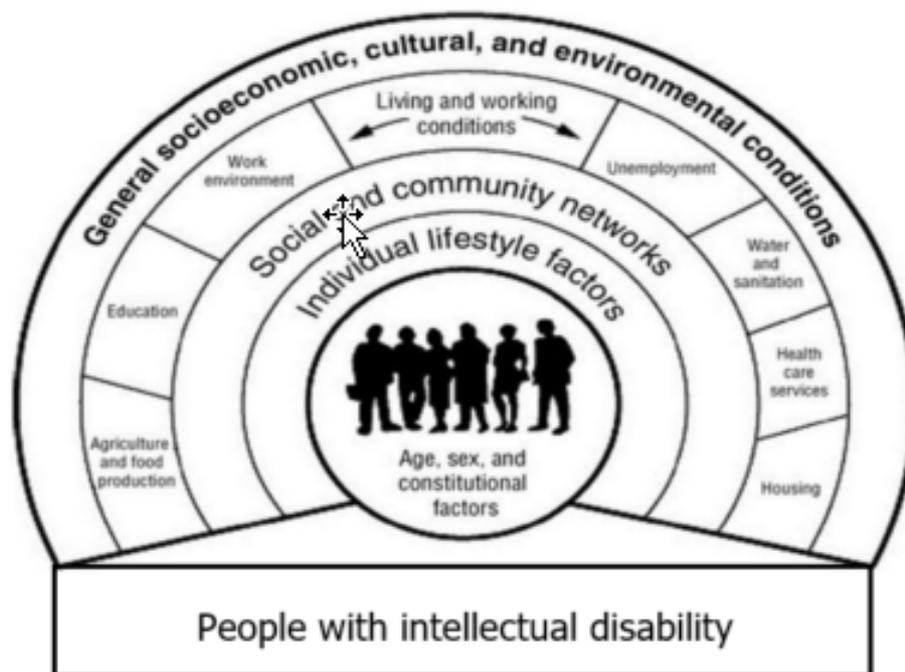


Figure 3. The Dahlgren and Whitehead 'rainbow model' of health determinants (adapted from Dahlgren and Whitehead, 1991)

This model or framework essentially maps the relationship between different layers that influence a population's health. In this model, the individual is at the centre where certain characteristics are largely fixed, for example age, sex and constitutional factors. However, across all the other layers it is now well recognised that these influences are largely modifiable with appropriate targeted interventions (Marmot, 2005a; Marmot & Bell, 2012; Whitehead & Dahlgren, 1991).

Deconstructing this further, this framework can be broadly applied to the circumstances of people with an intellectual disability.

2.10. Age, sex and constitutional factors

These characteristics are broadly fixed and play an important part in understanding the health of people with an intellectual disability. In certain syndromes where intellectual disability is also present, the concept of clinical phenotypes needs to be considered. Clinical phenotypes are the outward expression of genes and it is important in understanding the manifestation of particular sets of physical problems

commonly encountered with particular syndromes (Strydom et al., 2019). In Figure 4 the genetic syndrome and the major associated clinical phenotype in some common syndromes are detailed (Strydom et al. 2019). This is an important consideration as this understanding can delineate health risks and allow for targeted responses. In people with Down syndrome, cardiac defects are more common along with premature ageing and Alzheimer's disease (Lott and Head, 2019). Having an understanding of such clinical phenotypes allows health services to pre-empt and identify the potential trajectory of certain illnesses/diseases in certain people with intellectual disability.

Disorder	Incidence	Genetics	Intellectual disability	Major clinical phenotypes
Down Syndrome	1:1000	Trisomy 21	Mild to severe	Typical craniofacial features and short stature, congenital cardiac defects, gastro-intestinal malformations, premature aging and Alzheimer's disease.
Fragile X syndrome	1:4000	Unstable expansion of a CGG repeat in the <i>FMR1</i> gene on chromosome Xq27.3	Mild to moderate	Macro-orchidism, and distinct facial features, including long face, large ears, and prominent jaw. Increased risk of seizures.
Angelman syndrome	1:24,000	Maternal Chromosome 15q11.2 deletion	Severe to profound	Motor dysfunction, craniofacial abnormalities, protruding tongue, seizures, hypotonia, absent speech.
Cornelia de Lange	1:10,000–1:30,000	Mutation of the NIPBL gene on chromosome 5p13	Moderate to severe	Typical phenotype: small stature, limb abnormalities, characteristic facial features, self-injury, autistic behaviour, eye abnormalities. Mild phenotype also recognised. Associated with frequent infections, vision and hearing problems, GORD, cardiac defects, feeding problems, increased seizure risk.
Cri-du-chat syndrome	1:20,000–1:50,000	Chromosome 5p deletion (mostly sporadic)	Mild to severe	Failure to thrive, characteristic facial features with high pitched cry, microcephaly, cardiac and gastrointestinal malformations, frequent infections, psychomotor dysfunction.
Lowie syndrome	1–10: 1,000,000 Almost exclusively males	Mutation of <i>OCRL</i> gene on Chromosome Xq26	Moderate to severe (75% of cases)	Congenital eye abnormalities (hydrophthalmia), characteristic facial features, infantile hypotonia, renal dysfunction, serum enzyme and musculoskeletal abnormalities.

Figure 4. Clinical phenotypes in common syndromes - adapted from Strydom et al. (2019)

Regarding age, a more severe level of intellectual disability is associated with a shorter lifespan (Lavin et al., 2006) meaning people with severe and profound intellectual disabilities are more likely to die earlier than those with a milder intellectual disability (Tyrrer & McGrother, 2009). It is also acknowledged that women with intellectual disability are more likely to have earlier onset of menopause than those without, increasing their risks for dementia and early mortality (Coppus et al., 2012). It is also reported that women are also more likely to be obese and have osteoporosis (Burke et al., 2019). In both male and females, certain chromosomal

disorders may impact growth and cause reproductive disorders (Strydom et al., 2019) particularly syndromes like Turners or Prader-Willi Syndrome. Nonetheless, it is important to highlight that there is a lack of research regarding how gender influences the health and mortality of people with intellectual disability. Robertson and colleagues (2020) have recently called for further evidence on gender and mortality and cited that there needs to be an international agreement on recommendations for future research relating to gender and the premature deaths of people with intellectual disability.

2.11. Individual lifestyle factors

It is well acknowledged that individual lifestyle factors can accelerate poorer health (Marmot, 2005a). While obesity has tripled worldwide since 1975 and is considered an international epidemic (WHO, 2021), being overweight and obese are major causes of co-morbidities which can lead to further morbidity and mortality (Guh et al., 2009). This is an important issue for people with an intellectual disability as the evidence continues to suggest that adults with intellectual disability have higher prevalence rates of obesity and morbid obesity that exceed the general population (Hsieh et al., 2014; National Health Service Digital, 2021) and it is seen as a greater problem in this population than the general population *per se* (de Winter et al., 2012).

While there are non-modifiable factors associated with obesity, for example gender, severity and type of intellectual disability (Hsieh et al., 2014), the maintenance of a healthy weight is important in the prevention of disease burden through personal and environmental variables. For example physical activity (Bouzas et al., 2019) and maintaining a healthy diet (Martin et al., 2021) are central to being healthy and these variables are reported to be worse in these health risk behaviours in the intellectually disabled population (Scott & Haverkamp, 2016). Regarding substance misuse, it is understood that young people with mild to moderate intellectual disability are less likely to use substances than their non-disabled peers (Robertson et al., 2020). However, it needs to be kept in mind that smoking rates among people with intellectual disabilities who do not use intellectual disability services is

higher and therefore this may not be fully accounted for in the evidence (Emerson, 2011).

2.12. Social and community networks

Being socially excluded negatively impacts health (WHO, 2010). While aspects of social exclusion incorporate participating in society more broadly in terms of employment, purchasing goods and voting, more social aspects focus on participating socially with friends and community networks (Nicholson & Cooper, 2013). In the field of intellectual disability there are a number of related concepts such as community integration and participation and social inclusion. These are concepts central to the United Nations Convention on the Rights of Persons with Disabilities (2016). Indeed, social inclusion is seen as a core domain of quality of life for this population (Schalock, 2004) and it is also reported that a well-established and functioning social network can lead to greater social inclusion such as accessing services, leisure activities, employment, personal autonomy and enjoyment (Bhardwaj et al., 2018). While this concept is unique and personal to every individual, the evidence is not positive as people with an intellectual disability continue to be disadvantaged and socially excluded participants in society where they are less likely to be engaged in recreational programs (Merrells et al., 2018), have fewer friendships characterised by warmth/closeness and positive reciprocity (Tipton et al., 2013), are more likely to experience loneliness, low perceived social support and more social isolation (Emerson et al., 2021), and are more likely to be exposed to discrimination (Emerson et al., 2019). When this is considered with the degree to which individuals are interconnected and embedded in communities being positively related to health and wellbeing, it is clear that people with an intellectual disability are disproportionately impacted across this aspect of the framework (Berkman et al., 2014). This is reported as being more acute for people who may display behaviours that challenge (Bigby & Wiesel, 2011; Emerson et al., 2011) a common phenomenon among people with an intellectual disability (Bowring, 2018; Bowring, Totsika, Hastings, Toogood, & Griffith, 2017b; Lowe et al., 2007; Sheehan et al., 2015).

2.13. Living and working conditions

The principal measures of socioeconomic status or position^{§§} in the UK and in the majority of high-income countries is through measuring or quantifying education, occupation and income in a hierarchical fashion. It is well accepted that people of higher socioeconomic status live longer, enjoy better health, and are less likely to experience disability (Demakakos et al., 2008). In terms of living and working conditions, education, occupation and income are largely interdependent and interconnected, although the pathways through which socioeconomic status determines health in such an orderly way are not fully defined (Demakakos et al., 2008). It is important to highlight that it is difficult to measure the socioeconomic status of adults with an intellectual disability in the same way as for the general population, given the often atypical position they occupy in society as delineated below:

1. **Education:** In developed countries legislative and policy advances have opened up education for individuals with an intellectual disability. However, low educational attainment is common in this population and this is associated with downward social mobility (Emerson & Hatton, 2014) and theoretically this limits the type of employment that is available to people with a disability.
2. **Employment:** Employment is generally a source of economic benefit; however, for people with an intellectual disability they are less likely to be employed and are often excluded from the labour market (Brault, 2012; McGlinchey et al., 2013). A recent review (Garrels & Sigstad, 2021) indicates that people with intellectual disability value employment but different education related factors may hamper access to the labour market. Heslop (2013) further cites the atypical position of many people with intellectual disability. In the UK many people with intellectual disability rely on benefits as opposed to remuneration from employment. This is often an arbitrary sum that is aligned to a broad range of assessed care and mobility needs.

^{§§} Socioeconomic status is generally defined as one's position or standing in society as determined by one's combined economic and social status. This impacts one's ability to access resources that are important to one's ability to advance and progress in a social mobility context.

3. **Income:** Education and occupation influence income which in turn impacts on the concept of poverty. While different forms of poverty exist, (childhood poverty, pensioner poverty, fuel poverty, food poverty) poverty can be measured in two ways; absolute or relative poverty. Absolute poverty is where a household income is below a level to maintain basic living standards while relative poverty is where a household income is a certain percentage below median incomes (Foster, 1998). Poverty means much more than being able to buy food and provide heat, poverty restricts people from participating in society and from this perspective it is detrimental and damaging to a person's health (WHO, 2010). There is strong evidence to support the link between disability and poverty (Banks et al., 2017) and there is a significant association between poverty and the prevalence of intellectual disabilities (Emerson, 2007; Emerson & Parish, 2010; Harris, 2006). The relationship between both is thought to exist for two reasons. According to Emerson (2007) poverty is a cause of intellectual disability while the financial impact of caring for a child with an intellectual disability may cause poverty. An English study illustrates this further insofar as Emerson et al. (2010) found that families supporting a child with intellectual disability were (a) more likely to be poor, (b) more likely to become poor, and (c) less likely to escape from being poor. This highlights the exposure to poverty that families caring for a child with an intellectual disability experience while reinforcing the point that children with an intellectual disability are frequently born into and grow up in poverty (Emerson & Hatton, 2014).

When the socioeconomic status of adults with intellectual disability is considered through this lens, the impact of how these non-medical factors influence health becomes clearer. Another factor impacting on this aspect of the framework concerns housing and the right to an 'ordinary life'. It is well established that a person's residential situation (i.e. housing conditions) is a significant social determinant of health (Dahlgren & Whitehead, 1991; Marmot, 2005a), albeit the pathways of how this influences health are complex (Rolfe et al., 2020).

Over the last 50 years there has been a movement to de-congregate people with an intellectual disability from large campus base settings into smaller community based settings (i.e. their own home) with the aim of improving the lives of people with an intellectual disability (Emerson, 2004; Kim et al., 2001; Knapp et al., 2011; Kozma et al., 2009; Mansell & Beadle-Brown, 2009; Martínez-Leal et al., 2011; McCarron et al.,

2019). Across the UK, in Jersey and in Ireland the majority of adults with intellectual disability live in a wide range of living situations, from residential and nursing care through dispersed and supported living, to tenancies and home ownership (Hatton, 2017). Equally, many people with an intellectual disability continue to live with their family through much of their adult lives. Emerson (2007) has previously commented that where children and adults with intellectual disabilities live in the family home, families and people with intellectual disability may be further exposed to experiencing poverty due to the financial impact of caring.

Nonetheless, while there are also many social positives surrounding the change of living environments for people with an intellectual disability, it is important to highlight that many people with an intellectual disability do not choose where they live and this is inconsistent with the United Nations Convention on the Rights of Persons with Disabilities (2016). Rather, in many instances housing is determined by availability and finances, location and resources despite individualised housing options appearing to offer improved self-determination, choice and autonomy (Chowdhury & Benson, 2011; Fisher et al., 2021; Oliver et al., 2020). Indeed a recent systematic review by McCarron et al. (2019) identified that people who moved from institutional settings to any form of community settings experienced a greater quality of life. Furthermore, with regard to the quality of living environments, the COVID-19 pandemic has highlighted how residential and institutional settings — where a significant proportion of people with an intellectual disability live — has disproportionately impacted people with an intellectual disability (Das-Munshi et al., 2021; Public Health England, 2020; Landes et al., 2021c; McMahon et al., 2020b; Perera et al., 2020; Office of National Statistics, 2020; Turk et al., 2020).

There are other negative strands to these issues, such as the negative physical aspects of housing such as mould, toxins and temperature, linked to physical health (Marmot & Bell, 2012; Rolfe et al., 2020) that are also additional considerations that are important for people with an intellectual disability who live in atypical settings. The psychological benefit of having your own home is acknowledged in the literature (Kearns et al., 2000) and this may be particularly important for people with an

intellectual disability as there is tentative evidence to suggest that good physical housing conditions and housing tenure impact on subjective wellbeing (Clapham et al., 2018).

Finally, as highlighted above, people with intellectual disability often experience difficulties with accessing health care. A number of reports and publications (Ali et al., 2013; Brameld et al., 2018; Emerson et al., 2011; Emerson & Hatton, 2014; Heslop et al., 2013; Michael & Richardson, 2008; Ryan, 2017; Tuffrey-Wijne & Hollins, 2014) have documented how people with an intellectual disability are often discriminated against and denied equal access to health care thereby constituting an inequality. Issues such as poor medical and nursing care, diagnostic overshadowing, failure to adequately manage pain and communication difficulties has contributed to the unnecessary deaths of people with intellectual disability (Heslop et al., 2013; McCormick et al., 2021; Mencap, 2007, 2012; Ryan, 2017). Despite some important improvements, the increased use of hospital passports^{***} and the intellectual disability liaison nursing roles in acute services (McCormick et al., 2021). Northway 2017) contends that that significant challenges remain and continued efforts are required to reduce this inequality.

2.14. General socioeconomic, cultural and environmental conditions

General socioeconomic, cultural and environmental conditions are the full set of circumstances (outlined in Figure 1) within which people live and work and they have a deep impact on the society in which we live. These are perhaps the most important causal factors leading to health inequalities (Whitehead & Dahlgren, 2006). For example, political, economic, cultural and environmental conditions influence our health, income, employment, education, food, security, quality of housing and social opportunities. For people with an intellectual disability this is particularly important as the policies and strategies that shape the society in which they live will have a major impact on their wellbeing, especially given the above-

^{***} In this context, a hospital passport is a communication tool that is used to support people with an intellectual disability communicate their health and social care needs when they are in a hospital or other medical environment.

mentioned social and economic characteristics that are highly prevalent in this population such as poorer health, lower levels of education, atypical living environments and high levels of unemployment (Emerson, 2021). It is therefore concerning that the majority of evidence reported on in this chapter is not generally positive and much of this comes from high-income countries. It is therefore reasonable to conclude that the social determinants of health for people with intellectual disabilities who live in low to middle income countries may be worse (Emerson & Hatton, 2014).

Finally, another important aspect of the 'rainbow model' of health determinants concerns discrimination and attitudes. There is evidence that people with an intellectual disability are subjected to discrimination, more so than the general population. In the UK, Emerson et al. (2019) found that people with a disability were over three times more likely than their peers to be exposed to discrimination, and discrimination was more likely to be reported by people with an intellectual disability. Another Irish study found people with disabilities experience discrimination more than the general population and when they do, it has a more serious effect on their lives (Banks et al., 2018). Interestingly, this study identified that people experienced discrimination most frequently when they encountered health services, followed by financial institutions, shops, pubs and restaurants. While this is concerning given the frequency of contact with health services, it is perhaps not surprising as some research has previously identified the poorer attitudes of health professionals towards people with a disability (Ali et al., 2013; Lewis & Stenfert-Kroese, 2010) with such negative views adversely influencing health professionals' willingness to work with people with intellectual disabilities (Ee et al., 2021).

It also needs to be contextualised how elements of discrimination have particular relevance to understanding the health inequalities experienced by people with intellectual disabilities. Emerson and Hatton (2014) have identified that the extent and pervasiveness of pejorative and discriminatory cultural attitudes about people with intellectual disability are likely to shape the design and operation of mainstream institutions (p.68) which include health and education services. In this vein, services

that are offered to people with an intellectual disability are likely to be negatively impacted due to pejorative and discriminatory cultural attitudes in contrast to the general population. Such beliefs are considered to impact people with intellectual disability in two distinct ways. First, the extent to which such views are embedded in the structure of health, educational and social systems restricts access for people with an intellectual disability and this impacts how such services engage and provide for this population (for example, housing, secure and rewarding employment, access to timely and effective healthcare). This negatively impacts the health and well-being of people with intellectual disability (Emerson, 2021; Emerson & Hatton, 2014). Second, when people who hold strong negative beliefs also work in such institutions, they are more likely to provide substandard services. When this is considered in tandem, it becomes clear how a different picture emerges for people with an intellectual disability in respect of how non-medical factors influence their health and wellbeing in contrast to the general population

2.15. Conclusion

The evidence outlined in this chapter has detailed definitions of intellectual disability and health and considered the use of terminology, the prevalence and aetiology of intellectual disability and briefly examined prevalence regarding gender and ethnicity of intellectual disability. From examining health and mortality research, it is evident that this population present with greater levels of morbidity and die at an earlier age than the general population. In the majority of evidence reported in the chapter it is clear that people with an intellectual disability experience significant health inequalities, that is to say that people with intellectual disability experience unfair and avoidable differences in health in comparison to the general population. These inequalities are largely preventable (Marmot & Bell, 2012) but that they remain (Emerson, 2021; Emerson et al., 2011) is a major cause of concern.

In this chapter, I have also documented a framework (the 'rainbow model' of health determinants) by which the health inequalities that people with an intellectual disability experience can be mapped and delineated. Essentially, the Dahlgren-Whitehead rainbow illustrates that many health issues are determined and driven by

economic, social and environmental inequalities. Across all layers of the model people with intellectual disability are disadvantaged. While this offers a coherent framework to interpret these ideas, it is important to point out that due to the interconnectedness of the layers in this framework it is clear that people with an intellectual disability are very vulnerable to social, economic and environmental influences. An example of a typical cycle is outlined in Figure 5, which I have very simply set out how these exposures impact the health and wellbeing of people with an intellectual disability. This example is based on the foregoing review of the literature.

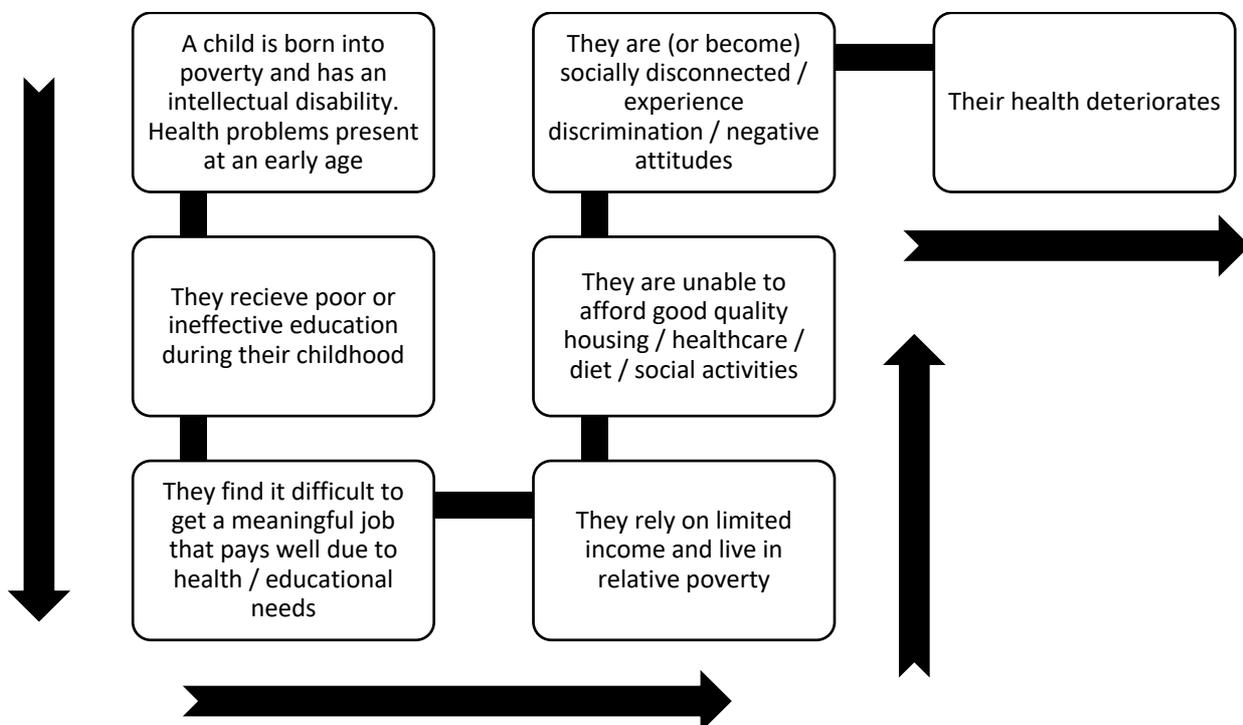


Figure 5. An example of the interpersonal, social, economic and environmental influences on health

It is important to point out that much of the research regarding health inequalities in the health research arena has been undertaken not with people with intellectual disabilities, but in the general population. While most of the health inequalities research has described a societal gradient or social hierarchy (Adler et al., 1994; Adler & Stewart, 2010; Singh-Manoux et al., 2003) by measuring a person's education, occupational, and income status and aligning this to their health, this may

not be an applicable approach for use with people with an intellectual disability, given their atypical socioeconomic status or position within society.

While the relationship between socioeconomic status and health has remained stable in the general population (Adler et al., 2007a; Singh-Manoux et al., 2005), emerging evidence has suggested that subjective socioeconomic status (an individual's opinion of their rank within society, also referred to as subjective social status) is more strongly associated with a person's health than conventional measures of objective socioeconomic status indicators (Cundiff & Matthews, 2017; Euteneuer, 2014). However, there is no available research that has considered this from an intellectual disability perspective. It can be argued, therefore, that subjective socioeconomic status is a suitable measure for this population given the low variation that objective indicators will have for people with an intellectual disability more broadly.

2.16. Aims of this thesis

Considering the aforementioned evidence, this thesis aims to examine the health and health inequalities that adults with an intellectual disability experience in the Island of Jersey. More specifically, this thesis focuses on three aspects of health inequalities:

- 4) The health and wellbeing and socioeconomic position of people with and without intellectual disability who live in Jersey
- 5) The subjective socioeconomic status and health in adults with intellectual disability
- 6) The relationship between objective and subjective socioeconomic status and health in adults with and without an intellectual disability in Jersey.

2.17. Objectives

In order to achieve the aims of the thesis, five studies and a review were undertaken. The objective for each study is set out below in Table 3.

Table 3. Layout of research studies and objectives of each study

Study Number	Title and publication history	Objective of study
Study 1 published	McMahon, M. , & Hatton, C. (2021). A comparison of the prevalence of health problems among adults with and without intellectual disability: a total administrative population study. <i>Journal of Applied Research in Intellectual Disabilities</i> , 34(1), 316-325. https://doi.org/10.1111/jar.12785	The objective of this study was to provide an overview of the health problems that adults with and without intellectual disability experience in Jersey using ICD-10 category headings. This was to compare and situate the health of this defined population in the international literature.
Study 2 published	McMahon, M. , Hatton, C., and Bowring, D. L. (2020) Polypharmacy and psychotropic polypharmacy in adults with intellectual disability: a cross-sectional total population study. <i>Journal of Intellectual Disability Research</i> , 64: 834– 851. https://doi.org/10.1111/jir.12775 .	The objective of this study was to examine the level of drugs that adults with an intellectual disability were prescribed. The rationale for this was to consider the level of morbidity and identify the exposure to polypharmacy and psychotropic polypharmacy that this population experience. Understanding and responding to polypharmacy is important as there are increased risks of adverse medical outcomes.
Study 3 Published	McMahon, M. , Hatton, C., Bowring, D. L., Hardy, C., and Preston, N. J. (2021) The prevalence of potential drug–drug interactions in adults with intellectual disability. <i>Journal of Intellectual Disability Research</i> , 65: 930– 940. https://doi.org/10.1111/jir.12844 .	The concept of this study arose when the analysis for study two was being undertaken. It became apparent that while drug–drug interactions are well mentioned in the general literature, little is known about the prevalence or associations of drug–drug interactions in the ID population. Therefore, the objective of this study was to highlight the associated risks of prescribing drug–drug pairings that

		could impact on the health and wellbeing of the person with an intellectual disability.
Study 4 Published	McMahon, M. , Bowring, D.L. and Hatton, C. (2019), "Not such an ordinary life: a comparison of employment, marital status and housing profiles of adults with and without intellectual disabilities", <i>Tizard Learning Disability Review</i> , Vol. 24 No. 4, pp. 213-221. https://doi.org/10.1108/TLDR-03-2019-0014	The objective of this study to highlight and compare the socioeconomic and social status of people with an intellectual disability in Jersey.
Study 5 – for resubmission	McMahon, M. , Hatton, C. and Alberici, S. Is subjective socioeconomic status a correlate of health in adults with intellectual disabilities? A scoping review	The objective of this study was to undertake a scoping review to answer the question of: is subjective socioeconomic status a correlate of health in adults with intellectual disabilities?
Study 6 Published	McMahon, M. , McMahon, M., Hatton, C., Hardy, C., & Preston, N. J. (2022). The relationship between subjective socioeconomic status and health in adults with and without intellectual disability. <i>Journal of Applied Research in Intellectual Disabilities</i> , 1– 13. https://doi.org/10.1111/jar.13028	The objective of this study is to examine if subjective socioeconomic status is positively related to self-rated and objective indicators of health in people with and without intellectual disability in Jersey. The MacArthur Scale of Subjective Social Status is used to measure subjective socioeconomic status and the Euro-Qol EQ-5D-5L is used as a generic health measure.

Chapter 3: Methodology

3.1. Introduction to this chapter

The chapter is divided into two sections. Section 1 describes and justifies the approach taken in this research and provides an overview of the researcher's philosophical perspective and how this led to the methods employed in this thesis. In section two of this chapter an overview of this research is provided to outline the demographic, socioeconomic and health characteristics of the island of Jersey. As highlighted in Chapter 1, there is published evidence relating to health inequalities that people with an intellectual disability experience. However, in Jersey, there is no original research that describes either the health of people with intellectual disability or the differences in health they experience in comparison to the general population. It is from this viewpoint that the philosophical basis for this research is set out. This is important to understand the differences that exist to contextualise the research site. This is followed by an outline of the methods that were employed for the research studies detailed in Chapters 4,5,6,7,8 and 9.

Section 1

3.2. Approach taken in this research

My approach in this research is broadly based on a directional and logical attitude to meeting the aims and objective of this research (Bryman, 2016; Grix, 2002). In doing so I have reflected on Figure 6, adapted from Grix (2002) as this sets out the interrelationship between the building blocks of science. Essentially, this sets out what a researcher believes can be researched based on what they consider reality to be, the links to how knowledge can be acquired and what procedures one can use to acquire that knowledge. This is a fundamentally important concept in the social sciences. It has been said by Grix (2018) that

“ontology and epistemology are to research what ‘footings’ are to a house: they form the foundations of the whole edifice” (p. 51).

While there are a number of paradigms that have been acknowledged, the most common paradigms that are used from a nursing perspective are positivist, post-positivist, interpretative and critical theory (LoBiondo-Wood & Haber, 2013; Weaver & Olson, 2006). According to Guba and Lincoln (1994) paradigms can be signified through their ontology, epistemology and methodology. It is therefore important for a researcher to be explicit about the philosophical assumptions underpinning their decisions. It is from this perspective that this research is being undertaken from a post-positivist standpoint. Post-positivism has evolved from the positivist paradigm and it is concerned with both the subjectivity and objectivity of reality. It distances itself from the wholly empirical perspective offered by positivism (Robson & McCartan, 2016) and it is essentially a set of assumptions that entail beliefs about reality, knowledge and value (Bisel & Adame, 2017). Nonetheless, post-positivists are true to objectivity from their perspective and they acknowledge biases in themselves as a researcher and how this can influence what is observed (Ryan, 2006). In doing so, the philosophy of post-positivism and indeed from a personal and professional (clinical) perspective I align to the work of Phillips and Burbules (2000) who contend that,

“Human knowledge is not based on unchallengeable, rock-solid foundations - it is conjectural. We have grounds, or warrants, for asserting the beliefs, or conjectures, that we hold as scientists, often very good grounds, but these grounds are not indubitable. Our warrants for accepting these things can be withdrawn in the light of further investigation.” (p.26)

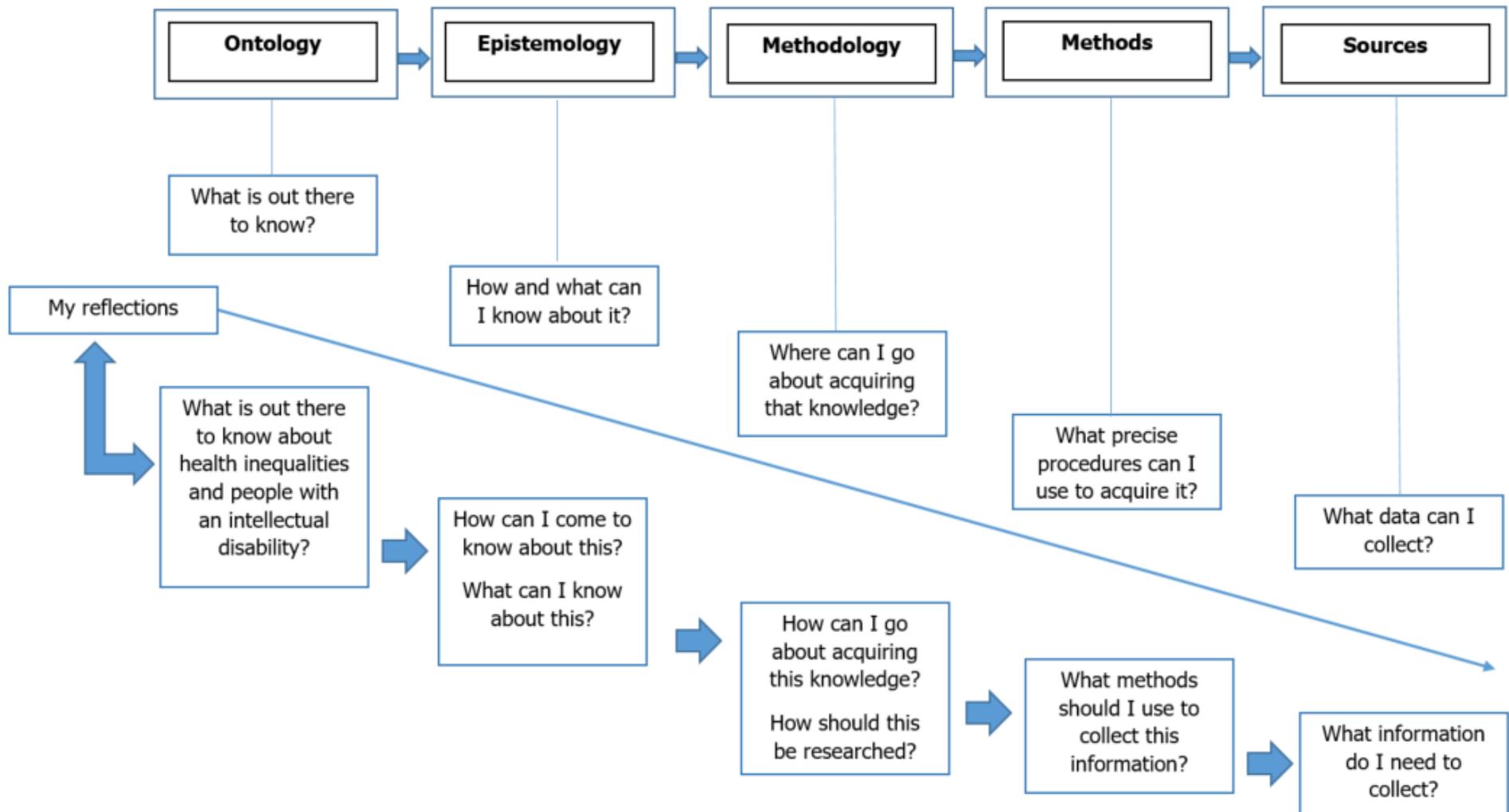


Figure 6. The interrelationship between the building blocks of science (adapted from Grix [2002])

3.3. Ontological Perspective

Ontology is essentially the nature of existence and structure of reality. Simply put, Crotty (2020) defines ontology as the study of being. It is important to consider what type of reality exists from a post-positivist perspective. They believe that while a reality exists, it can only be known imperfectly and probabilistically (Robson & McCartan, 2016). An important component of how this research aligns to this viewpoint from an ontological perspective is that post-positivist research aims to find the truth, and it accepts that not one study can do this (Grix, 2018; Robson & McCartan, 2016), rather when many studies point in the same direction one can progressively have more confidence in the conclusion. From a personal perspective and considering my own career as a health professional, I have always sought out and used rigorous evidence to make decisions relating to patient care and interventions and this general principle is well aligned with this perspective. This commitment towards objectivity while understanding my own limitations and a commitment to be guided by the best available evidence available at the time is fundamentally important and theoretically aligned within a post-positivist paradigm perspective (LoBiondo-Wood & Haber, 2013; Robson & McCartan, 2016).

3.4. Epistemological Perspective

Epistemology, a branch of philosophy that considers how and what can we know about something is based on the nature of knowledge (Grix, 2018). It has been reported that it is critically important for post-positivists to investigate their epistemologies and appreciate how this may affect you as a researcher (Ryan, 2006). From a personal perspective and considering how I make sense of reality, how I can know, or come to know something, I believe that knowledge can be developed and refined and research is, in part, about making claims which are refined or abandoned in light of new evidence. Essentially, post-positivist research considers that social reality is out there and there in enough permanency and patterning for that to be understood (Bisel & Adame, 2017).

In the context of the research objectives that are set out in this thesis, I argue that precise objectivity cannot be achieved but is approachable and it is this reason that I believe the post-positivist philosophy is well aligned with my approach. For example if this research can objectively and incrementally identify the difference in health between people with and without an intellectual disability and explain its associations with the social determinants of health, then this is a rational approach to understand reality (Robson & McCartan, 2016). In doing so, the researcher is not saying this is the whole truth, rather they are saying that this is developing and guiding the evidence and this is how I can come to approach the truth.

3.5. Methodological Perspective

Methodology is concerned with how research should be undertaken (Grix, 2018). From a post-positivist paradigm perspective, the purpose is to predict, test, and find the strength of association between variables using statistical analysis thereby constituting a quantitative approach (Grix, 2018; Robson & McCartan, 2016). Given the research objectives set out in this thesis, which have been established based on previous evidence, theories and concepts, the variables of interest have been set out and are operationally defined below. It is from this perspective that others can replicate this research, which in turn will enable the verification of findings.

Section 2

3.2.1. Population of Jersey

This research was undertaken in Jersey, or as it is officially known, the Bailiwick of Jersey. Jersey is the largest of the Channel Islands and is located in the Bay of St Malo, just 19 miles off the coast of Normandy, France and 85 miles south of the English coast. While Jersey is an English Crown dependency it is an autonomous self-governing state. Jersey is a small island approximately 8.7 miles in length and 5 miles in width. In the 2011 census, there were 97,857 inhabitants. Over the last decade this is estimated to be now somewhere in the region of 107,800 people (Government of Jersey, 2021b).

3.2.2. Residential status in Jersey

Jersey is not in the European Union and as a result there are controls on who can live and work in Jersey, and what entitlement they have to housing, work, income support and health. This is an important consideration due to the aforementioned atypical socioeconomic position of persons with an intellectual disability. These are outlined in Table 4.

Table 4. Overview of residential status on housing, work, financial support and health entitlements in Jersey

Residential status definitions	Definition	Housing	Work	Financial Support	Health Entitlement
Entitled	Someone who has lived in Jersey for 10 years (for example born in Jersey or living there for 10 years)	Can buy, sell or lease any property	Can work anywhere and doesn't need a licence to be employed	Eligible for income support if they meet two additional criteria – the asset & income test	Entitled to Health Entitlements i.e., secondary care free at the point of access – Social security co-payment to GP
Licensed	Someone who is an 'essential employee' (these are generally doctors, nurses, teachers and professionals the islands needs to function)	Can buy, sell or lease any property in their own name if they keep their 'licensed' status	Employer needs a licence to employ a 'licensed' person	Eligible for income support if they meet the whole criteria - resident, asset and income test	Entitled to Health Entitlements i.e. secondary care free at the point of access – Social security co-payment to GP
Entitled to work	Someone who has lived in Jersey for five consecutive years or is married to someone who is 'entitled', 'licensed', or 'entitled to work'	Can buy property jointly with an 'entitled' spouse / civil partner. Can lease 'registered' (previously 'unqualified') property as a main place of residence.	Can work anywhere and doesn't need a licence to be employed	Eligible for income support if they meet two additional criteria – the asset & income test	Entitled to Health Entitlements i.e. secondary care free at the point of access – Social security co-payment to GP
Registered	Someone who does not qualify under the other categories	Can lease 'registered' property as a main place of residence	Employer needs a licence to employ	Not eligible for income support	After 6 months eligible if paying contributions

3.2.3. Jersey's economy and employment

Jersey has a strong progressive economy with low unemployment or underemployment⁺⁺⁺. Private sector employment, financial and legal services in particular, is the largest employer by sector. The mean average weekly earnings for full-time employees in Jersey in June 2021 was £820 per week, the median was £610 per week and by sector, average earnings ranged from around £500 per week in hotels, restaurants and bars to £1,120 per week in financial services (Government of Jersey, 2021b).

3.2.4. Health of Jersey's population

Life expectancy at 65 years is 20 years for men and 23 years for women. The causes of death in Jersey are similar to the rest of the EU with the top three being cancers (neoplasms), accounting for 34% of all deaths, circulatory diseases (26%) and respiratory diseases (11%) (Government of Jersey, 2016b). A key difference in Jersey's health geography is that while circulatory diseases are the primary cause of death in the EU, cancers are the primary cause of death in Jersey. On the whole, cancers are 6% higher in Jersey (with head and neck cancer, skin cancer and lung cancer having high prevalence rates) than the south-west region of England (comparing like for like data) (Government of Jersey, 2017). There is currently no health intelligence specifically relating to the health of people with intellectual disability in Jersey.

3.2.5. Layout of Jersey's health service model

Jersey operates a unique health service model that aligns itself to a hybrid Beveridge model, insofar as it is financed by the government through tax payments. Secondary care is free at the point of access in Jersey but primary care is a private enterprise delivered by General Practitioners, Dentists, Pharmacists and Optometrists.

⁺⁺⁺ Underemployment is classified as an employee who works part time but would take up full time work if that were available.

3.2.6. Social security

Income support is Jersey's means-tested benefit for low-income households. Income support is available to individuals who are working, but on a low income; are unemployed or underemployed; are of pensionable age; are families who have children, but are on a low income(s); people who have disabilities and/or long term illnesses and for carers. Jersey has very strict rules for claiming income support and potential claimants need to satisfy three requirements; a residence test, a work test and an income and asset test. Potential claimants need at least five years continuous residence - Entitled to work residential status as assessed by the Social Security Department. Additionally, potential claimants who are Jersey born and have spent a continuous ten years in Jersey, or individuals who have lived in Jersey for at least ten years at any time in the past, without any breaks are residentially eligible. Income support is calculated in components and these add up a range of basic needs: accommodation, utilities, food.

3.2.7. Education

Education (Jersey) Law 1999 ensures "...that the people of Jersey have access to education and training opportunities which support the fulfilment of their potential and which meet the present and future needs of the island" (Government of Jersey, 2009). In Jersey, education is compulsory from age 4 until 16 and the standard of education is high, with GCSE and A level exam results consistently equal to the upper quartile of the UK education authorities (Government of Jersey, 2021a). For children with special educational needs there are provisions in the law where they are entitled to attend mainstream provision and they must also be provided with effective learning opportunities.

3.2.8. Health and social care services for people with an intellectual disability

Child and adult services for people with an intellectual disability in Jersey are relatively comprehensive and there is a bespoke intellectual disability team for

adults. Services include early intervention, residential care and respite services⁺⁺⁺. From a health and social care delivery perspective, the mode of delivery is peripatetic and the following services are provided: nursing, psychiatry, psychology, speech and language therapy, positive behaviour support, social work, autism services, physiotherapy and social work. Every adult with an intellectual disability who accesses services (or who has accessed services) has a record on CAREPARTNER (a digital planning and management program for health and social care).

3.2.9. Employment opportunities for people with an intellectual disability

Jersey Employment Trust (JET) is a charitable organisation in Jersey that helps individuals with disabilities find and sustain employment in the open market. It does not exclude any individual, and it provides support to individuals who have any disability. On this principle, its objectives fall into three categories:

- Job training and education
- Employment placement and support
- Retention and long-term support

In recent years, JET has become the main organisation that assists individuals with intellectual disabilities to seek and gain meaningful paid employment in Jersey. They work in collaboration with the individual, the employer and with Social Security.

3.3. Methods used in this research

The methods used in this thesis are guided by the research objectives identified above (Grix, 2002). The following section sets out the research design that was used in each of the studies set out in chapter 4,5,6,7 and 9. As Chapter 8 is a scoping review following the Arksey and O'Malley (2005) methodology, the methodological approach is outlined in this study. The rationale behind placing the scoping review at the latter part of this thesis is to bring continuity and coherence to the thesis as a whole. The scoping review addressed the concept of subjective socioeconomic status (SSS) and its relationship with health in people with an intellectual disability. This is

⁺⁺⁺ Residential care and respite services are provided by the Government and/or provider organisations.

an area that has received minimal attention and this review provides an explanation and justification for the final study in my thesis in Chapter 9^{§§§}. Placing it earlier in the thesis would be illogical and compromise the flow of the thesis as a whole.

3.3.1. Study design

The purpose of this study was to examine; a) the health and wellbeing and socioeconomic position of people with and without intellectual disability who live in Jersey; b) explore the concept of SSS and health in adults with intellectual disability; and, c) examine the relationship between objective and SSS and health in adults with and without an intellectual disability in Jersey. In order to meet these aims, this thesis used a cross-sectional methodology and data were collected from:

- 1) A representative general population sample over the age of 18 in Jersey
- 2) People with an intellectual disability over the age of 18 in Jersey identified as such in administrative data systems:
 - a. Where people with an intellectual disability did not have the cognitive capacity to consent to participate, proxy informants were used if consent was granted by others
 - b. Where people with an intellectual disability consented independently, if they gave the consent, proxy respondents were also asked some of the same questions.

3.3.2. Intellectual disability sample

This study uses an administrative total population sampling approach. All individuals over the age of 18 with an intellectual disability who were known to intellectual disability services in Jersey were eligible to participate in this study. At the commencement of this study in 2017, there were 285 people on the CAREPARTNER database who were known to services. In total, 217 people with an intellectual disability participated, a 76% response rate.

^{§§§} This scoping review is to be resubmitted elsewhere.

The demographic characteristics of the 68 individuals who withheld consent to participate are unknown. This is a common phenomenon in the intellectual disability literature and has been referred to as the 'hidden' or 'invisible' population (Rosencrans et al. 2021). The estimates of individuals who are known and not known to services also vary widely. For example, in England, Emerson (2011) estimates that just over 20% of adults with an intellectual disability are known to services, whereas in the USA, Rosencrans and colleagues (2021) estimate this at just over 40%. While there is remarkable little known about this population, there is some evidence in the UK that suggests that these individuals are more likely to be exposed to some of the non-medical factors that influence health such as greater material hardship, greater neighborhood deprivation and reduced community and social participation (Emerson, 2011).

All information was collected via face-to-face interviews following a comprehensive consenting process that is set out in Table 5. This protocol was developed based on guidance from the Mental Capacity Act (2005), the Health Research Authority (<http://www.hra.nhs.uk>) and guidance from Arscott et al. (1998) and it has been successfully used in three previous PhD theses involving people with intellectual disability (Bowring, 2018; Christian-Jones, 2013; Lofthouse, 2013). In total, 85 (39.2%) participants consented independently, while 132 (60.8%) participants were consented through proxy procedures.

Table 5. Process for identifying and gaining informed consent for persons with intellectual disability to participate in this research study

Step 1	The Principal Investigator identified a lead professional for each service user from the CAREPARTNER database.
Step 2	The researcher completed a 'Participant's capacity to consent form' with the lead professional to assess each service user's capacity to provide informed consent independently.
Step 3	If the individual was identified as having capacity to consent by the lead professional, the researcher further assessed this by completing a 'Protocol for determining capacity to consent in cases where a member of Health and Social Services staff have confirmed the individual's capacity to give or withhold consent'. Information was provided to the participant regarding the research

	in a 'participant information sheet'.
Step 4	If the potential participant was identified as not having capacity in step 2, the Principal Investigator identified a personal consultee from the CAREPARTNER database. Under the Mental Capacity Act (2005), when an individual lacks capacity to consent to taking part in a project, the researchers must take reasonable steps to identify a personal consultee. A personal consultee is someone who knows the individual very well. This may be a family member or close friend, but not a paid carer, professional or someone involved in the research study. If a personal consultee cannot be found a nominated consultee will be identified. This nominated consultee will be someone who knows the individual well in a voluntary capacity (e.g. charity / church, etc.) or in a paid capacity (e.g. social worker, paid carer, GP). They will not have any connection with the research study. The researcher will then complete the consenting process by proxy with the personal consultee. Information regarding the research was provided in 'Proxy information sheet'.
Step 5	If the potential participant was assessed as having capacity and consented to participate in the research, then the researcher completed a 'Participant consent form' in the presence of a witness. This confirmed whether the service user gave or withheld consent to participate in the study. The potential participant was also asked to consent to allow the researchers to also speak to a proxy respondent to administer the BPIS questionnaire and the EQ-5D-5L questionnaire to collect objective views to facilitate analysis and understanding. If the potential participant consented to participate then data collection commenced. If the service user withheld consent, then they did not participate in the research.
Step 6	If the personal consultee gave consent, then the researcher approached the named informant to proceed with data collection. If the personal consultee withheld consent, then the service user did not participate in the research. A named informant was an adult who knew the potential participant very well and had at least weekly contact with them. They could be carers, nurses and keyworkers.

3.3.3. General population sample

This study used a random stratified approach towards sampling the general population. The Jersey Land and Property Index database that lists all residential household addresses across the Island was used to draw a sample****. Any household that was included in the previous three Social Surveys (States of

**** The Jersey Land and Property Index database was searched by the Statistics Department on behalf of the researcher for the purpose of this study. This was to ensure that previous households were not burdened with questionnaires addressed to them and that the addresses use in this study would be excluded from the next survey administered by the Statistics Department.

Jersey, 2017) or the Disability Survey in 2015 was excluded from the sampling frame to minimise overburden on households and to increase response rates (final sampling frame n=28,000). It was considered that for a +/-2 percentage point confidence interval, a sample size of approximately 2,500 was necessary. Predicting a 30% response rate (Robson & McCartan, 2016), it was therefore estimated that approximately 8,000 addresses needed to be targeted.^{****} As Jersey has 12 parishes, random addresses were stratified in terms of the proportion of residential addresses in that parish based on the most recent census (States of Jersey, 2011) – for example St Helier has the biggest residential population and therefore 3158 addresses were randomly targeted while St Mary has the lowest amount of addresses and therefore only 131 addresses were targeted. The breakdown is outlined in Table 6.

Table 6. General population random stratified sample breakdown

Parish	Census households in 2011	Census people in 2011	Households	People	Total required
Grouville	2018	4806	5%	5%	398
St. Brelade	4182	10111	10%	11%	824
St. Clement	3688	9202	9%	10%	727
St. Helier	16020	32861	39%	34%	3158
St. John	1112	2911	3%	3%	219
St. Lawrence	2229	5367	5%	6%	439
St. Martin	1492	3707	4%	4%	294
St. Mary	663	1752	2%	2%	131
St. Ouen	1571	4092	4%	4%	310
St. Peter	2018	4800	5%	5%	398
St. Saviour	5358	13249	13%	14%	1056
Trinity	1244	3116	3%	3%	245
TOTAL	41595	95974	100%	100%	8200

3.3.4. Measures used in this thesis

^{****} 8,200 addresses were retrieved as holiday lets and hotel rooms were excluded from the overall sample.

The Jersey Health Assessment & Socioeconomic Status Questionnaire was developed to address the research objectives. This questionnaire is available in Appendix 1.2 for the general population, Appendix 1.3 for the intellectual disability population and Appendix 1.4 for the proxy questionnaire where the person with an intellectual disability has also answered independently. The following measures and variables were included in these questionnaires and administered to both the general and intellectual disability population****:

- 1) All occupational, educational and demographic questions (e.g. socioeconomic status factors) were taken from the 2017 Jersey Opinions and Lifestyle Survey as this was reflective of the demographic profile at that time (States of Jersey, 2017).
- 2) Health questions were developed based on ICD-10 (2015) English online version (<https://icd.who.int/browse10/2015/en>) chapter headings I to XV: viral or infective diseases; cancers, diseases of the blood; endocrine, nutritional or metabolic conditions; mental health illnesses or behavioural problems; neurological conditions; diseases of the eye; diseases of the ear; diseases of the circulatory system; diseases of the respiratory system; diseases of the digestive system; diseases of the skin; diseases of the musculoskeletal system; diseases of the genitourinary system; malformations or genetic problems; and injuries to your body as a result of trauma or poisoning.
- 3) The 36-Item Short Form Survey (SF-36) – this is a RAND 36-Item Short Form Health Survey. This is available from http://www.rand.org/health/surveys_tools/mos/36-item-short-form/terms.html (Hays et al., 1993).
- 4) Euro-Qol EQ-5D-5L Questionnaire – This EQ-5D-5L is a standardised instrument for use as a measure of health outcome. This is available from <https://euroqol.org/> (Devlin & Brooks, 2017; Devlin et al., 2018).
- 5) The MacArthur Scale of Subjective Social Status was developed to capture the common sense of social status across the socioeconomic status indicators. In an easy pictorial format, it presents a "social ladder" and asks individuals to place an "X" on the rung on which they feel they stand (Adler & Stewart, 2007b).

**** Permission from the copyright holders to use the instruments and measures in this research was granted where the instruments or measures did not explicitly license their use for any purpose.

The following measures were used in this study to collect data from the intellectual disability population only:

- 6) The Behaviour Problems Inventory^{§§§§} – short form for use with individuals with intellectual disabilities (BPI-S). This is available from <http://bpi.haoliang.me/> (Rojahn et al., 2012).
- 7) A medication recording chart that identified the drug taken, the strength, the route, the timing and the prescriber.

3.3.5. Timing and duration of data collection

For the general population sample, the questionnaire was posted out in two stages in September 2017 and January 2018. Four thousand questionnaires were posted in September 2017 and 4,000 were posted in January 2018 to different addresses. The rationale behind this approach was to minimise the impact that seasonal effects may have on respondents given the transient nature of the Jersey population. The questionnaire asked the person in the household who has the next birthday (and is 18 years old or over) to complete the questionnaire. A follow-up reminder letter was posted two weeks after the initial questionnaire was sent to help improve response rates. Figures 7 and 8 outline the responses returned. In total, 2,415 questionnaires were returned, a response rate of 30.2%. Of these, 2,350 questionnaires were included in the analysis for study 1, 4 and 6. For the intellectual disability population data were collected during 2018 and 2019.

^{§§§§} This data is not presented in this thesis as it is part of a different study examining the longitudinal prescribing of psychotropic medication and development of cumulative risk indices for people with intellectual disability – see:

- Bowring, D. L., Totsika, V., Hastings, R. P., Toogood, S., & McMahon, M. (2017a). Prevalence of psychotropic medication use and association with challenging behaviour in adults with an intellectual disability. A total population study. *Journal of intellectual disability research*, 61(6), 604-617. <https://doi.org/https://doi.org/10.1111/jir.12359>
- Bowring, D. L., Totsika, V., Hastings, R. P., Toogood, S., & Griffith, G. M. (2017b). Challenging behaviours in adults with an intellectual disability: A total population study and exploration of risk indices. *Br J Clin Psychol*, 56(1), 16-32. <https://doi.org/10.1111/bjc.12118>

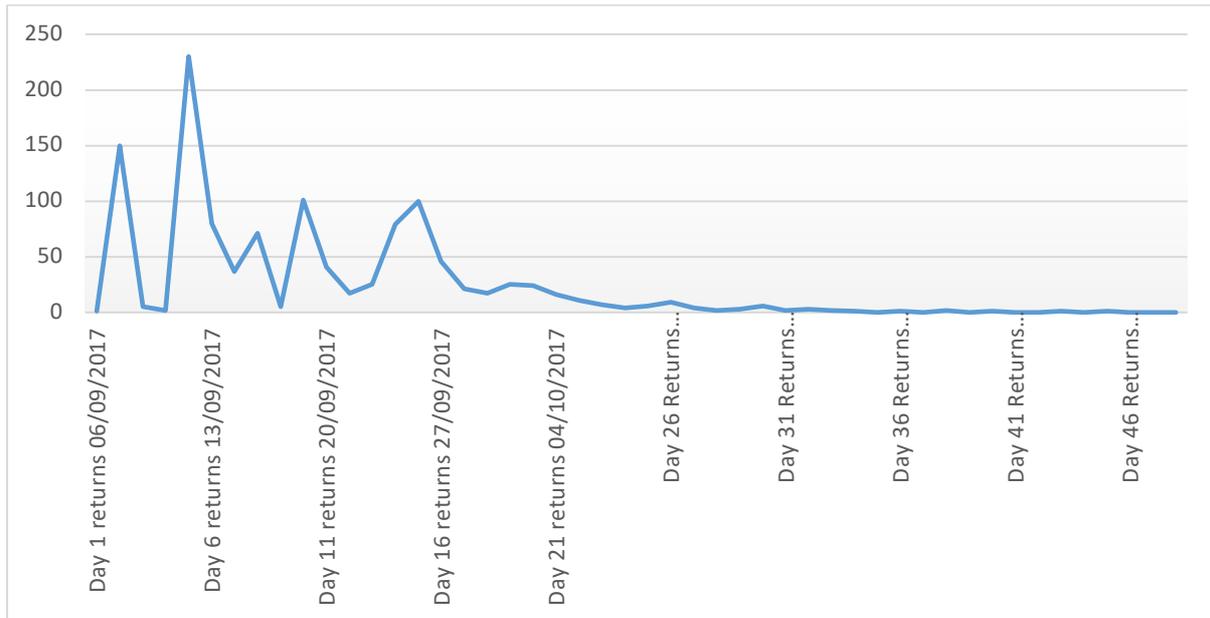


Figure 7. Questionnaire returns from September 2017 administration

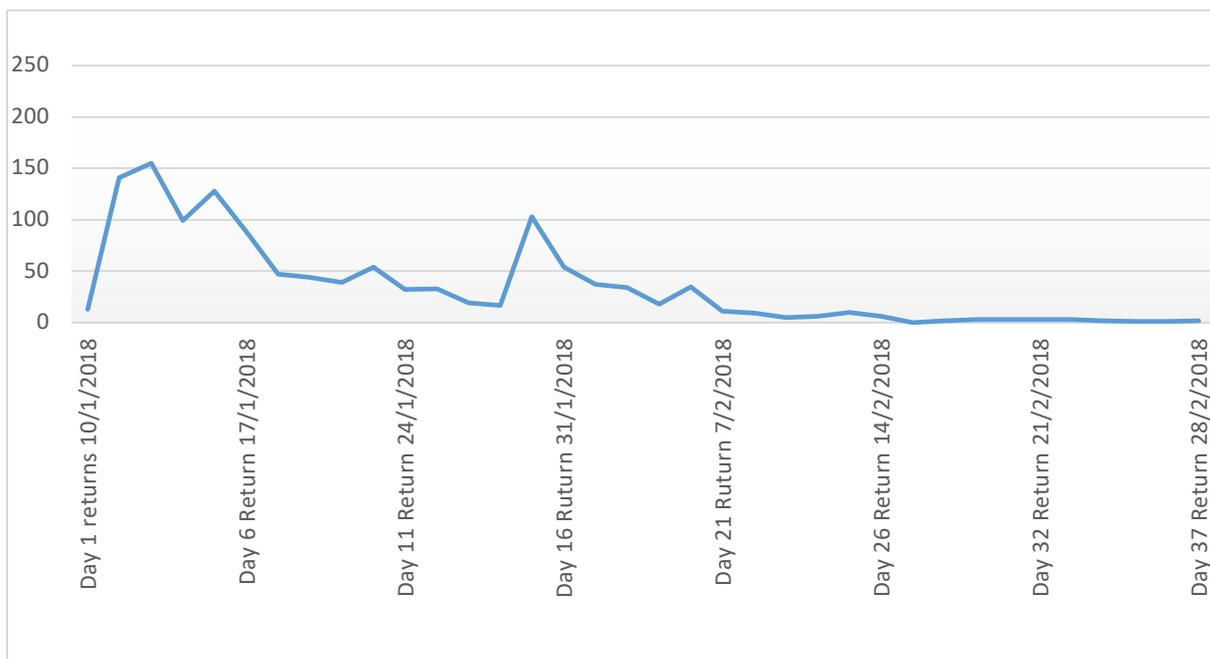


Figure 8. Questionnaire returns from January 2018 administration

3.3.6. Administration of questionnaire to people with an intellectual disability and their proxies

Once consent had been granted following the process set out in Table 5 data collection commenced. While the lead researcher undertook more than 120 face-to-face interviews with people with intellectual disabilities and/ or their proxy

respondents a number of health professionals also assisted in the collection of data. Prior to collecting data they received training and ongoing supervision from me to ensure:

- They were trained to complete the survey tools.
- They were trained to achieve adequate inter-rater reliability prior to the study commencing.
- They were aware of the need to conduct meetings sensitively.
- They had monthly team meetings to discuss progress, discuss any issues and ensure consistent application.
- They were aware of how to report concerns or issues promptly so the lead researcher could respond to them.
- They were aware of data protection guidelines when managing data collected.

By the nature of their employment, all investigators involved in data collection have had a Disclosure Check undertaken (formerly known as CRB check).

3.3.7. Ethical considerations and approval

Favorable ethical approval for this research was received from the Health and Social Services Department, Jersey Ethics Committee in March 2017 and the Faculty of Health and Medicine Research Ethics Committee (FHMREC) (reference FHMREC16083), Lancaster University, in April 2017 (attached in Appendix 1.5). In addition, this research was undertaken in accordance with the principles underlying the Declaration of Helsinki (General Assembly of the World Medical Association, 2014) while incorporating the four rights of human research: which include the right not to be harmed, the right to full disclosure, the right of self-determination and the rights of privacy, anonymity and confidentiality (Robson & McCartan, 2016).

3.3.8. Approaches to analysis

Two databases were created: an intellectual disability database and a general population database in SPSS (Statistical Package for the Social Sciences Version 25 Inc. Chicago, IL, USA). Each questionnaire was allocated a unique identification number and all data were coded according to the measure's analytical guidance and

inputted into the associated SPSS database and checked for errors. Frequency distributions were run on each variable to ensure that the data fell within the expected range and all errors were rectified. Missing data was not replaced, and it accounted for less than 2.5% for any variable in the dataset. Variables of interest from each database were then merged in a separate database to run the analysis for each study in this thesis. SPSS and 'R' was used for analysis and descriptive and inferential statistics were used depending on the objective of the research study. In the McMahon et al. (2021) study, case-control matching was used to randomly compare the general and intellectual disability samples according to age and gender. Age and gender are frequently used in observational studies to improve study efficiency by increasing precision when controlling for matching factors by reducing selection bias (Pearce, 2015). In the McMahon et al. (2021) study, this was achieved by matching the distribution of year of birth and gender (male/female) for the intellectual disability population. Out of 217 participants, 206 of these cases (95%) were matched for both years of birth and gender. This process was undertaken in the following sequence:

1. data was coded as 'demanders' (total general and intellectual disability population) and 'suppliers' (matched sample) coded as 1 and 0 respectively
2. case-control matching using the case matching procedure was run in SPSS
3. this generated a new database with the 206 suppliers from each population creating a total of 412 cases in total
4. The matched group were checked for similarities before analysing outcomes between groups.

The specific approach towards analysis is set out in each research study.

3.3.9. Conclusion

This chapter has provided an overview of the philosophical underpinning that guided this research and the choice of methods used. This was put forward by reflecting on the researcher's ontological and epistemological perspective. This guided the methodology in a directional and logical manner thereby following a post-positivist

approach by acquiring knowledge in a quantitative fashion. In doing so, this research uses a cross-sectional approach to meet the research aims and objectives. This chapter also provides a broad overview of the socioeconomic and health characteristics of the island of Jersey for contextualization. Finally, this chapter concludes with a brief overview of the procedures that were employed to undertake this research. This is to complement the procedures that are outlined in each of the research studies that precede this conclusion.

Chapter 4: Study 1

A comparison of the prevalence of health problems among adults with and without intellectual disability: A total administrative population study

Reference: McMahon, M., & Hatton, C. (2021). A comparison of the prevalence of health problems among adults with and without intellectual disability: A total administrative population study. *Journal of Applied Research in Intellectual Disabilities*, 34(1), 316-325. DOI: <https://doi.org/10.1111/jar.12785>

This study is cited as McMahon and Hatton (2021a) from Chapter 10 onwards.

Abstract

Introduction: There is considerable international research indicating health disparities between people with and without intellectual disabilities. It is important that comparative studies use representative population samples. This study compares a total administrative population of adults with intellectual disability to a random stratified general population sample in Jersey.

Methods: A total administrative population of 217 adults with intellectual disability and a random stratified sample of 2,350 adults without intellectual disability participated. A questionnaire using the International Classification of Diseases (ICD-10) Chapter Headings was administered to all participants to enable a like-for-like comparison across both populations.

Findings: Unadjusted comparisons identified that adults with intellectual disability have a greater prevalence of health problems. However, they were less likely to experience cancers and musculoskeletal diseases. The only significant impact of adjusting for between-group differences in age and gender was that a difference in genitourinary disorders became non-significant.

Conclusions: These findings are consistent with the hypothesis that adults with intellectual disabilities generally have greater prevalence rates of health problems than the general population.

Introduction

It is well documented that in high-income countries people with intellectual disability have poorer health than the general population (Emerson, Hatton, Baines & Robertson, 2016; Heslop & Glover, 2015), with people dying on average 20 years earlier than their non-disabled peers (O'Leary, Cooper, & Hughes-McCormack, 2018; Glover, Williams, Heslop, Oyinlola, & Grey, 2017; Heslop et al. 2014; Learning Disability Mortality Review, 2018; Troller, Srasuebku, Xu, & Howlett, 2017; Lauer & McCallion, 2015; McCarron, Carroll, Kelly, & McCallion, 2015).

There is substantial variation in the prevalence rates of major health problems for people with intellectual disabilities reported across different studies and how they compare to people without intellectual disabilities. For example, studies that have investigated cancer (Bonell, 2010; Tyler & McGrother, 2009; Patja, Molsa Livanainen, 2001; Duff et al. 2001; Cooke 1997) diabetes (Mac Rae et al. 2015; de Winter et al. 2012; Tyler et al. 2010; McDermott, Platt, & Dasari, 2006) and mental health problems (Hughes-McCormack et al. 2017; Buckles, Luckasson, & Keefe, 2013) have reported varying prevalence rates in people with intellectual disabilities. A range of potential methodological reasons for this principally focus on the inconsistent definition of intellectual disabilities; the diverse diagnosis tools, and small sample sizes used in studies. Although there is a growing body of research that uses representative samples of people with and without intellectual disabilities (Balogh, Brownell, Ouellette-Kuntz, & Colantonio, 2010; Hosking et al., 2016; Hughes-McCormack et al. 2018; Morin, Mélineau-Côté, Ouellette-Kuntz, Tassé, & Kerr, 2012), this continues to be one of the most important methodological limitations in intellectual disability research more broadly (Emerson & Hatton, 2014; Hogg, & Tuffrey-Wijne, 2008; Hughes-McCormack et al., 2017).

Acknowledging such methodological limitations, the aim of this brief report was to build upon and integrate existing literature to estimate the current prevalence of health problems using ICD-10 classification headings in a total administrative population of adults with intellectual disabilities and a comparison random stratified

general population sample in Jersey. The same variables were used to facilitate comparison across people with and without intellectual disabilities.

Method

Measures

A survey was developed based on ICD-10 (2015) English online version (<https://icd.who.int/browse10/2015/en>) chapter headings I to XV: viral or infective diseases; cancers, diseases of the blood; endocrine, nutritional or metabolic conditions; mental health illnesses or behavioural problems; neurological conditions; diseases of the eye; diseases of the ear; diseases of the circulatory system; diseases of the respiratory system; diseases of the digestive system; diseases of the skin; diseases of the musculoskeletal system; diseases of the genitourinary system; malformations or genetic problems; and injuries to your body as a result of trauma or poisoning. For the purpose of this paper, classification headings only were used to enable direct comparisons between groups in both populations. A dichotomous variable was created (yes/no) asking participants if they had diseases or disorders of the classification headings from these chapters. In each classification heading we provided examples of the most common diseases that were representative of that group. We included an open question for participants to record any other disease or disorders that they have not mentioned in the survey. For the intellectual disability sample, all electronic health and nursing notes held on Care Partner (an electronic health and social care database) by Jersey's Health and Community Services were reviewed. Demographic variables were collected on both surveys that mirrored the Jersey Opinions and Lifestyle Survey (States of Jersey, 2017). This data is reflective of the local population.

Ethics

Ethical approval was granted from Lancaster University and by the Government of Jersey, Health and Community Services Ethics Committee in January and March 2017. The consent process and accompanying documentation was designed using guidance from the Mental Capacity Act (2005) and the National Research Ethics Service (NRES)

(<http://www.nres.nhs.uk/>). Further details of the consenting procedure for adults with an ID are outlined in McMahon et al. (2019), Bowring et al. (2017a) and Bowring et al. (2017b).

Intellectual disability population

A total administrative sample of adults with intellectual disability known to services in Jersey were contacted to participate (i.e. people who were receiving, or had received, support from intellectual disability services in Jersey). 217 adults with intellectual disabilities participated (age range 18-85 [male n=122, female n=95]), a response rate of 76% (sampling frame n=285). Approximately 50% of participants were administratively defined by Jersey's Health and Community Services as having a mild intellectual disability (n =108), 25.8% (n = 56) as having a moderate intellectual disability, 15.7% as having a severe intellectual disability (n=34) and 8.8% (n=19) as having a profound intellectual disability.

All information was collected by face-to-face interviews with the participants themselves or through proxy respondents. In this regard, 132 (60.8%) adults were consented through proxy procedures and they answered on behalf of the person with an intellectual disability, whilst 85 (39.2%) participants consented and answered independently. All health records held on Care Partner were checked to corroborate findings. To receive a health and social service in Jersey individuals with an intellectual disability have a yearly assessment and they have a current care plan that includes a health assessment; therefore, this served as robust measure to identify the prevalence of disease in this population. However, in a pragmatic manner, where it was self-reported by the person or a proxy had a disease but there was no evidence to support this on Care Partner, their community nurse was requested to confirm. In this instance, if the finding was not corroborated it was excluded for our analysis.

General population

A random stratified sample approach was used to recruit general population adults. Jersey's 12 parishes were divided into strata. Each parish was weighted in terms of population considering the most recent population census and allowing for net inward migration (States of Jersey, 2011). Addresses were drawn at random from the list of residential, active addresses for each parish on the Jersey Land Property Index excluding any household which was sampled for one of the previous 2015, 2016, 2017 social surveys or the Disability Survey in 2015 - there were 28,000 households in the overall sampling frame. Eight thousand surveys were posted to cover the entire adult population at random. This was based on the initial estimation of having a +/-2 percentage point confidence interval and assuming a 30% response rate. The household member who next celebrated their birthday, and who was aged 18 years or over, was asked to complete the survey. A total of 2,415 (30.2% [age range 18 – 105, male n-941, female n-1,394]) surveys were returned with 65 of these being unusable. In total, 2,350 general population responses were included in the analysis.

Analysis

Initially, descriptive statistics and the frequency of ICD-10 disease presentation in the two populations were examined. To investigate the scale of any differences in disease prevalence between the intellectual disability and general population, Odds Ratios with 95% confidence intervals were calculated. Secondly, binary logistic regression analysis was undertaken to estimate the strength of any differences in disease prevalence between the intellectual disability and general population groups (odds ratios), once gender (binary variable) and age (split at the median [over and under 57 years]) were taken into account. Thirdly, an interaction term was fitted to determine if the effects of age and or gender differed across the intellectual disability and general populations. Finally, we matched 206 participants according to age and gender to determine if there was a difference in the frequency of health problems in both populations. This matching procedure was undertaken in SPSS using the case matching procedure.

There were no missing data in the intellectual disability dataset and less than 3% (range 2%-2.7%) across the general population dataset. The pregnancy complications variable was excluded from analysis as no person with an intellectual disability was pregnant during the study. Data were analysed using SPSS 25 and graphs were produced in 'R'. Effect sizes for Odds Ratios for 2x2 comparisons are interpreted as; small (OR < =0.82 or > =1.22), medium (OR < =0.54 or > =1.86), large (OR < =0.33 or > =3.00) [Olivier & Bell, 2013].

Results

Bivariate comparisons of health problems

The first stage of analysis involved simple bivariate comparisons between participants with and without intellectual disability with regard to the ICD-10 Chapter Headings. Odds Ratios were calculated and associated 95% confidence intervals with significance levels.

Table 1: Prevalence of Diseases in the Intellectual Disability and General Population with Associated ORs and 95% CI and P-Values

Variable		Intellectual Disability	General Population	Odds Ratio	95% CI	P Value
Participants		n = 217	n = 2,350			
Viral or infective diseases	Yes	n = 17 (7.8%)	n = 57 (2.5%)	3.3	1.90-5.81	p < 0.001
	No	n = 200 (92.2%)	n = 2284 (97.5%)			
	<i>Missing data</i>	<i>n = 0 (0%)</i>	<i>n = 66 (2.8%)</i>			
Cancers	Yes	n = 5 (2.3%)	n = 130 (5.7%)	0.39	0.16-0.97	p = 0.036
	No	n = 212 (97.7%)	n = 2164 (94.3%)			
	<i>Missing data</i>	<i>n = 0 (0%)</i>	<i>n = 56 (2.4%)</i>			
Diseases of the blood	Yes	n = 16 (7.4%)	n = 70 (3.1%)	2.52	1.44-4.42	p < 0.001
	No	n = 201 (92.6%)	n = 2217 (96.9%)			
	<i>Missing data</i>	<i>n = 0 (0%)</i>	<i>n = 63 (2.7%)</i>			
Endocrine, nutritional or metabolic conditions	Yes	n = 67 (30.9%)	n = 456 (19.9%)			

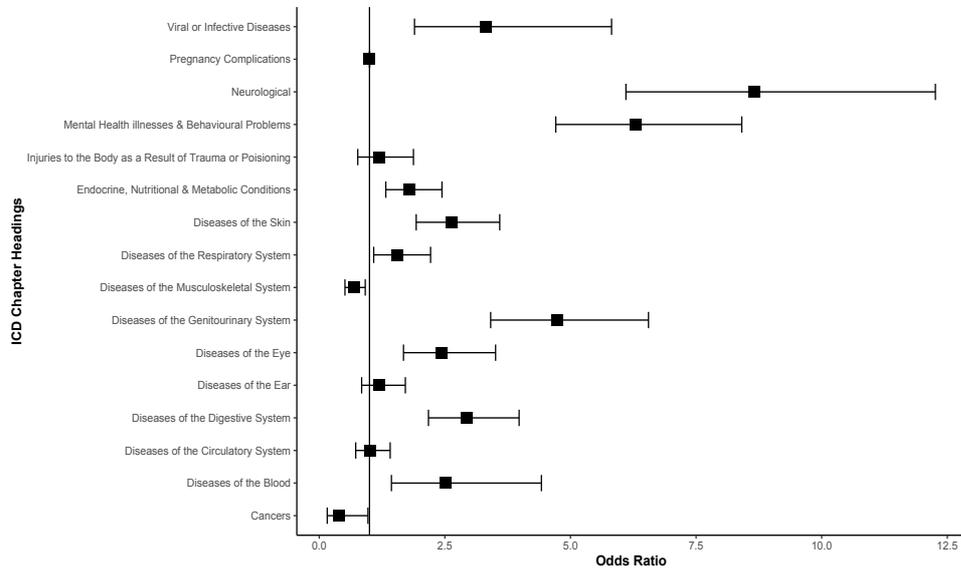
	No <i>Missing data</i>	n = 150 (69.1%) <i>n = 0 (0%)</i>	n = 1837 (80.1%) <i>n = 57 (2.4%)</i>	1.80	1.33-2.44	p < 0.001
Mental health illnesses or behavioural problems	Yes No <i>Missing data</i>	n = 114 (52.5%) n = 103 (47.5%) <i>n = 0 (0%)</i>	n = 343 (15%) n = 1950 (85%) <i>n = 56 (2.4%)</i>	6.29	4.70-8.41	p < 0.001
Neurological conditions	Yes No <i>Missing data</i>	n = 65 (30%) n = 152 (70%) <i>n = 0 (0%)</i>	n = 108 (4.7%) n = 2185 (95.3%) <i>n = 57 (2.4%)</i>	8.65	6.10-12.26	p < 0.001
Diseases of the eye	Yes No <i>Missing data</i>	n = 41 (18.9%) n = 176 (81.1%) <i>n = 0 (0%)</i>	n = 201 (8.8%) n = 2093 (91.2%) <i>n = 56 (2.4%)</i>	2.43	1.67-3.51	p < 0.001
Diseases of the ear	Yes No <i>Missing data</i>	n = 42 (19.4%) n = 175 (80.6%) <i>n = 0 (0%)</i>	n = 383 (16.6%) n = 1919 (83.4%) <i>n = 48 (2%)</i>	1.20	0.84-1.71	p = 0.307
Diseases of the circulatory system	Yes No <i>Missing data</i>	n = 49 (22.6%) n = 168 (77.4%) <i>n = 0 (0%)</i>	n = 514 (22.4%) n = 1784 (77.6%) <i>n = 52 (2.2%)</i>	1.01	0.73-1.41	p = 0.943
Diseases of the respiratory system	Yes No <i>Missing data</i>	n = 42 (19.4%) n = 175 (80.6%) <i>n = 0 (0%)</i>	n = 308 (13.4%) n = 1989 (86.6%) <i>n = 53 (2.3%)</i>	1.55	1.08-2.21	p = 0.016
Diseases of the digestive system	Yes No <i>Missing data</i>	n = 75 (34.6%) n = 175 (65.4%) <i>n = 0 (0%)</i>	n = 350 (15.2%) n = 1949 (84.8%) <i>n = 51 (2.2%)</i>	2.94	2.17-3.98	p < 0.001
Diseases of the skin	Yes No <i>Missing data</i>	n = 67 (30.9%) n = 150 (69.1%) <i>n = 0 (0%)</i>	n = 332 (14.5%) n = 1957 (85.5%) <i>n = 61 (2.6%)</i>	2.63	1.93-3.59	p < 0.001
Diseases of the musculoskeletal system	Yes No <i>Missing data</i>	n = 76 (35%) n = 141 (65%) <i>n = 0 (0%)</i>	n = 1014 (44%) n = 1288 (56%) <i>n = 48 (2%)</i>	0.69	0.51-0.91	p = 0.010
Diseases of the genitourinary system	Yes	n = 65 (30%)	n = 190 (8.3%)			

	No	n = 152 (70%)	n = 2101(91.7%)	4.73	3.41-6.55	P < .001
	Missing data	n = 0 (0%)	n = 59 (2.5%)			
Malformations or genetic problems	Yes	n = 64 (29.5%)	n = 20 (0.9%)	47.41	27.96-80.40	p < 0.001
	No	n = 153 (70.5%)	n = 2267 (99.1%)			
	Missing data	n = 0 (0%)	n = 63 (2.7%)			
Injuries to your body as a result of trauma or poisoning	Yes	N = 24 (11.1%)	n = 215 (9.4%)	1.20	0.77-1.88	p = 0.561
	No	n = 193 (88.9%)	n = 2074 (90.6%)			
	Missing data	n = 0 (0%)	n = 61 (2.6%)			

In summary, our main results suggest participants with intellectual disability were more likely than the general population to have: viral or infective diseases; mental health illnesses and behavioural problems; neurological disorders; diseases of the genitourinary system and malformations or genetic problems. In contrast, participants with intellectual disability were statistically less likely than the general population to have cancers and diseases of the musculoskeletal system, representing a medium and small effect size respectively. It was not possible to distinguish between mental health and behavioural disorders due to the lack of comparative data. Nevertheless, 33.6% of the intellectual disability sample have had a mental health diagnosis at some stage in their life.

See the Figure 1 Forest Plot (malformations or genetic problems are excluded from the Forest Plot as the OR of 47.14 is extreme) for a representation of these differences.

Figure 1: Forest Plot of ICD Chapter Headings and Associated Odds Ratios (with 95% CI)



Malformations or Generic Problems OR is 47.14 (95% CI 27.96-80.40) and had been omitted from this Forest Plot as it distorts interpretation

Binary logistic regression results

Table 2: Logistic Regression Model with Statistically Significant Results

		Nagelkerke	β	S.E.	Wald's X^2 (df 1)	Sig.	OR	95% CI for Odds Ratio	
		R^2						Lower	Upper
Viral & Infective Diseases	General/ Intellectual Disability Population*Age	0.035	-1.185	.593	4.00	*	0.30	0.10	0.97
Cancers	Gender	0.069	0.391	.183	4.572	*	1.48	1.03	2.11
	Age		-1.276	.213	35.804	***	0.28	0.18	0.42
Diseases of the Blood	General/ Intellectual Disability	0.027	-1.226	.461	7.062	**	0.29	0.12	0.72
Endocrine Nutritional & Metabolic Disorders	Gender	0.064	-.328	.111	8.725	**	0.72	0.58	0.89
	Age		-.937	.111	71.463	***	0.39	0.32	0.49
	General/ Intellectual Disability		-.840	.257	10.688	**	0.43	0.26	0.71
Mental Illness & Behavioural Disorders	Gender	0.122	-.451	.127	12.571	***	0.64	0.50	0.82
	Age		.611	.122	24.953	***	1.84	1.45	2.34
	General/ Intellectual Disability		-1.853	.226	66.976	***	0.16	0.10	0.24
	General/ Intellectual Disability Population*Gender		.785	.306	6.572	*	2.20	1.20	3.99
	General/ Intellectual Disability Population*Age		-1.318	.361	13.339	***	0.27	0.13	0.54
Neurological	Gender	0.137	-.491	.214	5.240	*	0.61	0.40	0.93
	Age		-.589	.204	8.353	**	0.56	0.37	0.83
	General/ Intellectual Disability		-2.592	.313	68.744	***	0.08	0.04	0.14
	Age		-1.351	.174	60.282	***	0.26	0.18	0.36

Eye	General/ Intellectual Disability	0.077	-1.564	.310	25.547	***	0.21	0.11	0.38
	General/ Intellectual Disability Population*Age		1.072	.434	6.093	*	2.92	1.24	6.85
Ear	Age	0.061	-1.056	.122	65.477	***	0.35	0.27	0.44
	General/ Intellectual Disability Population*Gender		-0.930	.373	6.174	*	0.40	0.19	0.82
Circulatory Disorders	Gender	0.145	.233	.107	4.757	*	1.26	1.02	1.56
	Age		-1.626	.118	190.147	***	0.20	0.16	0.25
Respiratory Disorders	Age	0.013	-.329	.124	7.059	**	0.72	0.57	0.92
Digestive Disorders	Age	0.057	-.665	.121	30.251	***	0.51	0.41	0.65
	General/ Intellectual Disability		-.996	.250	15.981	***	0.37	0.23	0.60
Skin	Age	0.031	0.300	.120	6.208	*	1.35	1.07	1.71
	General/ Intellectual Disability		-.537	.250	4.606	*	0.59	0.36	0.93
	General/ Intellectual Disability Population*Age		-.849	.361	5.541	*	0.43	0.21	0.87
Musculoskeletal Disorders	Age	0.067	-.927	.087	113.840	***	0.40	0.33	0.47
Malformations & Genetic Problems	General/ Intellectual Disability	0.379	-.3.647	.465	61.614	***	0.03	0.01	0.07

*p < 0.05, **p < 0.01, ***p < 0.001

Note: Any variables with a p-value > 0.05 are excluded. Each of the final models was assessed against the Hosmer–Lemeshow goodness of fit test statistic (Hosmer, Lemeshow, & Sturdivant, 2013). For each model, apart from diseases of the genitourinary system, a p-value above .10 was observed along with a small test statistic identifying that the models provided a good fit to the data.

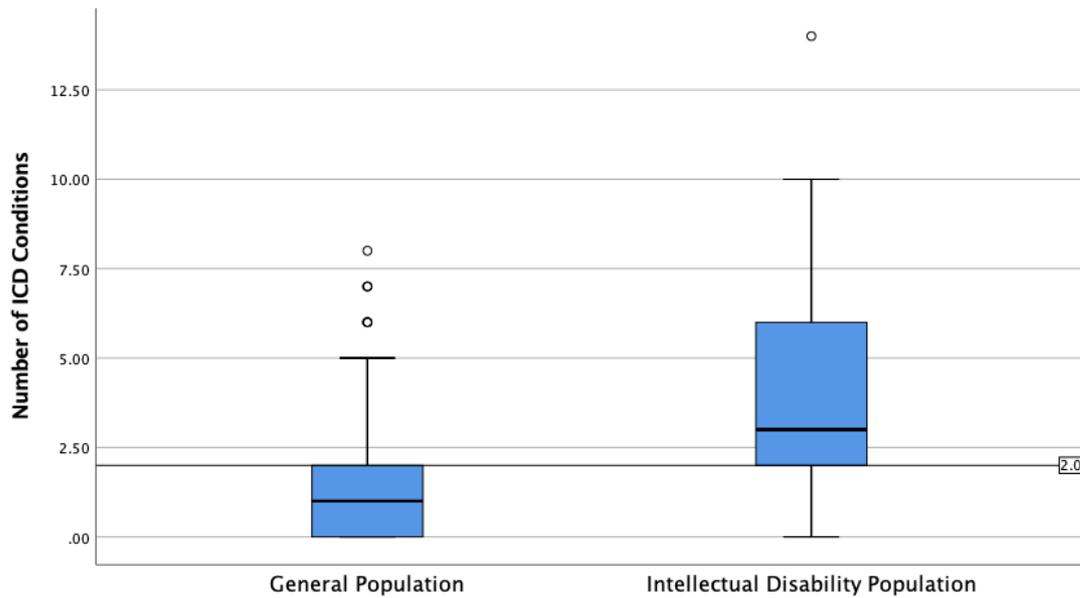
Injuries to your body as a result of trauma or poisoning excluded as they were not statistically significant

After adjusting for age, gender and presence of intellectual disability our principle results suggest that females are more likely to have cancers and circulatory disorders but less likely to have endocrine, nutritional and metabolic disorders mental illness and behavioural disorders or neurological disorder. Females with an intellectual disability without were significantly more likely to have mental illness and behavioural disorders but less likely to have diseases of the ear than females without an intellectual disability. Furthermore, increasing age increased the chances of having cancer; endocrine and metabolic disorders; neurological disorders; disorders of the eye; disorders of the ear; disorders of the circulatory system; disorders of the respiratory system; diseases of the digestive system and musculoskeletal disorders. In contrast, younger age increased the chances of having mental illnesses and behavioural disorders and disorders of the skin. Further statistically significant results are outlined in Table 2.

Matched sample comparison results

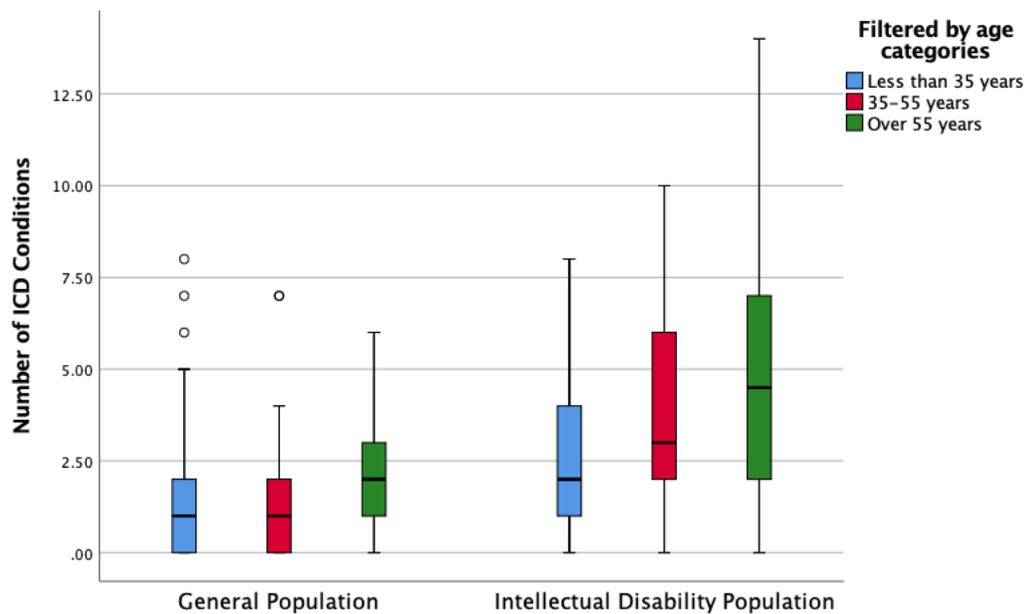
In the final stage of analysis, case control matching was used to compare the general and intellectual disability sample according to age and gender in an attempt to further minimise confounding and improve precision (Rothman, Greenland, & Lash, 2008). A total of 206 individuals were matched on a like-for-like basis. It can be concluded that people with intellectual disabilities ($n=206$) had a greater number of health problems, median (IQR) 3 (2,6) than the general population ($n=206$), median (IQR) 1 (0,2) and the difference in these distributions is significant ($U = 32836, p < .001$) (Figure 2).

Figure 2: A Matched Comparison Sample (n-206) Identifying the Cumulative Number of ICD-10 Conditions



We also compared age bands (less than 35 years, 35-55 years and over 55 years) across the two populations and used the cumulative number of ICD-10 conditions as the dependent outcome variable. Across all three age band categories, people with intellectual disabilities had a greater prevalence of ICD-10 conditions and these were statistically significant: less than 35 years ($U = 3048, p < .001$); 35-55 years ($U = 5182, p < .001$); over 55 years ($U = 3027, p < .001$) (Figure 3).

Figure 3: A Matched Comparison Sample (n-206) Identifying the Cumulative number of ICD-10 Conditions Filtered by Age Categories



Discussion

Consistent with the results of previous epidemiological research our results indicate that in unadjusted comparisons, adults with intellectual disabilities have considerably greater prevalence rates of viral or infective diseases; diseases of the blood; endocrine, nutritional and metabolic conditions; mental health illnesses and behavioural disorders; neurological disorders; diseases of the eye; diseases of the respiratory system; diseases of the digestive system; diseases of the skin; diseases of the genitourinary system and malformations or generic problems (Heslop et al. 2014; Bonell, 2010; Robertson et al. 2015; Straetmans *et al.* 2007; Hughes-McCormack et al. 2017; Timmeren et al. 2017; Henderson et al. 2009; Janicki & Dalton, 1998). Nevertheless, adults with intellectual disability were less likely to have cancers and diseases of the musculoskeletal system. No difference was observed between prevalence rates for diseases of the ear, diseases of the circulatory system or injuries to the body as a result of trauma or poisoning.

These results are consistent with previous research and are reflective of the health inequalities that adults with intellectual disabilities experience (Emerson & Baines, 2011; Emerson & Hatton, 2014; Krahn & Fox, 2014). Only diseases of the genitourinary system became non-significant after accounting for age and sex. Further adjusted comparisons identified a different topography of prevalence with regard to gender with cancers and circulatory disorders being more prevalent in females. In contrast, endocrine, nutritional and metabolic disorders, mental illness and behavioural disorders and neurological disorders were more prevalent in males. Our analysis only found two significant associations in the interaction component insofar as females with an intellectual disability were more likely to have mental illnesses and behavioural disorders but less likely to have diseases of the ear than their non-disabled peers. The age adjustment finding is not unique and suggests that older age increased the chances of having certain diseases. Notwithstanding, the age interaction effect between the general population and intellectual disability population identified that increasing age in the intellectual disability population increases the incidence of disorders of the eye, whereas reduced age in the general population identifies a lower prevalence of viral and infective diseases, mental illnesses and behavioural disorders and disorders of the skin. The matched sample analysis also highlights that people with an intellectual disability experience greater levels of ill health at a younger age and this trajectory continues throughout their life.

These results consolidate and extend existing knowledge about the health inequalities faced by people with intellectual disability in a number of ways. First, the use of a total administrative population in the intellectual disability sample is a strength of this study. Having access to participants' health records ensure accuracy of health data. Similarly, the random stratified sample that covered the whole residential address population of Jersey ensured a representative general population comparison sample of considerable numbers, although we were unable to check health data on the health system database due to large numbers of respondents and lack of consent.

Second, this study supports other evidence that cancer is less prevalent in the intellectual disability population (Cooke, 1997, Bonell, 2010) whilst mental health and behavioural disorders are more prevalent (Cooper *et al.* 2007; Hughes-McCormack *et al.* 2017; Bowring *et al.* 2017). This analysis did not distinguish between mental health and behaviours that challenge to ensure like-for-like comparison with the general population. The 33.6% prevalence rate for mental health disorders reported in this study is higher than two of most influential papers in this area that cite a 22.4% (Cooper *et al.* 2007) and 23.4% (Hughes-McCormack *et al.* 2017) prevalence rate respectively. This may be due to this study's total administrative population approach insofar as those known to services may have more health-related problems. In addition to the increased prevalence rate of the other conditions, these findings are not new and support the consistently highlighted poorer health of this population (Hoskings *et al.* 2016; Heslop *et al.* 2014) that are aligned to well-known determinants of health and wellbeing (Emerson & Hatton, 2014). In addition to this, the trajectory of ill-health and disease in the intellectual disability population needs to be considered from an age perspective. There is clear evidence in this study that people at a younger age experience a greater number of health problems. Medical advancements have meant that sustaining life in infancy has become more achievable and children who were born extremely premature or with complex needs are now living into adulthood where once they would have died. The consequence of such treatment can have a marked impact of these persons' health meaning they experience many morbidities earlier which continue throughout life. This potentially polarises the finding that younger age in the general population may not be a protective factor for people with an intellectual disability. Future research should use population level longitudinal evidence from universally standardised health coding systems to identify the burden of ill-health in both children and adults with an intellectual disability.

Four principle limitations need to be kept in mind when considering these results. Firstly, the ICD-10 classification structure used in this study does not specify what specific disease the person has as it groups disorders under an anatomical and physiological systems approach. Although examples of specific illnesses were used to

assist the general population to correctly identify and match their disease to the correct heading, we acknowledge there is the potential for error as we could not cross-check results as it was an anonymous postal questionnaire. Second, although the use of a random stratified sampling approach ensured that the sampling frame is highly representative of the general population, there was only a 30% response rate. Third, this study has used two different methods to recruit participants. Although we acknowledge that this is a significant limitation in itself, we are also of the firm belief that general population cohort surveys are wholly exclusive for individuals with intellectual disabilities with greater needs. Therefore, in making reasonable adjustments to include as many people as possible with intellectual disabilities, we have produced this limitation. Fourth, this study has included adults known to services and there may be a 'hidden majority' such as adults with mild intellectual disability who do not access intellectual disability services (Emerson & Hatton, 2014).

Although these four limitations introduce a source of methodological bias into the findings, there is a substantial evidence base that substantiates the prevalence of the reported disease in this study as it is broadly similar to other Jersey estimates over the last ten years (States of Jersey, 2012; 2014; 2016). Additionally, there was no evidence of any nonresponse variable correlation (Johnson & Wislar, 2012), and missing values were less than 2.7% across all variables. This goes a significant way to mitigate against the first and second limitations. Concerning the third and fourth limitation, the evidence-base in intellectual disability research continues to be challenged over how should individuals with an intellectual disability be included in general population cohort surveys (Hughes-McCormack et al. 2017; Emerson et al. 2014). Overcoming such challenges is inevitably going to create issues where sampling procedures are disconnected to a certain degree. Therefore, the use of a total population sample is considered an appropriate response to include people with intellectual disabilities in comparative research who have significant needs while ensuring the general population is equally representative. Our findings are suggestive of its appropriateness as it substantiates and integrates the existing literature.

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Chapter 5: Study 2

Polypharmacy and psychotropic polypharmacy in adults with intellectual disability: a cross-sectional total population study

Reference: McMahon, M., Hatton, C., and Bowring, D. L. (2020) Polypharmacy and psychotropic polypharmacy in adults with intellectual disability: a cross-sectional total population study. *Journal of Intellectual Disability Research*, 64: 834– 851. DOI: <https://doi.org/10.1111/jir.12775>.

This study is cited as McMahon et al. (2020a) from chapter 10 onwards.

Abstract

Background

Adults with intellectual disability are prescribed high levels of medication with polypharmacy and psychotropic polypharmacy common. However, reported rates vary between studies and there has been an over-reliance on obtaining data from convenience samples. The objective of this study was to determine the prevalence of medication use and polypharmacy in a population-level sample of adults with intellectual disabilities. Factors associated with polypharmacy and psychotropic polypharmacy are explored.

Methods

We used a total population sample of 217 adults with intellectual disabilities known to services in Jersey (sampling frame n=285). The Anatomical Therapeutic Chemical classification system was used to classify medications that participants were currently prescribed. We examined associations of polypharmacy and psychotropic polypharmacy with socioeconomic status, health and demographic variables using univariate and multivariate analysis.

Results

A total of 83.4% of participants were prescribed medication with high doses common. 38.2% of participants were exposed to polypharmacy while 23% of participants exposed to psychotropic polypharmacy. After controlling for demographic, health and socioeconomic characteristics, polypharmacy was significantly associated with older age, increased severity of intellectual disability, living in a residential setting and having increased co-morbidities. Psychotropic polypharmacy was associated with being male, being aged 50+ years and having had a psychiatric diagnosis over the life course.

Conclusions

Our results indicate that medication use, in high doses, alongside polypharmacy and psychotropic polypharmacy are highly prevalent in adults with intellectual disability. The exposure to multiple medications increases the risk of developing adverse drug events, drug-drug interactions and medication-related problems. Future population-level, prospective cohort studies should examine the prevalence of polypharmacy and psychotropic polypharmacy and consider the potential impact of adverse drug events, drug-drug interactions and medication related problems.

Keywords: Polypharmacy, psychotropic polypharmacy, intellectual disability, socioeconomic status, health, medication

Introduction

People with intellectual disability have considerably greater health needs than the general population (Kinnear *et al.* 2018; Hughes McCormack *et al.* 2018) and they are more likely to die at an earlier age than their non-disabled peers (Glover *et al.* 2017; O'Leary *et al.* 2018). As a result, they are prescribed more medication than people without intellectual disabilities and polypharmacy is common in this population (Emerson *et al.* 2016; O' Dwyer *et al.* 2017; 2019; Hove *et al.* 2019). Although polypharmacy may be clinically indicated and considered appropriate (Masnoon *et al.* 2017), the concurrent use of many drugs increases the risks of an individual developing adverse effects and it is related to poorer outcomes (O' Dwyer *et al.* 2018).

In recent years, the principal focus of medication research in people with intellectual disability has centred on psychotropic drug use (Glover *et al.* 2015; Seehan *et al.* 2015; Bowring *et al.* 2017; O' Dwyer *et al.* 2017). While it is important that the high use of psychotropic drugs in this population is addressed as a matter of urgency as it is associated with negative outcomes (Valdovinos *et al.* 2009; Matson and Mahon, 2010), it is also essential that overall prescribing patterns are examined. Medication use and polypharmacy, in particular, can serve as an important indicator of potential mortality as it generally represents the burden of disease that this population experience (Hove *et al.* 2019). Despite this, studies of the prevalence of polypharmacy in people with an intellectual disability varies from 11% to 60% (Stortz *et al.* 2014). There is also significant variation in the reported prevalence of psychotropic polypharmacy, with prevalence rates reported as anything from 22% to 40% (O'Dwyer *et al.* 2017; Lunskey and Modi, 2017). This is consistent with the range of reported psychotropic prescribing rates in the literature varying from 25% to 89% (Deb *et al.* 2015; Scheifes *et al.* 2016; Bowring *et al.* 2017). The high degree of reported variance in psychotropic prescribing rates and polypharmacy in general is a direct consequence of the heterogeneity of polypharmacy definitions (Masnoon *et al.* 2017), weak analytical approaches (for example bivariate analysis)

(Stortz *et al.* 2014) and convenience or clinic sampling being used in the majority of studies (Stortz *et al.* 2014 Haider *et al.* 2014, Bowring *et al.* 2017).

Another issue in this area of research concerns the factors associated with polypharmacy and psychotropic polypharmacy. Recent evidence has identified gender is not associated with polypharmacy in adults with intellectual disability (Stolker *et al.* 2001; Haider *et al.* 2014; O'Dwyer *et al.* 2016), whereas institutional or residential living is associated with increased psychotropic medication use and medication use in general (Bowring *et al.* 2017). Additionally, mental health or neurological conditions are reported to be strongly associated with polypharmacy (O'Dwyer *et al.* 2016); however, there is no consensus on whether older age is associated with polypharmacy as studies have reported conflicting findings (O'Dwyer *et al.* 2016; Haider *et al.* 2014).

Furthermore, despite the established evidence base in the general literature identifying that polypharmacy follows a societal gradient (Morin *et al.* 2018; Assari and Bazargan, 2019) there is an absence of research in the intellectual disability arena that focuses on socioeconomic issues. Haider *et al.* (2014) identified that unemployment was strongly related to polypharmacy in a representative sample of adults with intellectual disability; however, the association between socioeconomic status and medication use has received little attention in the intellectual disability literature. This is in contrast to socioeconomic status being robustly associated with polypharmacy in the general population more broadly (Haider *et al.* 2009; Rawle *et al.* 2018). The absence of such evidence may be a consequence of the low socioeconomic position that people with intellectual disability typically occupy within a societal gradient (Graham 2005; Emerson and Hatton, 2009), resulting in inadequate heterogeneity of participants for meaningful analysis.

It is clear that there is a need for population-based sampling studies examining patterns and prevalence of polypharmacy and psychotropic polypharmacy using a standardised polypharmacy definition (Stortz *et al.* 2014). It is also important to identify factors associated with polypharmacy and psychotropic polypharmacy.

Therefore, this present study investigated the prevalence of medication use in a total administrative population of adults with intellectual disability in Jersey. More specifically the primary aims of this study were:

- To determine the prevalence and patterns of polypharmacy and psychotropic polypharmacy in a total population sample of adults with intellectual disability.
- To examine the relationship between polypharmacy, psychotropic polypharmacy, socioeconomic status, health and demographic variables in a total population sample.

Methods

Study Design

Intellectual Disability Sample

A total administrative sample of adults (≥ 18 years) defined as having an intellectual disability in Jersey participated (i.e. who were receiving, or had received, support from intellectual disability services in Jersey). 217 adults with intellectual disability were recruited in this study, a 76% response rate (sampling frame $n=285$). Eighty-five (39.2%) participants consented independently, while 132 (60.8%) participants were consented through proxy procedures. All information was collected by face-to-face interview with the person and/or by a personal or nominated consultee (Department of Health, 2008). Medication data were collected directly from prescription charts, individual medication administration records or by examining any medication the person had in their possession.

Variables

Medication classification

Each participant or proxy representative was asked what medication they were prescribed, what dosage the medication was prescribed at, was it prescribed regularly, for a short course basis or on a PRN "*pro re nata*" basis. PRN medication

was included if it had been prescribed in the previous 28-day prescribing cycle by a medical prescriber. Medication included oral, intramuscular, subcutaneous, sublingual, buccal, rectal, vaginal, ocular, otic, nasal, inhaled, nebulised, cutaneous (topical) and transdermal preparations. Each participant's medication record was validated against their electronic health and social service record. All medicines were coded using the World Health Organisation (WHO) Anatomical Therapeutic Chemical (ATC) [WHO, nd] classification system. Neurological medicines were coded to pharmacological subgroup level (four elements), while all other medicines were coded to their main group level (one element) [Bowring *et al.* 2017]. For psychotropic preparations, the Defined Daily Dosage (DDD) for each drug was computed. The DDD is the assumed average maintenance dose per day for a drug used for its main indication in adults (WHO, nd). Twenty percent of entries were cross-checked by the third author for accuracy and no errors were reported.

Polypharmacy

A recent review by Masnoon *et al.* (2017) identified 138 different definitions of polypharmacy. Consequently, in the absence of a coherent approach towards defining polypharmacy, this study follows guidance from O'Dwyer *et al.* (2016) who define polypharmacy as the concurrent use of five or more drugs and excessive polypharmacy as ten or more drugs.

Psychotropic Polypharmacy

Similarly, in a separate study, O'Dwyer *et al.* (2017) defines psychotropic polypharmacy as the concurrent use of two or more psychotropic agents in one individual (Mojtabai and Olfson 2010; Lake *et al.* 2012). Therefore, psychotropic polypharmacy was operationally defined as concurrent prescriptions for two or more psychotropic agents from the following ATC classifications: N04A Anticholinergic Agents; N05A Antipsychotic drugs; N05B Anxiolytics; N05C Hypnotics & Sedatives; N06A Antidepressants; N06B Psychostimulants; N03A Antiepileptics as mood stabilisers.

Health

A number of health indicators were used. A continuous variable was developed using the ICD-10 (2015) English online version (chapter headings I to XV (McMahon & Hatton, 2020a) calculating the cumulative number of ICD-10 conditions a participant was reported to have (range 0-14). A binary measure (good vs poor) of self-rated (n=85) and proxy-rated health (n=82) was also used. This was adapted from the EQ-5D-5L health related quality of life questionnaire (EuroQol Research Foundation, 2009). Other binary variables such as epilepsy diagnosis, psychiatric diagnosis over the life course (diagnosed by a psychiatrist) and Down syndrome were also used.

Socioeconomic Status

Three objective indicators of socioeconomic status were used in this study; education, occupation and income. Due to the low variation in these three indicators for people with an intellectual disability, education was operationalised as 'formal education vs no formal education', income was classified as above or below £15,000pa and occupation was defined as 'in employment vs unemployed'. For unadjusted comparisons, a socioeconomic status score (SES Score) was calculated. No formal education, income below £15,000pa and unemployment were scored at '1' per variable. Formal education, income above £15,000pa and being in employment was scored at '2' per variable. A score of 3 represented a low SES score and an SES score of ≥ 4 represented a higher SES score. Any SES variable with missing data was excluded from analysis.

Demographic characteristics

This study is part of a larger comparative study and all demographic variables were collected to mirror the Jersey Opinions and Lifestyle Survey (States of Jersey, 2017). These data are reflective of trends in the local population. For residential status, a binary variable was created; residential care (full time residential care for single occupancy [n=4], residential setting for multiple occupancy [n=100] and nursing home setting [n=3] [total residential care n=107]; [49.3%]) vs non-residential care

(independent living [n=55] and family home [n=55] [total non-residential care n=110][50.7%]).

Ethical Approval

Ethical approval was granted from Lancaster University and by the Government of Jersey. The consent process and accompanying documentation was designed using guidance from the Mental Capacity Act (2005) and the Health Research Authority (<https://www.hra.nhs.uk/>). Further details of the consenting procedure for adults with an ID are outlined in McMahon et al. (2019), Bowring et al. (2017a) and Bowring et al. (2017b).

Analysis

Data analysis was performed using the Statistical Package for the Social Sciences Version 25 (SPSS, Inc., Chicago, IL, USA). In the first stage of analysis simple frequency and descriptive statistics were undertaken to describe the total population and categorise socio-demographic factors, health and the prevalence of polypharmacy and psychotropic polypharmacy. At the second stage of analysis a Pearson's χ^2 or Fishers Exact test of independence (or a Mann-Whitney U test or Kruskal–Wallis H test for continuous variables) were used to determine any significant relationships between the polypharmacy groupings. In the final stage of analysis, binary logistic regressions were undertaken to determine the unique contribution of demographic, health and socioeconomic characteristics on polypharmacy (no polypharmacy vs polypharmacy and excessive polypharmacy) and psychotropic polypharmacy (no psychotropic polypharmacy vs psychotropic polypharmacy). Statistically significant results of $p < 0.05$ are reported. There were no missing medication data. Apart from income where nine individuals refused to answer this question (4.1% of missing data) all other variables had less than 1% of missing data and this data was randomly distributed.

Results

Personal Characteristics

Selected personal characteristics of participants are presented in Table 1. The mean age of participants was 44.5 years (SD 16.2, range: 18–84 years). Just under half of the sample had a mild intellectual disability (n=108). A substantial majority of participants were single (87.1%), unemployed (76.4%) and, if employed, earning less than £15,000 per year (91.7%). The median (IQR) number of ICD-10 conditions was 3 (2,5.5).

Table 1: Selected Population Characteristics of the Total Population Sample

Characteristic	Total n=217 (%)	Men n=122 (56.2)	Women n=95 (43.8)
Age (years)			
Less than 35	79 (36.4)	54 (44.3)	25 (26.3)
35 - 49	53 (24.4)	29 (23.8)	24 (25.3)
50 - 64	58 (26.7)	24 (19.7)	34 (35.8)
Over 65	27 (12.4)	15 (12.3)	12 (12.6)
Marital Status			
In a relationship	20 (9.2)	9 (7.6)	11 (12.2)
Single	189 (87.1)	110 (92.4)	79 (87.8)
Level of ID			
Mild	108 (49.8)	64 (52.5)	44 (46.3)
Moderate	56 (25.8)	26 (21.3)	30 (31.6)
Severe	34 (15.7)	20 (16.4)	14 (14.7)
Profound	19 (8.8)	12 (9.8)	7 (7.4)
Socioeconomic Status			
Employed*	43 (23.6)	29 (29.0)	14 (17.1)
Unemployed	139 (76.4)	71 (71.0)	68 (82.9)
Earns over £15,000 pa	21 (10.1)	15 (12.5)	6 (6.8)
Earns under £15,000 pa	187 (89.9)	105 (87.5)	82 (93.2)

Formal qualifications	21 (9.8)	12 (9.9)	9 (9.6)
No formal qualifications	194 (90.2)	109 (90.1)	85 (90.4)
Health			
Number of ICD-10 Conditions	Median (IQR) 3 (2,5.5)	Median (IQR) 3 (1,5)	Median (IQR) 4 (2,6)

*People who are retired, in full time education or homemakers are excluded from analysis

Medication prevalence

A total of 83.4% (n=181) of participants were prescribed at least one medication (Mean=4.58 SD=4.42, range 0-21). The largest group of medications used were those coded to treat the nervous system (33.7% of drugs n=375), followed by those for the alimentary tract and metabolism (22.8% of drugs n=255) and those for the dermatological system (10.1% of drugs n=113). Table 2 outlines the Anatomical Therapeutic Chemical (ATC) Classification of all prescribed drugs by the number of people prescribed a particular class of medication.

Table 2: Anatomical Therapeutic Chemical (ATC) Classification of all Prescribed Drugs by Gender and Severity of Intellectual Disability

ATC Category	% of Total Men	% of Total Women	% of Total Mild/ Moderate Intellectual Disability	% of Total Severe/ Profound Intellectual Disability	Total Number Prescribed Drugs in ATC Class
	n (%)	n (%)	n (%)	n (%)	n (%)
Total	94	85	128	50	1117
N04A Anticholinergic agents	13 (7.2)	11 (6.1)	16 (8.8)	8 (4.4)	24 (2.1)
N05A Antipsychotic	44 (24.3)	17 (9.4)	41 (22.7)	20 (11.0)	61 (5.4)
N05B Anxiolytics	19 (10.5)	14 (7.7)	13 (7.2)	20 (11.0)	33 (2.9)
N05C Hypnotics and sedatives	8 (4.4)	2 (1.1)	9 (5.0)	1 (0.6)	10 (0.8)
N06A Antidepressants	22 (12.2)	24 (13.3)	40 (22.1)	6 (3.3)	46 (4.1)
N06B Psychostimulants	4 (2.2)	0	4 (2.2)	0	4 (0.36)
N03A Antiepileptic's as mood stabilisers	5 (2.8)	5 (2.8)	4 (2.2)	6 (3.3)	10 (0.8)
N02A/B/C Analgesia	40 (22.1)	50 (27.6)	63 (34.8)	27 (14.9)	90 (8.9)
N03A Antiepileptics for nerve pain	3 (1.7)	3 (1.7)	6 (3.3)	0	6 (0.5)
N03A Antiepileptics for epilepsy	42 (23.2)	43 (23.8)	50 (27.6)	35 (19.3)	85 (7.6)
N04B Dopaminergic agents	1 (0.6)	0	1 (0.6)	0	1 (0.08)
N07B Drugs used in nicotine dependence	1 (0.6)	0	1 (0.6)	0	1 (0.08)
N - Other Neurologicals	0	4 (2.2)	4 (2.2)	0	4 (0.36)
A – Alimentary tract and metabolism	132 (72.9)	123 (68.0)	151 (83.4)	104 (57.5)	255 (22.8)
B – Blood and blood forming organs	19 (10.5)	14 (7.7)	24 (13.3)	9 (5.0)	33 (2.9)
C – Cardiovascular system	41 (22.7)	46 (25.4)	75 (41.4)	12 (6.6)	87 (7.7)
D – Dermatological	58 (32.0)	55 (30.4)	69 (38.1)	44 (24.3)	113 (10.1)
G – Genito-urinary system and sex hormones	12 (6.6)	24 (13.3)	29 (16.0)	7 (3.9)	36 (3.2)

H – Systemic hormonal preparations	11 (6.1)	15 (8.3)	17 (9.4)	9 (5.0)	26 (2.3)
J – Anti-infectives for systemic use	11 (6.1)	21 (11.6)	22 (12.2)	10 (5.5)	32 (2.8)
L – Antineoplastic and immunomodulating agents	2 (1.1)	0	2 (1.1)	0	2 (0.16)
M – Musculoskeletal system	19 (10.5)	20 (11.0)	25 (13.8)	14 (7.7)	39 (3.4)
P – Antiparasitic products, insecticides and repellents	2 (1.1)	2 (1.1)	2 (1.1)	2 (1.1)	4 (0.36)
R - Respiratory	45 (24.9)	36 (19.9)	65 (35.9)	16 (8.8)	81 (7.2)
S – Sensory organs	5 (2.8)	10 (5.5)	11 (6.1)	4 (2.2)	15 (1.3)
V – Various	10 (5.5)	9 (5.0)	5 (2.8)	14 (7.7)	19 (1.7)

Notes: percentages and totals are based on respondents

Polypharmacy

In total, 38.2% (n=83) of participants were exposed to polypharmacy (≥ 5 medications) (Table 3) including 12.2% (n=33) who were exposed to excessive polypharmacy.

Table 3: Frequency of prescribed medications and polypharmacy classification

Number of Medications	Number of People	Polypharmacy Defined
0	39	No Polypharmacy
1	26	
2	23	
3	24	
4	22	
Total	134	61.8%
5	8	Polypharmacy
6	14	
7	13	
8	9	
9	6	
Total	50	23.0%
10	10	Excessive Polypharmacy
11	6	
12	5	
*13-21	12	
Total	33	15.2%

*Numbers below 5 are suppressed

Psychotropic polypharmacy

Almost half 45.7% (n=97) of participants were prescribed one class of psychotropic drug, and a further 23% of participants (n=50) were exposed to psychotropic polypharmacy (range 2-6). Antipsychotics were the most frequently prescribed class of psychotropic drug in this study (25.3%, n=55). Six participants (2.8%) were prescribed two antipsychotic drugs.

Of the 55 people prescribed antipsychotic medication, 22.9% of these individuals (n=12.6) were prescribed a dosage above the DDD, whereas 77.1% of individuals

(n=42.4) were prescribed antipsychotic medications below or equivalent to the DDD. Across the psychotropic drug classes, although drugs were generally more frequently prescribed equivalent to, or below the DDD, prescribing above the DDD was relatively common. For example: N04A Anticholinergic Agents 73.2% vs 26.8%; N05B Anxiolytics 73.1% vs 26.9%; N05C Hypnotics & Sedatives 69.1% vs 30.9%; N06A Antidepressants 73.3% vs 26.7%; N03A Antiepileptics as mood stabilisers 83.7% vs 16.3%. Psychostimulants were equally prescribed above and below the DDD (50% vs 50%).

Bivariate associations

No polypharmacy, polypharmacy and excessive polypharmacy

Bivariate associations between no polypharmacy, polypharmacy, excessive polypharmacy (all classes of medication), psychotropic polypharmacy specifically and the characteristics potentially associated with polypharmacy are presented in Table 4. Participants who were older (50+ years) ($p < 0.001$); lived in residential care ($p < 0.001$); had a more severe intellectual disability ($p < 0.001$); were unemployed ($p < 0.001$); had no formal qualifications ($p = 0.016$); had a lower SES score ($p < 0.001$); had an epilepsy diagnosis ($p = 0.040$); had a psychiatric diagnosis over their life course ($p = 0.005$); reported poorer self-rated health ($p < 0.004$) and had more ICD-10 conditions ($p < 0.001$) were all more likely to be exposed to polypharmacy. There was no significant association between gender, marital status, income or Down syndrome and polypharmacy.

Psychotropic polypharmacy

Participants who were 50+ years ($p = 0.02$); unemployed ($p = 0.008$); had a lower SES score ($p < 0.037$); had Down syndrome ($p = 0.004$); had a psychiatric diagnosis over the life course ($p < 0.001$) and had more ICD-10 conditions ($p < 0.008$) were all more likely to be exposed to psychotropic polypharmacy. There was no significant

association between gender, marital status, level of ID, residence, income, education, epilepsy, self or proxy rated health and psychotropic polypharmacy.

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Mild / Moderate	164	113 (68.9)	31 (18.9)	20 (12.2)	$\chi^2 = 14.448$	131 (79.9)	33 (20.1)	$\chi^2(1)=3.228$
Severe / Profound	53	21 (39.6)	19 (35.8)	13 (24.5)	$p<0.001$	36 (67.9)	17 (32.1)	$p=0.091$
Employment								
Employed*	43	37 (86.0)	5 (11.6)	1 (2.3)	$\chi^2 = 15.466$	40 (93.0)	3 (7.0)	$\chi^2(1)=7.801$
Unemployed	139	76 (54.7)	35 (25.2)	28 (20.1)	$p<0.001$	101 (72.7)	38 (27.3)	$p=0.008$
Income								
Earns under £15,000 pa	187	110 (58.8)	48 (25.7)	29 (15.5)	$\chi^2 = 5.333$	141 (75.4)	46 (24.6)	$\chi^2(1)=1.115$
Earns over £15,000 pa	21	17 (81.0)	1 (4.8)	3 (14.3)	$p=0.670$	18 (67.8)	3 (14.3)	$p=0.418$
Education								
No Formal qualifications	194	114 (58.8)	48 (24.7)	32 (16.5)	$\chi^2 = 7.831$	149 (76.8)	45 (23.2)	$\chi^2(1)=0.185$
Formal qualifications	21	19 (90.5)	1 (4.8)	1 (4.8)	$p=0.016$	17 (81.0)	4 (19.0)	$p=0.790$
SES Score								
Low SES Score	115	58 (50.4)	33 (28.7)	24 (20.9)	$\chi^2 = 21.906$	84 (73.0)	31 (27.0)	$\chi^2(1)=4.631$
Higher SES Score	62	53 (85.5)	5 (8.1)	4 (6.5)	$p<0.001$	54 (87.1)	8 (12.9)	$p=0.037$
Health								
Epilepsy	52	25 (48.1)	15 (28.8)	12 (23.1)	$\chi^2 = 6.307$	35 (67.3)	17 (32.7)	$\chi^2(1)=4.158$
No Epilepsy	162	108 (66.7)	34 (21.0)	20 (12.3)	$p=0.040$	131 (80.9)	31 (19.1)	$p=0.055$
Down Syndrome	29	16 (55.2)	11 (37.9)	2 (6.9)	$\chi^2 = 4.564$	28 (96.6)	1 (3.4)	$\chi^2(1)= 7.247$
No Down Syndrome	188	118 (62.8)	39 (20.7)	31 (16.5)	$p=0.086$	139 (73.9)	49 (26.1)	$p=0.007$
Psychiatric diagnosis over life course	73	36 (49.3)	18 (24.7)	19 (26.0)	$\chi^2 = 10.373$	38 (52.1)	35 (71.4)	$\chi^2(1)=37.890$

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No Psychiatric diagnosis over life course	137	94 (68.6)	29 (21.2)	14 (10.2)	p=0.005	123 (89.8)	14 (10.2)	p<0.001
Poor Self-Rated Health	23	12 (52.2)	7 (30.4)	4 (17.4)	$\chi^2 = 10.510$ p=0.004	17 (73.9)	6 (26.1)	$\chi^2(1)=3.119$ p=0.085
Good Self-Rated Health	62	52 (83.9)	9 (14.5)	1 (1.6)		53 (85.5)	9 (14.5)	
Poor Proxy-Rated Health	59	56 (94.9)	3 (5.1)	-	p=1.0	18 (78.3)	5 (21.7)	$\chi^2(1)= 1.292$
Good Proxy-Rated Health	23	22 (95.7)	1 (4.3)	-		52 (88.1)	7 (11.9)	p=0.303
Number of ICD-10 Conditions (Median [IQR])	217	2 (1,4)	4.5 (3,6)	7 (4.5,9)	$\chi^2(2) = 61.262$ p<0.001	3 (1,5)	4 (3,6)	$U= 3150.500$ p=0.008

Notes: Bold text indicates statistically significant result

Binary Logistic Regression

In the final stage of analysis two separate binary logistic regressions were undertaken. Polypharmacy and psychotropic polypharmacy were the dependent variables in each model respectively. Independent objective predictive variables that were significant and not mutually exclusive in bivariate analysis were entered into the models. Personal characteristics and circumstances such as age (50+ or below), gender (male or female), level of intellectual disability (mild/moderate or severe/profound), type of residence (residential care vs non-residential care), number of ICD-10 conditions (continuous variable), Down syndrome (yes or no), epilepsy diagnosis (yes or no), psychiatric disorder over the life course (yes or no), education (formal qualifications or no formal qualifications) and employment (employed or unemployed) were entered into each model.

Polypharmacy

The polypharmacy logistic regression model was statistically significant, $\chi^2(9) = 115.68$, $p < .0001$. It explained 59% (Nagelkerke R^2) of the variance in polypharmacy and correctly classified 82% of polypharmacy cases. Our results indicate (Table 5) that younger age (below 50 years) (OR = 0.11 95% CI 0.05-0.27), having a less severe intellectual disability (mild/moderate intellectual disability) (OR = 0.29 95% CI 0.11-0.79), not living in residential care (OR = 0.32 95% CI 0.13-0.80) and having fewer ICD-10 conditions (inverted OR = 0.63 95% CI 0.52-0.76) were associated with no polypharmacy exposure.

Table 5: Strength of association (odds ratio with 95% confidence intervals) between personal and demographic characteristics and health and socioeconomic characteristics and polypharmacy

	B	Sig.	Exp(B)	95% C.I.	
				Lower	Upper
Age	-2.217	<.001***	.109	.045	.267
Gender	-.013	.975	.987	.432	2.256
Level of ID	-1.240	.016*	.289	.106	.794
Residence	-1.140	.015*	.320	.128	.802

ICD-10 Conditions	.467	<.001***	1.595	1.323	1.923
Epilepsy Diagnosis	.247	.604	1.280	.503	3.258
Psychiatric Diagnosis	-.633	.157	.531	.221	1.277
Education	-.603	.515	.547	.089	3.369
Employment	.133	.617	1.142	.679	1.920
Constant	.814	.509	2.257		

Notes: *** $p < 0.001$ ** $p < 0.01$ * $p < 0.05$;

ORs & 95% CIs rounded up to two decimal points in main text

Some ORs & 95% CIs inverted for ease of interpretation

Psychotropic Polypharmacy

The psychotropic polypharmacy logistic regression model was statistically significant, $\chi^2(6) = 53.814$ $p < .0001$; it explained 34% (Nagelkerke R^2) of the variance in polypharmacy and correctly classified 80% of psychotropic polypharmacy cases. Our results indicate (Table 6) that younger age (50 years and younger) (OR 0.44 95% CI 0.02-0.96), being female (inverted OR = 0.33 95% CI 0.15-0.74), and not being diagnosed with a psychiatric diagnosis over the life course (OR = 0.15 95% CI 0.07-0.31) were associated with no psychotropic polypharmacy.

Table 6: Strength of association (odds ratio with 95% confidence intervals) between personal and demographic characteristics and health and socioeconomic characteristics and psychotropic polypharmacy

	B	Sig.	Exp(B)	95% C.I.	
				Lower	Upper
Age	-.832	.040*	.435	.197	.962
Gender	1.118	.007**	3.060	1.364	6.868
ICD-10 Conditions	.049	.491	1.050	.914	1.206
Psychiatric Disorder	-1.940	<.001***	.144	.066	.312
Employment	.371	.151	1.450	.874	2.406
Down Syndrome	-1.561	.143	.210	.026	1.693
Constant	-1.037	.111	.354		

Notes: *** $p < 0.001$ ** $p < 0.01$ * $p < 0.05$;

ORs & 95% CIs rounded up to two decimal points in main text

Some ORs & 95% CIs inverted for ease of interpretation

Discussion

This study provides population-based evidence about the polypharmacy of adults with intellectual disability living in Jersey. Our results indicate that 82% of adults with an intellectual disability were prescribed at least one medication (mean number of prescribed medications=4.58 SD=4.42). Nearly 40% of adults with an intellectual disability were exposed to polypharmacy. Of these, just over 15% were exposed to excessive polypharmacy. Apart from neurological drugs, drugs for the alimentary tract and metabolism and dermatological drugs were the most commonly prescribed class of drug.

Our findings also suggest that the prevalence of polypharmacy is lower than O' Dwyer *et al.*'s (2016) study (51.6%) but higher than Haider *et al.*'s (2014) study (21%). Furthermore, psychotropic drug use was extensive with just under half of the participants prescribed at least one psychotropic drug (45.7%). The prevalence of psychotropic drug use is lower, but broadly similar to those reported from other recent studies in the UK (e.g. Henderson *et al.* 2015, 49.1%; Sheehan *et al.* 2015, 49%) but higher than a recent Jersey-based study (Bowring *et al.* 2017, 37.7%). Of these drugs, antipsychotic agents were the most frequently prescribed drug with just over 25% of participants prescribed antipsychotic drugs. Psychotropic polypharmacy was common with 23% of participants were prescribed two or more psychotropic medications. These findings are consistent with the existing evidence base that suggest that polypharmacy is routine in this population and that psychotropic polypharmacy is highly prevalent (de Kuyper *et al.* 2010; Doan *et al.* 2013; Haider *et al.* 2014; Deb *et al.* 2015; Sheehan *et al.* 2015; O' Dwyer *et al.* 2016; Axmon *et al.* 2017). Furthermore, in this study people with intellectual disabilities were frequently prescribed psychotropic drugs above the recommended DDD.

In unadjusted comparisons, our results suggest significant relationships between polypharmacy and a number of associated variables, such as socioeconomic variables (lower SES score/employment and education). Additionally, living in residential care, poorer self and proxy rated health, age 50 or over, increased

morbidity including epilepsy and having a psychiatric diagnosis over the life course were also associated with general polypharmacy. Being older, unemployed, having Down syndrome, an increased number of ICD-10 conditions and having a psychiatric diagnosis over the life course were all associated with psychotropic polypharmacy. Again, these unadjusted analyses are broadly similar to recent findings (Haider *et al.* 2014; O' Dwyer *et al.* 2016; 2017; Bowring *et al.* 2017).

In adjusted comparisons, our models have identified some differences in the factors associated with general polypharmacy and psychotropic polypharmacy. Firstly, being male was identified as an associated variable in the psychotropic polypharmacy model only. Gender had not been identified across any bivariate comparisons in this study and it has not been considered as a significant association of psychotropic pharmacology (Stolker *et al.* 2001; O'Dwyer *et al.* 2017;). In contrast to our findings, Lunskey and Modi (2018) identified that women were more likely to be exposed to psychotropic polypharmacy. Second, an increased number of ICD-10 conditions is associated with general polypharmacy, but not psychotropic polypharmacy; however, having a psychiatric diagnosis over the life course has been identified as a predictor of psychotropic polypharmacy only. Third, age (50+ years) is associated with increased polypharmacy and psychotropic polypharmacy. Fourth, having a more severe intellectual disability and living in a residential setting was associated with polypharmacy.

These results add to the existing knowledge that highlights the major issues for individuals with intellectual disabilities in several ways. Firstly, the use of a total population sampling methodology and a clearly defined polypharmacy definition with no missing medication data is a strength of this study. The prevalence of general polypharmacy (38.2%) is lower in this study than in O' Dwyer *et al.'s.* (2016) Irish study (51.6%); however, it is higher than Haider *et al.'s* (2014) Australian study (21%) (≥ 5 medications). This may be explained insofar as O' Dwyer *et al.'s* (2016) study focused on adults aged over 40 years while Haider *et al.* (2014) had a low response rate of 14%. In addition, a Canadian study (Cobigo *et al.* 2013) identified that polypharmacy was seven times higher in the 55–64 age group compared with

those aged between 18 and 24 years old. Therefore, it is credible that data drawn from samples where participants are older is likely to skew the prevalence of medication usage over the adult life course and overestimate polypharmacy rates.

Furthermore, the inconsistent operationalisation of polypharmacy definitions have also led to variability in reported polypharmacy rates (Stortz *et al.* 2014). For example, a recent review by Masnoon *et al.* (2017) identified 138 different definitions of polypharmacy. Nevertheless, while it appears that there is now a consensus regarding the definition of polypharmacy, our study suggests that the true prevalence of polypharmacy is not currently known in the intellectual disability population. Therefore, there is a further need for prospective, population-based research that covers the entire adult age profile which utilises the consistent definitions from this and other recent studies.

Second, this study has demonstrated that the prevalence of morbidity (e.g. increased number of ICD-10 conditions and psychiatric diagnosis over the life course) (Heslop *et al.* 2014; Hughes McCormack *et al.* 2017; Troller *et al.* 2017) is associated with general polypharmacy. The increasing longevity of people with an intellectual disability means that people with intellectual disability will be prescribed more medications as they age. With this comes greater challenges as effective medications have the potential for producing desired and undesired effects (for example adverse drug events and drug-drug interactions). Although there is some older evidence to suggest that people with an intellectual disability may be more sensitive to psychotropic medication (Arnold, 1993), it is suggested that the likelihood of 'polypharmaceutical' side effects in people with intellectual disability is increased by comorbid somatic disorders and their treatment (Häßler *et al.* 2014). Although rare, a recent study examined drug-drug interactions in persons with an intellectual disability (Joos *et al.* 2015). In this sample of enteral tube-fed individuals with an intellectual disability, the prevalence of drug-drug interactions was high. Seventy-four of the 156 screened medication records (47%) contained at least one potential drug-drug interaction. While the significance of drug-drug interactions depends on many pharmacokinetic and pharmacodynamic factors, the risk of drug-

drug interactions (Kohler *et al.* 2000; Palleria *et al.* 2013) and adverse drug reactions (Gnjidic *et al.* 2012) increases exponentially with the number of medications prescribed. This presents a significant risk for people with an intellectual disability who are more likely to have increased medical comorbidities and communication difficulties (Troller *et al.* 2016).

Third, the level of intellectual disability was significant for general polypharmacy after accounting for health and socioeconomic characteristics. This again is consistent with O'Dwyer *et al.*'s (2016) study who found that individuals with a severe and profound intellectual disability were more likely to experience polypharmacy. In relation to psychotropic polypharmacy, Hurley *et al.* (2003) and O'Dwyer *et al.* (2017) found no association between psychotropic polypharmacy and severity of intellectual disability. This study supports this and concludes that of the people known to services with an intellectual disability, psychotropic polypharmacy is evenly distributed across individuals with mild/moderate and severe/profound intellectual disabilities.

Fourth, there is some evidence to suggest that people with intellectual disabilities who live in residential settings are more likely to experience polypharmacy (O'Dwyer *et al.* 2016). Consequently, it is reasonable to expect that as these individuals are known to services then they are less likely to be exposed to medication-related problems that individuals not in receipt of services may experience. However, there is evidence to the contrary; Scheifes *et al.* (2016) identified a high prevalence of medication-related problems in a clinic sample of people with intellectual disabilities and behavioural problems in an inpatient psychiatric facility. They highlighted the benefit of having a regular structured medication review. Our data cannot identify the incidence of medication-related problems; however, it does raise the possibility that people who are not known to services may be more exposed to this phenomenon and further research is warranted to determine where the incidence of drug-related problems is more common.

Fifth, in both adjusted models all socioeconomic factors became non-significant when health and personal characteristics are accounted for. The bivariate analysis identified that unemployment was associated with polypharmacy and psychotropic polypharmacy. As our study had only a small number of employed participants, it would be prudent to consider employment and polypharmacy in larger studies due to the well-established fact that employment is good for people's health and wellbeing and that people who are employed have greater levels of mental health (Butterworth *et al.* 2011; Hergenrather *et al.* 2015; Robertson *et al.* 2019).

There are a number of limitations to this study that need to be kept in mind when considering these results: (1) medication use reported in this study for individuals who lived independently without a MARs sheet or a prescription was based on participant or proxy self-report and through examining medication that the participant had in their possession. This increases the potential of information bias. While all medication was cross-checked with the individual's health and social care record, if this was not updated by health and social care staff then recently prescribed medication could be absent from our analysis; (2) we included all medication that had been prescribed in the preceding 28 days by a medical prescriber. There may be potentially medications prescribed that have not been taken by the participant and this could potentially inflate the prevalence of medication use; (3) these findings apply only to the administratively defined intellectual disability population in Jersey while there may also be adults with intellectual disability (Intelligence Quotient < 70) not known to services who were not included; (4) there was a reliance on proxy respondents to answer some questions. To mitigate this, only objective indicators were used in the multivariate analysis; and (5) although this was a total population sample, as it is relatively small in comparison to other studies the results need to be interpreted in this context.

Implications for practice

It is important to know the prevalence of polypharmacy and psychotropic polypharmacy as it generally represents the burden of ill-health in adults with

intellectual disability experience and how health services respond. The varying evidence in the literature demonstrates a further need to focus on designing prospective studies that examine the prevalence and predictors of polypharmacy and psychotropic polypharmacy using explicit definitions. Nevertheless, there are more immediate modifiable factors that can be addressed such as undertaking medication reviews (Scheifes *et al.* 2016; Nabhanizadeh *et al.* 2019) and identifying medication combinations that potentially result in drug-drug interactions in adults who are exposed to polypharmacy. The interruption of prescribing cascades is an important and actionable opportunity to improve the health, wellbeing and quality of life of people with an intellectual disability (Rochon and Gurwith, 2017). This is particularly true for older adults with severe and profound intellectual disabilities who have a number of co-morbidities and who live in residential settings.

Conclusion

This study has identified that polypharmacy and psychotropic polypharmacy is common. Although the prescribing of multiple drugs can be clinically justified and appropriate, it presents significant risks as it increases the potential of adverse drug events and drug-drug interactions. This study also raises questions with regard to the true prevalence of polypharmacy. There is an evident need for large, prospective based studies with a comparison group to fully ascertain the prevalence and predictive variables associated with polypharmacy and psychotropic polypharmacy.

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Chapter 6: Study 3

The prevalence of potential drug-drug interactions in adults with intellectual disability

Reference: McMahon, M., Hatton, C., Bowring, D. L., Hardy, C., and Preston, N. J. (2021). The prevalence of potential drug–drug interactions in adults with intellectual disability. *Journal of Intellectual Disability Research*, 65: 930– 940. <https://doi.org/10.1111/jir.12844>.

This study is cited as McMahon et al. (2021b) from chapter 10 onwards.

Abstract

Background

There is a high use of medications in adults with intellectual disability (ID). One implication of taking multiple medications is the potential for drug–drug interactions (DDIs). However, despite this being well highlighted in the mainstream literature, little is known about the incidence or associations of DDIs in the ID population.

Methods

This study describes the prevalence, patterns and associations of potential DDIs in a total administrative sample of adults with ID known to services in Jersey.

Demographic, health-related and medication data were collected from 217 adults known to ID services. Data were collected using a face-to-face survey. The Anatomical Therapeutic Chemical classification system was used to categorise medications, and Stockley’s Drug Interaction Checker was used to classify potential DDIs. Drug–drug pairings were considered to be of clinical significance if they were to be ‘avoided, adjusted, monitored or required further information’.

Results

Potential DDIs of clinical significance were common. Exposure to potential DDIs of clinical significance was associated with being female, taking more than five medications (polypharmacy), living in residential care and having more health conditions. A simple regression was used to understand the effect of number of prescribed medications on potential DDIs of clinical significance. Every prescribed drug led to a 0.87 (95% confidence interval: 0.72–1.00) increase in having a potential DDI of clinical significance.

Conclusion

Adults with ID who live in residential care, are female, exposed to polypharmacy and have more health conditions may be more likely to have potential DDIs of clinical

significance. Urgent consideration needs to be given to the potential of DDIs in this population given their exposure to high levels of medication.

Keywords

Adverse reaction, drug–drug interaction, intellectual disability, medication, polypharmacy

Introduction

People with intellectual disability (ID) have greater physical and mental health needs than the general population (Hughes-McCormack et al. 2018, Kinnear et al. 2018, McMahon and Hatton 2020). Health inequalities for people with ID start early in life and widen with age, with the age of death being distinctly earlier than the general population (Glover et al. 2017, Landes et al. 2020, O'Leary et al. 2018, Trollor et al. 2017). A direct consequence of poor health is the need for individuals with ID to take more medications to combat the influence of morbidity (Emerson et al. 2016, Arnold 1993, Hove et al. 2019, McMahon et al. 2020, O'Dwyer et al. 2019, O'Dwyer et al. 2016). There is a growing evidence base that describes the incidence and associations of polypharmacy and psychotropic polypharmacy in this population (Bowring et al. 2017, Haider et al. 2014, Lunsy and Modi 2017, O'Dwyer et al. 2018, O'Dwyer et al. 2016). A recent study (McMahon et al. 2020) has drawn attention to the need to consider the impact of adverse drug reactions in this population by considering the epidemiology of drug-drug interactions (DDI) given the potential to cause significant harm (Preston 2019).

A DDI can be defined as the effect that one drug has on another (Preston, 2019). They are considered pharmacokinetic when the absorption, distribution, metabolism or elimination of a drug is altered due to the presence of another drug (Palleria et al. 2013) or pharmacodynamic when interacting drugs have either additive or opposing effects (Preston 2019). Drug-drug interactions are an important consideration when prescribing medications for people with ID (McMahon et al. 2020). To date, the issue of DDIs has not been widely explored in people with ID, with most evidence found in the elderly population (Björkman et al. 2002, Juurlink et al. 2003, Novaes et al. 2017, Rodrigues and Oliveira 2016). Apart from Joos et al. (2016), Floch et al. (2018), and more recently, The Learning Disability Mortality Review (LeDeR) [2020], the present authors are not aware of other research investigating the presence of potential DDIs in the ID population. Both Joos et al. (2016) and Floch et al. (2018) identified a high proportion of potential DDIs in their studies. Joos et al (2016) cited Topiramate and Valproic acid as the most frequently occurring drug-pairing that

resulted in DDIs, while LeDeR (2020) highlighted a significant proportion of potential DDIs with Valproate products, Lamotrigine, Topiramate and Phenytoin being the most common.

Caution must be observed when interpreting evidence of potential DDIs, as they depend on many pharmacokinetic and pharmacodynamic factors. The risk of DDIs (Palleria et al. 2013; Kohler et al. 2000) and adverse drug reactions (Gnjidic et al. 2012) increases with the number of medications prescribed (Preston 2019). This presents a significant risk for people with ID, as they are more likely to have multiple health conditions, increased medication use, and communication difficulties, with some adults being unable to feedback side effects experienced (Kinnear et al. 2018, Smith et al. 2020).

This study builds upon the findings of previous research (McMahon et al. 2020) and describes the prevalence, patterns and associations of potential DDIs in a total administrative sample of adults with intellectual disability known to services in Jersey.

Method

Procedure

This study was undertaken in Jersey, Channel Islands, in a total administrative population sample of adults known to ID services. Further methodological details are available in the following (McMahon et al. 2020, McMahon and Hatton 2020, McMahon, Bowring and Hatton, 2019 and Bowring et al. 2017).

Setting and Participants

Jersey is a self-governing British Crown dependency with a population of just over 105 000 people (Government of Jersey, 2020). Of these inhabitants, approximately 86,000 are aged over 18. A previous meta-analysis indicating an administrative adult

ID prevalence rate of 4.94/1000 (95% CI: 3.66–6.22) (Maulik et al. 2011) would suggest that approximately 427 adults with ID may live in Jersey.

In sum, 285 adults with ID were known to services, and data were collected on 217, a 76% response rate [approximately 66.7% of all expected adults with ID in Jersey]. All individuals with ID in Jersey have access to specialist ID services that operate peripatetically. People with complex, physical, behavioural or psychiatric needs are assigned a community nurse who coordinates the necessary specialist health and social care support. All data were collected by a face-to-face survey and medication data were collected directly from prescription charts, individual medication administration records or by examining any medication the person had in their possession. Participants' degree of intellectual disability was administratively defined by Jersey's Health and Community Services in the participant's health and social care records. This classification was used to stratify the sample for analysis. Overall, 56.6% of the sample was male (n=122), the mean age of participants was 44.5 years (SD = 16.2, range = 18–84 years). Just under half of the sample had a mild ID (n=108), the mean number of ICD-10 conditions was 3.82 (SD=2.71), 24% of the sample had an epilepsy diagnosis (n=52), and over 50% (n=114) of participants had mental health or behavioural issues. Selected personal and health characteristics of participants are presented in Table 1.

Table 1 Demographic and health characteristics of the study population (n=217)

Characteristic	N (%)
Gender / Age	
Male	122 (56.2)
Female	95 (43.8)
Mean age in years	44.51 (SD: 16.24)
Degree of intellectual disability	
Mild intellectual disability	108 (49.8)
Moderate intellectual disability	56 (25.8)
Severe intellectual disability	34 (15.7)
Profound intellectual disability	19 (8.8)
Communication	
Never speaks a word	23 (10.6)
Uses a few words only	37 (17.1)
Speaks using sentences as normal	151 (69.6)
Can talk but does not speak	6 (2.8)
Polypharmacy	
No Polypharmacy	134 (61.8)
Polypharmacy (≥5 medications)	83 (38.2)

Psychotropic Polypharmacy	
No Psychotropic Polypharmacy	167 (77)
Psychotropic Polypharmacy (≥ 2 psychotropic medications)	50 (23)
Residence	
Non-residential care	110 (50.7)
Residential care	107 (49.3)
Down Syndrome	
Down Syndrome	29 (13.4)
No Down Syndrome	188 (86.6)
Epilepsy*	
Epilepsy Diagnosis	52 (24.0)
Query Epilepsy Diagnosis	3 (1.3)
No Epilepsy Diagnoses	162 (74.7)
Psychiatric disorder diagnosed over the life course*	
Psychiatric disorder	73 (33.6)
Unable to ascertain if disorder diagnosed over the life course	5 (2.3)
No Psychiatric disorder	137 (63.1)
Most prevalent ICD-10 Conditions	
Mental health illnesses or behavioural problems	114 (52.5)
Diseases of the musculoskeletal system	76 (35)
Diseases of the digestive system	75 (34.6)
Endocrine, nutritional or metabolic conditions	67 (30.9)
Diseases of the skin	67 (30.9)
Diseases of the genitourinary system	65 (30)
Neurological conditions	65 (30)
	(Mean, SD)
Number of ICD-10 Conditions	3.82 (2.71)

* Notes: Three participants did not have a definite diagnosis of epilepsy were excluded from analysis. It could not be determined in five instances if participants had a psychiatric disorder diagnosed over the life course and these were also excluded from analysis.

Ethical Approval

Ethical approval was granted from the Faculty of Health and Medicine Research Ethics Committee at Lancaster University and by the Government of Jersey, Health and Community Services Ethics Committee. Procedures for recruiting participants lacking capacity and including arrangements for identifying and consulting

consultees were developed using guidance from the Mental Capacity Act (2005) and the Health Research Authority (www.hra.nhs.uk).

Measures

Demographic and health data on each participant, for example, gender, age, residence, communication ability and health conditions using ICD-10 classification Chapter headings (McMahon and Hatton, 2020), was collected from face-to-face surveys with the participant or proxy informant. Medication data were collected on the medications the participant was prescribed, dosage, and whether the medication was prescribed regularly, for a short course basis, or on a 'pro re nata' (PRN) basis. PRN medication was included if it had been prescribed in the previous 28-day prescribing cycle by a medical prescriber. Our study included inhalation and transdermal routes of delivery but excluded topical agents that were applied as gels, creams, or ointments; as primary topical delivery systems are designed to deliver the active ingredient to local tissue so the risk of the drug entering systemic circulation is negligible (Benson et al. 2019). All data were cross-checked with the individual's electronic health and social care record and any inconsistencies were resolved with the community nurse.

All medications that participants took during the previous 28 days cycle were coded according to the World Health Organisation (WHO) Anatomical Therapeutic Chemical (ATC) [WHO, 2020] classification system and then entered into Stockley's Interactions Checker on the Medicines Complete platform (<https://about.medicinescomplete.com>). This interaction checker gives a description of the interaction under 'severity' level; provides guidance on the management of the interaction under 'action', and describes the weight of research behind the interaction under 'evidence'. Brief guidance of this is outlined in Appendix 1 to assist interpretation. To generate a dependent variable, we operationalised that potential DDIs were clinically significant if drug-drug interacting pairs were to be 'avoided, adjusted, monitored or required further information'.

Approach to analysis

The study took the following analytical approach. Firstly, we undertook descriptive statistics (mean, standard deviation, sum, range) to describe the frequency and cumulative incidence of demographic variables, medication use and potential DDIs. Secondly, inferential statistics were used (Mann-Whitney U test and Kruskal-Wallis H test) to test the null hypothesis that there was no statistical difference between independent groups and potential clinically significant DDIs (dependent variable). In the final stage of analysis, we used linear regression to assess the relationship between the number of prescribed drugs (independent variable) and potentially clinically significant DDIs. Statistical significance was accepted at the ≤ 0.05 level of probability in all analysis.

Results

In terms of medication, 83.4% (n = 181) of participants were prescribed at least one medication (mean = 4.58, SD = 4.42, range = 1–21) while 38.2% of participants were exposed to polypharmacy (≥ 5 medications) (O'Dwyer et al. 2016). The most frequently prescribed category of drugs from the ATC classification system were: neurologicals (n=375); alimentary tract and metabolism (n=255); dermatologicals (n=133); cardiovascular drugs (n=87) and drugs for the respiratory system (n=81). The five most frequently prescribed drugs were Paracetamol (n=58), Valproate (products) (n=34), Simvastatin (n=22) Risperidone (n=21) and Procyclidine (n=21).

In total, 519 potential DDIs of clinical significance were identified. 199 of these pairings needed to be avoided, adjusted or required close monitoring and 320 of these pairings required further information regarding potential interactions and adverse effects. Across all drug-drug pairings, in 235 instances, no DDIs of any potential clinical significance were identified. 105 participants had at least one potential DDI of clinical significance (mean=4.94 SD=4.84, range 1-25). Twenty-four drug combinations were recorded as needing adjustment. This primarily concerned the concomitant use of Lorazepam and Valproate products (study evidence) [n=7],

Levothyroxine and Calcium supplements (case evidence) [n=6]; the remainder broadly concerned pharmacokinetic drug interaction mechanisms that alter disposition (absorption, distribution, elimination) of a co-administered agent.

In the next stage of analysis, we identified combinations of drugs that had potentially severe outcomes when co-administered with another drug. Citalopram (n=13), Risperidone (n=21) and Valproate (products) (n=34) were the three most frequently prescribed drugs that had potentially severe outcomes when co-administered with another drug. Table 2 provides an overview of the frequencies of these potential DDIs and an overview of how these drugs potentially interacted with a range of other drugs where the source of evidence came from published studies only. These combinations, along with a brief overview of interactions are outlined.

Table 2: Potential drug-drug Interaction combinations of the top three drugs (Citalopram, Risperidone and Valproate) causing severe outcomes

ATC Interacting drug combination(s)	Drug names	Action	Brief overview of potential drug-drug interaction from UpToDate (Lexicomp)(February 2021)
Frequency: 13 participants were prescribed Citalopram and this was responsible for 24 potential DDIs in the study. The following are potential DDIs that are associated with severe outcomes and underpinned by study evidence.			
N06AB04+N06AA09	Citalopram & Amitriptyline (n=1)	Information	<ul style="list-style-type: none"> Amitriptyline may enhance the serotonergic effect of Citalopram and also increase the serum concentration of Citalopram. Citalopram may increase the serum concentration of Amitriptyline.
N06AB04+N05AH02 OR N05AH04	Citalopram & Clozapine (n=1)/ Quetiapine (n=1)	Information/ monitor	<ul style="list-style-type: none"> Citalopram may enhance the adverse/toxic effect of certain antipsychotic drugs. QT- Antipsychotics may enhance the QTc-prolonging effect of QT-prolonging Antidepressants.
N06AB04+M01AC06 OR M01AE02	Citalopram & Meloxicam (n=1) / Naproxen (n=2)	Information	<ul style="list-style-type: none"> Citalopram may enhance the antiplatelet effect of Nonsteroidal Anti-Inflammatory Agents (Nonselective). Nonsteroidal Anti-Inflammatory Agents (Nonselective) may diminish the therapeutic effect of Citalopram.
N06AB04+A02BC01 OR A02BC03	Citalopram & Omeprazole (n=1) / Lansoprazole (n=1)	Monitor/ information	<ul style="list-style-type: none"> Omeprazole and/or Lansoprazole may increase the serum concentration of Citalopram.
Frequency: 21 participants were prescribed Risperidone and this was responsible for 34 potential DDIs in the study. The following are potential DDIs that are associated with severe outcomes and underpinned by study evidence.			
N05AX08+N06AA09	Risperidone & Amitriptyline (n=1)	information	<ul style="list-style-type: none"> Anticholinergic Agents may enhance the adverse/toxic effect of other Anticholinergic Agents. CNS Depressants may enhance the adverse/toxic effect of other CNS Depressants. Serotonergic Agents may enhance the adverse/toxic effect of Antipsychotic Agents. Specifically, serotonergic agents may enhance dopamine blockade, possibly increasing the risk for neuroleptic malignant syndrome. Antipsychotic Agents may enhance the serotonergic effect of Serotonergic Agents. This could result in serotonin syndrome.
N05AX08+N06AB03	Risperidone & Fluoxetine (n=1)	Monitor	<ul style="list-style-type: none"> CYP2D6 Inhibitors may increase the serum concentration of Risperidone.
N05AX08+C03CA01	Risperidone & Furosemide (n=2)	Information	<ul style="list-style-type: none"> Loop Diuretics may enhance the adverse/toxic effect of Risperidone

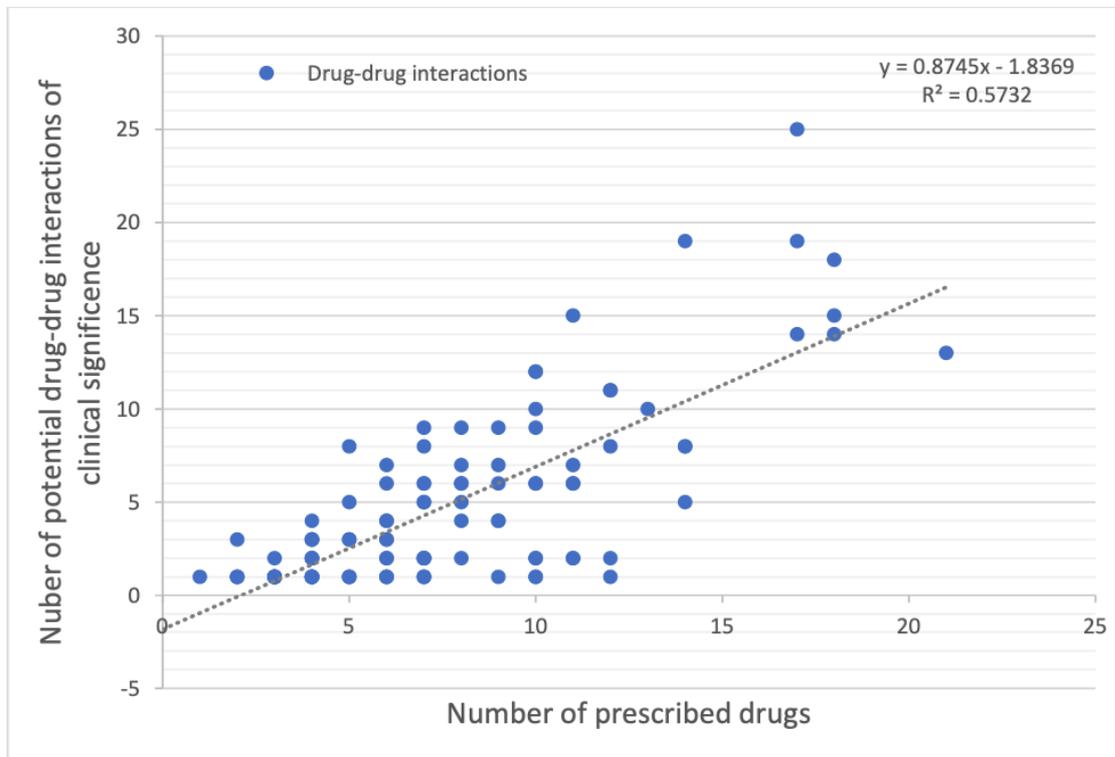
N05AX08+N06AX16	Risperidone & Venlafaxine (n=1)	Information	<ul style="list-style-type: none"> ▪ Serotonergic Agents may enhance the adverse/toxic effect of Antipsychotic Agents. Specifically, serotonergic agents may enhance dopamine blockade, possibly increasing the risk for neuroleptic malignant syndrome. Antipsychotic Agents may enhance the serotonergic effect of Serotonergic Agents. This could result in serotonin syndrome.
<p>34 participants were prescribed Valproate products and this was responsible for 31 potential DDIs in the study. The following are potential DDIs that are associated with severe outcomes and underpinned by study evidence.</p>			
N03AG01+N03AF01	Valproate & Carbamazepine (n=7)	Monitor	<ul style="list-style-type: none"> ▪ Valproate products may increase serum concentrations of the active metabolite(s) of Carbamazepine. Parent carbamazepine concentrations may be increased, decreased, or unchanged. Carbamazepine may decrease the serum concentration of Valproate products.
N03AG01+ N03AB02	Valproate & Phenytoin (n=1)	Monitor	<ul style="list-style-type: none"> ▪ Valproate products may decrease the protein binding of Fosphenytoin-Phenytoin.
N03AG01+N03AX11	Valproate & Topiramate (n=2)	Monitor	<ul style="list-style-type: none"> ▪ Topiramate may enhance the adverse/toxic effect of Valproate Products.
N03AG01+N03AX09	Valproate & Lamotrigine (n=1)	Monitor	<ul style="list-style-type: none"> ▪ Valproate products may enhance the adverse/toxic effect of Lamotrigine. Valproate products may increase the serum concentration of Lamotrigine.
N03AG01+N03AA03	Valproate & Primidone (n=1)	Monitor	<ul style="list-style-type: none"> ▪ Valproate products may decrease the metabolism of Primidone. More specifically, the metabolism of phenobarbital, primidone's primary active metabolite, may be decreased. Primidone may increase the serum concentration of Valproate products.

In the second stage of analysis, it was determined that being female ($U = 1054.5$, $p = .047$), polypharmacy ($U=339.0$, $p<.001$), living in residential care ($U=983.0$, $p=0.033$) and having more health conditions (as measured by ICD-10 classification) ($H(17) = 31.71$, $P = .016$) was associated with exposure to potential DDIs of clinical significance. There was no statistical association between exposure to potential DDIs of clinical significance and age ($H(17) = 21.48$, $P = .206$), severity of ID ($U = 1227.0$, $p=.498$), having had a psychiatric disorder diagnosed over the life course ($U = 1165.5$, $p=.364$), Down syndrome ($U=343.0$, $p=.143$) or epilepsy ($U=1113.0$, $p=.396$). Potential DDIs of clinical significance were statistically more likely people who had endocrine, nutritional and metabolic disease ($p < 0.001$), diseases of the ear ($p=0.029$), respiratory system ($p < 0.001$), circulatory system ($p < 0.001$), musculoskeletal system ($p=0.021$), genitourinary system ($p=0.044$), malformations and genetic problems ($p=0.021$) and injuries as a result of trauma and poisoning ($p=0.041$).

The incidence of required action by the severity of ID was also examined. There was no statistical difference observed across the degree of ID and adjusting ($H(3) = 3.62$, $P = .305$), monitoring ($H(3) = 6.39$, $P = .094$) or providing further information ($H(3) = 1.10$, $P = .780$) for potential clinically significant DDIs. We also examined the severity of potential DDIs and the ability to speak as the ability to self-report may be important for quickly identifying adverse effects. No statistically significant associations were observed ($p = 0.54$) identifying that there was no difference in the severity of potential DDIs across verbal and non-verbal participants.

In the final stage of analysis, a linear regression was undertaken to understand how the impact of prescribing drugs predicted the increase of potential DDIs of clinical significance (See Figure 1 for scatter diagram with linear regression line). The prediction equation was: number of potential drug-drug interactions of clinical significance = $-1.792 + 0.870 \times$ number of prescribed drugs. Increased numbers of prescribed medications statistically predicted potential DDIs of clinical significance $F(1, 103) = 137.34$, $p < .0001$, accounting for 57.2% of the variation in potential DDIs of clinical significance $R^2 = 56.7\%$ (a medium size effect [Cohen 1988]). Every extra prescribed drug increased the incidence of potential DDIs of clinical significance by 0.87 (95% CI: 0.72-1.00).

Figure 1: Scatterplot of potential drug-drug interaction vs. the number of prescribed drugs



Discussion

This study has identified a high prevalence of potential DDIs of clinical significance in an administrative population-level sample of adults with ID. Essentially, the more medications people with ID take, the greater the risk that an adverse reaction will occur (Preston 2015). This is important as people with ID are prescribed medications in high numbers and high doses. These findings are consistent with the current underdeveloped evidence base concerning pharmacological treatment in adults with ID (Floch et al. 2018; LeDeR 2020; Joos et al. 2016). These findings have important implications for a number of reasons: (1) the potential of developing DDIs of clinical significance is a genuine concern for this population. Just under half of this total administrative sample had at least one potential DDI of clinical significance and our study has illustrated that their incidence increases with the number of medications

prescribed. This concern is particularly acute in this population as they already experience high levels of morbidity (McMahon and Hatton 2020) are frequently exposed to off label prescribing (for example, being prescribed psychotropic medications to manage challenging behaviour) [Bowring et al. 2017; Henderson et al. 2020] and such cumulative effects may therefore negatively impact the health and wellbeing of this population. (2) Our results are similar to both Joos et al. (2016) and LeDeR (2020) who both identified that antiepileptics and Valproate products, in particular, are most commonly involved in potential DDIs. This study has identified that Valproate and Carbamazepine was the most frequently prescribed drug pairing that may produce severe DDIs. This underpins the need to ensure that there are comprehensive therapeutic drug monitoring regimes for individuals who are prescribed antiepileptic monotherapy or polytherapy to monitor for drug concentration levels. While this study had lower frequencies of antiepileptic combinations than Joos et al. (2016), their study was undertaken in an institution where participants were administered medications through enteral feeding tubes and nearly 50% were prescribed Valproate. (3) This study also identified specific cases where the concomitant use of medications such as Valproate and Lorazepam is a source for concern and prescribing adjustment may be necessary. For example, Valproate may increase the serum concentration of Lorazepam and decrease Lorazepam clearance, which could lead to augmented sedation (Samara et al. 1997). As Lorazepam is often prescribed as a PRN medication for people who have behaviours that challenge (Deb et al. 2015) the full effects of such an interaction may only manifest when an individual is in an already distressed state. (4) Being female, living in residential care, taking more than five medications (polypharmacy) and having greater health needs were associated with exposure to potential DDIs of clinical significance. It is important to highlight that having had a psychiatric disorder diagnosed over the life course, or epilepsy, was not associated with having statistically significantly higher numbers of potential DDIs of clinical significance, but the drugs used to treat such conditions are commonly associated with greater severity of potential DDIs. One reason for this may be that as every extra prescribed drug led to a 0.87 increase of having a potential DDI of clinical significance, then greater levels of poor

health (for example, having more ICD-10 conditions) is related to being prescribed more medications and consequent exposure to potential DDIs of

clinical significance. Subsequently, it is vitally important to ensure that there are regular health and medication reviews (Scheifes et al. 2016; Henderson et al 2020) for all people with ID along with appropriate training for staff to recognise DDIs and mitigate for diagnostic overshadowing (Mason and Scior 2004). (5) Given that our findings highlight that there were 320 instances where people should be provided with further information regarding potential adverse effects, there is also a critical need to ensure that people with ID are provided with an appropriate and understandable level of medication-related information (O'Dwyer et al. 2015). The Prescribing Competency Framework (RPS, 2016) in the UK sets out that prescribers have to understandably communicate potential unwanted effects; consequently, this should include potential DDIs to enable individuals to make informed decisions about treatment. This would assist people with ID to report any unwanted side effects. Additional adjustments should be made for individuals who have communication impairments. 6) Antiepileptics and psychotropic drugs are frequently involved in potential DDIs. As they are prescribed in high levels in this population (McMahon et al. 2020; Bowring et al. 2017; O' Dwyer et al. 2017) it is important that initiatives to stop inappropriate prescribing (e.g. stopping over medication of people [NHS, 2017]) are implemented and regularly evaluated to measure effectiveness as a matter of priority.

Notwithstanding these findings, there are important limitations of this study that need to be kept in mind. First, drug-drug interaction programs are known to report clinically minor or theoretical interactions, and this is likely to overestimate the prevalence of potentially relevant clinical DDIs (Kheshti et al. 2016, Muhič et al. 2017). Second, the sample was small and the self-reporting and proxy nature of the study increases the potential of information bias. Third, the inclusion of PRN medication prescribed within the previous 28 days may inflate the prevalence of medication use. Fourth, side effects potentially caused by DDIs were not assessed during data collection. This should be considered in future studies. Fifth, the presence of "requires further information" in the definition of potentially clinically significant DDIs may be considered overly inclusive.

However, it was determined that even potential DDIs that 'require further information' can have a severe impact which could incapacitate or result in either a permanent detrimental effect or a life-

threatening event. Consequently, their inclusion was considered necessary and proportionate to the identified risks.

Implications for Practice

While it is not possible to determine if medications were clinically justified and "appropriately" or "inappropriately" prescribed in this study, this brief report does offer some insight into the frequency and severity of potential DDIs that this population may experience. As far as we are aware, such data has not been published at a population level. The clinical implications of this study underline that frequent health and medication reviews are critically important (Scheifes et al. 2016). This is especially the case where individuals are prescribed antiepileptic and psychotropic drugs as these were associated with the greatest severity of potential DDIs. As there is still limited data supporting the efficacy and safety of most commonly employed psychotropic drug combinations in this population (O'Dwyer et al. 2017) such prescribing warrants careful contemplation. Nonetheless, as with all prescribing decisions, clinicians need to consider the risks and benefits and weigh up the intended outcome vs quality of life in consultation with the patient and relevant others.

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Appendix 1: Stockley's drug interaction guidance

- **Action:** This describes whether or not any action needs to be taken to accommodate the interaction. This category includes 'avoid', 'adjust', 'monitor', 'provide further information' and 'no action needed'.
- **Severity:** This describes the likely effect of an unmanaged interaction on the patient. This category includes 'nothing expected', 'mild', 'moderate', 'severe', and 'unknown'.
- **Evidence:** This describes the weight of evidence behind the interaction. This category includes 'theoretical', 'case', 'study' and 'extensive'

Chapter 7: Study 4

Not such an ordinary life. A comparison of employment, relationship and housing profiles of adults with and without intellectual disabilities

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This study is cited as McMahon et al. (2019) from chapter 10 onwards.

Abstract

Purpose – Having paid work, relationships and a choice of where to live are common policy priorities for adults with intellectual disabilities. The purpose of this paper is to compare outcomes with respect to these three priorities between adults with intellectual disability and the general population in Jersey. Design/methodology/approach – Data were collected from 217 adults with intellectual disability known to services, and 2,350 adults without intellectual disability using a stratified random sample. Data on employment, marital status and accommodation profiles were compared.

Findings – In sum, 87 per cent of adults with intellectual disability were currently single vs 16 per cent of adults without intellectual disability; 23 per cent of working-age adults with intellectual disability were in paid employment vs 92 per cent of working-age adults without intellectual disability; and 57 per cent of adults with intellectual disability lived-in sheltered housing vs 2 per cent of adults without intellectual disability.

Social implications – Very few adults with intellectual disability are in paid employment or intimate relationships, and the majority live in sheltered, supported housing, with very few owning their own home. There is a significant disconnect between policy and reality. Considerable work is required to make an ordinary life the reality for adults with intellectual disability.

Originality/value – This study adds to the body of evidence that suggests people with intellectual disabilities are less likely to experience an ordinary life. Furthermore, it illustrates that despite Jersey being an affluent society, the same difficulties and barriers exist there for persons with an intellectual disability as in other jurisdictions. Keywords Relationships, Employment, Housing, Intellectual disabilities, Ordinary life

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Introduction

The rights of people with intellectual disabilities to live an “ordinary life” have featured in government policy (e.g. DoH, 2001) and are enshrined in the 1998 Human Rights Act. Over the last 50 years, different parts of the UK have targeted large-scale deinstitutionalisation to varying degrees (DoH, 1971, 2001) with the ultimate aim of improving the lives and wellbeing of this population (Hatton, 2016). Since its inception, in England, Valuing People (DoH, 2001) set out the principles of person-centred support – offering the same choices, opportunities and rights as everyone else in their communities. This policy was set within a human rights framework and reflected the influence of values movements in this field including: self-determination (Wehmeyer and Schwartz, 1998); social role valorisation (Wolfensberger, 2013) and person-centred planning (Mansell and Beadle- Brown, 2004).

The Valuing People (DoH, 2001) policy included aims for employment, relationships and housing. At this time, very few people with intellectual disability (probably less than 10 per cent, according to DoH, 2001) were in paid employment and an increased target was set. Nearly 20 years on, there is continuing, strong English Government commitment to increasing the number of people with intellectual disability in paid work (Parkin et al., 2018); however, the reality is that employment rates remain low (Department of Work and Pensions and The Department of Health, 2017) and employment in the broadest sense is precarious for people with intellectual disability (Emerson et al., 2018).

Objectives were set to enable people with intellectual disability to live fulfilling lives which included developing relationships. The rights of people with intellectual disability to have relationships (World Health Organisation, 2006) are enshrined in UK law in the Human Rights Act (Human Rights Act, 1998), yet there has been little research into how many people are actually in relationships (Emerson et al., 2005) despite it being an important consideration for people with intellectual disability (Healy et al., 2009). While there is evidence that community-based structures of independent and supported living deliver better outcomes than institutions as long as they are appropriately set up and managed (Mansell et al., 2007), there remains a significant number of people with intellectual disabilities in institutional settings and/or residential care (Hatton, 2017).

In 2014, a UK-based intellectual disability charity – Stay Up Late – in 2014 produced a “Manifesto for an Ordinary Life” (<https://stayuplate.org/a-manifesto-for-an-ordinary-life/>). This featured a number of things people with intellectual disability in the UK were consistently asking for at various workshops, forums and conferences. This concurred with the aims of all

UK intellectual disability Policy and the United Nations (2007) Convention on the Rights of Persons with Disabilities focussing on community inclusion (article 19), relationships (article 23) and work and employment (article 27), namely:

- the right to have a proper paid job;
- the right to have relationships and a sex life; and
- the right to choose where to live and who to live with.

Indeed, the government paper, “Improving The Life Chances of Disabled People” (Prime Minister’s Strategy Unit, 2005), stated that, by 2025, disabled people in the UK would be equal members of society.

This paper aims to look at progress against these three aims by examining profiles of employment, marital status and housing between adults with and without intellectual disability in Jersey, Channel Islands. Apart from the Capacity and Self Determination (Jersey) Law (2016) and a generic Disability Strategy for Jersey (2017) which focussed on disability in its broadest sense, Jersey does not have its own specific policy concerning intellectual disability but mirrors English policy and guidance.

Method

Participants and procedure

Jersey context: The resident population of Jersey is estimated as 105,500 (Government of Jersey, 2018). A recent study by Bowring et al. (2017a) identified a 0.4 per cent administrative prevalence rate of intellectual disability in Jersey based on figures obtained from the 2011 census. This administrative prevalence is broadly similar to other jurisdictions (0.33–0.48 per cent: Jones et al., 2008; Lundqvist, 2013). In terms of employment, less than 5 per cent of working-age adults are unemployed and the median

weekly salary for full-time employees is currently £590 per week – with average income estimated at £440 per week for hotel/restaurant and bar work and at £1,020 for financial and legal work (Government of Jersey, 2019a, b). Since 2002, home ownership has become less attainable with the mean household income unable to service a mortgage on the purchase of a median price residence. It should also be noted that housing legislation in Jersey prohibits individuals who are not native to Jersey or essentially employed to purchase or rent certain types of property, e.g. there are some restrictions limiting people to renting lodging or tourist accommodation if they have not lived-in Jersey for five years. No existing evidence exists with regard to the prevalence of employment or home ownership for adults with intellectual disability in Jersey.

Intellectual disability sample: Data were collected between 2017 and 2018 from a total administrative sample of adults with intellectual disability known to services in Jersey. Participants were ≥ 18 years of age and administratively defined as having intellectual disability (i.e. were receiving, or had received, support from intellectual disability services in Jersey). Participants had different levels of intellectual disability ranging from those who lived independently to those who required wide-ranging support. In total, 217 adults with intellectual disability were recruited (age range 18-84, Mean = 44.5, SD = 16.2), indicative of a 76% response rate (sampling frame $n = 285$). Just under 50% of participants were administratively defined as having a mild intellectual disability ($n = 108$), 26% ($n = 56$) as having a moderate intellectual disability, 16% ($n = 34$) as having a severe intellectual disability and 9% ($n = 19$) as having a profound intellectual disability. Fifty-six percent ($n=122$) were male, 44% ($n=95$) female. All information was collected by face-to-face interview and there were no missing data in this sample.

Participants were selected using a stratified, random sampling approach. Jersey has twelve parishes, and these were divided into strata. Each parish was weighted in terms of population density reflecting the most recent population census and allowing for net inward migration (States of Jersey, 2011). Addresses were randomly drawn from the list of residential, active addresses for each parish on the Jersey Land Property Index. Any household which was sampled for one of the previous 2015, 2016, or 2017 social surveys, or for the Disability Survey in 2015, was excluded. Following these exclusions, 28,000 households were eligible for inclusion in the overall sampling frame. Eight thousand

surveys, weighted in terms of population density strata, were sent to households across the 12 parishes. To account for the entire adult population at random, the household member who was next to celebrate their birthday, and who was aged 18 years or over, was asked to complete the survey. A total of 2,415 surveys (30%) (age range 19 – 105, Mean = 57.67, SD = 16.3) were returned with 65 of these being unusable. In sum 60% (n=1394) of the respondents were female, whilst 40% (n=941) were male. Compared to the population profile from the most recent census (States of Jersey, 2011) this represents an estimated sample over-representation of females by approximately 8%. There was less than 2.5% missing data on any variable (range 0.8% - 2.3%).

Ethics

Ethical approval was granted by Lancaster University and by the Government of Jersey, Health and Community Services Ethics Committee in January and March 2017. The capacity to consent process and accompanying documentation were designed using guidance from the Mental Capacity Act (2005) and the National Research Ethics Service (www.nres.nhs.uk/). In sum, 85 (39 per cent) participants consented independently, whilst 132 (61 per cent) participated through a personal or nominated consultee process (DoH, 2008). Full details of the consenting procedure for adults with an intellectual disability are outlined in Bowring et al. (2017a, b).

Measures

The instruments used in this study were extracted from the Jersey Opinions and Lifestyle Survey (States of Jersey, 2017) as these are general measures covering demographics, economic activity and household structure that are aligned to Jersey census variables for annual monitoring.

Data analysis

Data were analysed using the Statistical Package for the Social Sciences Version 25 (SPSS, Inc., Chicago, IL, USA). Congruent with the paper's aim and to provide a detailed description of employment, marital status and housing activities, descriptive statistics using frequency counts were calculated. The employment, marital status and housing categories

in Table I were condensed and binary variables were created to represent: employed (working for an employer, self-employed, employing others, self-employed, not employing others) vs unemployed (unable to work because of long-term sickness/disability, unemployed, looking for work, unemployed, not looking for work); single (single) vs in a current relationship (married/civil partnership and cohabiting (includes same sex couples)); and home owner (owner occupied) vs non-home owner (staff/service accommodation, social housing, registered lodging, lodger paying rent in private household, private qualified rent,

other non-qualified accommodation). Supplementary Pearson χ^2 statistics and Odds Ratios were undertaken to determine potential differences between people with and without intellectual disabilities. Effect size categories for Odds Ratios for 2×2 comparisons were interpreted as small (OR ≤ 0.82 or ≥ 1.22), medium (OR ≤ 0.54 or ≥ 1.86) or large (OR ≤ 0.33 or ≥ 3.00) (Olivier and Bell, 2013).

Results

Table 1 displays employment, marital status and housing profiles for both the adult with intellectual disability and the general population samples.

Table 1. Employment, relationship and housing profiles of adults with ID and the general population sample without ID

Variable		Intellectual Disability	General Population
Participants		n = 217	n = 2,350
Male		n = 122 (56.2%)	n = 941 (40.3%)
Female		n = 95 (43.8%)	n = 1,394 (59.7%)
Relationships	Single	n = 189 (87.1%)	n = 373 (16%)
	Married / Civil Partnership	n = 12 (5.5%)	n = 1,192 (51.2%)
	Cohabiting (includes same sex couples)	n = 8 (3.7%)	n = 160 (6.9%)
	Separated (includes same sex couples)	n = 3 (1.4%)	n = 64 (2.8%)
	Divorced	n = 2 (0.9%)	n = 291 (12.5%)
	Widowed	n = 3 (1.4%)	n = 246 (10.6%)
	<i>Missing data</i>	<i>n = 0 (0%)</i>	<i>n = 24 (1%)</i>
Employment	Working for an employer	n = 42 (19.4%)	n = 1,157 (49.6%)
	Self-employed, employing others	n = 0 (0%)	n = 105 (4.5%)
	Self-employed, not employing others	n = 1 (0.5%)	n = 109 (4.7%)
	Retired	n = 17 (7.8%)	n = 766 (32.9%)
	Unable to work because of long-term sickness/disability	n = 76 (35%)	n = 50 (2.1%)
	Unemployed, looking for work	n = 20 (9.2%)	n = 24 (1%)
	Unemployed, not looking for work	n = 43 (19.8%)	n = 8 (0.3%)
	In full-time education	n = 3 (1.4%)	n = 10 (0.4%)
	A homemaker	n = 4 (1.8%)	n = 75 (3.2%)
	Other	n = 11 (5.1%)	n = 27 (1.2%)
	<i>Missing data</i>	<i>n = 0 (0%)</i>	<i>n = 19 (0.8%)</i>
Housing	Owner occupied	n = 18* (8.3%)	n = 1,604 (69%)
	Staff/ service accommodation	n = 5 (2.3%)	n = 35 (1.5%)
	Social housing	n = 78 (35.9%)	n = 202 (8.7%)
	Registered lodging	n = 7 (3.2%)	n = 45 (1.9%)
	Lodger paying rent in private household	n = 1 (0.5%)	n = 44 (1.9%)
	Private qualified rent	n = 107 (49.3%)	n = 353 (15.2%)
	Other non-qualified accommodation	n = 1 (0.5%)	n = 40 (1.7%)
	<i>Missing data</i>	<i>n = 0 (0%)</i>	<i>n = 27 (1.1%)</i>
Sheltered Housing	Sheltered / disabled Housing- Yes	n = 123 (56.7%)	n = 54 (2.4%)
	Sheltered / disabled Housing - No	n = 94 (43.3%)	n = 2,240 (97.6%)
	<i>Missing Data</i>	<i>n = 0 (0%)</i>	<i>n = 55 (2.3%)</i>

* of the 18 people reporting that they owned the property they currently lived in, 17 were living in a family home.

Employment

There were 19.4% of adults with intellectual disability (n=42) (proxy n=12, self-report n=30) in paid employment, compared to 49.6% (n=1157) of the general population. Just

one adult with intellectual disability was self-employed (0.25%) (self-report n=1) compared to 9.2% of the general population (n=214). Excluding retirees, homemakers, individuals in full time education and other categories of employment (Table 1), the prevalence of employment was 94.4% (n=1371) for the general population and 23.6% (n=43) for the intellectual disability population of working aged adults. People with intellectual disabilities were significantly less likely to be employed than the general population ($\chi^2=692.19$, $df=1$, $p<0.001$) representing a large effect size (OR=54.05 [95% CI: 35.93- 81.29]).

Of the general population, 32.9% (n=766) described themselves as retired compared to 7.8% (n=17) of the intellectual disability sample (proxy n=11, self-report n=6). This high retirement prevalence in the general population is reflective of the age structure in Jersey. Seventy-five adults in the general population sample (3.2%) described themselves as homemakers compared to 4 (1.8%) of the intellectual disability sample (proxy n=1, self-report n=3). A large percentage of the intellectual disability sample (35%, n=76) (proxy n=65, self-report n=11) were described as unable to work because of long term sickness or disability, compared to 2.1% (n=50) of the general population. Sixty-three adults with intellectual disability (29%) (proxy n=34, self-report n=29) were described as unemployed, with only 20 (9.2%) (proxy n=6, self-report n=14) actively looking for work.

Marital status

There were 87.1% (n=189) (proxy n=124, self-report n=65) of adults with intellectual disability who were single, compared to 16% (n=373) of the general population. Just 12 adults with intellectual disability (5.5%) (proxy n=1, self-report n=11) were married / in a civil partnership, compared to 51.2% (n=1192) of the general population. There were 3.7% (n=8) (proxy n=1, self-report n=7) adults with intellectual disability cohabiting compared to 6.9% (n=160) of the general population. People with intellectual disabilities were significantly more likely to be single (than married/in a civil partnership/cohabiting) than the general population ($\chi^2=428.13$, $df=1$, $p<0.001$) representing a large effect size (OR= 34.49 (95% CI: 21.28-55.56)).

Housing

The majority of adults with intellectual disability (56.7%, n=123) (proxy n=98, self-report n=25) lived in sheltered or housing for the disabled, compared to 2.4% (n=54) of the general population, a statistically significant difference ($\chi^2=887.01$, $df=1$, $p<0.001$ [OR=52.83 95% CI: 37.04-76.92]) representing a large effect size. Sheltered or disabled housing was defined as residential or nursing care where the person was in receipt of paid care in their usual place of abode. A large number of adults with intellectual disability (35.9%, n=78) (proxy n=31, self-report n=47) lived in social housing or accessed the private rental market (49.3%, n=107) (proxy n=82, self-report n=25). In the general population fewer people lived in social housing (8.7%, n=202) or rented accommodation (15.2%, n=353). Furthermore, very few adults with intellectual disability lived-in owner-occupied accommodation (8.3%, n=18) (proxy n=12, self-report n=6), with 17 of these living in the home owned by their family. In the general population, 69% (n=1604) of people lived-in owner-occupied accommodation. Overall, people with intellectual disabilities were statistically less likely to live-in owner-occupied accommodation ($\chi^2=315.75$, $df=1$, $p<0.001$) representing a large effect size (OR=24.54 [95% CI:15.03-40.06]). Despite less than 10% of people living in owner-occupied accommodation, 25% (n=55) of the intellectual disability sample lived with family members.

Discussion

The employment, marital status and housing profiles of adults with intellectual disability are very different compared to the general population sample. Despite these being key priority areas for adults with intellectual disability and policy makers, the reality is that outcomes remain poor. In this sample, of working-age adults, 23.5 per cent of adults with intellectual disability were in paid or self-employment compared to 92.4 per cent of the general population. At the first glance, this looks encouraging compared to the estimate of 5.7 per cent for paid/self-employment in England (Hatton, 2018). Further analysis is required to compare what this employment looks like and the level of pay/days worked experienced by both samples. Concerningly, Hatton (2018) suggested that paid employment rates seem to be slightly declining over time in England with a widespread variation across councils in reported paid and self-employment rates. In this sample, 67.4 per cent of adults with intellectual disability in paid employment were male (n 1/4 28), suggesting that

employment prospects may be particularly bleak for women with intellectual disability – a common theme in the literature (Hatton, 2018). Further research is required into why only 20 of the 63 adults with intellectual disability listed as unemployed are seeking work and why fewer adults with intellectual disability are listed as retired or are unable to work due to long-term sickness or disability. This may be linked to the earlier mortality ages this population experiences (O’Leary et al., 2018). Regarding seeking work, it may be that proxy respondents perceive that a large number of barriers across different domains prohibit employment (Kocman et al., 2018).

In this study, 9.2 per cent of adults with intellectual disability were either married or in a civil partnership or cohabiting compared to 58.1 per cent of the general population. In a previous study, only 3 per cent of people with intellectual disability were reported to be cohabiting as a couple, in comparison with 70 per cent of the general population (Emerson et al., 2005). Personal relationships can bring happiness, fulfilment, companionship and a greater sense of choice and control over the lives of people with intellectual disability (Mencap, n.d.). Nonetheless, the reality is that people with an intellectual disability are seldom in relationships and a climate of risk aversion appears to exist regarding supporting and maintaining relationships for people with intellectual disabilities (Bates et al., 2017).

Whilst adults with intellectual disability may have greater support needs, their housing profile is very different compared to the general population. Very few adults with intellectual disability lived-in owner-occupied accommodation, which must decrease the security of their accommodation. This study also suggests that a much lower number of adults with intellectual disability live with their family in Jersey (52 adults per 100,000) compared to England (97.8 adults per 100,000), Scotland (195.1 adults per 100,000) and Wales (203.5 adults per 100,000) (Hatton, 2017). Whilst we cannot determine the cause of this decreased prevalence in Jersey, it may mean that people with intellectual disability who live with family members are potentially less likely to be known to services.

Notwithstanding, there is a dependence on sheltered, social or rented housing potentially reflecting the lower economic status of adults with intellectual disability, possibly perpetuated by the lack of individuals in paid employment. Considering this in terms of median incomes in Jersey, it is clear that the significant majority of adults with intellectual

disabilities known to services will never be able to afford to be a home owner in Jersey. This potentially prohibits cohabiting with others as it is difficult to have control when there is no ownership of your own home.

There are four principal limitations to the study that should be kept in mind when considering its results. First, there is a possibility of bias in the general population sample insofar as there is an under representation of males and the percentage of working-age respondents was slightly less (59 vs 67 per cent) when compared to the 2011 census profile (States of Jersey, 2011). However, the corresponding unemployment rate (4.7 vs 5.6 per cent) and marital status of both population samples (married 48 vs 51 per cent; separated 2 vs 2.8 per cent; widowed 10 vs 10.6 per cent) are broadly similar (States of Jersey, 2011). Second, this sample represents individuals known to intellectual disability services and does not represent the “hidden majority” (Emerson and Hatton, 2014) of adults who are not known to services. These adults may be employed, in relationships and/or home owners. Third, there were no data collected on hours worked or history of previous employment for either population. Such data could further improve our interpretation of employment statistics for people with intellectual disabilities. Finally, we have not extended the concept of relationships to include friendships or other social networks which may be present and equally important for participants in this study. These limitations should be considered when designing future research.

Conclusion

In conclusion, this study illustrates that relatively few people with intellectual disability are in paid work or in current relationships and the majority live in sheltered, social or rented housing models. The reality is that, for adults with intellectual disability, life is very different to that experienced by a substantial majority of the general population.

Improving quality of life for persons with an intellectual disability in Jersey is a critically important issue. The Government of Jersey needs to engage people with intellectual disabilities and their families, along with relevant stakeholders, to ensure that they have the appropriate support to be able to live a better life.

Employment rates for adults with intellectual disabilities in England are lower than the rates reported in this study. This may potentially impact on relationships and home ownership and thus reinforces the view that these are priority areas for all jurisdictions to turn policy into reality for people with intellectual disabilities. This can, in part, be achieved by providing the necessary resources and support arrangements to allow adults with intellectual disabilities to be employed, have relationships and live in their own homes.

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Chapter 8: Study 5

Is subjective socioeconomic status a correlate of health in adults with intellectual disabilities? A scoping review^{***}**

This study is to be resubmitted: Authors McMahon, M, Hatton, C and Alberici, S.

Background: Subjective socioeconomic status, an individual's understanding of their socioeconomic position, is acknowledged as being a robust predictor of health over and above objective socioeconomic indicators. This scoping review systematically aims to identify research evidence relating to the association between subjective socioeconomic status and health amongst people with intellectual disabilities.

Methods: Due to the paucity of research evidence identified, results were collated and charted using a descriptive summary approach and thematic analysis.

Results: Seven studies were identified that related to a subjective socioeconomic status variable. No study examined subjective vs objective socioeconomic status in terms of the relative strength of associations with health. Indicators related to subjective socioeconomic status demonstrate that lower socioeconomic status was associated with poorer health for a wide range of adults with intellectual disabilities.

Conclusion: There is a weak evidence base concerning subjective socioeconomic status in the intellectual disability literature, and future research is urgently needed.

Keywords: Intellectual disability, subjective socioeconomic status, health status, socioeconomic disadvantage

^{*****} An associated publication (McMahon et al. 2018) describing the development and inter-professional collaboration of designing this search process is presented in Appendix 1.6.

8.1. Introduction

Internationally major health inequalities persist despite targeted decades-long interventions (Marmot et al., 2010). They are to an extent avoidable (Emerson & Hatton, 2014) as they are socially produced (Whitehead & Dahlgren, 2007; Emerson & Baines, 2011), and if not addressed are prejudiced and unjust (Marmot, 2017). Health inequalities for people with intellectual disabilities are most starkly seen in mortality figures, where a recent systematic review (O'Leary, Cooper, & Hughes-McCormack, 2018), and evidence from England (Glover, Williams, Heslop, Oyinlola, & Grey & 2017; Heslop et al., 2013; Hosking et al., 2016; Learning Disability Mortality Review, 2018), Australia (Troller, Srasuebku, Xu, & Howlett, 2017), the USA (Lauer & McCallion, 2015) and Ireland (McCarron, Carroll, Kelly, & McCallion, 2015) consistently report people with intellectual disabilities dying around 20 years earlier than other people.

Existing research on health inequalities has described a societal gradient or social hierarchy existing within societies (Adler et al., 1994, Singh-Manoux, Adler, & Marmot, 2003), reinforcing the established epidemiological evidence base that suggests a person's place on the gradient determines how long they will live and how healthy a life they will have (Marmot et al., 2010). Traditionally, a person's place on this gradient has been determined by measuring their socioeconomic status. Conventional objective indicators of socioeconomic status include education, occupational status and income. Whilst the relationship between socioeconomic status and a person's health status is deeply patterned, with each affecting the other, a person's position on the gradient affects their health, and in turn, their health affects their capability to reach higher levels on this gradient.

Although objective indicators of socioeconomic status are reliably associated with greater rates of mortality and morbidity (Donkin, Goldblatt, Allen, Nathanson, & Marmot, 2017), emerging evidence has suggested that subjective socioeconomic status [SSS]⁺⁺⁺⁺ (an individual's opinion of their rank within society, also referred to as subjective social status) is more strongly associated with a person's health than conventional objective socioeconomic status indicators (Euteneuer, 2014). Research investigating links between SSS indicators and health status have reported consistent associations internationally

⁺⁺⁺⁺ Subjective socioeconomic status is abbreviated as 'SSS' throughout this study.

(Singh-Manoux, Adler, & Marmot, 2003; Singh-Manoux, Marmot, & Adler, 2005; Adler et al., 2008), and in ethnically diverse samples (Allen, McNeely, Waldstein, Evans, & Zonderman 2014; Ostrove et al., 2000). Some researchers (e.g. Jackman, 1979; Singh-Manoux, Adler, & Marmot, 2003) refer to a cognitive averaging process whereby SSS is not only reflective of a person's socioeconomic status, but is a social phenomenon that captures a person's life chances, other previous, and current and future prospects that are independent of conventional objective measures of socioeconomic status.

Furthermore, evidence suggests that material deprivation cannot alone account for all biological indicators of health status (Nobles, Ritterman Weintraub, & Adler, 2013) and low SSS has been found to be correlated with cardiovascular diseases (Marmot et al., 1991; Allen et al., 2014), respiratory diseases (Cohen et al., 2008), oral disease (Sanders, Slade, Turrell, John Spenser, Marcenés & 2006), mental health problems (Demakakos, Nazroo, Breeze & Marmot, 2008) and obesity (Cheon & Ying-Yi Hong, 2017).

A recent meta-analysis (Cundiff & Matthews, 2017) identified that SSS provides a unique cumulative association with physical health, particularly self-rated health, above conventional objective indicators of socioeconomic status. This could have important implications for individuals with intellectual disabilities for two principal reasons. First, there is no evidence to suggest that this is any different for people with intellectual disabilities (Emerson, Robertson, Baines, & Hatton, 2014b; Fujiura, 2012). Second, objective measures of socioeconomic status are potentially unsatisfactory indicators in this population for several reasons; (1), the non-normative educational or occupational positions of individuals with intellectual disabilities mean that traditional socioeconomic indicators have low variation amongst this group; (2) some geography-based indicators (e.g. indices of deprivation) may be less relevant for a population where many people are living in services, the location of which are determined by a set of factors unrelated to socioeconomic status. As a result, the extent to which conventional objective measures of socioeconomic status have meaningful utility in evaluating health inequalities is questionable. Consequently, SSS should be examined as a separate construct, as it is potentially a more robust method for capturing the socioeconomic status of individuals with intellectual disabilities as it relates to people's health.

In summary, what we know about SSS and health is largely based on empirical studies concerning general populations. The evidence for the relationship between SSS and health in the general population is strong; however little attention has been paid to this relationship for persons with intellectual disabilities. As people with intellectual disabilities are more likely to occupy non-normative socioeconomic positions, SSS measures are worthy of further investigation. Correspondingly, the aim of this study is to undertake a scoping review to map and summarise existing evidence to address the question: is SSS a correlate of health in adults with intellectual disabilities?

8.2. Methods

Scoping reviews provide an overview of a broad field where key concepts are mapped and gaps in research are defined through systematically searching, selecting, and synthesising existing knowledge (Colquhoun, Letts, Law, MacDermid, & Missiuna, 2014). We followed an existing methodological framework proposed by Arksey and O'Malley (2005) that identifies five stages in the scoping review process: identifying the research question; identifying relevant studies; study selection; charting the data; collating, summarising and reporting the results.

Search Strategy & Identifying Search Terms

An information retrieval specialist (Author 3) was consulted to develop the search strategy. An electronic database literature search was conducted for research appearing between January 1990 and October 2018 on the EBSCO platform in the Cumulative Index to Nursing and Allied Health Literature [CINAHL], MEDLINE and PsycINFO. Additionally, Web of Science (SCI-EXPANDED, SSCI and A&HCI) was searched. Identifying search terms presented a challenge insofar as it is a wide-ranging search with multiple broad factors, lacking any keywords or concepts of high specificity; ultimately, this was not a conventional search question, so a conventional search framework such as PICO was not appropriate to employ. Rather it was an ill-defined concept that needed to be formalised and focused accordingly (McMahon et al. 2018). To this end, four components were identified to help define the concept in order to formalise our search: 1: People with intellectual disabilities; 2: SSS; 3: Health status; and 4: Objective social factors (Figure 9). Component 4, objective social factors was incorporated into this

search as a recent meta-analysis on SSS (Cundiff & Matthews, 2017) incorporated this as a concept for physical health as a correlate to SSS.

Component 4 was an improbably large set; however, when combined with the preceding three components using the Boolean 'AND', they did increase the precision of the final search sets.

Component 1	Component 2	Component 3	Component 4
People with intellectual disabilities	Subjective socioeconomic status	Health status	Objective social factors

Figure 9. Search components for scoping review

In order to ensure a comprehensive search set, we used Sandieson's (2006) "pearl harvesting" framework. This framework built upon standard information science techniques of "pearl growing" or "pearl building" (Hawkins & Wagers, 1982) to create a third way of "pearl harvesting". This is a process where keyword terms are identified and used to accurately search large psychological or educational databases on precise topics in a far-reaching manner by arranging keywords before a final search (Sandieson, 2006). It is becoming widely used in the intellectual disability information retrieval process (Robertson, Hatton, Baines, & Emerson, 2015), as the pearl growing methodology culminates in a customisable "synonym ring" (e.g. a list of relevant keywords/ phrases) that can be used by other researchers. We used Sandieson's (2010) validated synonym ring for searching component 1. Where synonym rings were not available for other components (components 2,3 & 4), the search progressed through using a combination of keyword searching, pearl growing and thesauruses to identify search terms. Some terms were initially explored by reiterating and refining in secondary searches, prior to being fed into the primary search history. Advanced database functions (e.g. proximity search and nesting) were used throughout to help steer the search to the satisfactory point in the information search process.

Inclusion & exclusion criteria

Articles were included if they met the following criteria:

- Peer-reviewed English language full-text

- Published from January 1990 to October 2018
- Any research design that presents results relating to both SSS and health status in persons with intellectual disabilities
- Samples in research studies will only be included where 50% or more of participants have intellectual disabilities or mixed samples where results are disaggregated for people with intellectual disabilities

Exclusion criteria were:

- Reviews, letters, commentaries, editorials, meeting or conference abstracts
- Studies on conditions where intellectual disabilities cannot be assumed
- Studies based on children only with an intellectual disability

8.3. Results

Study selection

The search returned 1,345 possible articles for consideration (Cinahl 243, Medline 568, PsycINFO 333, Web of Science, 201). In March 2018, an email request for information on research relevant to this review was also sent to a specialist intellectual disability academic mailing list. This returned two research articles – one was already included in our search set. All citations were imported into Covidence, an online data screening and extraction software program for screening. After de- duplication, a final set of 1,098 articles remained for title and abstract screening. Two reviewers (Author 1 & 2) separately screened these articles on the basis of 'title and abstract'. Of these articles, 18 potentially met the inclusion criteria and their full text was screened. Of these, seven articles met our inclusion criteria (Figure 10). As scoping reviews aim to describe and summarise the available literature, we did not use a formal assessment to determine methodological quality - this is congruent with the scoping review methodology (Arskey & O' Malley, 2005; Peters et al., 2015).

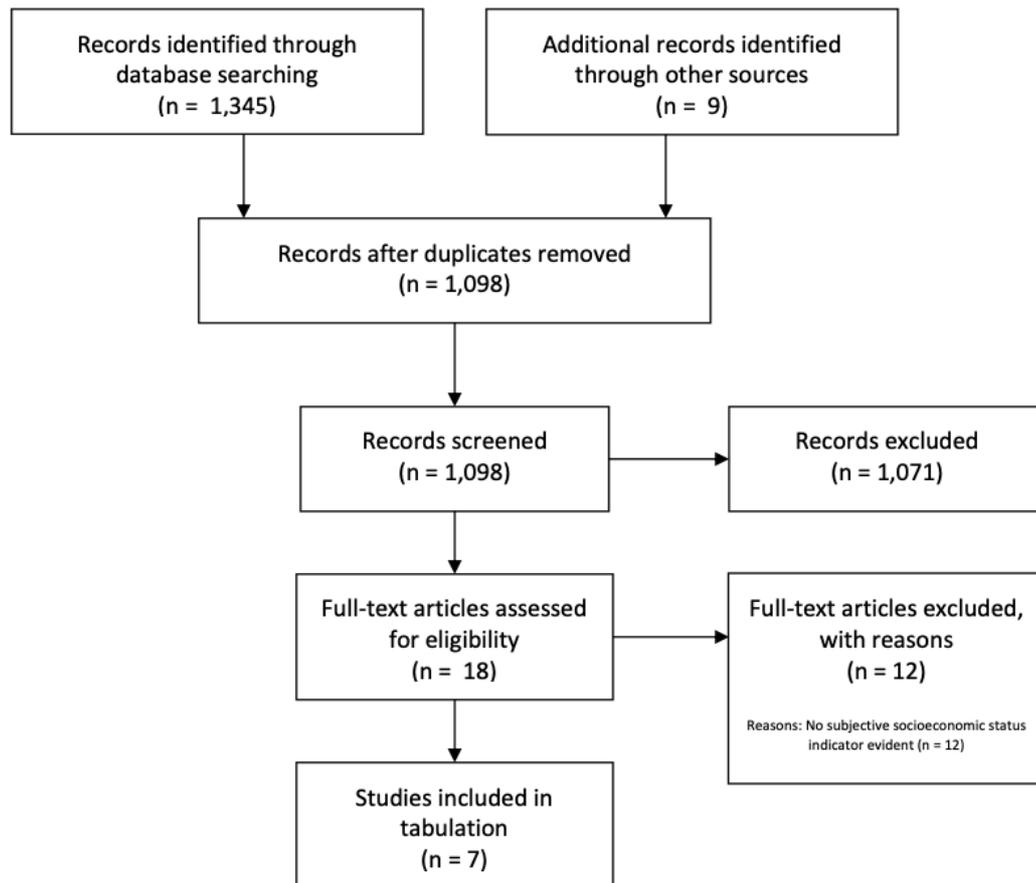


Figure 10. Flow chart of study identification

Seven studies were charted to identify: authors, year; origin; aims/purpose; study population and sample size; methodology, methods; subjective indicator of SSS; health outcome measures and key findings. We followed an iterative approach and the results were examined by the first and second author to consider which themes to extract (Levac, Colquhoun, & O'Brien, 2010). These data are summarised in Table 7.

Table 7. Summary of studies relating to subjective socioeconomic status (SSS)

Author(s)	Year	Origin	Aims/purpose	Study population and sample size	Methodology /methods	Subjective indicator of socioeconomic status	Health outcome measure	Key findings
Emerson & Hatton	2008	England	To explore the association between indicators of socio-economic disadvantage, social participation and networks and self-rated health status within a sample of adults with mild or moderate intellectual disabilities.	1,273 adults with mild to moderate intellectual disabilities	Secondary analysis of cross-sectional survey data	Hardship measure - Millennium Poverty and Social Exclusion Survey: 'Sometimes, when money is tight, people have to go without things. In the last year, have you always had enough money for [item] when you wanted it/them? The specific items included were: new clothes, new shoes, food, heating, telephoning friends or family, going out, visits to the pub or a club, a hobby or sport, and a holiday.'	Self-rated health: In the last year would you say your health was very good, fairly good or not good'	Socioeconomic indicators accounted for a statistically significant proportion of variation in the health status of people with mild or moderate intellectual disabilities. Hardship was more strongly associated with health status than either employment status or area-level deprivation.
Emerson	2010	England	To determine the association between exposure to disability and the health and well-being of adults with intellectual disabilities.	As above	As above	As above	As above	Individuals who self-reported exposure to bullying and overt acts of disability in the previous year reported poorer self-reported health outcomes. These associations were stronger when individuals had lower levels of material or social resources.

Emerson	2011	England	To compare the health and exposure to risk factors associated with poorer health among samples of adults with mild intellectual disability who were and were not receiving support from specialised intellectual disability health and welfare agencies.	1,022 people with mild intellectual disability	As above	As above	As above	Participants not receiving services were significantly more likely to experience greater material hardship, greater neighbourhood deprivation, reduced community and social participation. They were significantly less likely to have regular contact with friends who have ID and significantly less likely to have participated in an above median number of community activities in the previous month. Additionally, they were more likely to smoke tobacco and less likely to access some health services. However, when compared to people receiving services living in general households, they were more likely to be in paid employment
Emerson, Hatton, Robertson & Baines	2014a	Great Britain	To examine the relationship between the social connectedness of people with intellectual disabilities and their health.	279 participants with intellectual disability	As above	Understanding Society: 'How well would you say you yourself are managing financially these days? Would you say you are... 1 Living comfortably, 2 Doing alright, 3 Just about getting by, 4 Finding it quite difficult or 5 finding it very difficult?'	In general, would you say your health is ... (1) excellent, (2) very good, (3) good, (4) fair, (5) poor'.	Persons with ID had less favourable perceptions of important neighbourhood characteristics and lower levels of social and civic participation. More positive perceptions were associated with more positive self-rated health for adults with and without ID. For adults with ID this was particularly the case with regard to employment, feeling safe

								outside in the dark and being able to access services when needed. The between-group differences in perceptions of important neighbourhood characteristics and levels of social and civic participation accounted for a significant proportion of the elevated risk for poorer self-rated health. Overall, people with ID have higher rates of social exclusion and this may also partially account for their relatively poorer health status.
Emerson, Robertson, Baines & Hatton	2014b	Great Britain	To describe the self-rated general health status of British adults with intellectual disability and to examine the extent to which any between-group differences in health status may reflect between- group differences in rates of exposure to socio-economic disadvantage and discrimination.	Life Opportunities Survey: 316 participants with intellectual disability Understanding Society (US) 415 participants with intellectual disability	As above	Life Opportunities Survey: four items were included; 'Looking at this card, can I just check whether your household could afford the following? (1) To pay for a week's annual holiday away from home; (2) To eat meat, chicken or fish (or vegetarian equivalent) every second day; (3) Pay an unexpected, but necessary, expense of £500; (4) To keep your home adequately warm.	Life Opportunities Survey: 'How is your health in general; would you say it was. . . (1) very good, (2) good, (3) fair, (4) bad, (5) or very bad?'; Understanding Society: 'In general, would you say your health is. . . (1) excellent, (2) very good, (3) good, (4) fair, (5) poor'.	Results indicate that: (1) British adults with intellectual disability have markedly poorer self-rated health than their non-disabled peers; and (2) that a significant proportion of their risk of poorer self-rated health may be attributable to their poorer living conditions (rather than their intellectual disability per se)
Emerson, Hatton, Baines & Robertson	2016	Great Britain	To estimate the physical health status of a population-based	299 participants with	As above	Understanding Society: Self-assessed financial status was assessed at Wave 3 by a single item: 'How well would you say	The SF-12 was used to assess physical and mental health.	British adults with intellectual disability have markedly poorer health than their non-disabled peers on the

			<p>sample of British adults with and without mild intellectual disability; while controlling for any potentially confounding effects resulting from between-group differences in gender, age, socio-economic disadvantage and neighbourhood social capital.</p>	<p>intellectual disability</p>		<p>you yourself are managing financially these days? Would you say you are... 1 Living comfortably, 2 Doing alright, 3 Just about getting by, 4 Finding it quite difficult or 5 finding it very difficult?’</p>	<p>Self-rated health was evaluated by a single question incorporating five possible response options: ‘In general, would you say your health is ... (1) excellent, (2) very good, (3) good, (4) fair, (5) poor’.</p> <p>Participants were asked ‘Has a doctor or other health professional ever told you that you have any of the conditions listed on this card?’ Response options included: asthma, arthritis, congestive heart failure, coronary heart disease, angina, heart attack or myocardial infarction, stroke, emphysema, hyperthyroidism or an over-active thyroid, hypothyroidism or an under- active thyroid, chronic bronchitis, any kind of liver condition, cancer or malignancy, diabetes, epilepsy, high blood pressure.</p> <p>Participants were asked if since the</p>	<p>majority of indicators investigated including self-rated health, multiple morbidity, arthritis, cancer, diabetes, obesity, measured grip strength, measured lung function and polypharmacy.</p>
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							previous Wave they had had a hospital admission for any newly diagnosed health conditions (using previous headings on card).	
Hatton, Emerson, Robertson & Baines	2017	Great Britain	To estimate the risk of potential mental health problems of British adults with and without intellectual impairments in a population-based general household sample (ii) to evaluate the extent to which any between-group differences in risk of potential mental health problems may reflect between-group differences in rates of exposure to socio-economic disadvantage.	269 participants with intellectual impairments and 1,785 participants with borderline intellectual impairments	As above	Understanding Society: Self-assessed financial status was assessed at Wave 3 by a single item: 'How well would you say you yourself are managing financially these days? Would you say you are... 1 Living comfortably, 2 Doing alright, 3 Just about getting by, 4 Finding it quite difficult or 5 finding it very difficult?'	The 12-item version of the General Health Questionnaire (GHQ-12) and the six-item mental health subscale of the SF-12.	British adults with intellectual impairments living in general households are at significantly increased risk of potential mental health problems than their non-disabled peers. This risk may be attributable to their poorer living conditions rather than their intellectual impairments per se.

Methodological design

All seven studies were undertaken in England or Great Britain and are from the same author (Eric Emerson) or group of authors (Eric Emerson, Susannah Baines, Chris Hatton & Janet Robertson). All studies were quantitative and undertook secondary analysis of cross-sectional data from surveys in England or the UK more broadly: the Adults with Learning Difficulties in England Survey 2003/4 (n = 2,898) (Emerson, Malam, Davies, & Spencer, 2005); the Life Opportunities Survey (LOS) (n = 37,513) (Office for National Statistics, 2011), and Understanding Society (US) (n = 50,976) (Institute for Social and Economic Research, 2018).

Themes

We summarised the results through a thematic analysis using two themes relevant to the research objective. The following themes are explored: (1) SSS indicators; and (2) the relationship between SSS and health.

Charting the data

Subjective socioeconomic status indicators

Three of the seven studies (Emerson & Hatton, 2008; Emerson, 2010; 2011) used a hardship indicator derived from the Millennium Poverty and Social Exclusion Survey (Pantazis, Gordon, & Levitas, 2006) in the Adults with Learning Difficulties in England 2003/4 survey. Participants were asked: 'sometimes, when money is tight, people have to go without things. In the last year, have you always had enough money for [item] when you wanted it/them?'. The specific items included were: new clothes, new shoes, food, heating, telephoning friends or family, going out, visits to the pub or a club, a hobby or sport, and a holiday. Initially these indicators did not appear wholly reflective of a person's SSS appraisal. Nonetheless, following a pragmatic approach we included these studies as the variables considered are generally reflective of an individual's perception of their own financial strain (this is in contrast to an objective appraisal) and therefore we considered that these studies warranted inclusion. Likewise, in the Emerson, Robertson, Baines and Hatton (2014b) study, two socioeconomic status indicators were reported on: one objective indicator from Wave 1 of the Understanding Society study (Institute for Social and

Economic Research, 2018) and the other, a subjective indicator from Wave 1 of the Life Opportunities Survey study (Office for National Statistics, 2011). The subjective indicator asked participants: 'looking at this card, can I just check whether your household could afford the following? (1) To pay for a week's annual holiday away from home; (2) To eat meat, chicken or fish (or vegetarian equivalent) every second day; (3) Pay an unexpected, but necessary, expense of £500; (4) To keep your home adequately warm'. Again, this is on the peripheries of subjective judgements; however, it is more aligned to the subjective concept as it is again self-assessed. Three other studies (Emerson, Hatton, Robertson, & Baines, 2014a (Wave 3 of Understanding Society); Emerson, Hatton, Baines, & Robertson, 2016 (Waves 1-4 of Understanding Society); Hatton, Emerson, Robertson, & Baines, 2017 (Wave 3 of Understanding Society)) used a self-rated financial strain indicator that was more aligned to the subjective appraisal of one's own SSS. The single item: 'how well would you say you yourself are managing financially these days? Would you say you are... 1 Living comfortably, 2 Doing alright, 3 Just about getting by, 4 Finding it quite difficult or 5 finding it very difficult?'. Overall, the extraction and interpretation of SSS indicators in this review were from generic socioeconomic disadvantage measures.

No identified study used a well-defined SSS measure such as the MacArthur Scale of Subjective Social Status (Adler, Epel, Castellazzo, & Ickovics, 2000; Ostrove, Adler, Kuppermann, & Washington, 2000; Goodman et al., 2001; Singh-Manoux, Adler, & Marmot, 2003; Adler & Stewart, 2007). This is the principal measure that is used to capture an individual's perceived position in society. The MacArthur Scale of Subjective Social Status uses a 'social ladder' aligned to the social gradient within society and asks a respondent to rate the rung on which they feel they stand.

The relationship between subjective socioeconomic status and health

In six studies, apart from the Hatton et al. (2017) study, a general measure of self-rated health was used. This was evaluated by a single question incorporating five possible response options: 'in general, would you say your health is...(1) excellent, (2) very good, (3) good, (4) fair, (5) poor'. Additionally, objective health status measures were used in the Emerson et al. (2016) study that included three other

forms of self-reported health data; the SF-12 questionnaire (Jenkinson & Layte, 1997); a multi-item disease binary (yes/no) checklist; and a question regarding newly diagnosed health conditions since the previous wave of data collection. The Hatton et al. (2017) study reports on mental health which was available in Wave 3 of Understanding Society and on widely used and well-validated measures.

Data extracted from Adults with Learning Difficulties in England 2003/4 reported that hardship was strongly associated with variations in health status and that the association between hardship and health was greater than associations between employment status or area-level deprivation and health (Emerson & Hatton, 2008). Further data from this survey in both the Emerson (2010; 2011) studies reported that lower material resources were associated with poorer self-rated health whilst individuals not receiving services were more likely to experience greater hardship than their peers and this was associated with poorer self-rated health. The subjective socioeconomic measure from the Emerson, et al. (2014b) study taken from the Wave 1 of the Life Opportunities Survey and Wave 1 of Understanding Society study indicated that people with intellectual disabilities were more likely to report poorer self-rated health than peers without intellectual disability. Specifically, they were significantly less likely to rate their health as very good and also significantly more likely to report having fair or worse health than their peers. Emerson et al. (2014a) in Wave 3 of Understanding Society also report that more positive self-rated health was associated with socioeconomic advantage. Moreover, the Emerson et al. (2016) study that examined Waves 1-4 of Understanding Society identified that British adults with intellectual disability have markedly poorer health than their non-disabled peers on the majority of indicators investigated, including self-rated health, multiple morbidity, arthritis, cancer, diabetes, obesity, measured grip strength, measured lung function and polypharmacy. This is the only study included in this review that identified the direct assessment of objective general health status. However, Hatton et al. (2017) used objective measures to measure mental health in Wave 3 of Understanding Society. They found that poorer living conditions were related to poorer mental health rather than their intellectual disability *per se*. In this study, raw data on actual income poverty is reported on; however, the prevalence rate ratio for participants with intellectual disabilities was

considerably greater for 'objective' indicators of socioeconomic status as opposed to the 'subjective' self-assessment of financial strain.

8.4. Discussion

Overview of findings

A comprehensive literature search only identified seven studies, with substantial gaps relative to the research questions set for this review. The main findings of the review are that: (1) no studies had used robust SSS measures to investigate associations between SSS and health amongst people with intellectual disabilities, however indicators related to SSS demonstrate across the seven studies that lower socioeconomic status was associated with poorer health for a wide range of adults with intellectual disabilities; (2) the indicators identified in these seven studies are on the peripheries of acceptability and no study used a recognised instrument (e.g. the MacArthur Scale of Subjective Social Status) in the intellectual disability population to determine if SSS is associated with health status independent of objective socioeconomic indicators.

Interpretation of findings

There has only been recent empirical attention paid to socioeconomic status in adults with intellectual disabilities (Emerson & Hatton, 2014), with much of the evidence concerning people with intellectual disabilities drawn from secondary analyses of population cohort studies. Emerson and Hatton's (2008) study was the first that used a measure of hardship in the intellectual disability population. These are contributing factors for the lack of evidence in this area. Whilst we did identify subjective elements within the appraised studies, the use of a restricted range of indicators of socioeconomic disadvantage does not fully address the SSS of individuals with intellectual disabilities. Equally, such measures are not fully operationalised in any of the seven studies, insofar as the research objective at the outset was not to consider SSS, rather financial hardship or financial strain constituting socioeconomic disadvantage. Moreover, no discrimination was made between objective and subjective assessments in any of the seven studies. This is the primary limitation in all the indicators examined; they all relate to financial strain

or hardship. This is not fully congruent with the overall SSS concept which not only embodies a reflective assessment of a person's socioeconomic position, but it is also a social phenomenon that captures a person's life chances as well as other previous, current and future prospects (Singh-Manoux, Adler, & Marmot, 2003). A number of studies were excluded from this scoping review on this basis. In particular, the concept of 'subjective' in a number of studies was not subjective *per se* (for example, Hensel, Rose, Stenfert Kroese & Banks-Smith, 2002; Simões, Santos, & Claes, 2015; Simões & Santos, 2016), rather they were measures of satisfaction across quality of life domains incorporating a mixture of objective and satisfaction components.

Notwithstanding, the indicators we extracted related to SSS did demonstrate that lower SSS was associated with poorer health for a wide range of adults with intellectual disabilities, particularly self-rated health (Emerson & Hatton, 2008; Emerson, 2010, 2011; Emerson et al., 2014a; Emerson et al., 2014b; Emerson et al., 2016). This is consistent with the general literature (Adler et al., 2000) and the overall societal gradient (Adler et al., 1994, Singh-Manoux et al., 2003). Self-rated health instruments are rarely used in intellectual disabilities health research owing to measurement complications; for example, proxy- respondents and acquiescence (see Fujiura (2012) for a broad overview). Nonetheless, evidence (Emerson & Hatton, 2008; 2014; Haider, Ansari, Vaughan, Matters, & Emerson, 2013) suggests that individuals with intellectual disabilities are more likely to rate their health as poorer than the general population. This has important implications insofar as longitudinal evidence has identified that self-rated health in the general population is a strong predictor of morbidity and mortality (Heistaro, Jousilahti, Lahelma, Vartiainen, & Puska, 2001).

One study (Queirós, Wehby & Halpern, 2015) has used a SSS measure (the MacArthur Scale of Subjective Social Status) in individuals with a cognitive disability. Participants with a cognitive disability did not rate their SSS as lower than their non-disabled peers even though they had poorer educational attainment, occupational status and income. Nevertheless, whilst there is not enough evidence to deconstruct why individuals with a cognitive disability did not rate their SSS as lower than their

non-disabled peers despite obvious socioeconomic disadvantage, this theoretically reflects their adaptation to persistent deprivation that these individuals experience (Emerson, personal communication, 7/3/18).

Limitations

Our interpretations need to be considered together with considerable limitations: (1) some studies harvested data from large-scale general surveys and individuals with more severe intellectual disabilities were likely to be excluded; (2) no specific question in the Life Opportunities Survey or Understanding Society surveys asked about intellectual disability and there is a potential of inaccuracy in selecting participants from these samples; (3) no research used a predefined and validated SSS measure; (4) proxy responses were used for some people in the Adults with Learning Difficulties in England 2003/4 data set and this infringes on the *subjectivity* and validity of these results; (5) as only three data sets were used, there is a potential that participants across the original studies could overlap.

8.5. Conclusion

This is the first scoping review that has sought to identify if SSS is associated with health in adults with intellectual disabilities. Nevertheless, our results only imply that indicators related to SSS suggest that lower socioeconomic status was associated with poorer health for a wide range of adults with intellectual disabilities.

Considering this, future research should focus on investigating whether the associations found in non-disabled populations hold true for those with intellectual disabilities. This question should be addressed using a suitable SSS instrument such as the MacArthur Scale of Subjective Social Status in an appropriately defined sample to collect individual-level data in a prospective research approach. This will give a clearer indication if SSS is a correlate of health in the intellectual disability population.

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Chapter 9: Study 6

The relationship between subjective socioeconomic status and health in adults with and without intellectual disability

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The relationship between subjective socioeconomic status and health in adults with and without intellectual disability

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Abstract

Background: This study investigated if subjective socioeconomic status (SSS) is related to self-rated health (SRH) and objective indicators of health in people with and without intellectual disability.

Methods: Participants were 217 adults with, and 2350 adults without intellectual disability in Jersey. In the intellectual disability sample, 85 (39.2%) participants consented independently, while 132 (60.8%) participants consented through proxy procedures. The MacArthur Scale of Subjective Social Status was used to measure SSS. The Euro-QoL EQ-5D-5L and a five-point scale ranging from poor to excellent health were used to measure SRH.

Results: Higher SSS and younger age were predictors of better SRH for the proxy-report intellectual disability group. Being employed was associated with higher EQ-5D-5L index values for all intellectual disability groups.

Conclusion: As SSS was only related to SRH in the proxy intellectual disability group, further research with a larger intellectual disability sample is needed to explore its utility further.

KEYWORDS

health, health inequalities, intellectual disability, MacArthur Scale of Subjective Social Status, socioeconomic status, subjective socioeconomic status

1 | INTRODUCTION

People with intellectual disability have greater health needs (Hughes-McCormack et al., 2018; McMahon & Hatton, 2021) and are more likely to die at a younger age than the general population (Glover et al., 2017; Landes et al., 2021; O'Leary et al., 2018). Such differences may be regarded as health inequalities (Emerson & Hatton, 2014). Health inequalities generally have strong associations with social and economic conditions (Marmot, 2005a, 2020; World Health Organisation [WHO], 2008) and a significant body of evidence has documented the association between these factors and health (Adler & Stewart, 2007; Dignan, 2001; Marmot et al., 1991; WHO, 2008). These factors known

as social determinants of health are the non-medical factors that influence health outcomes. For adults with an intellectual disability this is a complex area that is shaped by both internal and external conditions and the interplay between these (McMahon, 2022). For some people with an intellectual disability this is an important consideration as they are potentially more likely to be exposed to health inequalities from both a biological and non-medical factor perspective. For example, regarding the concept of clinical phenotypes—which is the outward expression of genes—it is important to consider the manifestation of particular sets of physical problems commonly encountered with particular syndromes (for example Down syndrome and Alzheimer's type dementia) (Strydom et al., 2019). Additionally, people with intellectual disabilities are more

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likely to be disproportionately exposed to a cascade of disparities (Emerson & Hatton, 2014; Krahn & Fox, 2014; Marmot, 2005a) including unemployment (Hatton, 2018), poverty (Emerson, 2007; Emerson et al., 2006), exclusion (Merrells et al., 2018), low levels of education (McMahon et al., 2019), poorer access to healthcare (Krahn et al., 2015) and discrimination (Emerson, 2021).

Previous research on health inequalities has described societal gradients or social hierarchies existing within societies (Adler, 2009; Adler et al., 1994; Singh-Manoux et al., 2003) suggesting a person's place on the gradient determines how long they will live and how healthy a life they will have (Marmot, 2020; Marmot et al., 2010). Traditionally, a person's place on this gradient has been determined by measuring their socioeconomic status. Conventional objective indicators of socioeconomic status include education, occupational status and income. The relationship between socioeconomic status and a person's health status is deeply patterned, with each affecting the other. The place a person is positioned on the gradient affects their health, and in turn, their health affects their capability to reach higher levels on this gradient. It is now accepted that socioeconomic status is the principal indicator of inequality where greater rates of morbidity and mortality are experienced amongst individuals who are at the lower end of this gradient (Adler, 2009; Cundiff & Matthews, 2017).

Although objective indicators of socioeconomic status are reliably associated with greater rates of mortality and morbidity (Donkin et al., 2018), evidence has suggested that subjective socioeconomic status (an individual's opinion of their rank within society, also referred to as subjective social status) is more strongly associated with a person's health than conventional objective socioeconomic status indicators (Euteneuer, 2014). Some researchers (Jackman, 1979; Singh-Manoux et al., 2003) refer to a cognitive averaging process whereby subjective socioeconomic status is not only reflective of a person's socioeconomic position, but is a social phenomenon that captures a person's life chances, and other previous, current and future prospects that are independent of conventional objective measures of socioeconomic status. Substantial literature has considered the influence of subjective socioeconomic status on health, aligned to the notion that through individuals internalising their place within socioeconomic hierarchies, physiological stress-related pathways are activated, negatively impacting a person's health (Marmot, 2005b; McEwen & Gianaros, 2010). Research has also found that material deprivation cannot alone account for all biological indicators of health status (Nobles et al., 2013) and low subjective socioeconomic status is associated with a higher prevalence of cardiovascular diseases (Allen et al., 2014; Marmot et al., 1991), respiratory diseases (Cohen et al., 2008), oral disease (Sanders et al., 2006), mental health problems (Demakakos et al., 2008) and obesity (Goodman et al., 2003).

Links between subjective socioeconomic status and health status have been reported in the UK (Singh-Manoux et al., 2003; Singh-Manoux et al., 2005), the USA (Franzini & Fernandez-Esquer, 2006) and in ethnically diverse samples (Allen et al., 2014; Ostrove et al., 2000). Cundiff and Matthews (2017) identified that subjective socioeconomic status provides exclusive information for understanding health inequalities as it provides a unique cumulative association with physical health, particularly self-rated health (SRH), exceeding

conventional objective indicators of socioeconomic status. Theoretically, this has important implications for individuals with intellectual disabilities for two principal reasons. First, although SRH is under-researched with people with intellectual disabilities (Emerson et al., 2014; Fujiura et al., 2012), it has notable predictive validity with respect to mortality in the general population (Schnitker & Bacak, 2014). Furthermore, the evidence that does exist suggests that poorer SRH may be the consequence of poorer living environments rather than a person's intellectual disability per se (Emerson et al., 2014). As far as we are aware there is no evidence to suggest that subjective socioeconomic status does not provide a unique cumulative association with physical health or SRH in the intellectual disability population similarly to the general population. Second, objective measures of socioeconomic status are potentially poor indicators in the intellectual disability population due to a lack of variation in these indicators; with uniformly low educational attainment, very low employment rates and low income in this group (Hatton, 2018). Similarly, indicators based on area deprivation around people's homes may be less relevant when people are living in residential care. Consequently, subjective socioeconomic status could be a more robust indicator for capturing the overall socioeconomic position of individuals with intellectual disabilities.

The literature on subjective socioeconomic status focuses on the MacArthur Scale of Subjective Status (Adler et al., 2000; Goodman et al., 2001; Ostrove et al., 2000; Singh-Manoux et al., 2003). This is the principal measure used to capture an individual's perceived position within society. The MacArthur Scale of Subjective Social Status uses a 'social ladder' aligned to the social gradient within society and asks a respondent to rate the rung on which they feel they stand. The MacArthur Scale of Subjective Social Status was developed by Adler and Stewart (2007) and grounded in Cantril's (1965) earlier work investigating happiness using a similar self-report ladder. Aligned to the societal hierarchy, the MacArthur Scale of Subjective Status summarise an individual's sense of their place on this ladder using a holistic self-evaluation of socioeconomic status and social position. It appears to be a promising measure to determine the relationship between socioeconomic status and health status for people with intellectual disabilities, as it is potentially accessible and people with intellectual disabilities generally occupy atypical socioeconomic positions within society.

In a US based study, Queirós et al. (2015) used the MacArthur Scale of Subjective Status and identified that individuals with a cognitive disability did not rate their subjective social status as lower than their non-disabled peers even though they had poorer educational attainment, occupational status and income. Whilst Queirós et al. (2015) do not explore this further, this theoretically reflects adaptation to the persistent deprivation that these individuals experience. This phenomenon is supported by quality-of-life research (Hensel et al., 2002) showing that individuals with intellectual disabilities may self-report higher ratings on quality of life measures as they compare their own situation to other people with more severe intellectual disabilities (Simões et al., 2015; Stancliffe, 1999). Similarly, people with intellectual disabilities may have more of a positive outlook (Hartley & MacLean Jr, 2006) and may be less analytical of their environmental

conditions (Perry & Felce, 2005). Considering this, the MacArthur measure for assessing subjective socioeconomic status may have applied benefits for research with people with intellectual disabilities for two primary reasons. First, the ladder is relatively cognitively unchallenging, and therefore inclusive for most individuals with intellectual disabilities. Second, it measures a complex phenomenon allowing for individuals to include subtle subjective indicators of health and wellbeing alongside self-assessed objective indicators. This suggests that it is theoretically a robust measure to tease out where individuals position themselves on the socioeconomic hierarchy.

Given the substantial evidence for a positive association between subjective socioeconomic status and health in the general population, we are aware of no evidence that pertains to the intellectual disability population and its association with health. Understanding the interplay between this is an important consideration that needs prioritising given the atypical socioeconomic position that many people with intellectual disability occupy in society. Therefore, the aim of this study is to determine if subjective socioeconomic status is related to self-rated and objective indicators of health in people with and without intellectual disability in Jersey.

2 | METHODS

2.1 | Context

This study was undertaken in Jersey, Channel Islands, a self-governing British Crown dependency with a population of just over 105,000 (States of Jersey 2019). Jersey has a highly developed economy and a quality-of-life index of 163.35 (Europe range: Russia 101.67–Switzerland 190.82) (Numbeo, 2021). While employment has been impacted due to the COVID-19 pandemic, from 2015 to 2020 the labour market has grown across most sectors and in 2019, 90% of working age adults were economically active. The cost of living in Jersey is high, driven in part by the sizeable finance industry that exists. For example, average earnings for full time workers range from £1080 per week in financial services to around £410 per week in hotels, restaurants and bars (Government of Jersey, 2020). This impacts consumer prices which are 31% (excluding rent) or 49% (including rent) higher than in the UK (Numbeo, 2021). The proportions of individuals living in 'relative low income' in Jersey, where they are living in households with an income below 60% of the median in that year has been stable over the last 10 years standing at approximately 22% (Government of Jersey, 2020). This is, however, greater than the UK where 'relative low income' stood at 16% in 2020/2021 (Francis-Devine, 2022). No data exist regarding the proportion of people with an intellectual disability living in 'relative low income' in Jersey. However, a study by McMahon et al. (2019) describes a negative picture where they cite that the majority of people with an intellectual disability in Jersey have low levels of employment, poor income and rely on government benefits which are often aligned to physical and personal care needs. Homeownership is also low in Jersey with only 54% of people owning their own home in the last census (Government of Jersey, 2011); this compares to 63% of households in England owning their own homes in the 2 years from 2016 to 2018 [www.gov.uk, 2020]. The health of the

Jersey population compares favourably to other developed countries and the leading causes of mortality (cancers and heart disease) are broadly similar to other developed countries (Government of Jersey, 2016). The health of people with intellectual disability in Jersey is poorer than the general population (McMahon & Hatton, 2021), similar to other developed countries (Emerson et al., 2014; Emerson & Hatton, 2014; Hughes-McCormack et al., 2018; van Schroyen Lantman-de Valk, 2005).

2.2 | Ethics statement

Ethical approval was granted from the Faculty of Health and Medicine Research Ethics Committee at Lancaster University (reference FHMREC16083) and by the Government of Jersey, Health and Community Services Ethics Committee. The consent process and accompanying documentation was designed using guidance from the Mental Capacity Act (2005) and the Health Research Authority (<https://www.hra.nhs.uk/>). Further details of the consenting procedure for adults with an intellectual disability are outlined in Bowring (2017), McMahon et al. (2019), McMahon et al. (2020), Bowring et al. (2017a) and Bowring et al. (2017b).

2.3 | Procedure

This was an original study and the structured survey instrument was specifically designed to collect data from people with and without intellectual disability in Jersey.

2.4 | General population sample

After accounting for population density and excluding addresses that had previously been sent the 2015, 2016 or 2017 Annual Social Surveys, or the Disability Survey in 2015, 8000 surveys (weighted in terms of population density strata for each parish) were sent to households across the 12 parishes in Jersey. To account for the entire adult population at random, the household member who next celebrated their birthday, and who was aged 18 years or over, was asked to complete the survey. A total of 2415 surveys (30.2%) (age range 19–105, mean = 57.67, SD = 16.3) were returned with 65 of these being unusable. There was less than 2.5% missing data on any variable (range 0.8%–2.3%).

2.5 | Intellectual disability sample

At the time of data collection, 285 adults were known to access intellectual disability services in Jersey. To access intellectual disability services in Jersey, individuals are assessed against three criteria by health and social care professionals. These criteria include significant limitations in intellectual functioning and adaptive behaviour with an onset before the age of 18. Individuals were asked to participate independently or where they lacked capacity they were consented through proxy procedures with the person and/or a personal or nominated

consultee (Department of Health, 2008). The 217 adults with an intellectual disability who participated represented a 76% response rate. All information was collected by face-to-face interviews with participants or through proxy respondents. The proxy respondent was the person who knew the participant best and respondents included family members, key workers and friends. Eighty-five (39.2%) participants consented independently, while 132 (60.8%) participants were consented through proxy procedures.

2.6 | Subjective socioeconomic status

Subjective Socioeconomic Status was measured using the MacArthur Scale of Subjective Social Status (Adler & Stewart, 2007) (SSS ladder herein). Standard wording that accompanies the MacArthur Scale of Subjective Social Status was used to ask both populations of participants or proxies. For example: 'Think of this ladder as showing where people stand in Jersey. At the top of the ladder are the people who are best off – those who have the most money, the best education, and the most respected jobs. At the bottom are the people who are worst off – those who have the least money, the least education, and the least respected job or no job. The higher up you are on this ladder, the closer you are to the people at the top; the lower you are, the closer you are to the people at the bottom'.

- Where would you place yourself (*or person you are answering on behalf of if proxy*) on this ladder?
- Place an 'X' on the rung where you think you (*or person you are answering on behalf of if proxy*) stand at this time of your life relative to other people in Jersey.

2.7 | Objective socioeconomic status

Education, occupation and income were used as objective indicators of socioeconomic status. These variables along with other sociodemographic variables were collected to mirror the general population 'Jersey Opinions and Lifestyle Survey' (States of Jersey, 2017) and therefore were reflective of the educational and occupational landscape at the time of data collection. Education was categorised as; no formal education, GNVQ/BTEC Introductory Diploma (Foundation), 'O' levels/CSE/GCSE/ BTEC First/ GNVQ (Intermediate), AS-Level, /A2-Level/BTEC National/GNVQ (Advanced), First Degree, Higher Degree (e.g., Masters/PhD) or other. Occupation was categorised as; working for an employer, self-employed, not employing others, unable to work because of long-term sickness or disability, unemployed, looking for work, unemployed, not looking for work, in full-time education, a homemaker, retired or other. Individual income was categorised as income less than £15,000, increasing in £10,000 increments to income above £105,000.

2.8 | Health

To measure SRH, participants or proxies were asked if their health was 'excellent, very good, good, fair or poor'. The EQ-5D-5L EuroQol

questionnaire was used to measure health-related quality of life (HRQoL) across both populations (Devlin & Brooks, 2017). The EQ-5D-5L is a generic objective measure of health that comprises of a simple descriptive system and a visual analogue scale (VAS). The VAS is subjective in nature and comprises of a scale ranging from 0 to 100 asking respondents how they rate their health on the day of completing the questionnaire.

The descriptive element of this measure can be converted into a single summary index value from five dimensions of health: mobility, ability to self-care, ability to undertake usual activities, pain/discomfort and anxiety/depression. These dimensions have five levels of severity for each dimension (no problems, slight problems, moderate problems, severe problems, and extreme problems). The present study used the corresponding English Crosswalk value set as advised by EuroQol for the EQ-5D-5L. This converts one of the different 3125 different health states into an index value ranging from –0.285 to 0.95, where –0.285 represents extreme problems on all dimensions and 0.95 represents full health (Devlin et al., 2018).

2.9 | Sociodemographic variables

This study is part of a larger comparative study undertaken by the researchers and all demographic variables were collected to mirror the general population 'Jersey Opinions and Lifestyle Survey' (States of Jersey, 2017) that included variables such as gender, age and marital status.

2.10 | Approach towards analysis

Data analysis was performed using the Statistical Package for the Social Sciences Version 25 (SPSS Inc., Chicago, IL, USA). Our approach to analysis was undertaken in six stages. First, due to the low variation and non-normal distribution across populations, objective socioeconomic status indicators for adults with intellectual disabilities were recoded from ordinal and scale variables into binary variables. Education was recoded as 'formal education vs no formal education', income was recoded as 'above or below £15,000 per annum' and occupation was defined as 'in employment vs unemployed'. Given the high number of retired respondents in the general population sample, we only analysed respondents in the occupation variable who identified as working for an employer, self-employed, employing others, self-employed, not employing others, unemployed, unable to work because of long-term sickness/disability, unemployed, looking for work, or unemployed not looking for work. Self-rated health was also recoded into a binary variable that represented 'good to excellent' health (excellent, very good and good) or poor health (fair or poor).

Second, we used descriptive statistics to describe the objective (education, occupation and income) and subjective socioeconomic status (SSS ladder) and health (EQ-5D-5L index values, visual analogue scale [0–100] and dichotomised self-rated health [good to excellent vs poor to fair SRH]) of all three groups of respondents (general population, intellectual disability—self report and intellectual disability—

TABLE 1 Demographic, objective and subjective socioeconomic status characteristics of the general and intellectual disability populations

		General population <i>n</i> -2350		Intellectual disability—Self report <i>n</i> -85		Intellectual disability—Proxy report <i>n</i> -132		<i>F</i> -statistic	<i>p</i>
		57.65 (16.3)		39.2 (12.3)		47.9 (17.0)		72.38	<.001
Age (Mean, SD)		<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	χ^2	<i>p</i>
Sex	Male	941	40.3	51	60.0	71	53.8	21.53	<.001
	Female	1394	59.7	34	40.0	61	46.2		
Degree of intellectual disability	Mild/moderate	–	–	84	98.8	80	60.6	3050.98	<.001
	Severe/profound	–	–	1	1.2	52	39.4		
Education	No formal education	498	21.5	67	78.8	127	96.2	468.29	<.001
	Formal education	1817	78.5	18	21.2	5	3.8		
Occupation	Employed	1371	94.4	31	43.7	12	10.8	732.16	<.001
	Unemployed	82	5.6	40	56.3	99	89.2		
Income	Under £15,000	476	22.0	65	82.3	122	94.6	438.46	<.001
	Above £15,000	1689	78.0	14	17.7	7	5.4		
		<i>n</i>	Median (IRQ)	<i>n</i>	Median (IRQ)	<i>n</i>	Median (IRQ)	χ^2	<i>p</i>
SSS Ladder Median (IRQ)		2350	6 (4,7)	82	4 (2,6)	131	3 (2,5)	110.51	<.001

Note: Bold value indicates statistical significance.

proxy report). Third, error line graphs with 95% confidence intervals were used to graphically represent the variability of mean SSS ladder scores of all three groups stratified by age, SRH, employment, income and education. Fourth, inferential statistics aligned to the distribution of data (for example, chi-square, Kruskal–Wallis *H* test, Mann Whitney *U* Tests, *t*-tests and ANOVAS with Hochberg post hoc tests) to compare health by objective and subjective socioeconomic status.

Fifth, we used binary logistic regression to examine the association of subjective and objective socioeconomic status and demographic characteristics with SRH (good to excellent vs. poor to fair SRH) in people with and without intellectual disability. Finally, multiple regression using the stepwise procedure was used across stratified groups to determine the relationship between subjective and objective socioeconomic status and demographic characteristics with EQ-5D-5L index values. The stepwise procedure is an iterative construction of a regression model that involves the selection of independent variables to be used in a final model. Statistical significance was accepted at the ≤ 0.05 level of probability in all analysis.

3 | RESULTS

Demographic and bivariate associations between personal characteristics, living circumstances, and indicators of socioeconomic status are presented in Table 1. Individuals with intellectual disability who self-reported were older than people with proxy respondents but younger than the general population. All individuals with intellectual disability were more likely than the general population to have no formal education ($p < .001$), be unemployed ($p < .001$), and have an income of less than £15,000 ($p < .001$).

People with intellectual disability were more likely to self-report 'poor to fair' SRH than the general population (general population 'good to excellent' 79.9% versus 'poor to fair' 20.1%; intellectual disability self-report 'good to excellent' 72.9% versus 'poor to fair' 27.1%; intellectual disability proxy report 'good to excellent' 66.7% versus 'poor to fair' 33.3%) ($\chi^2(2) = 15.26, p < .001$). No statistically significant difference was observed between the EQ-5D-5L index values for the general population and the intellectual disability self-report group; however, the intellectual disability proxy-report group had statistically significant lower index values than the self-report group and general population ($p < 0.001$). In the VAS scores, while there were no differences between the intellectual disability groups, both the intellectual disability groups had significantly lower scores than the general population ($p < .001$) (Table 2).

Distributions of the SSS ladder scores for all groups are outlined in both Figure 1 and Table 1. There was a statistically significant difference in median between the different groups, $\chi^2(2) = 110.51, p < .001$. This post-hoc analysis revealed statistically significant differences in median scores between the general population (median (IQR) 6 (4,7)), the intellectual disability self-report group (median (IQR) 4 (2,6), $p = <.001$) and the intellectual disability proxy-report group (median (IQR) 3 (2,5), $p < .001$). No significant difference was observed between the two intellectual disability groups ($p = .082$).

The SSS ladder scores were stratified further to investigate the measure's relationship with, gender, age (split at median [less than or more than 57 years]) objective indicators of socioeconomic position (employment, education and income) and SRH (see Figure 2). Only older age (57 years or above) was associated with lower SSS ladder score in the intellectual disability self-report population ($U = 1420.500, z = -2.438, p = .015$). Men had a higher SSS ladder score than women

TABLE 2 Self-rated health, EQ-5D-5L index values and the distribution of EQ-5D-5L dimension responses for the general and intellectual disability populations

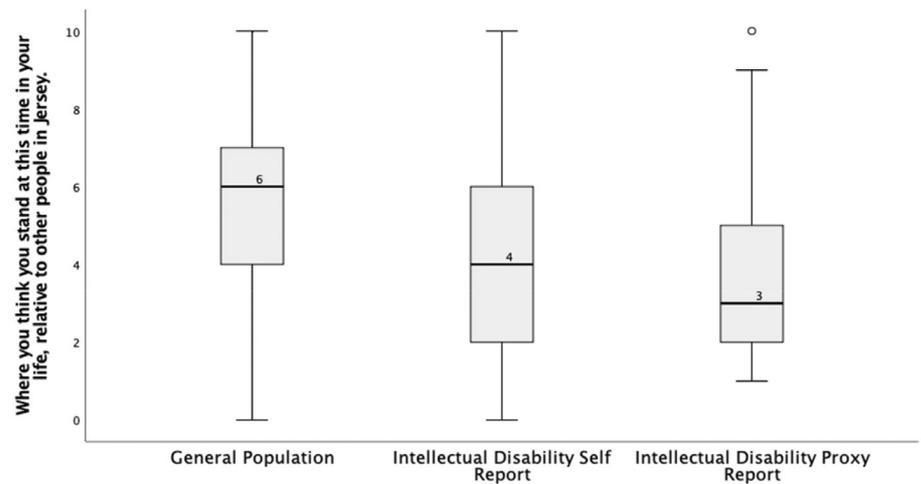
Self-reported health	General population N (%)	Intellectual disability—Self report N (%)	Intellectual disability—Proxy report N (%)	Test statistic χ^2	p-value
Good to Excellent SRH	1862 (79.2%)	62 (72.9%)	88 (66.7%)	15.26	<0.001
Poor to Fair SRH	467 (19.9%)	23 (27.1%)	44 (33.3%)		
EQ-5D-5L index values with SPSS using the United Kingdom (UK) value set	N	Minimum/maximum	Mean (SD)	Test Statistic F	p-value
General Population	2316	−.43–1.0	0.80 (0.20)		
Intellectual Disability Self Report	85	0.02–1.0	0.80 (0.18)	72.121	<0.001 ^a
Intellectual Disability Proxy Report	129	−0.39–1.0	0.58 (0.35)		
Visual Analogue Scale (0–100)	General population	Intellectual Disability—Self Report	Intellectual Disability—Proxy Report	Test Statistic F	p-Value
Mean (Standard Deviation)	77.14 (19.01)	70.74 (24.29)	70.27 (20.89)	11.92	<0.001 ^b
Mobility	General Population N (%)	Intellectual Disability—Self Report N (%)	Intellectual Disability—Proxy Report N (%)	Test Statistic df (2) χ^2	p-value
No problems	1694 (72.1%)	60 (70.6%)	68 (51.5%)		<0.001
Slight problems	331 (14.1%)	9 (10.6%)	16 (12.2%)		
Moderate problems	203 (8.6%)	11 (12.9%)	16 (12.1%)	39.696	
Severe problems	91 (3.9%)	4 (4.7%)	9 (6.8%)		
Unable to walk about	12 (0.5%)	1 (1.2%)	23 (17.4%)		
Self-care					
No problems	2155 (91.7%)	72 (84.7%)	40 (30.3%)		< 0.001
Slight problems	105 (4.5%)	10 (11.8%)	30 (22.7%)		
Moderate problems	47 (2.9%)	2 (2.4%)	26 (19.7%)	476.421	
Severe problems	14 (0.6%)	0	9 (6.8%)		
Unable to wash or dress	13 (0.6%)	1 (1.2%)	27 (20.5%)		
Usual activities					
No problems	1672 (71.1%)	60 (70.6%)	77 (58.3%)		0.001
Slight problems	392 (16.7%)	19 (22.4%)	23 (17.4%)		
Moderate problems	196 (8.3%)	2 (2.4%)	19 (14.4%)	13.010	
Severe problems	44 (1.9%)	4 (4.7%)	10 (7.6%)		
Unable to do usual activities	30 (1.3%)	0	3 (2.3%)		
Pain/discomfort					
No pain/discomfort	907 (38.6%)	51 (60.0%)	76 (58.9%)		< 0.001
Slight pain/discomfort	928 (39.5%)	21 (24.7%)	29 (22.5%)		
Moderate pain/discomfort	397 (16.9%)	9 (10.6%)	17 (13.2%)	23.986	
Severe pain/discomfort	81 (3.4%)	4 (4.7%)	5 (3.9%)		
Extreme pain/discomfort	18 (0.8%)	0	2 (1.6%)		
Anxiety/depression					
Not anxious/depressed	1453 (61.8%)	43 (50.6%)	60 (45.5%)		< 0.001
Slightly anxious/depressed	590 (25.1%)	27 (31.8%)	35 (26.7%)		
Moderately anxious/depressed	230 (9.8%)	15 (17.6%)	27 (20.6%)	21.699	
Severely anxious/depressed	43 (1.8%)	0	5 (3.9%)		
Extremely anxious/depressed	15 (0.6%)	0	4 (3.1%)		

Note: Bold value indicates statistical significance.

^aThere is no statistical difference between the general population and intellectual disability self-report.

^bThere is no statistical difference between the intellectual disability self-report and intellectual disability proxy-report.

FIGURE 1 Boxplots presenting SSS ladder scores for the general and intellectual disability populations



in the general population ($U = 598,408$, $z = -3.612$, $p \leq .001$) but there were no statistically significant differences in SSS by gender in the intellectual disability populations ($p \geq .05$). Being employed was associated with higher SSS ladder scores for both the general population ($U = 24455.000$, $z = -8.704$, $p \leq .001$) and the self-report intellectual disability population ($U = 343.500$, $z = -2.778$, $p = .005$) but not for the proxy report population ($p = 0.133$). Formal education ($U = 275,672.500$, $z = -13.524$, $p \leq .001$) and income above £15,000 ($U = 295,179.00$, $z = -8.961$, $p \leq .001$) were only associated with higher SSS scores in the general population. Good to excellent SRH was associated with higher SSS ladder scores in both the general population ($U = 273,900$, $z = -12.520$, $p \leq .001$) and the proxy report intellectual disability population ($U = 1339.00$, $z = -2.840$, $p = .005$) but not in the self-report intellectual disability population ($p = .172$). Additionally, there was a moderately positive significant correlation between SSS ladder scores and EQ-5D index values in the general population, ($r [2227] = .32$, $p < .0001$) but not for any of the intellectual disability populations.

Binary regression analysis was conducted on the combined three groups. The model was statistically significant ($\chi^2(6) = 187.90$, $p < .0001$) and indicated that higher SSS ladder scores, being employed and younger age were significantly associated with better SRH for the combined samples (data not shown). A second model was created that stratified the groups into 'general population' and 'combined intellectual disability groups'. For the general population the effects of higher SSS ladder scores, being employed and younger age remained significant predictors of better SRH (see Table 3 Model 1) [$\chi^2(6) = 173.851$, $p < .0001$]. However, for the combined intellectual disability group the effects of employment and SSS ladder scores attenuated, and younger age remained the only significant predictor of better SRH (Table 3 Model 2 = $\chi^2(6) = 16.203$, $p = .013$). In the final model, the intellectual disability groups were further stratified into self-report and proxy report groups. The self-report group became non-significant and all demographic, objective and subjective socioeconomic effects attenuated (data not shown as non-significant). However, higher SSS ladder scores and younger age remained significant predictors of better SRH for the proxy-report group (Table 3 Model 3) [$\chi^2(6) = 13.229$, $p = .040$].

Finally, multiple regression using the stepwise procedure using the EQ-5D-5L Crosswalk index value as the outcome variable was undertaken. Again, we stratified the groups into 'general population', 'intellectual disability self-report' and 'intellectual disability proxy report'. Results and test diagnostics considerations are outlined in Table 4. In summary, the final models predict that for the general population, people who are employed had higher EQ-5D-5L index values than those people who are unemployed, and an increase in one rung on the SSS ladder is associated with an increase in EQ-5D-5L index values. It also predicts that an increase in age by 1 year is predicted to decrease the EQ-5D-5L index values and earning less than £15,000 was associated with lower EQ-5D-5L index values. For the self-report intellectual disability group, those who are employed have EQ-5D-5L index values that are higher than people who are unemployed and an increase in age of 1 year is also associated with lower EQ-5D-5L index values. For the proxy-report intellectual disability population, that model predicted that people who are employed had EQ-5D-5L index values that are higher than people who are unemployed. No other significant associations were observed.

4 | DISCUSSION

In broad terms, our results indicate that adults with intellectual disability in Jersey are more likely to occupy lower socioeconomic positions than the general population with lower levels of education, employment and income. They are also more likely to report lower levels of SSS as measured on the MacArthur Scale of Subjective Social Status and lower SRH than the general population. For adults with intellectual disability who participated through proxy respondents, they were more likely to experience lower levels of health as measured by the EQ-5D-5L index value. For this group, employment was associated with better scores on the EQ-5D-5L index value. For self-reporting adults with intellectual disabilities, employment and younger age were significant predictors of increased levels of health as measured on the EQ-5D-5L index value. Whereas for the general population, education, higher levels of SSS, younger age, and earning more than

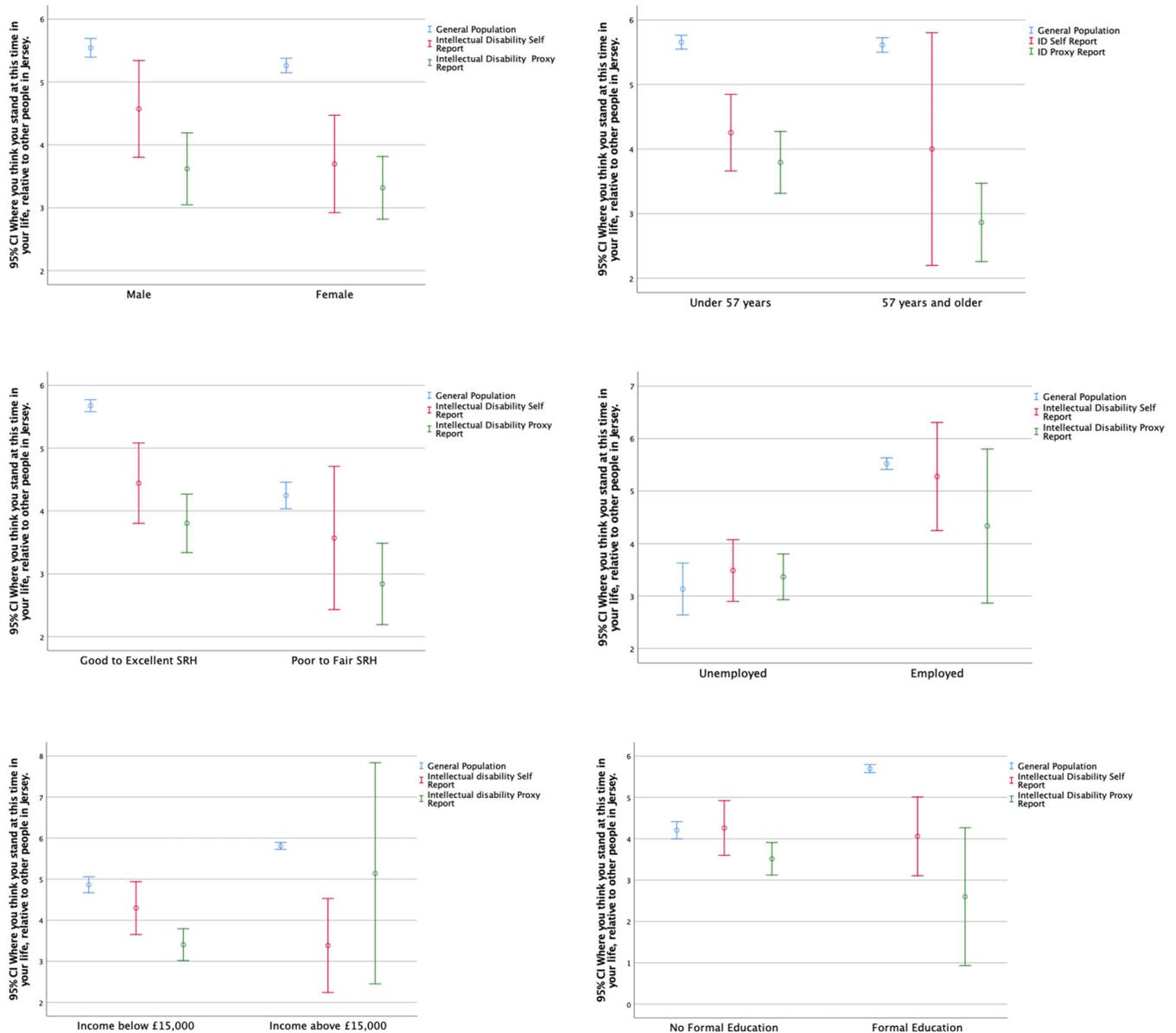


FIGURE 2 Stratified error line graph [95% confidence interval (CI)] representing the mean SSS ladder score by gender, age, self-rated health, employment, income and education. Note: Error line graph is used to visualise the concentratedness of the SSS scores. People with an intellectual disability who self-reported had higher mean SSS ladder scores for unemployment and no formal education than the general population. People with an intellectual disability who responded through proxy reporting had higher mean scores on the SSS ladder for unemployment and income below £15,000 than the general population.

£15,000 were significant predictors of better health as measured on the EQ-5D-5L index value. Equally, for the general population, higher SSS, being employed and younger age were significant predictors of SRH. In contrast to these findings, higher SSS and younger age were only significant predictors of better SRH for the proxy-report intellectual disability group.

These findings add to the existing evidence that individuals with intellectual disability have poorer SRH than the general population (Emerson et al., 2014) and are more likely to occupy low socioeconomic positions within society (Emerson & Hatton, 2014; Krahn &

Fox, 2014). While the intellectual disability population had lower MacArthur SSS scores than the general population, this study found that SSS was associated with SRH in the proxy reported intellectual disability group, and likely to reflect people with greater intellectual disabilities. The relationship between SS and health held after accounting for demographic and objective socioeconomic status indicators in the general population; a finding consistent with international evidence (Präg et al., 2016). Notwithstanding this, it should be kept in mind that the self-report intellectual disability sample was small in this study and the lower distribution of MacArthur scores

TABLE 3 Binary logistic regression analysis: associations between demographic, objective and subjective socioeconomic status and self-rated health

General population (Nagelkerke R^2 .211)						
Model 1	β	S.E.	Wald's X^2 (df 1)	Sig.	OR	95% CI for odds ratio
SSS Ladder	-.254	.039	43.453	<.001	.775	.719-.836
Income	.266	.246	1.172	.279	1.305	.806-2.113
Employment	-2.031	.309	43.100	<.001	.131	.072-.241
Education	-.219	.231	.901	.343	.803	.510-1.263
Age	.017	.008	5.032	<.001	1.017	1.002-1.033
Gender	.095	.174	.299	.584	1.100	.782-1.547
Constant	.496	.648	.587	.443	1.643	
Model 2 Combined Intellectual Disability Population (Nagelkerke R^2 .127)						
SSS Ladder	-.116	.084	1.909	.167	.890	.755-1.050
Income	-.327	.549	.355	.551	.721	.246-2.116
Employment	-.662	.506	1.709	.191	.516	.191-1.392
Education	.031	.708	.002	.965	1.032	.258-4.130
Age	.034	.012	7.753	.005	1.035	1.010-1.060
Gender	-.082	.361	.051	.821	.921	.454-1.869
Constant	-1.444	.918	2.475	.116	.236	
Model 3 Proxy-report Intellectual Disability Population (Nagelkerke R^2 .112)						
SSS Ladder	-.223	.111	4.049	.044	.800	.644-.994
Income	-.768	.873	.774	.379	.464	.084-2.568
Employment	-.564	.856	.434	.510	.569	.106-3.048
Education	-20.13	28037.50	.000	.999	.000	.000-
Age	.031	.014	4.650	.031	1.031	1.003-1.061
Gender	-.151	.450	.112	.737	.860	.356-2.077
Constant	-.433	1.265	.117	.732	.649	

Note: Bold value indicates statistical significance.

would suggest that it would be sensible to undertake further research in larger intellectual disability samples. This is of particular importance as SSS offers the potential to reveal the effects of social hierarchy on health (Singh-Manoux et al., 2005) given its association with a range of health markers and physical health, as well documented in the literature (Cundiff & Matthews, 2017; Singh-Manoux et al., 2003; Singh-Manoux et al., 2005).

Other considerations also need to be taken into account when determining the findings of this study, particularly when the relationship between SSS and SRH in the proxy report population is observed but not in the self-report population. For example, the self-reporting nature of what SSS means to people with an intellectual disability is an important deliberation. In the early examination of this area of research, Jackman and Jackman (1973) reported that SSS refers to the individual's perception of 'his' position in the social hierarchy. Therefore, it is theoretically plausible that due to social disconnectedness, isolation and other negative life events that this population often experiences (Amado et al., 2013; Emerson, 2021) many people with intellectual disability experience a social hierarchy that is shaped by limited and atypical life experiences and this may impact what SSS

means for this population. This may be in direct contrast to the proxy respondents who may have an altogether different experience. This is worthy of further critique given that SSS largely represents the nuances of a person's social position (Adler et al., 2000; Adler & Stewart, 2007). Furthermore, as this is one of the first studies to use the MacArthur Scale of Subjective Social Status in a total population of adults with intellectual disability, the suitability of this measure needs further examination. While there is no question that people with an intellectual disability should be the primary source of comment on their perceived social status, opinions, feelings and thoughts (Kooijmans et al., 2022) and indeed this is well established as being the case (Emerson et al., 2013), in the general intellectual disability literature there remains a paucity of psychometrically sound self-reporting measures (Vlissides et al., 2017) and this needs to be accounted for. It is therefore reasonable to conclude that further research is required to examine the psychometric properties of this measure to determine the reliability of the MacArthur Scale in this population.

Nevertheless, the results of the study also clearly highlight the importance of employment for all people. Being employed was a

TABLE 4 Multiple regression using the stepwise procedure across the general and intellectual disability populations

EQ-5D-5L index value			Unstandardized coefficients		Standardised coefficients	95.0% confidence interval for B		R ²	Δ R ²	Durbin-Watson statistic
			B	Std. error	Beta	Lower bound	Upper bound			
General Population	Model							.237	.235	1.977
	1	(Constant)	.498	.019		.461	.536			
		Employment	.346***	.020	.436	.308	.384			
	2	(Constant)	.446	.020		.407	.484			
		Employment	.304***	.020	.384	.266	.343			
		SSS Ladder	.017***	.002	.201	.013	.021			
	3	(Constant)	.515	.028		.461	.570			
		Employment	.297***	.020	.374	.258	.335			
		SSS Ladder	.017***	.002	.203	.013	.021			
		Age	-.001***	.000	-.085	-.002	-.001			
	4	(Constant)	.537	.030		.479	.595			
		Employment	.279***	.021	.352	.237	.321			
		SSS Ladder	.017***	.002	.196	.012	.021			
	Age	-.001***	.000	-.083	-.002	-.001				
	Income	-.031***	.014	-.057	-.060	-.003				
Intellectual Disability Self Report	Model							.149	.121	1.603
	1	(Constant)	.759	.030		.698	.819			
		Employment	.116*	.046	.304	.024	.209			
	2	(Constant)	.905	.079		.748	1.063			
		Employment	.120**	.045	.313	.029	.210			
	Age	-.004*	.002	-.237	-.008	.000				
Intellectual Disability Proxy Report	Model							0.094	0.085	1.428
	1	(Constant)	.519	.036		.448	.591			
	Employment	.351***	.107	.306	.138	.563				

Note: Model = 'Stepwise' method in SPSS; R 2 = coefficient of determination; ΔR² = adjusted R2. *p < .05. **p < .01. ***p < .001.

significant predictor of better health in this study over and above any other indicators for people with an intellectual disability. Although this supports the well-established link between employment and health in the general population (Ross & Mirowsky, 1995) there is a very limited amount of research that has focused on health outcomes of employment for adults with intellectual disability (Dean et al., 2018). While both Robertson et al. (2019) and Emerson et al. (2018) have identified that the association between employment and better health is similar for adults with and without intellectual disabilities, the evidence is inconsistent. Conversely McGlinchey et al. (2013) identified that employment status was only significantly related with health status when no other variables were controlled for. When variables such as age, level of intellectual disability, gender and residence were considered, employment did not predict health status.

Additionally, while our results find a link between employment and better health, it is difficult to make inferences to determine if

employment is a cause of better health, or a consequence of better health. That is to say, healthier people with intellectual disabilities are more likely to be in employment and employment also brings health benefits. Therefore, it is probably reasonable to conclude that remarkably little is known about this relationship in the intellectual disability population (Emerson, 2007) and therefore these results should be interpreted with caution.

Notwithstanding this, it is of particular interest that our study observed that of all of those unemployed, people with intellectual disability had higher mean scores on the SSS ladder scale than the general population. This may suggest that unemployment is a common socioeconomic disadvantage experienced by this population (McMahon et al., 2019) and consequently, it may not alter SSS ladder scores to the same as it did in the general population, thereby reinforcing the adaptation to persistent deprivation that these individuals may experience. Finally, for the intellectual disability self-report group,

younger age was associated with better health on the EQ-5D-5L. However, this needs to be considered from the perspective that people with intellectual disability are more likely than their peers to experience increased morbidities at a younger age (Heslop et al., 2014; McMahon & Hatton, 2021) and when considered through the lens that this sample was approximately 18 years younger than the general population, this may account for this difference.

5 | LIMITATIONS

When considering these results the following six limitations need to be kept in mind; (1) these findings apply only to the administratively defined intellectual disability population in Jersey, while there may also be adults with intellectual disability not known to services who were not included; (2) the sample sizes are unequal and as can be observed from the results the magnitude of the differences between the medians across the intellectual disability populations for the SSS ladder is large. This is, in effect a result of the small sample size for the intellectual disability populations; (3) there was only a 30% response rate and there was a high number of respondents who were retired. However, it needs to be acknowledged that this is representative of the general population in Jersey; (4) as this study used two different methods to recruit participants, it is theoretically that people with an intellectual disability also completed the general population survey. To account for this, a variable was included in the survey to indicate if the returned survey was completed by someone with an intellectual disability. Nonetheless, given that general population cohort surveys are generally wholly exclusive for individuals with intellectual disabilities with greater needs, the methods used in this study were reasonable adjustments to include as many people as possible with intellectual disabilities; (5) the use of proxy subjective measure such as the SSS ladder is of questionable utility as a proxy measure and, (6) the psychometric properties of the SSS measure have not been examined in the intellectual disability population, and (6).

Notwithstanding these limitations, this is the first study that has considered the concept of subjective socioeconomic status in the intellectual disability population. Our results identify that while the SSS ladder shows promise, at this stage it is only related to SRH in the proxy intellectual disability group. Further research is needed to explore its utility further.

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CONFLICT OF INTEREST

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on reasonable request from the corresponding author. The data are not publicly available due to ethical restrictions.

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Chapter 10: Discussion Chapter

10.1 Introduction to chapter

It is well known that health follows a gradient where higher socioeconomic status is associated with better health (Marmot, 2005b; Singh-Manoux et al., 2003). The order of the research studies in my thesis is intended to tell a story about the health and socioeconomic circumstances that adults with an intellectual disability experience in Jersey. Essentially, this research has posited that all inequality is not created equal and it is clear people with an intellectual disability are disproportionately disadvantaged from a health and general socioeconomic status perspective in comparison to the general population. It is equally clear that for people with an intellectual disability, many forms of inequality aggravate each other and as a result compound the cumulative effects of their exposure to inequality (Crenshaw, 2017). This was illustrated in Figure 3 (Chapter 1).

The factors that influence health were also set out in the introductory chapter of this thesis and contextualised through the Dahlgren-Whitehead rainbow model (Dahlgren & Whitehead, 1991). While the studies in my thesis have not addressed all aspects of this model, nor did they intend to given the parameters they occupy, they have identified that when people with an intellectual disability are placed at the centre of the model, there are many non-medical factors that influence the health of this population. The use of this model has allowed me as a researcher to understand, examine and explain how economic, environmental and social inequalities are associated with the health of people with an intellectual disability. Table 14 maps the relationship between the findings^{****} of this thesis and the Dahlgren and Whitehead model of health determinants^{§§§§}.

**** Not all findings in this thesis are aligned to the Dahlgren and Whitehead rainbow model and a summary of all findings is presented for each study in the discussion section under each study.

§§§§ As this research did not examine individual and lifestyle factors this is excluded from Table 14.

Table 8. An overview of how the findings in this thesis are aligned to the Dahlgren and Whitehead rainbow model

Dahlgren and Whitehead determinants	Finding from study	McMahon & Hatton (2021a)	McMahon et al. (2020a)	McMahon et al. (2021b)	McMahon et al. (2019)	Study 5 – scoping review	McMahon et al. (2022)
Age, sex and constitutional factors	People with intellectual disability in Jersey are living with greater levels of health problems than the general population (for example, <i>viral and infective diseases, diseases of the blood, endocrine, nutritional and metabolic conditions, mental health illnesses and behavioural problems, neurological conditions, diseases of the eye, diseases of the respiratory system, diseases of the digestive system, diseases of the skin, diseases of the genitourinary system, malformations or genetic problems</i>)	X					
	People with intellectual disability in Jersey are living with greater levels of health problems than the general population at a younger age on a like-for-like matched sample comparison	X					
	45.7% (n = 97) of participants with intellectual disability were prescribed one class of psychotropic drug, and a further 23% of participants (n = 50) were exposed to psychotropic polypharmacy (range 2–6). Being male was associated with being exposed to psychotropic polypharmacy.		X				
	In people with an intellectual disability, polypharmacy was associated with greater severity of intellectual disability, epilepsy, having a psychiatric diagnosis over the life course and having more health problems		X				
	Women with an intellectual disability are more likely to have mental health and behavioural disorders in comparison to the non-disabled female population, they are more likely to experience potential DDIs of clinical significance (despite being less likely to experience psychotropic polypharmacy) be	X		X			X

	unemployed in comparison to men with an intellectual disability and report lower subjective socioeconomic status (SSS)*****.							
Social and community networks	87% of adults with intellectual disability were currently single vs 16 per cent of adults without intellectual disability					x		
	People with intellectual disability reported lower SSS than the general population						x	
General Socioeconomic. Cultural and environmental conditions	23% of working-age adults with intellectual disability were in paid employment vs 92 per cent of working-age adults without intellectual disability					x		
	57% of adults with intellectual disability lived-in sheltered housing vs 2 per cent of adults without intellectual disability					x	x	
	Being unemployed was associated with lower SSS for persons with an intellectual disability who consented to participate independently						x	
	People with intellectual disability were more likely than the general population to have low incomes of under £15,000 per year (for example 22% [n=476] of the general population earned less than £15,000 while 86% [n=187] of the intellectual disability population earned less than £15000).							x
	38.2% (n=83) of participants with intellectual disability were exposed to polypharmacy (≥5 medications) and this was associated with living in residential care, being unemployed			x				
	In people with an intellectual disability, psychotropic polypharmacy was associated with unemployment and lower socioeconomic status			x				
	One hundred and five participants (69% of persons prescribed two or more medications) with an intellectual disability had at least one potential DDI of clinical significance (mean = 4.94 SD = 4.84, range 1–25). People with an intellectual disability who live in residential care are vulnerable to developing				x			

***** Subjective socioeconomic status is abbreviated as 'SSS' throughout this chapter.

	adverse drug reactions from potential drug-drug interactions of clinical significance. This risk increases for every drug prescribed.						
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Explaining these findings using this model as an analytic tool is achieved throughout this chapter in the following ways:

- Study one sets out that people with an intellectual disability have greater health needs than the general population and these health problems start at a younger age and continue throughout life.
- Study two examines the concepts of polypharmacy and psychotropic polypharmacy. Essentially, this tells the story of the health needs of the intellectual disability population in a different way, insofar as high rates of drug use is, in part, a consequence of the high levels of multimorbidity in the intellectual disability population.
- Study three identifies and examines an under researched and largely unconsidered topic concerning potential drug-drug interactions (DDIs). As far as I am aware, this is the first study that describes the prevalence, patterns and associations of potential DDIs of clinical significance in a representative sample of people with an intellectual disability. From a 'real world' perspective this has important implications for people with an intellectual disability and indeed the health and social care community more broadly who prescribe, administer and support these individuals given the exposure to high levels of medication that this population experience.
- Study four identifies that this population are less likely to experience an ordinary life and the employment, marital status and housing profiles of adults with intellectual disability are very different compared to the general population sample. These are important aspects of life that people with an intellectual disability have reported are important to them. It is from this lens that this study illustrates the social and occupational deprivation that many people with an intellectual disability experience in Jersey despite it being an affluent society. Essentially this descriptive study illustrates the divide in

societal circumstances of people with and without intellectual disability and signals that this population are at the lower end of the societal gradient.

- Study five examines the concept of SSS in a scoping review to determine if there is any research evidence relating to the association of SSS and health amongst people with intellectual disabilities. This question is asked for two reasons. First, SSS is a robust predictor of health in the general population. Second, the use of objective measures of socioeconomic status, typically indicators addressing occupation, education and income, are potentially of limited use in this population due to the low socioeconomic position these individuals typically occupy.
- Study six examines the association of SSS and health in people with and without intellectual disability. The main findings suggest that people with an intellectual disability are more likely to occupy lower socioeconomic positions and be of poorer health. While SSS is not associated with better health for people with an intellectual disability who consented independently, being employed is. While this study does not offer any significant evidence that SSS is related to health in people who consented and reported independently, it does offer an insight into this under researched area and establishes a line of inquiry for future research, notwithstanding the fact that people with an intellectual disability reported they have lower SSS than the general population.

10.2 Layout of this chapter

This discussion chapter presents the findings from this PhD thesis and situates the contribution that these studies have made to the scientific intellectual disability literature. This is achieved in the following ways. Firstly, my original and unique contribution is set out to demarcate the incremental importance and significance of this work. This includes what new ground has been addressed in my research that has not been addressed in the intellectual disability literature. Secondly, the findings

from each study in this thesis are set out and considered in a general discussion to critically analyse the meaning of this research more broadly and to demonstrate the systematic understanding of this area of research and practice. Studies one to four are addressed individually while studies five and six are discussed and evaluated together. It is important to indicate that the objective of this chapter is not to repeat each argument that is contained within the discussion section of each study, rather a higher order general discussion is constructed with a specific emphasis on what this research means. Thirdly, the interconnected nature of these findings are considered from a health inequality perspective, where the question of 'what these findings mean?' is examined. Fourth, the strengths and limitations of this research are set out. Finally, this chapter concludes with an overview of the implications of what this research means from a 'real world' policy, practice and research perspective and a personal reflection on the experience of undertaking my PhD.

10.3. Original contribution to knowledge

It is important to highlight that the sampling methodology used in this thesis is unique owing to the infrequency of its use in the intellectual disability arena due to time, logistical and budget constraints. The use of the total administrative population sample of adults with intellectual disability and a representative random stratified comparator sample that captures the entire population is a real strength that adds to the robustness of the findings. From this perspective, this work has advanced intellectual disability scholarship in six ways:

1. In the McMahon and Hatton (2021a) study, the results consolidate and extend the existing health inequality research illustrating the prevalence of ill health in this population that starts early in life and continues on this trajectory. This study increases the international evidence by presenting a coherent picture of the differences in health experienced by people with an intellectual disability (for example people with intellectual disability are less likely to have cancers) in Jersey and illustrating the gender differences that this population experience. In particular, females with an intellectual disability

were significantly more likely to have mental illness and behavioural disorders but less likely to have diseases of the ear than females without an intellectual disability. Robertson et al. (2015) identified that there is a significant lack of evidence on physical health conditions in adults with intellectual disability with most studies focusing on single conditions. This study advances this scholarship and understanding of this area by taking a broad overview of classifying the prevalence of different disorders using ICD-10 categories while also identifying the health of people with and without intellectual disability in Jersey.

2. The McMahon et al. (2020a) study uses a population based study to examine patterns and prevalence of polypharmacy and psychotropic polypharmacy. In doing so, this study reports the prevalence of polypharmacy and psychotropic polypharmacy and identifies variables that are associated with this, in particular, the association between polypharmacy and lower socioeconomic status and men being more exposed to psychotropic polypharmacy. This study makes a distinctive contribution to the evidence base as most studies have focused on psychotropic drug use only (Bowring et al., 2017a; Sheehan et al., 2015), and had samples drawn from older populations (O'Dwyer et al. (2016) or from non-representative populations (Emerson et al., 2016). This study clearly identifies the prevalence and patterns of medication use in this population and identifies a subset of the population who are particularly vulnerable. The findings from this study provide the framework to take action at a local and national level and it also directs future research in this area to extend the scholarship further by focusing on these sub-populations.
3. As far as I am aware, the McMahon et al. (2021b) study is the first study to examine the concept of potential DDI in a representative sample of adults with intellectual disability. Other studies in this area, for example Joos et al. (2016), Floch et al. (2018), and more recently, the LeDeR report (2020) are not representative samples and therefore this contribution provides solid evidence in this limited area of investigation. This study makes a significant

contribution from a scholarship perspective and also from a practical clinical perspective as it highlights that just under half of this total administrative sample had at least one potential DDI of clinical significance. This study has illustrated that the prevalence of potential DDI increases with the number of medications prescribed. For example, every prescribed drug led to a 0.87 (95% CI: 0.72-1.00) increase in having a potential DDI of clinical significance. Furthermore, in contrast to women being less likely to be exposed to psychotropic polypharmacy (McMahon et al., 2020a), this study outlines that women are more likely to be exposed to potential DDIs of clinical significance, clearly signalling an at risk population.

4. Fourth, the scoping review identified that no previous study has used a robust SSS measure to investigate associations between SSS and health amongst people with intellectual disabilities. This review identified a clear gap in the evidence base and calls for the examination and application of SSS and its association with health in the intellectual disability population.
5. The McMahon et al. (2022) study found that SSS is related to self-rated health (SRH) in the general population and the proxy intellectual disability population but not for people with an intellectual disability who consented independently. While SSS was associated with SRH in the proxy respondents, given that the proxy respondent is a member of the general population *per se*, these results suggest the need for further research and deeper reflection on the meaning of SSS for adults with intellectual disability.
6. The sixth and final contribution in the McMahon et al. (2022) study sets out that after adjusting for confounders, employment is associated with better health for all groups irrespective of intellectual disability. While the mechanisms of this are uncertain, that is to question if employment is a cause or consequence of good health, it is clear that employment is positively associated with increased levels of health as measured by the objective EQ-5D-5L index values. Furthermore, it is important to identify that as a society

we do not need to know the precise mechanisms to act and therefore creating employment opportunities for adults with an intellectual disability signals a very important and actionable area to improve the wellbeing of this population.

10.3.1 New ground addressed in this thesis

As identified above, in Table 14 and section 10.3 this research has advanced the scholarship in a number of ways. While some of the findings in my thesis support, complement and extend the existing intellectual disability research, this thesis has also encroached into entirely new ground in respect of SSS and its relationship with health in the intellectual disability population. No previous research has been published that examined this association, and while the scoping review (study 5) is unpublished, I am aware of no other published research to date that addresses this topic in the area of intellectual disability. This makes the contribution of my work novel, and even though the findings are not wholly conclusive, they do extend the evidence base. This is an important aspect as understanding the interplay between SSS and health is an important consideration that should be prioritised given the atypical socioeconomic position that many people with an intellectual disability occupy in society.

Additionally, the impact of potential DDIs of clinical significance in the intellectual disability population was also new ground at the time of publication in May 2021. My study was the first to identify the prevalence, patterns and associations of potential DDIs of clinical significance in a total and representative population of adults with an intellectual disability. These findings highlight the potential clinical implications of DDIs and in this vein, extend the evidence into a new sphere given that this is an under-researched and under-considered issue in this area of practice. This has particular importance given the potential for real harm that DDIs may cause an already exposed population to the negative impacts of taking multiple medications.

10.4. Summary of findings and general discussion

Study 1: A comparison of the prevalence of health problems among adults with and without intellectual disability: A total administrative population study (McMahon & Hatton, 2021a)

This research study compared a total administrative population of people with intellectual disability and a comparison random stratified sample of people without intellectual disability on the island of Jersey. The sample used in this study is robust and this is a real strength of this study. In the intellectual disability literature, having a comparator group that is representative of the population under investigation is unique. The main findings from this study extend the evidence and set out that adults with intellectual disabilities have considerably greater prevalence rates of viral or infective diseases; diseases of the blood; endocrine, nutritional and metabolic conditions; mental health illnesses and behavioural disorders; neurological disorders; diseases of the eye; diseases of the respiratory system; diseases of the digestive system; diseases of the skin; diseases of the genitourinary system; and malformations or genetic problems. Adults with intellectual disability were less likely to have cancers and diseases of the musculoskeletal system. No difference was observed in prevalence rates for diseases of the ear, diseases of the circulatory system or injuries to the body as a result of trauma or poisoning. Furthermore, my results indicate that people with an intellectual disability experience greater levels of ill health at a younger age and they also experience a greater number of health problems throughout their life course. Given that my results identify that such systematic differences exist between the intellectual disability and general population health in Jersey, it is reasonable to conclude that this constitutes a health inequality. This is especially true as such differences are not inevitable or fixed and can be improved through targeted interventions (Kings Fund, 2022).

These results underline the importance of regular health screening for people with an intellectual disability from a proactive perspective in order to identify and manage the health needs of this population. Systematic reviews (Robertson et al., 2011) (Robertson et al., 2014) have consistently identified that undertaking health checks

has provided evidence of targeted actions to address identified common and serious health needs of this population. Equally, undertaking annual health checks in people with an intellectual disability is a recognised reasonable adjustment (Disability Rights Commission, 2006) and their importance is well highlighted in the intellectual disability literature (Carey et al., 2017; Emerson et al., 2010; Hoghton et al., 2012; McConkey et al., 2015). The major intended impact of this intervention is to reduce morbidity given its independent association with mortality in the intellectual disability population (Reppermund et al., 2020; Schoufour et al., 2018).

Since my study was published (online in July 2020) an extensive systematic review by Liao et al. (2021) that covered published material up until the 21st May 2020 reported on the prevalence and incidence of physical health conditions in people with an intellectual disability. Liao et al. (2021) cited gaps in the evidence and placed particular emphasis on the need for representative data and identified that much of the available evidence is lacking in this regard. The implications of these findings fit squarely with the need to accurately identify and respond to the health needs in this population. For example, in this study, respiratory disease (OR 1.55 95% CI:1.08-2.21, $p = 0.016$) was more prevalent in this population where cancers (OR 0.39 95% CI: 0.16-0.97, $p = 0.036$) were less prevalent in comparison to the general population. This finding is in line with mortality data where people with intellectual disability are more likely to die from respiratory disorders as opposed to neoplasms (McMahon et al., 2021c; O'Leary et al., 2018). Equally, the understanding of the prevalence of cancer in this population is complicated due to the lack of epidemiological studies and conflicting evidence (Satgé et al., 2020). Despite some studies citing similar rates of cancers in this population (Ng et al., 2017; Patja et al., 2001; Sullivan et al., 2004) a recent Swedish study (Satgé et al., 2020) reports that cancer is diagnosed less often in this population. One theory that may explain this is that people with intellectual disabilities don't live long enough to develop age related cancers or that they are diagnosed too late or not at all. This is a situation that has been reported particularly in women with intellectual disability where it has been reported they are frequently omitted from accessing cervical and breast cancer screening programmes (Cobigo et al., 2013). From a respiratory disease perspective,

a recent meta-analysis examining this described that people with intellectual disabilities experience excess respiratory-associated deaths, with a respiratory mortality nearly 11 times more than the general population and identified a pooled standardised mortality rate for pneumonia of 27 compared to the general population (Truesdale et al., 2021). This meta-analysis calls for urgent action to construct and implement evidence-based guidelines to reduce premature mortality among people with intellectual disabilities. Previous research on this topic (Robertson et al., 2018) has cited dysphagia as being a primary contributor to respiratory disease and reports that it often goes unrecognised. It is therefore of critical importance that the respiratory needs of this population are thoroughly assessed, appropriately managed and maintained accordingly.

Furthermore, data from the McMahon and Hatton (2021a) study also indicate that this population were also more likely to have viral or infective diseases (OR 3.3 95%CI: 1.90-5.81 $p < 0.001$). While this data was collected pre-COVID-19, it is a significant concern and illustrates the risks and vulnerability of this population and how they may be disproportionately impacted by the global pandemic. For example, a Dutch study (Cuypers et al., 2020) examined excess mortality during the 2017-2018 influenza epidemic and found that excess mortality was three times higher for people with intellectual disability. This reality is now being borne out in recent publications that report that people with intellectual disability were more likely to be disproportionately impacted and die from COVID-19 (Das-Munshi et al., 2021; Public Health England, 2020; Henderson et al., 2021; Landes et al., 2021c; Lunskey et al., 2021; Office for National Statistics, 2021; Williamson et al., 2021).

While being at risk is a real concern in itself, another issue identified in a recent study addresses UK hospitals and their management of people with intellectual disability presenting with COVID-19 in comparison to a control general population cohort. Baksh et al. (2021) identified that while people with an intellectual disability were admitted to hospital with greater respiratory rates and were more likely to require oxygen therapy, they were less likely to receive non-invasive respiratory support, less likely to be incubated and less likely to be transferred to ICU than the

general population control group (intellectual disabled group n=506, matched cohort study with a 1:3 ratio). It is therefore not difficult to conclude why Baksh et al. (2021) calculated that these individuals died 1.44 times faster (95% CI 1.13 to 1.84) compared to controls. This is a significant inequality incongruent with Article 25 of the Convention of Rights for Persons with Disabilities that specifies that “persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability” (United Nations, 2006, para 1). A recent review by McCormick et al. (2021) examining the experiences of adults accessing hospital services has reported equally worrying findings. In sum, this review identified that there is evidence to suggest that healthcare professionals continue to lack knowledge or awareness of people with intellectual disabilities. The consequence of this results in poor communication and information sharing which puts persons with an intellectual disability at risk.

Another finding in the McMahon and Hatton (2021a) study concerns gender – findings in this study indicated that females are more likely to have cancers and circulatory disorders but less likely to have endocrine, nutritional and metabolic disorders, mental illness and behavioural disorders or neurological disorders than men with intellectual disability. Females with an intellectual disability were significantly more likely to have mental illness and behavioural disorders but less likely to have diseases of the ear than females without an intellectual disability. The association of being female and mental illness has previously been identified in the literature. The largest study to find a similar association comes from a Scottish study (Cooper et al., 2007) with a robust methodology that included comprehensive case ascertainment procedures, a large cohort sample and detailed assessments.

Nonetheless, the issue of gender, ill-health and mortality in this population is not clear (Robertson et al., 2021) but women with intellectual disabilities are reported to experience greater inequality regarding mortality than men do compared with their general population counterparts (O’Leary et al., 2018). While this has been borne

out in a number of studies (Florio & Trollor, 2015; Glover et al., 2017; Ouellette-Kuntz et al., 2015), the evidence is insufficient⁺⁺⁺⁺⁺.

In an attempt to improve the evidence in this area, Robertson et al. (2021) recently undertook an International Expert Consultation (n=18) to seek the views of international experts concerning evidence relating to female gender and the premature deaths of people with intellectual disabilities and to ascertain their observations on priorities for future research. They identified that while research should focus on cause-specific death rates and age trends in mortality compared to the general population, further evidence on gender and mortality is urgently needed.

Study 2: Polypharmacy and psychotropic polypharmacy in adults with intellectual disability: a cross-sectional total population study (McMahon et al., 2020a)

In summary, people with intellectual disability are prescribed more medication than people without intellectual disability. While medication use is a worthy indicator of morbidity, for people with intellectual disability this is often complicated as they are often prescribed psychotropic drugs, particularly antipsychotic drugs, in the absence of a mental illness. From this perspective, McMahon et al. (2020a) sought to determine the prevalence and patterns of polypharmacy and psychotropic polypharmacy and to examine the relationship between polypharmacy and psychotropic polypharmacy, and socio-economic status, health and demographic variables in a total population sample of adults with intellectual disability.

The findings of this study highlight that polypharmacy and psychotropic polypharmacy are common. For example, nearly 40% (n=83) of all participants were exposed to polypharmacy (≥ 5 medications) and over 12% (n=33) were exposed to excessive polypharmacy (≥ 10 medications). Over 45.7% (n=97) of participants were prescribed one class of psychotropic drug, and a further 23% of participants (n=50) were exposed to psychotropic polypharmacy (range 2–6). Where people were

⁺⁺⁺⁺⁺ Studies presented in Table 2 (Age at death for people with intellectual disability from 1931-2021 from selected studies) also adds to this argument given the varying findings regarding the mean and median age of death for men and women.

prescribed antipsychotic medications (n = 55), these medications are often prescribed above the defined daily dosage (DDD). Bivariate comparisons indicated that polypharmacy was associated with being aged over 50 years, living in residential care, having a severe intellectual disability, being unemployed, having a lower SES score, having epilepsy, being diagnosed with a psychiatric diagnosis over the life course, having poorer SRH and having a greater number of health illnesses (as measured by the ICD-10 in the McMahon & Hatton (2021a) study). For psychotropic polypharmacy, bivariate comparisons indicated that being over 50 years, being unemployed, having a lower SES score, having Down syndrome, having a psychiatric disorder over the life course and more health needs were statistically significant.

Finally, this study identified that (using binary logistic regression) younger age (below 50 years), having a less severe intellectual disability (mild/moderate intellectual disability) not living in residential care and having fewer ICD-10 conditions were associated with no polypharmacy exposure. For psychotropic polypharmacy, younger age (50 years and younger) being female and not being diagnosed with a psychiatric diagnosis over the life course were associated with no psychotropic polypharmacy.

When considering these findings, it should be kept in mind the influence of socioeconomic status as a predictor of polypharmacy and psychotropic polypharmacy. For example, while the bivariate comparisons found a significant relationship between socioeconomic status and polypharmacy and psychotropic polypharmacy, in the adjusted analysis, all socioeconomic status variables did not reach statistical significance once health and personal characteristics were accounted for. This is an important consideration given the typically low variation in socioeconomic status indicators in this population. From this perspective, this finding should not be generalised and its value of being or not being a predictor of polypharmacy and psychotropic polypharmacy is questionable. While its inclusion in future analysis warrants consideration, the study cannot say if it has a place in future analysis; rather, this research cautions its utility if future studies typically see

the same low variation observed as in this research. This should be addressed in a sample-by-sample basis.

Nonetheless, this study conveys the concerning reality of a total population of people with an intellectual disability. In simple terms, given the representative sample of adults known to services, eight out of every ten adults are prescribed at least one medication (mean = 4.58, SD = 4.42) and nearly every second person is prescribed a psychotropic drug. This is well aligned to the notion that persons with an intellectual disability are one of the most medicated groups in society (Häßler et al., 2015; O'Dwyer et al., 2018; Peklar et al., 2017) and given that polypharmacy is independently associated with mortality in this population, this is particularly stark (Schoufour et al., 2018). Although the evidence for this is extensive and largely consistent (Bowring et al., 2017a; de Kuyper et al., 2010; Haider et al., 2014; Holden & Gitlesen, 2004; Matson & Neal, 2009; O'Dwyer et al., 2016; Scheifes et al., 2013; Sheehan et al., 2015; Tsiouris et al., 2013), debate has arisen regarding the actual prevalence of polypharmacy in people with an intellectual disability, with rates varying from 11% to 60% (Stortz et al. 2014). The McMahon et al. (2020a) study advances the evidence in this regard.

While the polypharmacy associations identified in this study are aligned (for example older age and increased comorbidities), the narrative surrounding polypharmacy is not just confined to the intellectual disability population. Research concerning polypharmacy and excessive polypharmacy (which can also be referred to as hyperpolypharmacy) in older adults is extensive, contentious, contested and conflicting (Davies et al., 2020). Principally, there is much debate surrounding what polypharmacy actually is. In the McMahon et al. (2020a) study, polypharmacy is operationally defined as taking five or more medications. This is one of the most commonly used numerical definitions.

In a systematic review of the literature, Masnoon et al. (2017) identified 138 definitions of polypharmacy of which numerical definitions represented 80.4% (n=111) of all definitions, with five or more medications accounting for over half of

these. It is therefore understandable how this is a complex issue and herein lies the difficulty. It is argued that there needs to be a shift away from the numerical classification of polypharmacy to a sphere where the concepts of 'appropriate' and 'inappropriate polypharmacy' are used (Hughes, 2021) as until polypharmacy is understood in a more clinically relevant manner, the adverse consequences linked with it will not be fully understood (Davies et al., 2020). This too, while appearing to be a coherent and sensible approach is also fraught with difficulty. More specifically, a Cochrane review by Rankin et al. (2018) identified that there was minimal evidence supporting how to achieve appropriate polypharmacy. Subsequently, if there is no robust evidence of how to achieve appropriate polypharmacy and reduce potentially inappropriate prescribing, when this is considered within the context of the results for the adjusted regression modelling in the McMahon et al. (2020a) study, it becomes clear why this is difficult. For example, the people who are frequently exposed to polypharmacy are generally people who have more severe intellectual disabilities, are older, live in residential care, have more health conditions and this creates difficulties for prescribers and persons involved in the supporting these individuals.

On an adjacent level, when the concept of psychotropic polypharmacy is considered, the situation becomes more complex. The McMahon et al. (2020a) study highlighted the concept of 'off label' prescribing where individuals are potentially being prescribed psychotropic medications to manage challenging behaviour, a common phenomenon reported in this population (Bowring et al., 2017a; Henderson et al., 2020). Additionally, a very recent study has identified that the COVID-19 pandemic may have caused an increase in psychotropic prescribing in this population in England (Naqvi et al., 2022), a phenomenon also described by Perera et al. (2020) in an analysis of 66 deaths from COVID-19 in people with an intellectual disability in England and Ireland.

It is therefore imperative that in order for the population of people with an intellectual disability to shift from being one of the most medicated groups in society to experiencing clinically appropriate [psychotropic] polypharmacy which is beneficial,

there needs to be a shift away from current practices. Again, in the intellectual disability sphere this is difficult, as to date, no evidence based research has developed a tool to identify potentially inappropriate prescribing (O'Dwyer et al., 2018). This may in part be explainable as prescribing guidelines are commonly derived from randomised controlled clinical trials which have specifically excluded certain populations (Curtin et al., 2019). As outlined in the McMahon and Hatton (2021a) study, people with intellectual disability experience neurological disorders 8.8 times more frequently than the general population and in the McMahon et al. (2020a) study, the use of anti-epileptic drugs was common. However, in a recent systematic review of the literature to identify measures which identify side effects of anti-epileptic drugs, out of 108 tools identified, only two were found to be potentially appropriate for use in this population (Copeland et al., 2017). This fairly typically highlights the gap in the evidence base in this area and this is particularly acute in this example as people with intellectual disability are 20 times more likely to have epilepsy than the general population (Robertson et al., 2015).

While it is welcome that there have been recent improvements in this area in the UK regarding STOMP and STAMP^{*****} initiatives, (Branford et al., 2019; NHS 2017) it is argued that it is not just psychotropic drugs that need monitoring, it is also important to monitor potentially inappropriate medication use more broadly. In the general older persons literature two of the most frequently reported tools are the Beers criteria (Campanelli, 2012) and the screening tool of older persons' potentially inappropriate prescriptions (STOPP) (O'Mahony et al., 2014) to characterise overall prescribing quality, including explicit prescribing indicator sets. Given their use and success in the older population (Grace et al., 2014), this clearly signals an avenue for further research in the intellectual disability arena.

Nevertheless, the evidence base in this area is again limited. One pilot study in the Netherlands (Zaal et al., 2016) has used a modified STOPP tool, referred to as the

^{*****} STOMP—STAMP Stopping over medication of people with a learning disability, autism or both and Supporting Treatment and Appropriate Medication in Paediatrics) stands for stopping over medication of people with a learning disability, autism or both with psychotropic medicines

STRIP tool (Systematic Tool to Reduce Inappropriate Prescribing), to identify drug-related problems in this population. While this observational study was small (n=27) and although it did show promise, the implementation of recommendations by the prescriber (physician) was low and after six months only 15.7% of recommendations were implemented. Consequently, the McMahon et al. (2020a) draws on the recommendation by (Cadogan et al., 2016) that outlines that there is a critical need for careful medication reviews and these should embrace the concepts of multidisciplinary collaboration, medication optimisation and deprescribing where appropriate alongside, and in consultation with the person with intellectual disability and their significant others. Furthermore, the biological, physical, social, environmental and psychological needs of the individual need to be at the forefront of all prescribing decisions as the interface between them influences outcomes. Taking such an approach should help improve the quality of life for the person and reduce the potential of prescribing cascades^{§§§§§§} to further reduce the risk of side effects and interactions (O'Dwyer et al., 2018). This is a particularly important consideration as a recent study has identified that for people with an intellectual disability they were more likely than the general population to have a hospital admission (OR 1.28: 95% CI 1.19–1.38) (Erickson et al., 2020).

Study 3: The prevalence of potential drug-drug interactions (DDIs) in adults with intellectual disability (McMahon et al., 2021b)

Considering the aforementioned complexities outlined in the McMahon et al. (2020a) study, this McMahon et al. (2021b) study builds on the previous study and describes the prevalence, patterns and associations of potential DDIs in a total administrative sample of adults with intellectual disability known to services in Jersey. DDIs are an important consideration in this population as people with an intellectual disability are more likely to have multiple health conditions, take multiple medications and have communication difficulties. The findings from this study identified that potential DDIs of clinical significance were common. For example, 519 potential DDIs of clinical

^{§§§§§§} A cascade is when a drug is prescribed, an adverse drug event occurs that is misunderstood and diagnosed as a new medical condition, and a subsequent drug is prescribed to treat this drug-induced adverse event (Rochon and Gurwitz, 2017).

significance were identified in this study. Of these pairings 199 needed to be avoided, adjusted or required close monitoring, and 320 of these pairings required further information regarding potential interactions and adverse effects. Exposure to potential DDIs of clinical significance was associated with being female, taking more than five medications (polypharmacy), living in residential care and having more health conditions. Every prescribed drug led to a 0.87 (95% CI 0.72–1.00) increase in having a potential DDI of clinical significance.

Since the McMahon et al. (2021b) study was published in May 2021, another study examining DDIs in the USA was published by Erickson et al. (2021). While the results are broadly similar, the USA study had a higher rates of DDIs (80% of all participants vs 50% of all participants in the (McMahon et al., 2021b)); however, these differences can be accounted for. For example, Erickson et al. (2021) did not discriminate if DDIs were clinically significant or not, whereas the McMahon et al. (2021b) study did. It is argued that this is an important distinction to make as many DDIs may be reported by drug interaction checkers where they are tolerated and not clinically significant (Preston, 2016). Therefore, without making this distinction it is highly probable that the numbers are inflated and not a true reflection of the real rate of DDIs. Equally, both studies found that polypharmacy was, but age and severity of intellectual disability were not, significantly associated with the number of DDIs. Interestingly, the USA study did not find that female gender was associated with a higher numbers of DDIs while McMahon et al. (2021b) did. This is an interesting finding that requires further examination. There is evidence from the general population that suggests that women experience more DDIs than men (Venturini et al., 2011). This is an important consideration as the physiological differences between men and women affect pharmacokinetics, with women being described as being more susceptible than men (a 1.5- to 1.7-fold greater risk) to adverse drug reactions (Drici & Clément, 2001; Rademaker, 2001; Zucker & Prendergast, 2020).

Notwithstanding these findings, the key messages from these studies suggest that the clinical implications further reaffirm that regular health checks (Carey et al.,

2017; Lennox et al., 2007; Lennox et al., 2011) and medication reviews are critically important (Axmon et al., 2017; Nabhanizadeh et al., 2019; Scheifes et al., 2016), and that this is especially necessary where individuals are prescribed antiepileptic and psychotropic drugs.

In the McMahon et al. (2021b) study the top three drugs that were involved in drug-drug combinations that could cause severe outcomes or the drug pairing combination required adjustments were Citalopram, Valproate and Risperidone. On many levels, this gives rise to a number of concerns. First, the evidence presented throughout this thesis has identified the high prevalence of drug use, particularly these categories of drugs predisposes this population to potential DDIs.

Secondly, a recent longitudinal study from Scotland (Henderson et al., 2020) identified that while fewer antipsychotic drugs are now being commenced (in the last decade), once people are commenced on antipsychotic medication they are usually not withdrawn. This clearly identifies a reluctance to stop such drugs once commenced. Furthermore, Henderson et al. (2020) illustrated the link between problem behaviour and increased psychotropic prescribing along with a remarkable increase in the prescribing of antidepressants. While the McMahon et al. (2020a) and McMahon et al. (2021b) studies were cross-sectional, the Henderson et al. (2020) study supports the findings of my studies that prescribing in this population is a contentious issue and despite some improvements this issue is far from addressed.

Third, given that potential DDIs were more common in adults who live in residential care where paid care staff (usually non-medically educated staff members) are more likely to administer such medications (Joos et al., 2014), there is an educational component to this issue, particularly given the scant evidence available in this population. It is important that staff should receive training to help understand and recognise potential DDIs along with adverse drug events especially in the absence of validated tools. Equally, given the multitude of prescribers who may prescribe for a single person with an intellectual disability it is critically important that there is clear communication between prescribers to ensure prescribing is integrated and safe.

The role of the pharmacist in this sphere is of paramount importance as they can be the co-ordinator to ensure safety and improve the quality and appropriateness of medication prescribing and use (O'Dwyer et al., 2015). Equally, further research is necessary in this area to determine the clinical impact of potential DDIs. This could be achieved by undertaking a large-scale cohort study of healthcare databases of people with intellectual disability with a particular focus on known drug interacting combinations that can be compared against clinical records.

Finally, given the complexity of polypharmacy more broadly in this population and the potential negative effects it can cause, one approach to increasing the wellbeing and reducing the medication burden in this population may be the development of a modified Patient Reported Outcome Measure (PROM) for adults with intellectual disability. This would need to be easy to comprehend, brief and contain only the most relevant questions (Kotronoulas et al., 2019). Such measures are typically *“questionnaires or related forms of assessment that patients complete by themselves or, when necessary, others on their behalf complete, in order that evidence is obtained of their experiences and concerns in relation to health status, health-related quality of life (QoL) and the results of treatments received”* (Fitzpatrick et al., 1998, p.1).

O'Dwyer et al. (2020) has recently commented that there should be a focus on developing a tool to optimise medicine use in this population, which includes targeting inappropriate use of sedative and anticholinergic medicines. While this is critically important, the findings from my study suggest that it could be argued that this should be expanded to include all classifications of medications. Nonetheless, in any event, it would be important that any tool would be underpinned by the basic PROM principles of feasibility, appropriateness, reliability, validity, responsiveness, precision, interpretability and acceptability while accounting for adjustments to meet the diverse needs of this population (for example, include visuals, examples, consider the components of consent, capacity and communication) (Copeland et al., 2017; Schwartz et al., 2018; Thornicroft & Tansella, 2010).

Study 4: Not such an ordinary life. A comparison of employment, relationship and housing profiles of adults with and without intellectual disabilities (McMahon et al., 2019)

The focus of this descriptive study was to examine the profiles of employment, marital status and housing between adults with and without intellectual disability in Jersey. These areas are seen as important priorities for adults with intellectual disability and aligned to the Convention on the Rights of Persons with Disabilities (United Nations, 2006) focusing on community inclusion. The findings from this study identified that 87% of the sample with intellectual disability were currently single versus 16 per cent of adults without intellectual disability; 23% of working-age adults with intellectual disability were in paid employment versus 92% of working-age adults without intellectual disability; and 57% of adults with intellectual disability lived in sheltered housing versus 2% of adults without intellectual disability. This study adds to the body of evidence that suggests people with intellectual disabilities are less likely to experience an ordinary life. The imbalance between people with and without intellectual disability in this study is striking but not uncommon, and this reflects the spectrum of the social status gradient that exists in society.

The Marmot (2005) review called out that inequalities in health 'exist across a range of social and demographic indicators, including income, social class, occupation and parental occupation, level of education, housing condition, neighbourhood quality, geographic region, gender and ethnicity' (p.45). Reflecting on this and the findings from the McMahon et al. (2019) study regarding the social positioning of people with an intellectual disability the rainbow model of health inequalities comes to the fore. For example, there is a social gradient in health and the lower people are on this gradient the worse their health is (Marmot, 2005a). The McMahon et al. (2019) study has clearly identified the large divide in the population in Jersey and the study demonstrates the atypical life people with an intellectual disability live and the difference in socioeconomic status that is evident. It is important to highlight that the social gradient in health does not only reflect material disadvantage. For example, Wilkinson and Pickett (2006) analysed 155 studies on income inequality

and found that while it is associated with health, it also serves as a measure of the depth of social class differences in a society. This contributes toward the understating of how the different layers of cumulative disadvantage contribute to the health inequalities this population experiences.

Nevertheless, considering the three concepts that were included in this study, relationships, housing and employment, aspects of life that people with intellectual disabilities consider important, a bleak picture emerges that further reinforces the predisposition to health inequalities that this population experience. There is strong evidence that adults with intellectual disability are socially excluded and experience loneliness (Amado et al., 2013; McCausland et al., 2016) and are therefore potentially less likely to develop relationships. People with an intellectual disability want to experience sexual autonomy (Healy et al., 2009), love (Bates, 2019) and have a relationship that provides a source of meaning (McCarthy et al., 2021). However, many people with an intellectual disability are often disadvantaged due to negative views and barriers (Martenson, 2004) and the prohibitive climate in which they live (Kelly et al., 2009).

From a housing perspective, the right to choose where one lives and who they live with is adopted in Article 19a of the UN Convention on the Rights of Persons with Disabilities (United Nations, 2006) and people with an intellectual disability should have control over their living arrangements and who provides support to them (Carnemolla, 2020). Nevertheless, this is not that straightforward. Over the last few decades there has been a clear endorsement from developed countries to promote dispersed and individualised living settings (Stancliffe et al., 2011) as these afford more choice and independence (Mansell & Beadle-Brown, 2009), with a recent systematic review citing a stable pattern identifying that moving from institutional care into the community was related to a better quality of life (McCarron et al., 2019). However, the reality of the situation is that progress has been slow. A typical example of this comes from the Republic of Ireland. In 2011 a report on

congregated settings^{*****} identified that there were approximately 4000 people living in congregated settings in Ireland (HSE, 2011) and wide ranging policy initiatives were proposed to close these congregated settings and create more independent dispersed community settings for these individuals. However, the reality is different. Ten years on a recent report from the regulator of disability services in the Republic of Ireland reports that 2,841 residents still live in congregated centres and the change in these figures does not account for expected mortality that would typically occur (Health Information and Quality Authority [HIQA], 2021). This illustrates the complexities that exist in this landscape.

From an employment perspective, the difference identified in the McMahon et al. (2019) study illustrated the stark reality for working age adults who have an intellectual disability where only 23% as opposed to 93% of the general population are in employment. Although the association between better health, particularly for depression and general mental health, and employment is well acknowledged in the general literature (Ross & Mirowsky, 1995; van der Noordt et al., 2014), the processes behind the relationship in the intellectual disability literature are not abundantly clear. While it is thought that work provides structure, meaningful goals and social connectedness, it also provides monetary reward, but there is limited evidence that has concentrated on health outcomes of employment for adults with intellectual disability (Dean et al., 2018). A systematic review by Dean et al. (2018) in this area reported that the mechanisms between employment and health are broadly similar for the intellectual disability population and despite very little research being undertaken in this domain, there is a positive relationship between employment and quality of life and employment and mental health. They do warn that the evidence base is small and that most evidence about health outcomes is related to participation in employment, and call for more research to understand these relationships. Equally, Robertson et al. (2019) indicated that there is a well-established association between employment and better health for people with

***** "Congregated settings are where 10 or more people with a disability live together in a single living unit or are placed in accommodation that is campus based. In most cases, people are grouped together and often live isolated lives away from the community, family and friends. Many experience institutional living conditions where they lack basic privacy and dignity" (HIQA, 2021, p.59-60).

intellectual disability; however, they caution that evidence establishing causality is lacking. Furthermore, Taylor et al. (2022) undertook another systematic review to determine the impact of competitive integrated employment (CIE)⁺⁺⁺⁺⁺ on the economic and health outcomes for people with an intellectual disability. Again, they found similar results insofar as there was a lack of people with an intellectual and developmental disability participating in CIE. However, their results broadly parallel other studies (Dean et al., 2018; Robertson et al., 2019) where there is a link between paid employment and better health outcomes. This review also identified that those in CIE had higher wages that resulted in greater upward mobility which brings about a range of benefits. It needs to be kept in mind that there was limited evidence available in this review and in particular, of the studies included many of the variables did not control for CIE or health outcomes as primary variables of interest. Notwithstanding this, it does appear that there are positive associations and many studies have demonstrated the association with employment and greater levels of social and civic participation (Blick et al., 2016; Emerson et al., 2014b; McGlinchey et al., 2013; Robertson et al., 2019).

Marmot (2005) is clear in his view that being in good employment is protective and unemployment contributes to poor health, and cites that this is a critical factor to reduce health inequalities. There is no reason to suggest that this is any different for people with an intellectual disability. However, caution must be expressed as Marmot (2005) uses the word 'good employment', therefore, the concepts of 'non-standard' and 'precarious' employment are a particular concern for the intellectual disability population. A study by Emerson and colleagues (2018) identified that adults with intellectual disability are more likely to experience job insecurity and those who were in non-standard employment were more likely to become

⁺⁺⁺⁺⁺ The Workforce Innovation and Opportunity Act (WIOA) defines competitive integrated employment as "work that is performed on a full-time or part-time basis for which an individual is: (a) compensated at or above minimum wage and comparable to the customary rate paid by the employer to employees without disabilities performing similar duties and with similar training and experience; (b) receiving the same level of benefits provided to other employees without disabilities in similar positions; (c) at a location where the employee interacts with other individuals without disabilities; and (d) presented opportunities for advancement similar to other employees without disabilities in similar positions" (Office of Disability Employment Policy, 2022, para.1).

unemployed; while becoming employed was associated with better health, transitioning into unemployment was associated with poorer health. Equally, Taylor et al. (2022) reported an 'hours cliff' where people with intellectual and developmental disability work no more than 20 hours a week. Consequently, there are important components of employment that need careful thought and consideration. Finally, to compound this issue further it is also important to illustrate how the COVID-19 pandemic may impact on employment for this population. For example, given that this population typically experience low levels of employment and as identified in this study they are more likely to be employed as opposed to self-employed, they may be particularly disadvantaged. A recent study from Emerson et al. (2021) which investigated the impact of employment and financial security during COVID-19 in the UK found that people with a disability were more likely than their peers to not be in employment and where they were in employment, they were working reduced hours and experiencing financial stress. This clearly signals that the situation since COVID-19 could have further deteriorated.

In sum, the McMahon et al. (2019) study has advanced the understanding of the determinants of health that people with an intellectual disability experience in Jersey. It illustrates that despite Jersey being an affluent society, the same difficulties and barriers exist there for persons with an intellectual disability as in other jurisdictions. It is also important to highlight that while the previous three studies (McMahon & Hatton, 2021a; McMahon et al., 2020a; McMahon et al., 2021b) have largely focused on health and indicators of health (by exemplifying polypharmacy and polypharmacy), this study also advances the narrative that identifies that the societal conditions in which people live, work and age all contribute to poorer health rather than a person's intellectual disability per se (WHO, 2011). Therefore, as depicted in the rainbow model, this suggests that people with an intellectual disability are disadvantaged by multiple sources on the societal and living and working conditions tiers that in turn shape the complex social and economic inequalities they experience. This is then borne out in health inequalities (Emerson & Hatton, 2014) and further underlines the objective that in order to reduce such

health inequalities, it requires action across all the social determinants of health (Marmot, 2005a).

It also must be noted however that the differences observed in this study may be attributable to the context in which this study was undertaken. A typical example is where fewer adults with intellectual disability lived with their families in the McMahon et al. (2019) study in comparison to the UK (Hatton, 2017). While such differences may impact the generalisability of this study's results, it should be kept in mind that this study was representative of the entire population of adults known to health and social care services who consented to participate in Jersey. In contrast, while the McMahon et al (2019) study had lower figures for adults with intellectual disability who lived in the family home, it remains difficult to make direct comparisons in the data collected and reported across the UK and internationally. This is principally due to the differences in data collection and reporting where countries have different social care policies and approaches towards data collection. For example, in England, only adults receiving support from councils are reported in social care statistics, while adults known to local authorities not getting such support are excluded from social care statistics (Hatton, 2017). Equally, NHS Digital in England publish data on people with an intellectual disability known to general practice which doesn't provide coverage of all general practices in England (NHS Digital, 2021). It is therefore important to recommend that the generalisation of these findings is accompanied by an associated caveat with international comparisons being difficult to make.

Study 5: Is subjective socioeconomic status a correlate of health in adults with intellectual disabilities? A scoping review (for resubmission)

Study 6: The relationship between subjective socioeconomic status and health in adults with and without intellectual disability (McMahon et al., 2022)

In the previous studies reported on in this thesis, objective indicators of socioeconomic status have clearly set out that people with an intellectual disability have low levels of education, earn less than £15,000 pa and have low levels of

employment. Therefore, there was a need for this scoping review to examine if SSS is related to health in adults with intellectual disabilities. The rationale behind this review is positioned in the general population literature that suggests the evidence for the relationship between SSS and health in the general population is strong, even more so than for objective indicators of socioeconomic status (Cundiff & Matthews, 2017; Nobles et al., 2013; Präg et al., 2016); however, little to no attention has been paid to this relationship for persons with intellectual disabilities. This was seen as an important consideration as people with intellectual disabilities are more likely to occupy non-normative socioeconomic positions and therefore SSS measures are worthy of further investigation given the low variation in objective indicators of socioeconomic status.

This study followed the Arksey and O'Malley (2005) methodological framework and seven studies were identified and charted. In the main, these findings suggested that no studies had used robust SSS measures to investigate associations between SSS and health amongst people with intellectual disabilities, however indicators related to SSS demonstrated across the seven studies that lower socioeconomic status was associated with poorer health for a wide range of adults with intellectual disabilities. Nonetheless, the indicators identified in these seven studies are on the peripheries of acceptability and no study used a recognised instrument (e.g. the MacArthur Scale of Subjective Social Status) in the intellectual disability population to determine if SSS is associated with health status independent of objective socioeconomic indicators. The findings from this review suggested that future research should focus on investigating whether the SSS associations with health found in non-disabled populations hold true for those with intellectual disabilities.

It is from this lens that the final study (McMahon et al., 2022) was undertaken. This study compared these associations separately for 217 adults with, and 2350 adults without intellectual disability in Jersey. In the intellectual disability sample, 85 (39.2%) participants consented independently, while 132 (60.8%) participants consented through proxy procedures. The MacArthur Scale of Subjective Social Status was used to measure SSS (Adler & Stewart, 2007b) and the Euro-Qol EQ-5D-

5L (Devlin & Brooks, 2017) and a five-point scale ranging from poor to excellent health were used to measure SRH.

The findings from this study have important consequences for understanding the implications of SSS and how it is related to health in this population. First and foremost, it is important to highlight that for the general population the associations that have been previously identified in the literature broadly held and increased SSS was associated with better health. This finding was expected (Cundiff & Matthews, 2017; Singh-Manoux et al., 2003). However, there were notable differences in the intellectual disability comparisons which are considered from a number of perspectives.

First, across the three objective indicators of socioeconomic status people with an intellectual disability were more disadvantaged than the general population (all comparisons $p < .001$). Second, the median scores for the SSS ladder indicated that the general population had higher scores than those with an intellectual disability who consented independently ($p < .001$), and for those who consented independently they had higher median scores than the proxy report group, however this difference was not of statistical significance. The trend in the data suggested that there is a hierarchy where people with more severe intellectual disabilities are placed lower than people with an intellectual disability who consented independently, notwithstanding there was no statistical difference. This must be considered with caution as the proxies who reported are theoretically part of the 'general population' and this may influence the scores as this may express the proxy's feeling towards these individuals which may include where they believe they belong in a particular stratum of society.

Third, regarding gender, in the general population men tended to report themselves as having higher SSS than women and this is similar to an English study using cross-sectional data from the second wave (2004–05) of the English Longitudinal Study of Ageing (Demakakos et al., 2008). This significant association was not seen in the intellectual disability population despite men being ranked higher than women.

Fourth, an interesting finding regarding the distribution of SSS scores in the univariate analysis identified that the lowest score for the general population was associated with unemployment and both intellectual disability groups had higher mean scores than the general population. This is an important consideration that theoretically suggests the adaptation to persistent deprivation that this population experience. For example, people with an intellectual disability are more used to being unemployed in comparison to the general population and such exposure to deprivation is not as impactful to this population and this signals an area for further exploration (Emerson, 2021).

Fifth, from a health outcome perspective, in adjusted comparisons for SRH, higher SSS ladder scores, being employed and younger age were significant predictors of better SRH for the general population. However, no significant associations were observed for the self-report group of people with intellectual disability but higher SSS ladder scores and younger age were significant predictors of better SRH for the proxy-report group. It is difficult to interpret this finding given the proxy nature of this reporting but given that there was no association in the self-reporting group this must be interpreted with caution.

Sixth, for adults with intellectual disability who participated through proxy respondents, they were more likely to experience lower levels of health as measured by the EQ-5D-5L index value. Employment was also associated with better scores on the EQ-5D-5L index value for this group. For self-reporting adults with intellectual disabilities, employment and younger age were significant predictors of better levels of health as measured on the EQ-5D-5L index value. For the general population education, higher levels of SSS, younger age, and earning more than £15,000 were significant predictors of better health as measured on the EQ-5D-5L index value.

The obvious question at this stage is to consider what my findings mean and how they advance knowledge in this arena. This can be addressed from a number of perspectives. Evidence on SSS as a correlate to poor health is well accepted and SSS is thought to reflect the cognitive averaging of standard markers of socioeconomic status (Singh-Manoux et al., 2003). A particular problem with this study is that the

self-reporting sample may be underpowered. The trend towards having lower SSS scores and poorer health is evident albeit non-significant and therefore there is a need for larger prospective studies to investigate this further, as the small intellectual disability sample group in this study may be under-powered to examine this association.

From this perspective, it must also be questioned if there is any value in following this avenue of research further, given the non-statistically significant associations observed between SSS and health in the self-report intellectual disability population. At this stage, I would argue that this does have merit for several reasons. First, given that this is the first body of research to examine these associations in the intellectual disability population, it would be naïve to conclusively rule out that this association in the intellectual disability population has no importance, particularly when the trend in the data suggests that for the self-reporting intellectual disability population, they have lower SSS and poorer health than the general population. Secondly, this research has underlined that traditional socioeconomic indicators have low variation amongst this group – a trend observed internationally (Emerson, 2021) – and they may be less relevant for a population who experience atypical socioeconomic circumstances. Therefore, I would argue that with regard to the findings of this study, and considering the empirical and theoretical associations in the general literature, it is worthwhile to pursue this approach further since the current evidence base accounts for such strong associations in the general population (Cundiff & Matthews, 2017). Nonetheless, it may also be that to understand this future approach and the direction of some of the research questions in this area, there needs to be a greater development of theory to support the empirical work in this area (Hoebel and Lampert, 2020).

For example, it may be that there needs to be a deeper reflection on what SSS means to people with an intellectual disability. While Jackman and Jackman (1973) reported that SSS refers to the individual's perception of 'his' own position in the social hierarchy, it is theoretically plausible that due to the social disconnectedness

and isolation this population experience (Amado et al., 2013; Emerson et al., 2021) people with intellectual disability experience a social hierarchy that is shaped by limited life experiences and this may impact what SSS means for this population. Equally, there is an evidence base that many people with an intellectual disability experience low self-esteem and self-stigma which may be associated with negative or downward social comparisons (Abraham et al., 2002; Benson & Ivins, 1992; Dagnan & Sandhu, 1999; Dagnan & Waring, 2004; Paterson et al., 2012). However, this evidence base is largely inconsistent and inconclusive (Paterson et al., 2012). An early study by Dagnan and Sandhu (1999) found that positive self-esteem and social comparison scores are positively associated whereas Paterson et al. (2012) identified that social comparison was not found to have a moderating effect on the relationship between stigma and self-esteem. A key weakness in much of this research is that sample sizes are small and have typically involved around 40 people with an intellectual disability. Therefore, the next step in this area of research could try and tease out if an association exists between low self-esteem and self-stigma and SSS. Given that SSS largely represents the nuances of a person's social position (Adler et al., 2007b; Adler et al., 2000) it may be useful to examine to what extent low self-esteem and self-stigma influence a person with an intellectual disability's assessment of their own SSS position. In the general literature, a recent study (Bharat et al., 2020) concluded that SSS may be associated with adverse social consequences of health conditions that are considered stigmatising (e.g. depression) therefore this offers an avenue for further exploration in this population.

Another element needs to be kept in mind where people with an intellectual disability may be sheltered from the socioeconomic realities that the general population may experience. In the McMahon et al. (2019) and McMahon et al. (2022) studies, it is very clear that divergence exists concerning the socioeconomic status of people with and without intellectual disability. Nonetheless, it must also be pointed out that in this research, over 50% of adults with intellectual disabilities lived in residential type accommodation in comparison to 2.4% of the general population. This is likely to reflect the distinct difference that these populations experience. For example, people who live in residential-type accommodation may

not experience the same financial realities or societal conditions that exist more broadly in society. On a practical level, this means that such individuals may have their housing, food security, transport and other economic responsibilities provided for. Consequently, the low variation in indicators of objective socioeconomic status in such settings is not likely to capture the finely graded socioeconomic position that these people experience (Graham, 2005). From this perspective, this theoretically underpins the value of the SSS measure as McMahon et al. (2022) have highlighted that SSS largely represents the nuances of a person's social position (Adler et al. 2000). Subsequently, the SSS measure is more likely to capture the discrete socioeconomic status of individuals when they occupy atypical socioeconomic positions where uniformly low objective indicators are of minimal value for people who live in such settings and are divorced from such economic realities.

In contrast to this, however, and reinforced by Graham (2005) and Emerson and Hatton (2014), some people with an intellectual disability may be particularly vulnerable to the impact of low socioeconomic status in a different way than people who live in residential care as they are exposed to the same financial realities and societal conditions that impact the general population. In these circumstances, it is also accepted that such individuals are to a greater degree more impacted by the social determinants of health and they are more likely to face health inequalities (Emerson and Hatton, 2014). Consequently, despite objective indicators being uniformly low, the reality is objective indicators may function in the same way for people with an intellectual disability who do not live in residential care as it highlights the social and economic resources available to them and is indicative of where they fall in the social hierarchy in society (Cundiff and Matthews, 2017). Nevertheless, research in this area is severely lacking and the value of subjective and objective indicators needs further evaluation in the intellectual disability research.

Other considerations also need to be taken into account when interpreting the findings of this study, particularly when subjective factors are being reported on by proxy respondents. For example, there are lower proxy scores observed between

SSS and SRH in the proxy report population than in the self-report population. While there is no question that people with an intellectual disability should be the primary source of comment on their opinions, feelings, thoughts (Kooijmans et al., 2022) and health status (Emerson and Hatton, 2014) and indeed this is well established as being the case (Emerson et al., 2013), in the intellectual disability arena researchers rely heavily on proxy respondents when people do not have the cognitive ability to consent to participate and self-report on their own behalf. This, therefore, asks the question of what can be extrapolated from these findings. It must be considered that lower proxy scores may be a function of proxies underestimating the experience of people with an intellectual disability from a socioeconomic and health status perspective. Scott and Haverkamp (2018) have identified that proxy reports are limited by the fact that a proxy can never know the internal physical and mental state of another person and caution that a person who knows them well should be used as a proxy informant. In this research, every effort was made to ensure that the proxy who knew the person best was chosen to participate. However, the fact cannot be escaped that without proxy respondents some people with an intellectual disability are excluded from participating in research and this underlines the decision to include proxy respondents in this research. Emerson et al. (2013) have considered this quandary and report that while research in the intellectual disability arena is characterised by several methodological compromises, with such compromises not easily resolved, it is important to recognise these constraints when interpreting research based on this data. It is from this sphere that these results should be interpreted.

Notwithstanding this, despite the inconclusive SSS findings observed in this study, the main conclusion that can be drawn is that employment is associated with better health as measured by the EQ-5D-5L index value. While the importance of employment was addressed earlier in this chapter (Dean et al., 2018; McCausland et al., 2016; Robertson et al., 2019; Taylor et al., 2022), this study signals how critically important employment is for everyone. On this basis my overall findings from this study indicate that while the SSS ladder shows promise, at this stage it is only related to SRH in the proxy intellectual disability group and further research is

needed to explore its utility further. It may be that this research examines what SSS means to people with an intellectual disability and consider how concepts such as self-esteem and self-stigma and objective indicators of socioeconomic status influence this position.

10.5. What do these findings mean?

These findings outline the health inequalities that people with intellectual disability experience. The studies and associated supporting evidence presented in this thesis highlight the multi-layered inequality that is best understood through the seminal work of the Dahlgren and Whitehead 'rainbow model' of health determinants (Dahlgren & Whitehead, 1991) (Figure 3). Across all layers of the model, people with an intellectual disability experience inequality. Aligning the general population literature and drawing on the work of Marmot (2005), decreasing health inequalities is a matter of fairness and social justice. The health inequalities that people with an intellectual disability experience are not driven by their genetic makeup (*albeit it is accepted that they may be predisposed to some genetic associated morbidities in the context of clinical phenotypes*), they are caused and driven by social and economic inequities in society (Marmot, 2020). Confronting these health inequalities is critically important.

Throughout my thesis, I have identified that people with an intellectual disability experience a greater burden of ill health than the general population which starts earlier in life. People with intellectual disability are likely to be burdened with polypharmacy and they have a high risk of developing potential DDIs of clinical significance. They are less likely to be in relationships, be employed and live in their own home. These disadvantages are contrasting to the ordinary life people with an intellectual disability want. People with an intellectual disability also report lower SSS than the general population, and while its association with health was not statistically significant, it does advance the evidence further to suggest it is a concept worthy of further investigation in this population. A key message that

extends beyond the initial scope of this study highlights the importance of paid employment for people with and without intellectual disability.

While some of the findings in my thesis support the existing evidence base in the intellectual disability field of research, some of my findings tilt our understanding to a greater degree in several directions. The first direction where my research does this is in respect of gender and health inequalities. For example, when the findings from this thesis are considered in their entirety, a pattern is beginning to emerge insofar as women with an intellectual disability may be particularly vulnerable to health inequalities. As highlighted by Robertson et al. (2021), the evidence in this area is not clear. Nonetheless, the research in my thesis identifies that women with an intellectual disability are more likely to have mental health and behavioural disorders in comparison to the non-disabled female population, they are more likely to experience potential DDIs of clinical significance (despite being less likely to experience psychotropic polypharmacy), be unemployed in comparison to men with an intellectual disability and report lower SSS. The WHO has drawn attention to this issue regarding gender-based health inequalities for women (Schwab et al., 2017). A recent scoping review examining if policies tackling gender inequalities in health have been realised, reports barren findings, insofar as Crespí-Lloréns et al. (2021) identified that internationally there is a lack of awareness and that policies reducing gender inequalities are scarce and infrequently implemented. In their totality, my findings raise important issues that suggest that it is reasonable to infer that women with an intellectual disability are likely to be disproportionately exposed to some non-medical factors that influence health and this demands meaningful consideration.

The second example of where my research advances the understanding concerns the prevalence of potential DDIs of clinical significance and their impact. While there is extensive evidence that highlights the prevalence and impact of polypharmacy (Bowring et al., 2017a; O' Dwyer et al., 2018), no research firmly addresses this to any significant degree and not in the manner that the McMahon et al. (2021b) study did. My research findings in this sphere bring into sharp focus the clinical importance of DDIs in this population and call for urgent consideration to be given to their

potential impact, especially as people with an intellectual disability are one of the most medicated groups of people in society (Häßler et al., 2015; O'Dwyer et al., 2018; Peklar et al., 2017).

The third area where my research advances the field of intellectual disability research despite there being an evidence base is concerning paid employment and its association with health in people with an intellectual disability. Robertson et al. (2019) and Dean et al. (2018) have indicated that while there is an association between employment and better health for people with intellectual disability, they do caution that this evidence base is small. While the McMahon et al. (2022) study also supports this association, my research goes further and underlines that this is the most important association over and above other subjective and objective indicators of socioeconomic status. This has important implications for the field of intellectual disability research as it tilts our understanding further in this direction and underlines the importance of getting people with an intellectual disability into employment from a practical perspective, but also underscores the need to further examine the role of employment and its broader benefits for adults with an intellectual disability.

Finally, in simple terms, these results suggest that people with an intellectual disability experience substantial inequalities. These are unjust and avoidable as they are determined by non-medical factors not within their control and they limit the opportunity of these individuals to live a life comparable to the general population that is longer and healthier. From this sphere the following implications for policy, practice and research are considered important to drive improvement in this arena. For a policy and practice sphere these relate to Jersey as the research was undertaken there. However, they may be equally applicable internationally.

10.6. Implications for policy, practice and future research

There are a number of key messages and implications that can be inferred from a policy, practice and future research perspective that would help tackle the health

inequalities that this population experience. Responding to this is critically important and these are set out below.

People with an intellectual disability are exposed to many non-medical factors that inhibit them from living a long and healthy life. Macro level policies should focus on reducing the exposure of people with an intellectual disability to the well-known social determinants of poor health. Marmot and colleagues (2005) have introduced the concept of 'proportionate universalism', meaning that resources should be planned and delivered at a scale and intensity proportionate to the degree of need. In order to achieve this, there needs to be commitment and action from the Government of Jersey to reduce the economic and social inequalities that exist in society. A framework for addressing this at a macro level can be taken from the World Health Organization's Social Determinants of Health Conceptual Framework (Organization, 2008; World Health Organisation, 2008) which sets out that policy should:

- 1) Improve the conditions of daily life for people with an intellectual disability through improving the conditions in which they grow up in, live, are educated and work in and age
 - a. In Jersey, this should include making reasonable adjustments to ensure they are equal opportunities to access education and employment and healthcare.

- 2) Take action about how resources are distributed as these influence the condition of how people with an intellectual disability live their life
 - a. In Jersey, there should be a focus on reducing income inequality with a particular focus on securing adequate pay for people who are in the weakest position in the labour market. People with an intellectual disability should not be financially disadvantaged by virtue of being in employment and thereby surrendering income support.

- 3) Measure and evaluate the actions that are taken and educate and expand the knowledge of the determinants of health for the population as a whole
 - a. In Jersey, actions should be evaluated by the Government or responsible organisation to identify if changes are reflected in reality.

This research has highlighted that people with intellectual disability have poorer health than their non-disabled peers and many experience polypharmacy and psychotropic polypharmacy. From a policy and practice perspective there should be a focus on the identified barriers to accessing healthcare, applying a public health lens to prevent illness and disease, improve health, early identification and management of illness in this population and prescribing oversight. This should include:

- 1) Applying a public health and health promotion approach to empower people with intellectual disability to have healthier lives
 - a. For example, ensure that people with an intellectual disability are offered and included in pre-emptive screening for specific health needs and included in vaccination programmes that are made available to the general population on an age appropriate or clinical need basis.
 - b. There also needs to be a concerted effort for health professionals to identify barriers that inhibit access to healthcare
 - i. This would include challenging attitudes and beliefs and holding organisations to account who infringe or inhibit people with an intellectual disability accessing healthcare services by virtue of their disability.
- 2) Ensure that every individual who has an intellectual disability has the choice to receive an annual health check by a suitably qualified health professional
 - a. Health checks should be broad enough to cover the overall health needs of this population and specific enough to be gender sensitive to meet the discrete needs of specific sexes.

- b. The concept of clinical phenotypes should be considered within health checks. That is to say known syndrome specific associations should be scrutinised (for example the association between Down syndrome and Alzheimer's type dementia).
- 3) People with an intellectual disability should have their medication reviewed regularly and prescribing profiles should be examined to consider if it is appropriate or not.
- a. Efforts should be made to reduce polypharmacy and psychotropic polypharmacy where possible.
 - b. People who are prescribed drugs which are known to interact with other drugs should be regularly reviewed.
 - c. Individuals who prescribe for people with an intellectual disability and those who administer and dispense medication should receive training in the area of drug-drug interactions and adverse drug events.
 - d. People with an intellectual disability should be provided with material that details the medications that they are prescribed and it should contain the potential side effects and reporting processes. This should be made available in a medium that is understandable to them.

Given the finding that people with an intellectual disability have low levels of employment in Jersey and the association between employment and better health, policy should focus on getting people with an intellectual disability into secure paid employment and supporting them during this process and if necessary to maintain employment. There needs to be a strategic and united approach between social services and employment agencies towards employment for people with an intellectual disability. This should be central in a person-centred care plan where work is a key objective and a realistic outcome for people with an intellectual disability. This should not be undertaken in isolation by one agency and it should include:

- 1) People with an intellectual disability should be consulted with and their will and preference respected regarding employment opportunities that are presented to them.
- 2) A targeted campaign to ensure that the expectation and culture around people with an intellectual disability is one where they are seen as valuable and important contributors to the labour market.
- 3) Planning for employment should start early in life.
- 4) There needs to be a focus on moving from sheltered employment toward open employment.
- 5) People with intellectual disability and their families must be actively involved in job training, job placement and long-term support (where the person with an intellectual disability is in agreement).
- 6) People with an intellectual disability who are in employment should not be negatively penalised by cutting social supports that makes employment unrealistic and financially unviable.
- 7) People with an intellectual disability should be encouraged to engage in a range of training that is congruent with their cognitive and physical abilities. The training they receive should be bespoke to their preferences regarding employment roles and it should be aligned to pre-determined outcomes.
- 8) When people achieve employment there needs to be a focus on retention and long term support.

During the course of this research it became apparent that people with intellectual disability need to navigate multiple systems that are frequently independent of each other. The fundamental interconnectedness of all areas of people's lives are connected to health; however, the reality for people with intellectual disability is that each area is segmented into systems that don't necessarily engage with each other. This is difficult for people with an intellectual disability and their family and may negatively impact their health and wellbeing. Consequently, the experience of undertaking this research and within the broader literature identified in this thesis, it is reasonable to conclude that people with an intellectual disability should be

supported by a case coordinator who acts as a coordinator for health, social and occupational services. This should ensure that:

- 1) The voice of the person in receipt of services is heard and their wishes are respected.
- 2) The intersections of services are identified and known to each other and risks are identified, assessed and managed appropriately.
- 3) The health literacy and understanding of people with an intellectual disability is assessed on a continual basis and bespoke strategies are implemented to improve the health and wellbeing of the person.
- 4) There is a free flow of information between services to ensure that interventions are person centred and conducive to the needs to the person in receipt of services.

10.7. Implications for future research

From a research standpoint, there are a number of areas that should be addressed. From a health prevalence and surveillance perspective, there is a critical need for future studies to utilise longitudinal data to determine the prevalence rates of health conditions in this population. The stratifying of age in McMahon and Hatton (2021a) demonstrated that younger age in the intellectual disability population is associated with greater prevalence of illness compared to the general population. Future research should attempt to link this type of data in a longitudinal manner to increase the usefulness of these findings and to identify causal links. It would also be important to capture the same variables (socioeconomic and health) as primary outcomes to ensure like-for-like comparisons and to be able to identify participation in health screening that was availed of, and not availed of by each participant. The stratifying of findings in this manner would help improve the knowledge in this area. Furthermore, given the difference identified in the health profiles of men and women, it is imperative that future health research also examines this issue and stratifies these populations.

From a polypharmacy and psychotropic polypharmacy perspective there is an urgent need to further explore the concept of appropriate polypharmacy in this population. In the first instance, there is a need for larger prospective based studies with a comparison group to fully ascertain the prevalence and predictive variables

associated with polypharmacy and psychotropic polypharmacy using standardised definitions. Such research needs to focus on demarcating the difference between 'appropriate' and 'inappropriate polypharmacy' in this population. This will help to strengthen this area given the variation in some research findings. The development of tools to identify potentially inappropriate medication use in this population does offer value for future research and practice, However, given the issues with implementing findings from the pilot study in the Netherlands (Zaal et al., 2016) that used a modified STOPP tool to identify drug-related problems in this population, the research also needs to focus on the concept of the implementation of potentially inappropriate medication use interventions in practice given such failures. Additionally, the high use of psychotropic medication in this research signals that research should focus on the effects of long-term antipsychotic drug use in this population (Henderson et al., 2020; Matson & Mahan, 2010). It is particularly important to understand the efficacy, effectiveness and tolerability of such drugs given the significant associated negative metabolic and neurological outcomes (Correll et al., 2018).

From a DDI viewpoint, research in this area is at an early stage and a sensible approach would be to focus on the clinical impact of potential DDIs. This could be achieved by examining known drug interacting combinations and comparing these against clinical records and the rates of adverse drug reactions. Ideally, a prospective study that has real time prescribing and clinical assessment data with follow up phases would provide the strongest evidence. Equally, retrospective clinical and prescribing data – including mortality data - could also be examined to further examine the prevalence of DDIs in larger samples. Nevertheless, it is important to understand what people with an intellectual disability understand and experience regarding DDIs. It is important to triangulate this approach to ensure the voice of the person is central to this research and their experiences of taking many drugs is carefully considered. This is particularly true because as far as I am aware, the evidence is completely absent regarding this concept, notwithstanding the slender evidence base in this area concerning the poor knowledge surrounding adverse effects (Smith et al., 2019).

From an SSS perspective, there is a need for larger studies where more participants are included with the cognitive capacity to consent to participate. At this stage, the findings only support there is a trend (not statistically significant) towards having lower SSS scores and poorer health for people who consented and participated independently. Therefore, there is a need for larger prospective studies to investigate this further as the SSS measure may not be sensitive to the referent group for that reason. It is important that future research has a comparator general population sample and uses validated tools to measure SSS and health. Future research should consider this along with examining what SSS means to people with an intellectual disability.

This thesis has highlighted that the objective indicators of socioeconomic status are uniformly low for people with an intellectual disability. Given that many people with an intellectual disability live in residential care, objective indicators of socioeconomic status may not reflect the true reality of their socioeconomic status in contrast to people with an intellectual disability who do not live in such settings. Future research is needed to confirm the value of using objective indicators in intellectual disability populations when they are disconnected from the societal and economic realities that exist more broadly in society.

From an employment perspective there are two principal avenues for research. First, my research points towards a positive relationship between employment and better health. This is well acknowledged in the literature (Dean et al., 2018; Robertson et al., 2019). However, the causal mechanisms behind this relationship in this population are not well understood. From a research perspective this could be potentially overcome by undertaking a randomised controlled trial (RCT). However, from an ethical perspective the use of a RCT would not be appropriate as it may preclude employment for a participant. Therefore, future research should use prospective designs, with appropriate sample sizes and comparable instruments to identify its impact. The second avenue of research should be concerned with what is the most appropriate way to get people with an intellectual disability into employment. Irrespective of causal mechanisms, employment is good for people's health and this research should underpin policy.

Finally, it needs to be emphasised that research in the area of intellectual disability predominantly excludes the hidden majority of adults with intellectual disability who are not known to services (Emerson & Hatton, 2014). It has been reported that these individuals are more likely to be exposed to the social determinants of poor health (Emerson, 2011). As a result, it is highly probable that these individuals have the same or even greater needs than those known to services. Emerson and Hatton (2014) have previously commented that using administrative samples is a reasonable approach towards understanding the health needs of people with an intellectual disability; however, making inferences to all people with an intellectual disability is potentially flawed. Therefore, there is a responsibility on researchers in the field of intellectual disability to try and include the hidden majority of people with an intellectual disability in research.

A recent study by Rosencrans et al. (2021) highlights that researchers need to go beyond disability services and engage with non-governmental organisations, local community groups and organisations along with pushing to modify national surveys to include more distinguishable questions to identify and accommodate people with intellectual disability. When this is coupled with administrative data sets, Rosencrans and colleagues report that this may be the most productive approach. Such consideration needs to be taken for future research in this sphere.

10.7.1 Variables influencing health

From an implication for future research standpoint, it is important to reflect on critical variables influencing health to help guide future research. Based on my findings, it is evident that typical objective indicators of socioeconomic status – income, education and occupation – which are associated with a range of health statuses' in the general population may not function in the same way for all people (Darin-Mattsson, Fros & Kåreholt, 2017) and it is reasonable to conclude this also includes people with an intellectual disability. As socioeconomic realities are potentially different for people with intellectual disability who live in residential care settings, it is likely that objective socioeconomic status indicators have different meanings for different groups of people with intellectual disability. Nonetheless, in

the literature, there is no obvious or clear distinction between the two (Graham, 2005). If such objective indicators are used in further research to examine their association with different health outcomes, to fully understand their impact and determine their true utility, there is a need for deeper investigation. Principally, this may be addressed by removing blunt 'cut-off' points or hierarchies regarding education, income and occupation. Such variables should be carefully and fully operationalised into more granular detail to try and tease out and capture the discrete socioeconomic status that may exist. It is from this granular position that any stepwise gradient or pattern where improving socioeconomic position is observed with incremental improvements in health status may offer a more holistic approach and greater understanding of such associations. This would contribute to the refinement and development of theoretical and empirical models of objective indicators of socioeconomic status and their association with health outcomes in this population.

Additionally, a special mention needs to be called out on the role of paid employment given it is associated with better health in the McMahon et al. (2022) study across all populations. This study supports the view that employment is associated with better health (Robertson et al., 2019; Emerson et al., 2018); however, we do not know in the intellectual disability research sphere what the causal mechanisms behind this are, nor do we know how various forms of employment for people with an intellectual disability (for example non-standard, part-time, or insecure employment) impacts health outcomes (Emerson et al., 2018). Consideration of such variables is important given the diversification of the labour market more broadly in society (Government of Jersey, 2021b).

Nevertheless, despite the inconclusive findings, this research does signal that it may be judicious to further explore the SSS variable given its strong association with health in the general population (Cundiff and Matthews, 2017) and trends observed in the McMahon et al. (2022) study. Given its nuanced assessment and potential ability to capture all individual elements of what socioeconomic status means for people with an intellectual disability, this may offset some of the difficulties observed

with objective measures. From such a viewpoint further research needs to further appraise the SSS concept and how it is associated with health in adults with an intellectual disability.

Furthermore, in the McMahon et al. (2020; 2021a) studies it is also apparent there is a need for researchers to use standardised coding in terms of classifying polypharmacy and categorising health. In this sphere, across the published research in the field of intellectual disability, it is often difficult to interpret and synthesise the findings and associations with health due to the diverse classification of many variables used in across studies. This is a critically important issue to develop the evidence base in the field of intellectual disability research that demands meaningful attention.

10.7.2 What variables should be considered in future research

The findings from this research do not put forward any new variables that should be considered regarding the examination and conceptualisation of health inequalities in adults with intellectual disabilities, rather, it underlines the importance of fully understanding and operationalising the atypical conditions in which people with and intellectual disability are born into, grow up, and live in to further develop this evidence base. Research has highlighted that the most enduring structure of health inequalities are socioeconomic differences that exist in society (Marmot et al., 2005; Graham, 2009). To highlight their predominant importance, Marmot (2007) refers to these as the “causes of the causes” (p.1). While the evidence for this is strong, it needs to be highlighted that the evidence that supports this is generally drawn from general population samples (Emerson and Hatton, 2014; Graham, 2005) and the evidence in the intellectual disability area is largely underdeveloped.

In this regard, there is an urgent need to understand and recognise the importance of how socioeconomic status influences the health and well-being of people with intellectual disability across their life course (Graham, 2005). To reduce health inequalities, this requires a complete understanding of the variables that influence

this, how these variables interact and the causal pathways that are involved. Without this evidence, policies to address such inequalities are based on evidence from the general population, and may not be wholly implementable or effective for people with intellectual disabilities (Graham, 2005). It is from this viewpoint, that my research signals that as researchers in this area, there is a critical need to incorporate the atypical socioeconomic positions that people with an intellectual disability occupy in society in future research. This may help build more nuanced models where the interplay between socioeconomic status and health inequalities can be examined in more granular detail. In theory, this should help to incrementally build on this work in this area of health inequalities. Further appraisal of the SSS concept offers a good starting point.

10.8. Strengths and limitations

This study has a number of strengths and limitations. The strengths of this study lie in the methodological approach towards the collection of data. The inclusion of a total administrative sample of adults with intellectual disability and the comparator random stratified general population sample is unique and this increases the confidence in the research findings. In the intellectual disability arena, this detailed level of data is not often possible, especially as many of the larger studies use secondary data. Notwithstanding this, there are also limitations that need to be considered when interpreting these findings. While limitations are acknowledged within each study, the following principal methodological limitations need to be kept in mind when considering the findings from this research in its entirety.

First, as previously identified the intellectual disability population in this research includes all people who are known to services and it does not include people with an intellectual disability who are not known, or have previously been known to intellectual disability services. This is a particular problem in this area of research and this excluded population is often referred to as the 'hidden majority' (Emerson & Hatton, 2014; Rosencrans et al., 2021). From this perspective, it can be argued that fully-informed conclusions cannot be drawn as the findings relate to people who are

known to intellectual disability services only. Recent commentary from Rosencrans et al. (2021) identified that those who are known to intellectual disability services are typically white and of higher socioeconomic status and therefore people not known to services with an intellectual disability may occupy even more disadvantaged positions within society. This is an important consideration when considering the findings of this research. Although consideration was given to try and recruit people with an intellectual disability through different procedures (for example advertising in local media and in GP surgeries), given the scope and timing pressures of a PhD study it was considered that this was not feasible.

Second, although the use of a random stratified sampling approach ensured that the sampling frame is highly representative of the general population, there was only a 30% response rate and older people were over represented. This is a significant issue with postal surveys (Robson & McCartan, 2016). However, this response rate was not unexpected and it was anticipated by the Statistical Department in Jersey; therefore, this was the justification for posting 8,200 questionnaires. Additionally, as the sampling frame included the residential addresses of the Island of Jersey as a whole, the impact of coverage error, sampling error, nonresponse error and measurement error were somewhat reduced (Smith et al., 2019).

Third, indicators of socioeconomic status such as education, occupation and income had uniformly low variation in the intellectual disability population. Alongside this, a much lower number of adults with intellectual disability live with their family in Jersey as reported by McMahon et al. (2019). Consequently, while it is accepted that people with an intellectual disability typically have lower socioeconomic status than the general population (Emerson and Hatton, 2014), the reasons behind why fewer people with an intellectual disability live with families in Jersey is unknown.

Therefore, the application of this study's findings to a wider target population of people with intellectual disability should be undertaken with a degree of caution, particularly where individuals have less severe intellectual disabilities as they are more likely to have higher socioeconomic status or where they live with their family.

Fourth, there was a reliance on proxy respondents to answer questions in this research. This is an important consideration when the concepts of SRH and SSS are considered given their subjective nature. There is an evidence base to suggest that researchers can evaluate proxy agreement by comparing proxy responses to those who can answer on their own behalf with self-reports from the same respondents (Stancliffe, 1999; Stancliffe, 2000). This is an important consideration and I have plans to examine this further with future analysis. This may mitigate the impact of confounding and any divergence in difference of reporting can be addressed in data analysis.

Fifth, the sample of people with and without an intellectual disability in this research may not be fully reflective of the diversity in the population of Jersey more broadly. Although the intellectual disability population includes all people known to services, it cannot be discounted that there are people from ethnic minorities who live in Jersey but did not participate in the research whether known or unknown to services. Equally, this limitation extends to the general population who were typically white, older and English speaking.

Finally, upon reflection, it would have been worthwhile to include measures of self-esteem and self-stigma in this survey as it would be meaningful to understand to what extent low self-esteem and self-stigma influences one's own SSS position.

10.9. Overall personal reflection

There have been many hurdles since I started my part-time PhD in October 2016 but the experience has been overwhelmingly positive. Irrespective of the COVID-19 pandemic, of which I consider myself lucky to have had the data collected at that stage, the experience of undertaking 'Real World Research' (Robson & McCartan, 2016) and following the steps throughout this research project and indeed the PhD process has been challenging but motivating. A colleague once told me that you don't write about 90% of the actual work you do for a PhD and this now this resonates with me. From a practical perspective, at the outset of my PhD I wanted

to undertake a research project that was achievable but also meaningful. When I first had contact with my supervisor, I had lot of ideas and areas for investigation. I now realise they lacked coherence and in essence if they were followed through, I would not be in my current position. These ideas were not dispelled or dismissed, rather they were cultivated, realigned and strengthened and in essence helped me develop as a researcher.

There were a number of stages throughout this PhD which were influential, some positive and some not so positive; however, they were equally important. Perhaps the first influential stage came when my scoping review study that is included in this thesis was not accepted for publication. The comments from the Editor centred on it being 'inconclusive with its findings'. While I accepted the decision, I did internally wonder if I was not good enough to complete this PhD and equally if the topic was not worth pursuing given the deflation I felt at that time. Feelings of inadequacy, shame and fear of failure clouded my mind and stunted my confidence for a short time. However, I now feel this rejection so early on in my PhD made me more resilient and while it was disappointing and frustrating, I quickly moved on taking the lessons learnt and I refocused on the objectives of this work.

After this disappointment, I immersed myself into data collection and this took about eighteen months to complete and while it was challenging, more so with the logistical issues and rescheduling appointments, I really got an insight into the lives of people with an intellectual disability. While this might seem strange as I spent years supporting people with an intellectual disability and their families, this was genuinely a very different experience. As a researcher, I wasn't trying to fix something or be someone's nurse, I was being objective and listening to what I was being told. This was a very positive experience and from this I learned so much about the challenges people with an intellectual disability experience. During this time, I became really focused on using research as a medium to tell the story of the health and socioeconomic status of people with an intellectual disability. This is where the concept and title of the McMahon et al. (2019) study came from. I was witnessing day in, day out, the unordinary life that people with an intellectual

disability were living – in many cases participants told me they wanted a relationship, a job and their own home. As a result, the basis of this study was conceived. Accordingly, I feel that this study really sets out the different lives that people with an intellectual live in a simple way and that it really sets out the inequalities between people with and people without an intellectual disability.

The next influential stage in my PhD came where I had collected all the data and the next logical step was to input the data. I never comprehended the amount of time and effort this would take. While the general population data was relatively straightforward, the intellectual disability data was more complex and this required a lot of work. For example coding the medications and associated variables was very time-consuming. For some of the cases there were more than 200 variables that needed to be created and correctly classified. While this was a challenge and time consuming, by immersing myself in the data I became so much more familiar with the discrete issues and became more able to understand the context. In hindsight, this process was particularly important for the conceptualisation of the McMahon et al. (2021b) study. When I was inputting the data, I began to question how these medications interacted with each other. Having worked as a non-medical prescriber, I knew that in reality there was no way that it could be possibly conceived that anyone could know how one drug alters the pharmacological effect of another drug when someone was prescribed so many drugs. Reflecting on this now for me personally highlights the importance of being immersed in the data. While this is frequently cited in qualitative research methods, I equally feel this was very important for me undertaking my quantitative study.

While there have been many important milestones since data input, particularly with the publication of the four main studies contained in my thesis and others disconnected with this thesis, I feel I am currently living within the next influential point, bringing it all together to form a coherent unit of work. While this is challenging, it has afforded me the opportunity to engage in a deeper level of reflection about the process, about the meaning of this work and about the impact that it may have.

In hindsight, there are many issues I think I could have handled better throughout my PhD. During my PhD there were many life changes. I moved country, jobs, house and my family grew. During this time, there were periods where the PhD work was abandoned and while that on the surface may seem entirely reasonable, in reality there were times I could have done more than I did. There were many opportunities where I should have written more and if I had taken these opportunities, the load towards the end of this process would not have been as heavy. The advice I would give anyone is, 'just write'.

The experience of doing a PhD has challenged me and I always keep close that I will have 'blind spots' and the belief that I 'don't know what I don't know'. I am aware that while I have learned a great deal and contributed to the evidence in this area, I am equally aware that there will be gaps in my knowledge, gaps I may never fully know, but like everyone, they are there. However, I have a curious mind and I am eager and comforted that I will continue to grow and develop as a researcher. I consider that this level of self-awareness is a key safeguard to enable me to become a balanced and ethical researcher in the area of intellectual disability research.

10.10 Conclusion

People with intellectual disability experience significant health inequalities. These inequalities are driven by non-medical factors that exist within society. My thesis has demonstrated that people with an intellectual disability in Jersey have greater health needs than the general population, are prescribed high levels of medication and are at high risk of developing adverse effects from potential drug-drug interactions which is increased as they are frequently exposed to polypharmacy and psychotropic polypharmacy. Equally, they live an atypical life where they are socioeconomically disadvantaged in comparison to the general population with high levels of unemployment, low income and limited education. The socioeconomic position is reflected in the lower SSS position they report themselves to be in. While the MacArthur Scale of SSS shows promise, it is not associated with health for adults with an intellectual disability who consented to participate in this research and self-reported independently. Future research in larger samples of people with an intellectual disability is warranted. Nonetheless it is important to highlight that employment was associated with better health for all populations and this is a very actionable and achievement policy objective to try to get people with an intellectual disability into paid employment and to support them to maintain successful employment.

This research has also drawn on the rainbow model and situated the findings of this research across the different layers to try and illustrate the disproportionate health inequalities that people with an intellectual disability experience, inequalities that are driven by non-medical general socioeconomic factors that influence health outcomes. As highlighted throughout this research these influences are largely modifiable; however, to date they endure and are sustained by failure to act. This inaction is borne out in research in this thesis through demonstrating the prevalence of ill health and medication use (McMahon & Hatton, 2021a; McMahon et al., 2020a; McMahon et al., 2021b), and the atypical lives people with an intellectual disability live in Jersey (McMahon et al., 2019) and through the lower self-reported socioeconomic position they occupy. There is therefore a moral and ethical

requirement for action across all levels of the rainbow model to help improve the conditions in which people with an intellectual disability live in, grow, work and age. This is a matter of life and death. Implications for policy, practice and future research has been outlined to help advance this cause.

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Appendices

Appendix 1 – Statement of authorship

Title: Not such an ordinary life: a comparison of employment, marital status and housing profiles of adults with and without intellectual disabilities

PUBLICATION STATUS: Published

JOURNAL: Tizard Learning Disability Review

PUBLICATION DETAILS: McMahon, M., Bowring, D. L., & Hatton, C. (2019). Not such an ordinary life: a comparison of employment, marital status and housing profiles of adults with and without intellectual disabilities. *Tizard Learning Disability Review*. 24(4), 213-221. <https://doi.org/10.1108/TLDR-03-2019-0014>

By signing the Statement of Authorship, each co- author certifies that:

- a) Martin McMahon is the main author of this publication with substantial contribution to its conceptualisation, realisation and documentation; and that
- b) Permission is granted for the publication to be included in the candidate’s thesis.

NAME OF CO-AUTHOR: Dr Darren L. Bowring

Signature:

NAME OF CO-AUTHOR: Professor Chris Hatton

Signature:

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Title: A comparison of the prevalence of health problems among adults with and without intellectual disability: A total administrative population study.

PUBLICATION STATUS: Published

JOURNAL: Journal of Applied Research in Intellectual Disabilities

PUBLICATION DETAILS: McMahon, M., & Hatton, C. (2021). A comparison of the prevalence of health problems among adults with and without intellectual disability: a total administrative population study. *Journal of Applied Research in Intellectual Disabilities*, 34(1), 316-325.

By signing the Statement of Authorship, each co- author certifies that:

- a) Martin McMahon is the main author of this publication with substantial contribution to its conceptualisation, realisation and documentation; and that
- b) Permission is granted for the publication to be included in the candidate's thesis.

NAME OF CO-AUTHOR: Professor Chris Hatton

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Title: The prevalence of potential drug–drug interactions in adults with intellectual disability

PUBLICATION STATUS: Published

JOURNAL: Journal of Intellectual Disability Research

PUBLICATION DETAILS: McMahon, M., Hatton, C., Bowring, D. L., Hardy, C., & Preston, N. J. (2021). The prevalence of potential drug–drug interactions in adults with intellectual disability. *Journal of Intellectual Disability Research*. 65: 930– 940. <https://doi.org/10.1111/jir.12844>.

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- a) Martin McMahon is the main author of this publication with substantial contribution to its conceptualisation, realisation and documentation; and that
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NAME OF CO-AUTHOR: Dr Claire Hardy

Signature: C.Hardy

NAME OF CO-AUTHOR: Professor Nancy J. Preston

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Title: Is subjective socioeconomic status a correlate of health in adults with intellectual disabilities? A scoping review

PUBLICATION STATUS: rejected – for resubmission

JOURNAL: Journal of Applied Research in Intellectual disability

PUBLICATION DETAILS: for resubmission

By signing the Statement of Authorship, each co- author certifies that:

- a) Martin McMahon is the main author of this publication with substantial contribution to its conceptualisation, realisation and documentation; and that
- b) Permission is granted for the publication to be included in the candidate’s thesis.

NAME OF CO-AUTHOR: Professor Chris Hatton

Signature:

NAME OF CO-AUTHOR: Simon Alberici

Signature:

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Title: The relationship between subjective socioeconomic status and health in adults with and without intellectual disability

PUBLICATION STATUS: Under peer review

JOURNAL: Journal of Applied Research in Intellectual Disabilities

PUBLICATION DETAILS: Under review

By signing the Statement of Authorship, each co- author certifies that:

- a) Martin McMahon is the main author of this publication with substantial contribution to its conceptualisation, realisation and documentation; and that
- b) Permission is granted for the publication to be included in the candidate’s thesis.

NAME OF CO-AUTHOR: Professor Chris Hatton

Signature:

NAME OF CO-AUTHOR: Dr Claire Hardy

Signature: C.Hardy

NAME OF CO-AUTHOR: Professor Nancy J. Preston

Signature: _____

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Title: Professional collaboration in searching the evidence for an ill-defined concept

PUBLICATION STATUS: Published

JOURNAL: Health Information and Libraries Journal

PUBLICATION DETAILS: for resubmission

By signing the Statement of Authorship, each co- author certifies that:

- a) Martin McMahon is the main author of this publication with substantial contribution to its conceptualisation, realisation and documentation; and that
- b) Permission is granted for the publication to be included in the candidate's thesis.

NAME OF CO-AUTHOR: Professor Chris Hatton

Signature:

NAME OF CO-AUTHOR: Simon Alberici

Signature: _____

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Appendix 1.2 – General population questionnaire



Dear Jersey resident,
Your household has been randomly selected to take part in the:

Jersey Health Assessment & Socioeconomic Status Questionnaire **Please complete and return this questionnaire within the next 28 days**

Who should fill in this questionnaire?



Please could the person in your household who has the **next** birthday (and is **18 years old or over**) complete the questionnaire



Post your completed questionnaire back using the enclosed **Freepost envelope**

What is this questionnaire about

- This questionnaire is part of a PhD study being undertaken at the Faculty of Health & Medicine at Lancaster University
- The information gathered in this study will provide a picture of the health and wellbeing of the Jersey population
- This questionnaire is different from other surveys as it will link socioeconomic status and health characteristics to try and identify health inequalities within the Jersey population
- From this, we can identify what characteristics are associated with health inequalities
- When we know this, we can develop appropriate strategies to reduce these inequalities
- This questionnaire will take approximately 15 – 20 minutes to complete

Why we need your response

- Your address has been **randomly** chosen from all households in Jersey
- Now that you've been selected, we can't replace you with someone else
- Your answers will inform policy decisions that will affect **all** Jersey residents
- Your responses not only represent you, but people and households like you in Jersey

This survey is run independently of all States of Jersey departments

Confidentiality

Any information you give will be treated in the **strictest confidence**. Your responses will only be used to produce total numbers. No individual identifiable data will be shared with any other department. If, in the future, you decide you want your data to be excluded from this study, then please provide a contact number or email in the following box – this will act as your unique number to facilitate your request.

<p>Please provide either a phone number or email contact:</p>	
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Consent

By proceeding to the survey you confirm that:

- You understand what is expected of you
- You confirm that you understand that any responses/information you give will remain anonymous
- Your participation is voluntary
- You consent for the information you provide to be discussed with my supervisor(s) at Lancaster University
- Material gathered during this research will be coded and kept confidential. It will be securely stored in line with The States of Jersey's Data Protection Law (2005)
- You consent to Lancaster University keeping the anonymised data for a period of 10 years after the study has finished

Recognition of participation

To recognise that you have generously given your time to complete this questionnaire you have the chance of winning one of two **£50 Amazon vouchers**. Two completed questionnaires will be randomly selected after data collection. If you are selected, you will be contacted through the means of contact you have given above i.e. phone or email address. Your contact details will be kept separate from the data that we analyse and report on. Your contact information will be stored on an encrypted hard drive. Only Martin McMahon, the Principal instigator will be able to access this information.

Please tick this box if you want to be entered into this prize draw

Finally

Please post the questionnaire back to the **Freepost** address in the stamped address envelope. If you have any questions relating to the questionnaire, please contact Mr. Martin McMahon (tel: 445720; email: m.mcmahon@health.gov.je or m.mcmahon2@lancaster.ac.uk) or Professor Chris Hatton (chris.hatton@lancaster.ac.uk).

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Professor Bruce Hollingsworth - Head of Department: Health Research Faculty of Health and Medicine
(Division of Health Research) Lancaster University Lancaster LA1 4YG
Tel: +44 (0)1524 594154 Email: b.hollingsworth@lancaster.ac.uk

If you wish to speak to someone outside of the PhD Health Research Programme, you may also contact:

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Thank you in advance for your time.

Yours faithfully

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Section 1: Demographics and Socioeconomic Status

1.1 Are you? *(Tick one only)*

- ⁰¹ Male
⁰² Female
⁰³ Other

1.2 In what year were you born?

1.3 What is your marital status? *(Tick one only)*

- ⁰¹ Single
⁰² Married / Civil partnership
⁰³ Cohabiting (includes same sex couples)
⁰⁴ Separated (includes same sex couples)
⁰⁵ Divorced
⁰⁶ Widowed

1.4 When did your present period of continuous residence in Jersey begin? *(Ignore periods of absence on holiday and absences during the Occupation years)*

- ⁰¹ At birth or In (year):

1.5 Where were you born? *(Tick one only)*

- ⁰¹ Jersey
⁰² Elsewhere in the British Isles* or the Republic of Ireland
⁰³ Portugal or Madeira
⁰⁴ Poland

- ⁰⁵ Other European country, *specify country:*

- ⁰⁶ Elsewhere, *specify country:*

**includes: England, Wales, Scotland, Northern Ireland, other Channel Islands, Isle of Man.*

1.6 Which cultural and ethnic group do you consider you belong to? *(Tick one only)*

White:

- ¹ Jersey ² British ³ Irish ⁴ Polish ⁵ Portuguese / Madeiran

Asian:

- ⁶ Bangladeshi ⁷ Chinese ⁸ Indian ⁹ Pakistani ¹⁰ Thai

Black:

- ¹¹ African ¹² Caribbean Other, or mixed: ¹³ *Please specify:* _____

1.7 What is your highest educational qualification? (Tick *one* only)

- | | |
|--|---|
| <input type="radio"/> ⁰¹ No formal qualifications | <input type="radio"/> ⁰⁵ A/ A2-Level/ BTEC National/ GNVQ (Advanced) |
| <input type="radio"/> ⁰² GNVQ/BTEC Introductory Diploma (Foundation) | <input type="radio"/> ⁰⁶ First Degree |
| <input type="radio"/> ⁰³ 'O' levels/CSE/GCSE/ BTEC First/ GNVQ (Intermediate) | <input type="radio"/> ⁰⁷ Higher Degree (e.g. Masters/PhD) |
| <input type="radio"/> ⁰⁴ AS-Level | <input type="radio"/> ⁰⁸ Other, <i>please specify</i> : _____ |

1.8 Do you have residential qualifications? (Tick *one* only) *In other words are you entitled to buy a property, or rent 'qualified accommodation', in Jersey under the current 'Control of Work and Housing Law'?*

- ⁰¹ Yes
 ⁰² No
 ⁰³ Don't know

1.9 Have you been resident in Jersey for 5 years or more? (Tick *one* only)

- ⁰¹ Yes
 ⁰² No
 ⁰³ Don't know

2.0 Are you currently? (Tick the *one* which is most appropriate to you)

- | | |
|---|---|
| <input type="radio"/> ⁰¹ Working for an employer | <input type="radio"/> ⁰⁶ Unemployed, looking for work |
| <input type="radio"/> ⁰² Self-employed, employing others | <input type="radio"/> ⁰⁷ Unemployed, <i>not</i> looking for work |
| <input type="radio"/> ⁰³ Self-employed, not employing others | <input type="radio"/> ⁰⁸ In full-time education |
| <input type="radio"/> ⁰⁴ Retired | <input type="radio"/> ⁰⁹ A homemaker |
| <input type="radio"/> ⁰⁵ Unable to work due to long-term sickness/disability | <input type="radio"/> ¹⁰ Other, <i>please specify</i> : _____ |

2.1 Which industry do you work in, for your main job? (Tick the *one* which is most appropriate to you)

- | | |
|--|--|
| <input type="radio"/> ⁰¹ Agriculture and fishing | <input type="radio"/> ⁰⁶ Private education or Private health |
| <input type="radio"/> ⁰² Finance (including legal work) | <input type="radio"/> ⁰⁷ Hotels, restaurants and bars |
| <input type="radio"/> ⁰³ Construction and tradesmen | <input type="radio"/> ⁰⁸ Electricity, gas and water |
| <input type="radio"/> ⁰⁴ Wholesale & retail
Transport & communications | <input type="radio"/> ⁰⁹ Public sector |
| <input type="radio"/> ⁰⁵ (including Jersey Airport, Harbours, Post & Telecom) | <input type="radio"/> ¹⁰ Other, <i>please specify</i> : _____ |

2.2 What is your job title (for your main job)? , *please specify*: _____

2.3 How many people are currently living in your household, including yourself?

- Number of people
- Of these people, how many are children?
- Of these people, how many are adults?
- Of the adults, how many bring income into the household?

2.4 Which of the following best describes the work you do for your main job? (Tick one only)

- ⁰¹ Routine, Semi-routine, Manual or Service occupation *e.g. HGV or van driver, cleaner, porter, packer, sewing machinist, messenger, labourer, waiter/waitress, bar staff, postal worker, machine operative, security guard, caretaker, farm worker, catering assistant, receptionist, sales assistant*
- ⁰² Technical or Craft occupation *e.g. motor mechanic, fitter, inspector, plumber, printer, tool maker, electrician, gardener*
- ⁰³ Clerical or intermediate occupation *e.g. secretary, personal assistant, clerical worker, office clerk, call centre agent, nursing auxiliary, nursery nurse*
- ⁰⁴ Professional occupation (normally requiring a professional qualification)
e.g. accountant, solicitor, medical practitioner, scientist, civil / mechanical engineer, teacher, nurse, physiotherapist, social worker, welfare officer, artist, musician, police officer (sergeant or above), software designer, fund administrator
- ⁰⁵ Middle or Junior Manager *e.g. office manager, retail manager, bank manager, restaurant manager, warehouse manager, publican*
- ⁰⁶ Senior Manager (usually responsible for planning, organising and co-ordinating work) *e.g. finance manager, chief executive*
- ⁰⁷ Not sure
- ⁰⁸ Currently unemployed
-

2.5 What type of property does your household occupy? (Please tick one box only)

- ⁰¹ Bedsit
- ⁰² Flat or maisonette
- ⁰³ Semi-detached/terraced house or bungalow
- ⁰⁴ Detached house or bungalow

2.6 If you live in a bedsit, flat or maisonette, is your home on the ground floor?

- ⁰¹ Yes
- ⁰² No
- ⁰³ Not applicable

2.7 What is the type of accommodation? (Please tick one box only)

- ⁰¹ Owner occupied
- ⁰² Staff/service accommodation
- ⁰³ Social housing rent ('Andium homes' previously)
- ⁰⁴ Registered lodging house (States housing, housing trust and parish rent)
- ⁰⁵ Lodger paying rent in private household
- ⁰⁶ Qualified Private rent
- ⁰⁷ Other Non-qualified accommodation
-

2.8 Is your home sheltered or disabled housing? *Sheltered/disabled housing is designed so that elderly or physically disabled people can live independently. The homes are often built in groups and provided with a warden or emergency call facilities.*

- ⁰¹ Yes ⁰² No *please specify:* _____
-

2.9 Approximately, what is your total income (before tax)?

- ⁰¹ Less than £15,000
- ⁰² £15,000 - £24,999
- ⁰³ £25,000 - £34,999
- ⁰⁴ £35,000 - £44,999
- ⁰⁵ £45,000 - £54,999
- ⁰⁶ £55,000 - £64,999
- ⁰⁷ £65,000 - £74,999
- ⁰⁸ £75,000 - £84,999
- ⁰⁹ £85,000 - £95,499
- ¹⁰ £95,500 - £105,000
- ¹¹ More than £105,000

2.10 Approximately, what is your total household income (before tax)?

- ⁰¹ Less than £15,000
- ⁰² £15,000 - £24,999
- ⁰³ £25,000 - £34,999
- ⁰⁴ £35,000 - £44,999
- ⁰⁵ £45,000 - £54,999
- ⁰⁶ £55,000 - £64,999
- ⁰⁷ £65,000 - £74,999
- ⁰⁸ £75,000 - £84,999
- ⁰⁹ £85,000 - £95,499
- ¹⁰ £95,500 - £105,000
- ¹¹ More than £105,000

2.11 Approximately, what is your total discretionary income each month? *Discretionary income is the income remaining after deduction of taxes, social security charges, and basic living costs.*

- ⁰¹ Less than £50
- ⁰² £50 - £75
- ⁰³ £75 - £100
- ⁰⁴ £100 - £125
- ⁰⁵ £125 - £150
- ⁰⁶ £150 - £175
- ⁰⁷ £175 - £200
- ⁰⁸ £200 - £300
- ⁰⁹ £300 - £400
- ¹⁰ £400 - £500
- ¹¹ More than £500

2.12 Approximately, what is your household's discretionary income each month? *Discretionary income is the income remaining after deduction of taxes, social security charges, and basic living costs.*

- ⁰¹ Less than £100
- ⁰² £100 - £200
- ⁰³ £200 - £300
- ⁰⁴ £300 - £400
- ⁰⁵ £400 - £500
- ⁰⁶ £500 - £600
- ⁰⁷ £600 - £700
- ⁰⁸ £700 - £800
- ⁰⁹ £800 - £900
- ¹⁰ £900 - £1,000
- ¹¹ More than £1,000

Section 2: Health and Wellbeing

3.0 In general, would you say your health is:

- ⁰¹ Excellent
- ⁰² Very good
- ⁰³ Good
- ⁰⁴ Fair
- ⁰⁵ Poor

3.1 Compared to one year ago, how would you rate your health in general now?

- ⁰¹ Much better now than one year ago
- ⁰² Somewhat better now than one year ago
- ⁰³ About the same
- ⁰⁴ Somewhat worse now than one year ago
- ⁰⁵ Much worse now than one year ago

The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

	Yes, limited a lot	Yes, limited a little	No, Not limited at all
3.2. Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	01 <input type="radio"/>	02 <input type="radio"/>	03 <input type="radio"/>
3.3. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	01 <input type="radio"/>	02 <input type="radio"/>	03 <input type="radio"/>
3.4. Lifting or carrying groceries	01 <input type="radio"/>	02 <input type="radio"/>	03 <input type="radio"/>
3.5. Climbing several flights of stairs	01 <input type="radio"/>	02 <input type="radio"/>	03 <input type="radio"/>
3.6. Climbing one flight of stairs	01 <input type="radio"/>	02 <input type="radio"/>	03 <input type="radio"/>
3.7. Bending, kneeling, or stooping	01 <input type="radio"/>	02 <input type="radio"/>	03 <input type="radio"/>
3.8. Walking more than a mile	01 <input type="radio"/>	02 <input type="radio"/>	03 <input type="radio"/>
3.9. Walking for 15 minutes	01 <input type="radio"/>	02 <input type="radio"/>	03 <input type="radio"/>
3.10. Walking for a few minutes	01 <input type="radio"/>	02 <input type="radio"/>	03 <input type="radio"/>
3.11. Bathing or dressing yourself	01 <input type="radio"/>	02 <input type="radio"/>	03 <input type="radio"/>

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

	Yes	No
4.0. Cut down the amount of time you spent on work or other activities	01 <input type="radio"/>	02 <input type="radio"/>
4.1. Accomplished less than you would like	01 <input type="radio"/>	02 <input type="radio"/>
4.2. Were limited in the kind of work or other activities	01 <input type="radio"/>	02 <input type="radio"/>
4.3. Had difficulty performing the work or other activities (for example, it took extra effort)	01 <input type="radio"/>	02 <input type="radio"/>

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

	Yes	No
4.4. Cut down the amount of time you spent on work or other activities	01 <input type="radio"/>	02 <input type="radio"/>
4.5. Accomplished less than you would like	01 <input type="radio"/>	02 <input type="radio"/>
4.6. Didn't do work or other activities as carefully as usual	01 <input type="radio"/>	02 <input type="radio"/>

4.7 During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?

- ⁰¹ Not at all
- ⁰² Slightly
- ⁰³ Moderately
- ⁰⁴ Quite a bit
- ⁰⁵ Extremely

4.8 How much bodily pain have you had during the past 4 weeks?

- ⁰¹ None
- ⁰² Very mild
- ⁰³ Mild
- ⁰⁴ Moderate
- ⁰⁵ Severe
- ⁰⁶ Very severe

4.9 How much bodily pain have you had during the past 4 weeks?

- ⁰¹ None
- ⁰² Very mild
- ⁰³ Mild
- ⁰⁴ Moderate
- ⁰⁵ Severe
- ⁰⁶ Very severe

4.9 During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

- ⁰¹ Not at all
- ⁰² A little bit
- ⁰³ Moderately
- ⁰⁴ Quite a bit
- ⁰⁵ Extremely

4.10 During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

- ⁰¹ All of the time
- ⁰² Most of the time
- ⁰³ Some of the time
- ⁰⁴ A little of the time
- ⁰⁵ None of the time

These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling....

How much of the time during the past 4 weeks	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
5.1 Did you feel full of pep?	⁰¹ <input type="radio"/>	⁰² <input type="radio"/>	⁰³ <input type="radio"/>	⁰⁴ <input type="radio"/>	⁰⁵ <input type="radio"/>	⁰⁶ <input type="radio"/>
5.2 Have you been a very nervous person?	⁰¹ <input type="radio"/>	⁰² <input type="radio"/>	⁰³ <input type="radio"/>	⁰⁴ <input type="radio"/>	⁰⁵ <input type="radio"/>	⁰⁶ <input type="radio"/>
5.3 Have you felt so down in the dumps that nothing could cheer you up?	⁰¹ <input type="radio"/>	⁰² <input type="radio"/>	⁰³ <input type="radio"/>	⁰⁴ <input type="radio"/>	⁰⁵ <input type="radio"/>	⁰⁶ <input type="radio"/>
5.4 Have you felt calm and peaceful?	⁰¹ <input type="radio"/>	⁰² <input type="radio"/>	⁰³ <input type="radio"/>	⁰⁴ <input type="radio"/>	⁰⁵ <input type="radio"/>	⁰⁶ <input type="radio"/>

How much of the time during the past 4 weeks	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
5.5 Did you have a lot of energy?	01 <input type="radio"/>	02 <input type="radio"/>	03 <input type="radio"/>	04 <input type="radio"/>	05 <input type="radio"/>	06 <input type="radio"/>
5.6 Have you felt downhearted and blue?	01 <input type="radio"/>	02 <input type="radio"/>	03 <input type="radio"/>	04 <input type="radio"/>	05 <input type="radio"/>	06 <input type="radio"/>
5.7 Did you feel worn out?	01 <input type="radio"/>	02 <input type="radio"/>	03 <input type="radio"/>	04 <input type="radio"/>	05 <input type="radio"/>	06 <input type="radio"/>
5.8 Have you been a happy person?	01 <input type="radio"/>	02 <input type="radio"/>	03 <input type="radio"/>	04 <input type="radio"/>	05 <input type="radio"/>	06 <input type="radio"/>
5.9 Did you feel tired?	01 <input type="radio"/>	02 <input type="radio"/>	03 <input type="radio"/>	04 <input type="radio"/>	05 <input type="radio"/>	06 <input type="radio"/>

How TRUE or FALSE is each of the following statements for you

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
5.10 I seem to get sick a little easier than other people	01 <input type="radio"/>	02 <input type="radio"/>	03 <input type="radio"/>	04 <input type="radio"/>	05 <input type="radio"/>
5.11 I am as healthy as anybody I know	01 <input type="radio"/>	02 <input type="radio"/>	03 <input type="radio"/>	04 <input type="radio"/>	05 <input type="radio"/>
5.12 I expect my health to get worse	01 <input type="radio"/>	02 <input type="radio"/>	03 <input type="radio"/>	04 <input type="radio"/>	05 <input type="radio"/>
5.13 My health is excellent	01 <input type="radio"/>	02 <input type="radio"/>	03 <input type="radio"/>	04 <input type="radio"/>	05 <input type="radio"/>

5.14 When was the last time you went to a GP?

- 01 within the last 6 months
- 02 within the last 7-12 months
- 03 more than 1, but less than 2 years ago
- 04 more than 2, but less than 3 years ago
- 05 more than 3, but less than 5 years ago
- 06 more than 5, but less than 10 years ago
- 07 more than 10 years ago or never

5.15 When was the last time you saw a hospital consultant?

- 01 within the last 6 months
- 02 within the last 7-12 months
- 03 more than 1, but less than 2 years ago
- 04 more than 2, but less than 3 years ago
- 05 more than 3, but less than 5 years ago
- 06 more than 5, but less than 10 years ago
- 07 more than 10 years ago or never

please specify consultant specialty e.g. neurology/ cardiology

5.16 When was the last time you attended a dentist for treatment/checkup?

- 01 within the last 6 months
- 02 within the last 7-12 months
- 03 more than 1, but less than 2 years ago
- 04 more than 2, but less than 3 years ago
- 05 more than 3, but less than 5 years ago
- 06 more than 5, but less than 10 years ago
- 07 more than 10 years ago or never

Under each heading, please tick the ONE box that best describes your health TODAY.

6.5 MOBILITY

- | | |
|---|--------------------------|
| I have no problems in walking about | 01 <input type="radio"/> |
| I have slight problems in walking about | 02 <input type="radio"/> |
| I have moderate problems in walking about | 03 <input type="radio"/> |
| I have severe problems in walking about | 04 <input type="radio"/> |
| I am unable to walk about | 05 <input type="radio"/> |

6.6 SELF-CARE

- | | |
|---|--------------------------|
| I have no problems washing or dressing myself | 01 <input type="radio"/> |
| I have slight problems washing or dressing myself | 02 <input type="radio"/> |
| I have moderate problems washing or dressing myself | 03 <input type="radio"/> |
| I have severe problems washing or dressing myself | 04 <input type="radio"/> |
| I am unable to wash or dress myself | 05 <input type="radio"/> |

6.7 USUAL ACTIVITIES (e.g. work, study, housework, family or leisure activities)

- | | |
|--|--------------------------|
| I have no problems doing my usual activities | 01 <input type="radio"/> |
| I have slight problems doing my usual activities | 02 <input type="radio"/> |
| I have moderate problems doing my usual activities | 03 <input type="radio"/> |
| I have severe problems doing my usual activities | 04 <input type="radio"/> |
| I am unable to do my usual activities | 05 <input type="radio"/> |

6.8 PAIN / DISCOMFORT

- | | |
|------------------------------------|--------------------------|
| I have no pain or discomfort | 01 <input type="radio"/> |
| I have slight pain or discomfort | 02 <input type="radio"/> |
| I have moderate pain or discomfort | 03 <input type="radio"/> |
| I have severe pain or discomfort | 04 <input type="radio"/> |
| I have extreme pain or discomfort | 05 <input type="radio"/> |

6.9 ANXIETY / DEPRESSION

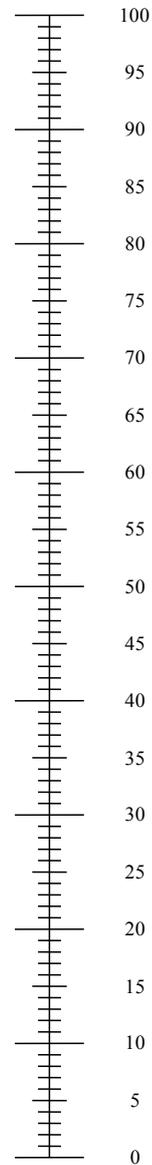
- | | |
|--------------------------------------|--------------------------|
| I am not anxious or depressed | 01 <input type="radio"/> |
| I am slightly anxious or depressed | 02 <input type="radio"/> |
| I am moderately anxious or depressed | 03 <input type="radio"/> |
| I am severely anxious or depressed | 04 <input type="radio"/> |
| I am extremely anxious or depressed | 05 <input type="radio"/> |

6.10

- We would like to know how good or bad your health is TODAY.
- This scale is numbered from 0 to 100.
- 100 means the best health you can imagine. 0 means the worst health you can imagine.
- Mark an X on the scale to indicate how your health is TODAY.
- Now, please write the number you marked on the scale in the box below.

YOUR HEALTH TODAY =

The best health
you can imagine



The worst health
you can imagine

These questions are linked to the International Classification of Disease headings [ICD-10]. Please add as much information as you can. This will help the researchers gain a coherent picture of the health of people in Jersey. Examples are provided for guidance only

Do you have any of the following conditions	Yes	No
7.0 Viral or infective diseases (<i>e.g. hepatitis, viral or bacterial diseases</i>) If applicable please specify:	01 <input type="radio"/>	02 <input type="radio"/>
7.1 Cancer(s) (<i>e.g. lung cancer, skin cancer</i>) If applicable please specify:	01 <input type="radio"/>	02 <input type="radio"/>
7.2 Diseases of the blood (<i>e.g. anaemia, hemochromatosis, haemophilia</i>) If applicable please specify:	01 <input type="radio"/>	02 <input type="radio"/>
7.3 Endocrine, nutritional or metabolic conditions (<i>e.g. diabetes, thyroid problems, hormone disorders, high cholesterol</i>) If applicable please specify:	01 <input type="radio"/>	02 <input type="radio"/>
7.4 Mental health illnesses or behavioural problems (<i>e.g. depression, anxiety, substance misuse</i>) If applicable please specify:	01 <input type="radio"/>	02 <input type="radio"/>
7.5 Neurological conditions (<i>e.g. epilepsy, fainting, multiple sclerosis, Parkinson's disease</i>) If applicable please specify:	01 <input type="radio"/>	02 <input type="radio"/>
7.6 Diseases of the eye (<i>e.g. glaucoma, visual disturbances, blindness</i>) If applicable please specify:	01 <input type="radio"/>	02 <input type="radio"/>
7.7 Diseases of the ear (<i>e.g. impacted wax, infection, hearing loss, ringing sound in the ear</i>) If applicable please specify:	01 <input type="radio"/>	02 <input type="radio"/>
7.8 Diseases of the circulatory system (<i>e.g. high blood pressure, angina, heart disease</i>) If applicable please specify:	01 <input type="radio"/>	02 <input type="radio"/>
7.9 Diseases of the respiratory system (<i>e.g. asthma, COPD, persistent cough</i>) If applicable please specify:	01 <input type="radio"/>	02 <input type="radio"/>
7.10 Diseases of the digestive system (<i>e.g. Hernia, Liver disease, Reflux, Ulcers</i>) If applicable please specify:	01 <input type="radio"/>	02 <input type="radio"/>
7.11 Diseases of the skin (<i>e.g. eczema, rashes, acne</i>) If applicable please specify:	01 <input type="radio"/>	02 <input type="radio"/>
7.12 Diseases of the musculoskeletal system (<i>e.g. back/joint pain, arthritis, gout</i>) If applicable please specify:	01 <input type="radio"/>	02 <input type="radio"/>

7.13 Diseases of the genitourinary system (e.g. prostate problems, incontinence, reoccurring urinary tract infections) 01 02
If applicable please specify

7.14 If you are pregnant, are you experiencing any complications (e.g. gestational diabetes, hypertension) 01 02
If applicable please specify

7.15 Malformations or genetic problems (e.g. history of cleft lip or palate, Spina bifida, Downs syndrome) 01 02
If applicable please specify

7.16 Injuries to your body as a result of trauma or poisoning (e.g. fractures, nerve damage, lacerations) 01 02
If applicable please specify

7.17 If you suffer from any other condition(s) please use the space below to identify further:

Any other conditions

7.18 How often do you have a drink containing alcohol?

- 01 a: Never
02 b: Monthly or less
03 c: 2 -4 times a month
04 d: 2 -3 times a week
05 e: 4 or more times a week

7.20 How often do you have six or more drinks on one occasion?

- 01 a: Never
02 b: Less than monthly
03 c: Monthly
04 d: Weekly
05 e: Daily or almost daily

7.19 How many standard drinks containing alcohol do you have on a typical day?

- 01 a: 1 or 2
02 b: 3 or 4
03 c: 5 or 6
04 d: 7 - 9
05 e: 10 or more

7.21 Do you smoke?

- 01 Yes 02 No

Please specify amount _____ (if applicable)

Finally please consider the following two questions

8.0 Think of this ladder as representing where people stand in their communities.

People define community in different ways; please define it in whatever way is most meaningful to you. At the **top** of the ladder are the people who have the highest standing in their community. At the **bottom** are the people who have the lowest standing in their community.

Where would you place yourself on this ladder?

Please place a large '**X**' on the rung where you think you stand at this time in your life, relative to other people in your community.



8.1 Think of this ladder as representing where people stand in Jersey.

At the **top** of the ladder as then people are the best off – those who have the most money, the most education, and the most respected jobs. At the **bottom** are the people who are the worst off – who have the least money, least education, and the least respectable jobs or no job. The higher up you are on this ladder, the closer you are to the people at the very top; the lower you are, the closer you are to the people at the very bottom.

Where would you place yourself on this ladder?

Please place a large 'X' on the rung where you think you stand at this time in your life, relative to other people in Jersey.



Thank you for taking the time to fill out the
Jersey Health & Socioeconomic Status Assessment Questionnaire
Your response is very important to us

Do you have any other comments?

Please return your completed form using the **pre-paid envelope provided**, or alternatively send by **freepost** to:
Martin McMahon, Senior Lecturer, Nursing and Midwifery Higher Education Department, Health and Social
Services, General Hospital, St Helier, Jersey, JE1 3QS
m.mcmahon@health.gov.je



Appendix 1.3 – Intellectual disability population questionnaire



Participant ID Code as Per Consent form (form 3) and Excel database



Before you fill in this questionnaire please confirm that consent has been granted: j Yes
Ensure the Consent form number corresponds to this questionnaire

Person filling out this questionnaire is: _____

Is this questionnaire being filled in by?

^{01j} The individual

^{02j} By-Proxy, if so please state consultee has approved _____

This questionnaire is being completed in the persons (e.g. home) _____

This person has a

^{01j} **Mild intellectual disability**

(IQ score of 50-69. Most people with mild learning disability can live independently in ordinary surroundings, though they may need help in coping with family responsibilities, housing and employment, or when under unusual stress)

^{02j} **Moderate intellectual disability**

(IQ score of 35-49. Activities of daily living such as dressing, feeding and attention to hygiene are usually acquired over time but extended activities of daily living such as use of money and road sense generally require support. Similarly, supported employment and supported education are the rule)

^{03j} **Severe intellectual disability**

(IQ score of 20-34. Many people in this group can be helped to look after themselves but only under close supervision and to communicate in a simple way. They may be able to undertake simple tasks and engage in limited social activities, but they need supervision and a clear structure to their lives).

- ⁰⁴j **Profound Intellectual Disability**
(IQ score of less than 20. They require help and supervision for even the simplest activities of daily living).
- ⁰⁵j **Not assessed / cannot say**

Specific Intellectual Disability Demographics

<p>A. Type of Residence</p> <p>⁰¹j Family home ⁰²j Paid carer ⁰³j Congregate care ⁰⁴j Independent living</p>	<p>b. Marital Status</p> <p>⁰¹j Single ⁰²j Married/ lives with partner ⁰³j Separated / divorced ⁰⁴j Widowed</p>
<p>Are the following conditions present?</p>	
<p>c. Downs Syndrome</p> <p>⁰¹j Yes, definite ⁰²j Yes, query ⁰³j No ⁰⁴j Don't know</p>	<p>d. Autism</p> <p>⁰¹j Yes, definite ⁰²j Yes, query ⁰³j No ⁰⁴j Don't know</p>
<p>e. Dementia</p> <p>⁰¹j Yes, definite ⁰²j Yes, query ⁰³j No ⁰⁴j Don't know</p>	<p>f. Other known syndrome? (Specify)</p>
<p>g. How long has the individual been living in this setting? (in years. If less than one year enter 1)</p>	
<p>h. Has the individual ever been diagnosed with a Psychiatric disorder (only enter if such a diagnosis has been made by a psychiatrist – do not guess)</p> <p>⁰¹j Don't know ⁰²j No psychiatric disorder ⁰³j Depressive illness ⁰⁴j Other affective disorder ⁰⁵j Schizophrenia ⁰⁶j Psychotic condition (unclassified) ⁰⁵j Neurosis ⁰⁶j Other (specify)</p>	<p>i. Daytime engagement</p> <p>⁰¹j Paid Work ⁰²j Voluntary work ⁰³j Vocational training ⁰⁴j Education ⁰⁵j Day service ⁰⁶j No daytime occupation</p>
<p>j. Hearing</p>	<p>k. Vision</p>

<p>⁰¹j Deaf or almost</p> <p>⁰²j Poor</p> <p>⁰³j Normal or corrected normal (e.g. wearing hearing aid)</p> <p>l. Speech</p> <p>⁰¹j Never speaks a word</p> <p>⁰²j Uses a few words only</p> <p>⁰³j Speaks using sentences and normal</p> <p>⁰⁴j Can talk but does not speak</p>	<p>⁰¹j Blind or almost blind</p> <p>⁰²j Poor</p> <p>⁰³j Normal or corrected normal (e.g. wearing glasses)</p> <p>m. If this person speaks in sentences is his / her speech...</p> <p>¹j Difficult to understand even by acquaintances, impossible for strangers</p> <p>⁰²j Easily understood for acquaintances, difficult for strangers</p> <p>⁰³j Clear enough to be understood by anyone</p>
<p>n. Does this person communicate in another format? (e.g. BSL, Makaton, etc)</p> <p>⁰¹j Yes – Please specify ⁰²j No</p>	
<p>o. Understanding communication (circle the highest number that applies only)</p> <p>⁰¹j Understands little or nothing</p> <p>⁰²j Understands a few simple commands (e.g. come here, sit down)</p> <p>⁰³j Understands a fair range of instructions or questions related to practical needs</p> <p>⁰⁴j Understands comments, questions, instructions related to personal needs and experiences (e.g. did you enjoy the trip to the zoo?)</p> <p>⁰⁵j Understands information about things outside own immediate experiences (e.g. stories or accounts of other people’s experiences)</p>	
<p>p. Continence</p> <p>⁰¹j Doubly incontinent</p> <p>⁰²j Incontinent (soiling or wetting) once a week or more</p> <p>⁰³j Sometimes incontinent but less often than once a week</p> <p>⁰⁴j Usually fully continent</p>	<p>q. Does the person suffer from seizures?</p> <p>⁰¹j No (no medication, no seizures)</p> <p>⁰²j No (controlled by medication)</p> <p>⁰³j Occasional seizures (less often than monthly)</p> <p>⁰⁴j One or more seizures per month</p>
<p>r. Does the person have a diagnosis of epilepsy?</p> <p>⁰¹j Yes, definite</p> <p>⁰²j Yes, query</p> <p>⁰³j No</p> <p>⁰⁴j Don’t know</p>	<p>s. Current physical health</p> <p>⁰¹j Poor</p> <p>⁰²j Fair</p> <p>⁰³j Good</p> <p>⁰⁴j Very good</p> <p>⁰⁵j Excellent</p>

t. Mobility (please indicate which best applies)

- ⁰¹ | Walks by self indoors, upstairs and outdoors
- ⁰² | Walks by self indoors and upstairs only
- ⁰³ | Walks by self indoors only, no stairs
- ⁰⁴ | Mobile with aid or wheelchair indoors, upstairs and outdoors
- ⁰⁵ | Mobile with aid or wheelchair indoors and upstairs only
- ⁰⁶ | Mobile with aid or wheelchair indoors only, no stairs
- ⁰⁷ | Gets around with human aid only

Section 1: Demographics and Socioeconomic Status

1.1 Are you? *(Tick one only)*

- ⁰¹ | Male
- ⁰² | Female
- ⁰³ | Other

1.2 In what year were you born?

1.3 What is your marital status? *(Tick one only)*

- ⁰¹ | Single
- ⁰² | Married / Civil partnership
- ⁰³ | Cohabiting (includes same sex couples)
- ⁰⁴ | Separated (includes same sex couples)
- ⁰⁵ | Divorced
- ⁰⁶ | Widowed

1.4 When did your present period of continuous residence in Jersey begin? *(Ignore periods of absence on holiday and absences during the Occupation years)*

⁰¹ | At birth or In (year):

1.5 Where were you born? *(Tick one only)*

- ⁰¹ | Jersey
- ⁰² | Elsewhere in the British Isles* or the Republic of Ireland
- ⁰³ | Portugal or Madeira
- ⁰⁴ | Poland
- ⁰⁵ | Other European country, *specify country:* _____
- ⁰⁶ | Elsewhere, *specify country:* _____

**includes: England, Wales, Scotland, Northern Ireland, other Channel Islands, Isle of Man.*

1.6 Which cultural and ethnic group do you consider you belong to? (Tick one only)

White:

¹ Jersey ² British ³ Irish ⁴ Polish ⁵ Portuguese / Madeiran

Asian:

⁶ Bangladeshi ⁷ Chinese ⁸ Indian ⁹ Pakistani ¹⁰ Thai

Black:

¹¹ African ¹² Caribbean Other, or mixed: ¹³ Please specify: _____

1.7 What is your highest educational qualification? (Tick one only)

- | | |
|--|---|
| ⁰¹ No formal qualifications | ⁰⁵ A/ A2-Level/ BTEC National/ GNVQ (Advanced) |
| ⁰² GNVQ/BTEC Introductory Diploma (Foundation) | ⁰⁶ First Degree |
| ⁰³ 'O' levels/CSE/GCSE/ BTEC First/ GNVQ (Intermediate) | ⁰⁷ Higher Degree (e.g. Masters/PhD) |
| ⁰⁴ AS-Level | ⁰⁸ Other, please specify: _____ |
-

1.8 Do you have residential qualifications? (Tick one only) *In other words are you entitled to buy a property, or rent 'qualified accommodation', in Jersey under the current 'Control of Work and Housing Law'?*

- ⁰¹ Yes
⁰² No
⁰³ Don't know

1.9 Have you been resident in Jersey for 5 years or more? (Tick one only)

- ⁰¹ Yes
⁰² No
⁰³ Don't know
-

2.0 Are you currently? (Tick the one which is most appropriate to you)

- | | |
|---|---|
| ⁰¹ Working for an employer | ⁰⁶ Unemployed, looking for work |
| ⁰² Self-employed, employing others | ⁰⁷ Unemployed, <i>not</i> looking for work |
| ⁰³ Self-employed, not employing others | ⁰⁸ In full-time education |
| ⁰⁴ Retired | ⁰⁹ A homemaker |
| ⁰⁵ Unable to work due to long-term sickness/disability | ¹⁰ Other, please specify: _____ |
-

2.1 Which industry do you work in, for your main job? (Tick the one which is most appropriate to you)

⁰¹ j	Agriculture and fishing	⁰⁶ j	Private education or Private health
⁰² j	Finance (including legal work)	⁰⁷ j	Hotels, restaurants and bars
⁰³ j	Construction and tradesmen	⁰⁸ j	Electricity, gas and water
⁰⁴ j	Wholesale & retail	⁰⁹ j	Public sector
⁰⁵ j	Transport & communications (including Jersey Airport, Harbours, Post & Telecom)	¹⁰ j	Other, <i>please specify</i> : _____

2.2 What is your job title (for your main job)?

please specify: _____

2.3 How many people are currently living in your household, including yourself?

- Number of people
- Of these people, how many are children?
- Of these people, how many are adults?
- Of the adults, how many bring income into the household?

2.4 Which of the following best describes the work you do for your main job? (*Tick one only*)

- ⁰¹j Routine, Semi-routine, Manual or Service occupation *e.g. HGV or van driver, cleaner, porter, packer, sewing machinist, messenger, labourer, waiter/waitress, bar staff, postal worker, machine operative, security guard, caretaker, farm worker, catering assistant, receptionist, sales assistant*
- ⁰²j Technical or Craft occupation *e.g. motor mechanic, fitter, inspector, plumber, printer, tool maker, electrician, gardener*
- ⁰³j Clerical or intermediate occupation *e.g. secretary, personal assistant, clerical worker, office clerk, call centre agent, nursing auxiliary, nursery nurse*
- ⁰⁴j Professional occupation (*normally requiring a professional qualification*)
e.g. accountant, solicitor, medical practitioner, scientist, civil / mechanical engineer, teacher, nurse, physiotherapist, social worker, welfare officer, artist, musician, police officer (sergeant or above), software designer, fund administrator
- ⁰⁵j Middle or Junior Manager *e.g. office manager, retail manager, bank manager, restaurant manager, warehouse manager, publican*
- ⁰⁶j Senior Manager (*usually responsible for planning, organising and co-ordinating work*) *e.g. finance manager, chief executive*

⁰⁷ | Unemployed

⁰⁸ | Not sure

2.5 What type of property does your household occupy? *(Please tick one box only)*

⁰¹ | Bedsit

⁰² | Flat or maisonette

⁰³ | Semi-detached/terraced house or bungalow

⁰⁴ | Detached house or bungalow

2.6 If you live in a bedsit, flat or maisonette, is your home on the ground floor?

⁰¹ | Yes

⁰² | No

⁰³ | Not applicable

2.7 What is the type of accommodation? *(Please tick one box only)*

⁰¹ | Owner occupied

⁰² | Staff/service accommodation

⁰³ | Social housing rent (*'Andium homes' previously*)

⁰⁴ | Registered lodging house (*States housing, housing trust and parish rent*)

⁰⁵ | Lodger paying rent in private household

⁰⁶ | Qualified Private rent

⁰⁷ | Other Non-qualified accommodation

2.8 Is your home sheltered or disabled housing? *Sheltered/disabled housing is designed so that elderly or physically disabled people can live independently. The homes are often built in groups and provided with a warden or emergency call facilities.*

⁰¹ | Yes ⁰² | No *please specify*

2.9 Approximately, what is your total income (before tax)?

- 01 | Less than £15,000
- 02 | £15,000 - £24,999
- 03 | £25,000 - £34,999
- 04 | £35,000 - £44,999
- 05 | £45,000 - £54,999
- 06 | £55,000 - £64,999
- 07 | £65,000 - £74,999
- 08 | £75,000 - £84,999
- 09 | £85,000 - £95,499
- 10 | £95,500 - £105,000
- 11 | More than £105,000

2.10 Approximately, what is your total household income (before tax)?

- 01 | Less than £15,000
- 02 | £15,000 - £24,999
- 03 | £25,000 - £34,999
- 04 | £35,000 - £44,999
- 05 | £45,000 - £54,999
- 06 | £55,000 - £64,999
- 07 | £65,000 - £74,999
- 08 | £75,000 - £84,999
- 09 | £85,000 - £95,499
- 10 | £95,500 - £105,000
- 11 | More than £105,000

2.11 Approximately, what is your total discretionary income each month? *Discretionary income is the income remaining after deduction of taxes, social security charges, and basic living costs.*

- 01 | Less than £50
- 02 | £50 - £75
- 03 | £75 - £100
- 04 | £100 - £125
- 05 | £125 - £150
- 06 | £150 - £175
- 07 | £175 - £200
- 08 | £200 - £300
- 09 | £300 - £400
- 10 | £400 - £500
- 11 | More than £500

2.12 Approximately, what is your household's discretionary income each month? *Discretionary income is the income remaining after deduction of taxes, social security charges, and basic living costs.*

- 01 | Less than £100
- 02 | £100 - £200
- 03 | £200 - £300
- 04 | £300 - £400
- 05 | £400 - £500
- 06 | £500 - £600
- 07 | £600 - £700
- 08 | £700 - £800
- 09 | £800 - £900
- 10 | £900 - £1,000
- 11 | More than £1,000

2.13 Is your income dependent on benefits?

- 01 | Yes 02 | No *please specify as much as possible*

Section 2: Health and Wellbeing

3.0 In general, would you say your health is:

- ⁰¹ Excellent
- ⁰² Very good
- ⁰³ Good
- ⁰⁴ Fair
- ⁰⁵ Poor

3.1 Compared to one year ago, how would you rate your health in general now?

- ⁰¹ Much better now than one year ago
- ⁰² Somewhat better now than one year ago
- ⁰³ About the same
- ⁰⁴ Somewhat worse now than one year ago
- ⁰⁵ Much worse now than one year ago

The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

	Yes, limited a lot	Yes, limited a little	No, Not limited at all
3.2. Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	⁰¹	⁰²	⁰³
3.3. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	⁰¹	⁰²	⁰³
3.4. Lifting or carrying groceries	⁰¹	⁰²	⁰³
3.5. Climbing several flights of stairs	⁰¹	⁰²	⁰³
3.6. Climbing one flight of stairs	⁰¹	⁰²	⁰³
3.7. Bending, kneeling, or stooping	⁰¹	⁰²	⁰³
3.8. Walking more than a mile	⁰¹	⁰²	⁰³
3.9. Walking for 15 minutes	⁰¹	⁰²	⁰³
3.10. Walking for a few minutes	⁰¹	⁰²	⁰³
3.11. Bathing or dressing yourself	⁰¹	⁰²	⁰³

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

	Yes	No
4.0. Cut down the amount of time you spent on work or other activities	01 j	02 j
4.1. Accomplished less than you would like	01 j	02 j
4.2 Were limited in the kind of work or other activities	01 j	02 j
4.3 Had difficulty performing the work or other activities (for example, it took extra effort)	01 j	02 j

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

	Yes	No
4.4 Cut down the amount of time you spent on work or other activities	01 j	02 j
4.5 Accomplished less than you would like	01 j	02 j
4.6 Didn't do work or other activities as carefully as usual	01 j	02 j
4.7 During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?		

- 01 j Not at all
- 02 j Slightly
- 03 j Moderately
- 04 j Quite a bit
- 05 j Extremely

4.8 How much bodily pain have you had during the past 4 weeks?

- 01 j None
- 02 j Very mild
- 03 j Mild
- 04 j Moderate
- 05 j Severe
- 06 j Very severe

4.10 During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

- ⁰¹ | Not at all
- ⁰² | A little bit
- ⁰³ | Moderately
- ⁰⁴ | Quite a bit
- ⁰⁵ | Extremely

4.11 During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

- ⁰¹ | All of the time
- ⁰² | Most of the time
- ⁰³ | Some of the time
- ⁰⁴ | A little of the time
- ⁰⁵ | None of the time

These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling....

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
5.1 Did you feel full of pep?	⁰¹	⁰²	⁰³	⁰⁴	⁰⁵	⁰⁶
5.2 Have you been a very nervous person?	⁰¹	⁰²	⁰³	⁰⁴	⁰⁵	⁰⁶
5.3 Have you felt so down in the dumps that nothing could cheer you up?	⁰¹	⁰²	⁰³	⁰⁴	⁰⁵	⁰⁶
5.4 Have you felt calm and peaceful?	⁰¹	⁰²	⁰³	⁰⁴	⁰⁵	⁰⁶
5.5 Did you have a lot of energy?	⁰¹	⁰²	⁰³	⁰⁴	⁰⁵	⁰⁶
5.6 Have you felt downhearted and blue?	⁰¹	⁰²	⁰³	⁰⁴	⁰⁵	⁰⁶
5.7 Did you feel worn out?	⁰¹	⁰²	⁰³	⁰⁴	⁰⁵	⁰⁶
5.8 Have you been a happy person?	⁰¹	⁰²	⁰³	⁰⁴	⁰⁵	⁰⁶
5.9 Did you feel tired?	⁰¹	⁰²	⁰³	⁰⁴	⁰⁵	⁰⁶

How TRUE or FALSE is each of the following statements for you

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
5.10 I seem to get sick a little easier than other people	01 <input type="checkbox"/>	02 <input type="checkbox"/>	03 <input type="checkbox"/>	04 <input type="checkbox"/>	05 <input type="checkbox"/>
5.11 I am as healthy as anybody I know	01 <input type="checkbox"/>	02 <input type="checkbox"/>	03 <input type="checkbox"/>	04 <input type="checkbox"/>	05 <input type="checkbox"/>
5.12 I expect my health to get worse	01 <input type="checkbox"/>	02 <input type="checkbox"/>	03 <input type="checkbox"/>	04 <input type="checkbox"/>	05 <input type="checkbox"/>
5.13 My health is excellent	01 <input type="checkbox"/>	02 <input type="checkbox"/>	03 <input type="checkbox"/>	04 <input type="checkbox"/>	05 <input type="checkbox"/>

Under each heading, please tick the ONE box that best describes your health TODAY.

6.5 MOBILITY

I have no problems in walking about	01 <input type="checkbox"/>
I have slight problems in walking about	02 <input type="checkbox"/>
I have moderate problems in walking about	03 <input type="checkbox"/>
I have severe problems in walking about	04 <input type="checkbox"/>
I am unable to walk about	05 <input type="checkbox"/>

6.6 SELF-CARE

I have no problems washing or dressing myself	01 <input type="checkbox"/>
I have slight problems washing or dressing myself	02 <input type="checkbox"/>
I have moderate problems washing or dressing myself	03 <input type="checkbox"/>
I have severe problems washing or dressing myself	04 <input type="checkbox"/>
I am unable to wash or dress myself	05 <input type="checkbox"/>

6.7 USUAL ACTIVITIES (e.g. work, study, housework, family or leisure activities)

I have no problems doing my usual activities	01
I have slight problems doing my usual activities	02
I have moderate problems doing my usual activities	03
I have severe problems doing my usual activities	04
I am unable to do my usual activities	05

6.8 PAIN / DISCOMFORT

I have no pain or discomfort	01
I have slight pain or discomfort	02
I have moderate pain or discomfort	03
I have severe pain or discomfort	04
I have extreme pain or discomfort	05

6.9 ANXIETY / DEPRESSION

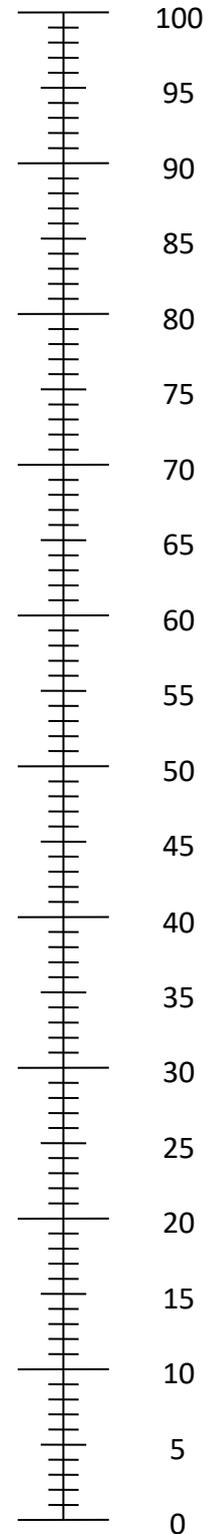
I am not anxious or depressed	01
I am slightly anxious or depressed	02
I am moderately anxious or depressed	03
I am severely anxious or depressed	04
I am extremely anxious or depressed	05

6.10

- We would like to know how good or bad your health is TODAY.
- This scale is numbered from 0 to 100.
- 100 means the best health you can imagine.
0 means the worst health you can imagine.
- Mark an X on the scale to indicate how your health is TODAY.
- Now, please write the number you marked on the scale in the box below.

YOUR HEALTH TODAY =

The best health
you can imagine



The worst health imaginable

These questions are linked to the International Classification of Disease headings [ICD-10]. Please add as much information as you can. This will help the researchers gain a coherent picture of the health of people in Jersey. Examples are provided for guidance only

Do you have any of the following conditions	Yes	No
7.0 Viral or infective diseases (<i>e.g. hepatitis, viral or bacterial diseases</i>) If applicable please specify:	01 j	02 j
7.1 Cancer(s) (<i>e.g. lung cancer, skin cancer</i>) If applicable please specify:	01 j	02 j
7.2 Diseases of the blood (<i>e.g. anaemia, hemochromatosis, haemophilia</i>) If applicable please specify:	01 j	02 j
7.3 Endocrine, nutritional or metabolic conditions (<i>e.g. diabetes, thyroid problems, hormone disorders, high cholesterol</i>) If applicable please specify:	01 j	02 j
7.4 Mental health illnesses or behavioural problems (<i>e.g. depression, anxiety, substance misuse</i>) If applicable please specify:	01 j	02 j
7.5 Neurological conditions (<i>e.g. epilepsy, fainting, multiple sclerosis, Parkinson's disease</i>) If applicable please specify:	01 j	02 j
7.6 Diseases of the eye (<i>e.g. glaucoma, visual disturbances, blindness</i>) If applicable please specify:	01 j	02 j
7.7 Diseases of the ear (<i>e.g. impacted wax, infection, hearing loss, ringing sound in the ear</i>) If applicable please specify:	01 j	02 j
7.8 Diseases of the circulatory system (<i>e.g. high blood pressure, angina, heart disease</i>) If applicable please specify:	01 j	02 j
7.9 Diseases of the respiratory system (<i>e.g. asthma, COPD, persistent cough</i>) If applicable please specify:	01 j	02 j

The worst health
you can imagine

7.10 Diseases of the digestive system (e.g. hernia, liver disease, reflux, ulcers)

01 |

02 |

If applicable please specify:

7.11 Diseases of the skin (e.g. eczema, rashes, acne)

01 |

02 |

If applicable please specify

7.12 Diseases of the musculoskeletal system (e.g. back/joint pain, arthritis, gout)

01 |

02 |

If applicable please specify

7.13 Diseases of the genitourinary system (e.g. prostate problems, incontinence, reoccurring urinary tract infections)

01 |

02 |

If applicable please specify

7.14 If you are pregnant, are you experiencing any complications (e.g. gestational diabetes, hypertension)

01 |

02 |

If applicable please specify

7.15 Malformations or genetic problems (e.g. history of cleft lip or palate, Spina bifida, Downs syndrome)

01 |

02 |

If applicable please specify

7.16 Injuries to your body as a result of trauma or poisoning (e.g. fractures, nerve damage, lacerations)

01 |

02 |

If applicable please specify

Any other conditions

7.18 When was the last time you went to a GP?

- ⁰¹ | within the last 6 months
- ⁰² | within the last 7-12 months
- ⁰³ | more than 1, but less than 2 years ago
- ⁰⁴ | more than 2, but less than 3 years ago
- ⁰⁵ | more than 3, but less than 5 years ago
- ⁰⁶ | more than 5, but less than 10 years ago
- ⁰⁷ | more than 10 years ago or never

7.20 When was the last time you attended a dentist for treatment/checkup?

- ⁰¹ | within the last 6 months
- ⁰² | within the last 7-12 months
- ⁰³ | more than 1, but less than 2 years ago
- ⁰⁴ | more than 2, but less than 3 years ago
- ⁰⁵ | more than 3, but less than 5 years ago
- ⁰⁶ | more than 5, but less than 10 years ago
- ⁰⁷ | more than 10 years ago or never

7.22 How many standard drinks containing alcohol do you have on a typical day?

- ⁰¹ | a: 1 or 2
- ⁰² | b: 3 or 4
- ⁰³ | c: 5 or 6
- ⁰⁴ | d: 7 - 9
- ⁰⁵ | e: 10 or more

7.19 When was the last time you saw a hospital consultant?

- ⁰¹ | within the last 6 months
- ⁰² | within the last 7-12 months
- ⁰³ | more than 1, but less than 2 years ago
- ⁰⁴ | more than 2, but less than 3 years ago
- ⁰⁵ | more than 3, but less than 5 years ago
- ⁰⁶ | more than 5, but less than 10 years ago
- ⁰⁷ | more than 10 years ago or never

*please specify consultant specialty e.g. neurology/
cardiology*

: _____

7.21 How often do you have a drink containing alcohol?

- ⁰¹ | a: Never
- ⁰² | b: Monthly or less
- ⁰³ | c: 2 -4 times a month
- ⁰⁴ | d: 2 -3 times a week
- ⁰⁵ | e: 4 or more times a week

7.23 How often do you have six or more drinks on one occasion?

- ⁰¹ | a: Never
- ⁰² | b: Less than monthly
- ⁰³ | c: Monthly

7.23 Do you smoke?

⁰¹ | Yes ⁰² | No

Please specify amount _____ (if applicable)

⁰⁴ | d: Weekly

⁰⁵ | e: Daily or almost daily

5.17 Do you receive care from any other health professionals?

⁰¹ | Yes ⁰² | No *Please specify e.g. physiotherapist*

8.0 Please consider the following two questions

Think of this ladder as representing where people stand in their communities.

People define community in different ways; please define it in whatever way is most meaningful to you (or _____ if proxy informant). At the **top** of the ladder are the people who have the highest standing in their community. At the **bottom** are the people who have the lowest standing in their community.

Where would you place yourself (or _____ if proxy respondent) on this ladder?

Please place a large 'X' on the rung where you think you (or _____ if proxy respondent) stand at this time in your life, relative to other people in your community.



8.1 Think of this ladder as representing where people stand in Jersey.

At the **top** of the ladder are the people who are the best off – those who have the most money, the most education, and the most respected jobs. At the **bottom** are the people who are the worst off – who have the least money, least education, and the least respectable jobs or no job. The higher up you are on this ladder, the closer you are to the people at the very top; the lower you are, the closer you are to the people at the very bottom.

Where would you place yourself (or _____ if proxy informant). on this ladder?

Please place a large 'X' on the rung where you think you (or _____ if proxy informant). stand at this time in your life, relative to other people in Jersey.



8.2. Medication Name	Dose	Regular or PRN	Prescribed by
Example Sodium Valproate	500MG 3 times a day	Regular medication	Neurologist
a			
b			
c			
d			
e			
f			
g			
h			
i			
j			
k			

BPI-S Questionnaire

Instructions

Below you will find broad definitions followed by specific items for three types of behavior problems: self-injurious behaviors (items 1-8), aggressive/destructive behaviors (items 9-18), and stereotyped behaviors (items 19-30). Indicate which behaviors you have observed in this individual **during the past six months** by circling the number in the appropriate boxes (1) how often a described behavior typically occurs and (2) how serious a problem the behavior is. If the behavior has not occurred during the past six months and therefore poses no problem check "never/no problem" ("0"). If the behavior has occurred, rate the approximate frequency of its occurrence and its severity (use the definitions below). Finally, for each item, multiply the frequency and severity scores and enter the product of the multiplied scores in the far right column. For subscale total scores, add the product sum. (No severity scale is provided for stereotyped behavior.)

	Mild Problem	Moderate Problem	Severe Problem
Self-Injurious Behavior	Behavior occurs but does not inflict significant damage on the individual (e.g., temporary reddening of the skin, very light bruising).	Behavior may inflict moderate damage on the individual (e.g., moderate bruising, scratching through the skin, repeatedly picking scabs).	Behavior may inflict moderate to severe damage on the individual (e.g. biting through the skin, eye gouging, fracturing bones) minor or major medical intervention required.
Aggression/ Destruction	Behavior occurs but does not inflict significant damage on other people (e.g., temporary reddening of the skin, very light bruising); or disruption or mild damage to property, e.g., objects thrown, furniture tipped, doors slammed, meals spoiled, paint scratched. Item does not require repair or replacement.	The behavior may inflict moderate damage on other people (e.g., moderate bruising, scratching through the skin, repeatedly picking scabs; or moderate damage to property (e.g., curtains torn, furniture partly broken). Item requires repair but can be used.	The behavior may inflict moderate to severe damage on other people (e.g. biting through the skin, eye gouging, fracturing bones) minor or major medical intervention required; or significant damage to property. Item requires repair and cannot be used.

SELF-INJURIOUS BEHAVIOR

<p><i>Self-injurious behavior (SIB) causes damage to the person's own body; i.e., damage has either already occurred, or it must be expected if the behavior remained untreated. SIBs occur repeatedly in the same way over and over again, and they are characteristic for that person.</i></p>		Never /no problem	Average Frequency of Occurrence				Severity of the Problem		
			Monthly	Weekly	Daily	Hourly	Mild	Moderate	Severe
1	Self-biting	0	1	2	3	4	1	2	3
2	Head hitting	0	1	2	3	4	1	2	3
3	Body hitting (except for the head) with own hand or with any other body part	0	1	2	3	4	1	2	3
4	Self-scratching	0	1	2	3	4	1	2	3
5	Pica (ingesting non-food items)	0	1	2	3	4	1	2	3
6	Inserting objects in nose, ears, anus, etc.	0	1	2	3	4	1	2	3
7	Hair pulling (tearing out patches of hair)	0	1	2	3	4	1	2	3
8	Teeth grinding (evidence of ground teeth)	0	1	2	3	4	1	2	3

AGGRESSIVE/DESTRUCTIVE BEHAVIOR

Aggressive or destructive behaviors are deliberate overt attacks directed towards other individuals or property:		Never/no problem	Average Frequency of Occurrence				Severity of the Problem		
			Monthly	Weekly	Daily	Hourly	Mild	Moderate	Severe
9	Hitting others	0	1	2	3	4	1	2	3
10	Kicking others	0	1	2	3	4	1	2	3
11	Pushing others	0	1	2	3	4	1	2	3
12	Biting others	0	1	2	3	4	1	2	3
13	Grabbing and pulling others	0	1	2	3	4	1	2	3
14	Scratching others	0	1	2	3	4	1	2	3
15	Pinching others	0	1	2	3	4	1	2	3
16	Verbally abusive with others	0	1	2	3	4	1	2	3
17	Destroying things (e.g., rips clothes, throws chairs, smashes tables)	0	1	2	3	4	1	2	3
18	Bullying - being mean or cruel (e.g., grabbing toys or food from others)	0	1	2	3	4	1	2	3

STEREOTYPED BEHAVIOR

Stereotyped behaviors look unusual, strange, or inappropriate to the average person. They are voluntary acts that occur repeatedly in the same way over and over again, and they are characteristic for that person. However, they do NOT cause physical damage.		Never/no problem	Average Frequency of Occurrence			
			Monthly	Weekly	Daily	Hourly
19	Rocking, repetitive body movements	0	1	2	3	4
20	Sniffing objects, own body	0	1	2	3	4
21	Waving or shaking arms	0	1	2	3	4
22	Manipulating (e.g., twirling, spinning) objects	0	1	2	3	4
23	Repetitive hand and/or finger movements	0	1	2	3	4
24	Yelling and screaming	0	1	2	3	4
25	Pacing, jumping, bouncing, running	0	1	2	3	4
26	Rubbing self	0	1	2	3	4
27	Gazing at hands or objects	0	1	2	3	4
28	Bizarre body postures	0	1	2	3	4
29	Clapping hands	0	1	2	3	4
30	Grimacing	0	1	2	3	4

Total Scores		
	Frequency	Severity
SIB		
Aggression		
Stereotypy		

Thank you for taking the time to fill out the
Jersey Health & Socioeconomic Status Assessment Questionnaire
Your response is very important to us

Do you have any other comments?

If you have any concerns please contact:

Martin McMahon, Senior Lecturer, Nursing and Midwifery Higher Education Department, Health and
Social Services, General Hospital, St Helier, Jersey, JE1 3QS

m.mcmahon@health.gov.je



Appendix 1.4 – Proxy Questionnaire where person has capacity to consent and has already filled out Appendix 1.3



Proxy Questionnaire with specific questions when the participant has already filled in the whole questionnaire

Participant ID Code as Per Consent form (form 3) and Participant Questionnaire

Researcher filling out this questionnaire is: _____

Proxy Relationship to Participant (e.g.. Parent, Keyworker): _____

Read this to the proxy

You are being asked to fill out this questionnaire as 'Name Person' has consented to participate in a study where we are trying to understand the health and healthcare needs of people who live in Jersey. We want to identify how different socioeconomic aspects in life, for example employment and wealth, influences people's health. This is important as this research has not been undertaken before in Jersey, and it will help departments plan for the future. Additionally, we are asking some questions about the person's behaviour and current health status. This will take no more than 5 -10 minutes to complete. We would very much value your input, as this will allow us to compare self-report vs proxy report views on health and wellbeing.

Read this to the proxy

By proceeding to the survey you confirm that:

- _____ has consented for you to answer these questions
- You understand what is expected of you
- You confirm that you understand that any responses/information you give will remain anonymous
- Your participation is voluntary
-

Section 3 Questions

3.0 In general, would you say _____ health is:

⁰¹ | Excellent

⁰² | Very good

- ⁰³ | Good
- ⁰⁴ | Fair
- ⁰⁵ | Poor

3.1 Compared to one year ago, how would you rate _____ health in general now?

- ⁰¹ | Much better now than one year ago
- ⁰² | Somewhat better now than one year ago
- ⁰³ | About the same
- ⁰⁴ | Somewhat worse now than one year ago
- ⁰⁵ | Much worse now than one year ago

Section 5 Questions

How TRUE or FALSE is each of the following statements for _____

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
5.10 _____ seems to get sick a little easier than other people	⁰¹	⁰²	⁰³	⁰⁴	⁰⁵
5.11 _____ am as healthy as anybody I know	⁰¹	⁰²	⁰³	⁰⁴	⁰⁵
5.12 You expect _____ health to get worse	⁰¹	⁰²	⁰³	⁰⁴	⁰⁵
5.13 _____ health is excellent	⁰¹	⁰²	⁰³	⁰⁴	⁰⁵

By placing a tick in one box in each group below, please indicate which statements (*insert name of person whose health is being assessed, e.g. Mr/Ms. Smith or Jane*) would choose to describe his/her health state TODAY if he/she could tell us.

6.5 MOBILITY

I have no problems in walking about	01 j
-------------------------------------	------

I have slight problems in walking about	02 j
---	------

I have moderate problems in walking about	03 j
---	------

I have severe problems in walking about	04 j
---	------

I am unable to walk about	05 j
---------------------------	------

6.6 SELF-CARE

I have no problems washing or dressing myself	01 j
---	------

I have slight problems washing or dressing myself	02 j
---	------

I have moderate problems washing or dressing myself	03 j
---	------

I have severe problems washing or dressing myself	04 j
---	------

I am unable to wash or dress myself	05 j
-------------------------------------	------

6.7 USUAL ACTIVITIES (e.g. work, study, housework, family or leisure activities)

I have no problems doing my usual activities	01 j
--	------

I have slight problems doing my usual activities	02 j
--	------

I have moderate problems doing my usual activities	03 j
--	------

I have severe problems doing my usual activities	04 j
--	------

I am unable to do my usual activities	05 j
---------------------------------------	------

6.8 PAIN / DISCOMFORT

I have no pain or discomfort	01 j
------------------------------	------

I have slight pain or discomfort	02 j
----------------------------------	------

I have moderate pain or discomfort	03 j
------------------------------------	------

I have severe pain or discomfort	04 j
----------------------------------	------

I have extreme pain or discomfort	05 j
-----------------------------------	------

6.9 ANXIETY / DEPRESSION

I am not anxious or depressed	01 j
-------------------------------	------

I am slightly anxious or depressed	02 j
------------------------------------	------

I am moderately anxious or depressed	03 j
--------------------------------------	------

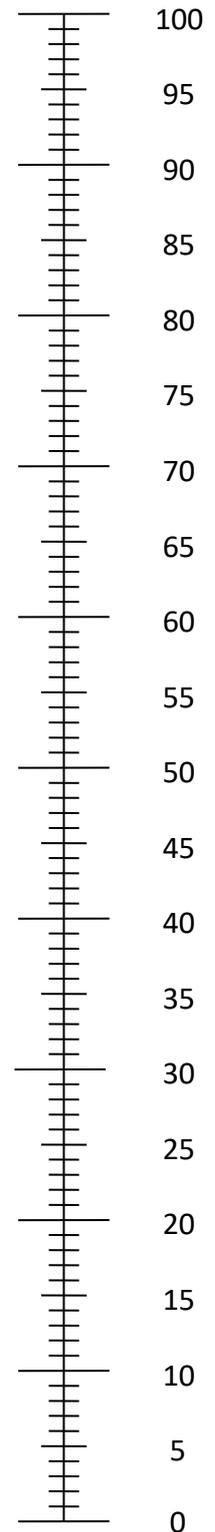
I am severely anxious or depressed	04 j
------------------------------------	------

I am extremely anxious or depressed	05 j
-------------------------------------	------

6

THE SUBJECT'S HEALTH TODAY

- We would like to know how good or bad you think the subject's (e.g. Mr. Smith's or John's) health is TODAY.
- This scale is numbered from 0 to 100.
- 100 means the best health imaginable.
0 means the worst health imaginable.
- Mark an X on the scale to indicate how good or bad you think the subject's (e.g. Mr. Smith's or John's) health is TODAY.
- Now, please write the number you marked on the scale in the box below.



The worst health imaginable

8.0 Please consider the following two questions

Think of this ladder as representing where people stand in their communities.

People define community in different ways; please define it in whatever way you think is most meaningful to _____. At the **top** of the ladder are the people who have the highest standing in their community. At the **bottom** are the people who have the lowest standing in their community.

Where would you place _____ on this ladder?

Please place a large 'X' on the rung where you think you stand at this time in your life, relative to other people in your community.



8.1 Think of this ladder as representing where people stand in Jersey.

At the **top** of the ladder are the people that are the best off – those who have the most money, the most education, and the most respected jobs. At the **bottom** are the people who are the worst off – who have the least money, least education, and the least respectable jobs or no job. The higher up you are on this ladder, the closer you are to the people at the very top; the lower you are, the closer you are to the people at the very bottom.

Where would you place _____ on this ladder?

Please place a large 'X' on the rung where you think _____ stand at this time in your life, relative to other people in Jersey.



BPI-S

The Behavior Problems Inventory for Individuals with Intellectual Disabilities - Short Form

The Target Individual:

ID (please leave blank): _____
 Age: ___ years ___ months; Gender: male female
 Ethnicity/Race: _____
 Intellectual Disability: no ID ID-level unknown mild (ID 56-70) moderate (ID 41-55) severe (ID 26-40) profound (ID < 26)

The Respondent:

Relationship to the person: _____
 Time you typically spent with the person per day: _____
 How long have you known the person: _____

Instructions

Below you will find broad definitions followed by specific items for three types of behavior problems: self-injurious behaviors (items 1-8), aggressive/destructive behaviors (items 9-18), and stereotyped behaviors (items 19-30). Indicate which behaviors you have observed in this individual during the past six months by circling the number in the appropriate boxes (1) how often a described behavior typically occurs and (2) how serious a problem the behavior is. If the behavior has not occurred during the past six months and therefore poses no problem check "never/no problem" (0). If the behavior has occurred, rate the approximate frequency of its occurrence and its severity (use the definitions below). Finally, for each item, multiply the frequency and severity scores and enter the product of the multiplied scores in the far right column. For subscale total scores, add the product sum. (No severity scale is provided for stereotyped behavior.)

	Mild Problem	Moderate Problem	Severe Problem
Self-Injurious Behavior	Behavior occurs but does not inflict significant damage on the individual (e.g., temporary reddening of the skin, very light bruising).	Behavior may inflict moderate damage on the individual (e.g., moderate bruising, scratching through the skin, repeatedly picking scabs).	Behavior may inflict moderate to severe damage on the individual (e.g. biting through the skin, eye gouging, fracturing bones) minor or major medical intervention required.
Aggression/ Destruction	Behavior occurs but does not inflict significant damage on other people (e.g., temporary reddening of the skin, very light bruising); or disruption or mild damage to property, e.g., objects thrown, furniture tipped, doors slammed, meals spoiled, paint scratched. Item does not require repair or replacement.	The behavior may inflict moderate damage on other people (e.g., moderate bruising, scratching through the skin, repeatedly picking scabs; or moderate damage to property (e.g., curtains torn, furniture partly broken). Item requires repair but can be used.	The behavior may inflict moderate to severe damage on other people (e.g. biting through the skin, eye gouging, fracturing bones) minor or major medical intervention required; or significant damage to property. Item requires repair and cannot be used.

SELF-INJURIOUS BEHAVIOR

	Never no problem	Average Frequency of Occurrence				Severity of the Problem		
		Monthly	Weekly	Daily	Hourly	Mild	Moderate	Severe
Self-injurious behavior (SIB) causes damage to the person's own body; i.e., damage has either already occurred, or it must be expected if the behavior remained untreated. SIBs occur repeatedly in the same way over and over again, and they are characteristic for that person.								
1 Self-biting	0	1	2	3	4	1	2	3
2 Head hitting	0	1	2	3	4	1	2	3
3 Body hitting (except for the head) with own hand or with any other body part	0	1	2	3	4	1	2	3
4 Self-scratching	0	1	2	3	4	1	2	3
5 Pica (ingesting non-food items)	0	1	2	3	4	1	2	3
6 Inserting objects in nose, ears, anus, etc.	0	1	2	3	4	1	2	3
7 Hair pulling (tearing out patches of hair)	0	1	2	3	4	1	2	3
8 Teeth grinding (evidence of ground teeth)	0	1	2	3	4	1	2	3

AGGRESSIVE/DESTRUCTIVE BEHAVIOR

		Never no problem	Average Frequency of Occurrence				Severity of the Problem		
			Monthly	Weekly	Daily	Hourly	Mild	Moderate	Severe
Aggressive or destructive behaviors are deliberate overt attacks directed towards other individuals or property.									
9	Hitting others	0	1	2	3	4	1	2	3
10	Kicking others	0	1	2	3	4	1	2	3
11	Pushing others	0	1	2	3	4	1	2	3
12	Biting others	0	1	2	3	4	1	2	3
13	Grabbing and pulling others	0	1	2	3	4	1	2	3
14	Scratching others	0	1	2	3	4	1	2	3
15	Pinching others	0	1	2	3	4	1	2	3
16	Verbally abusive with others	0	1	2	3	4	1	2	3
17	Destroying things (e.g., rips clothes, throws chairs, smashes tables)	0	1	2	3	4	1	2	3
18	Bullying - being mean or cruel (e.g., grabbing toys or food from others)	0	1	2	3	4	1	2	3

STEREOTYPED BEHAVIOR

		Never no problem	Average Frequency of Occurrence			
			Monthly	Weekly	Daily	Hourly
Stereotyped behaviors look unusual, strange, or inappropriate to the average person. They are voluntary acts that occur repeatedly in the same way over and over again, and they are characteristic for that person. However, they do NOT cause physical damage.						
19	Rocking, repetitive body movements	0	1	2	3	4
20	Sniffing objects, own body	0	1	2	3	4
21	Waving or shaking arms	0	1	2	3	4
22	Manipulating (e.g., twirling, spinning) objects	0	1	2	3	4
23	Repetitive hand and/or finger movements	0	1	2	3	4
24	Yelling and screaming	0	1	2	3	4
25	Pacing, jumping, bouncing, running	0	1	2	3	4
26	Rubbing self	0	1	2	3	4
27	Gazing at hands or objects	0	1	2	3	4
28	Bizarre body postures	0	1	2	3	4
29	Clapping hands	0	1	2	3	4
30	Grimacing	0	1	2	3	4

Total Scores		
	Frequency	Severity
SIB		
Aggression		
Stereotypy		

Thank you for taking the time to fill out the
Jersey Health & Socioeconomic Status Assessment Questionnaire
Your response is very important to us

Do you have any other comments?

If you have any concerns please contact
Martin McMahon, Senior Lecturer, Nursing and Midwifery Higher Education Department, Health
and Social Services, General Hospital, St Helier, Jersey, JE1 3QS

m.mcmahon@health.gov.je



Appendix 1.5 – Ethical Approval from Lancaster University Faculty of Health and Medicine Research Ethics Committee and the States of Jersey Health and Social Service Jersey Ethics Committee



Applicant: Martin McMahon
Supervisor: Chris Hatton
Department: Health Research
FHMREC Reference: FHMREC16083

24 April 2017

Dear Martin,

Re: Socioeconomic status, health inequalities and individuals with intellectual disabilities in Jersey: A matched sample total population study

Thank you for submitting your research ethics amendment application for the above project for review by the **Faculty of Health and Medicine Research Ethics Committee (FHMREC)**. The application was recommended for approval by FHMREC, and on behalf of the Chair of the Committee, I can confirm that approval has been granted for the amendment to this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact me if you have any queries or require further information.

Tel:- 01542 592838

Email:- fhmresearchsupport@lancaster.ac.uk

Yours sincerely,

Research Integrity and Governance Officer, Secretary to FHMREC.

Health and Social Services Department

Jersey Ethics Committee,
General Hospital, Gloucester Street
St Helier, Jersey, JE1 3QS



3rd March, 2017

Private & Confidential

Mr Martin McMahon
Senior Lecturer
Nursing and Midwifery Higher Education Department
Health and Social Services
Gloucester Street
St Helier
JE1 3QS

Our ref: MJ/MT/LC

Dear Martin

Project: Socioeconomic status, health inequalities and individuals with intellectual disabilities in Jersey: A matched sample total population study

Thank you for submitting your research application form and accompanying information to the Jersey Ethics Committee, and attending the meeting which took place on 9th February, 2017.

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research based on the very thorough information provided in your excellent application. However, please note that this is provisional, subject to receipt of signed approval from Lancaster University Ethics Committee.

I would like to convey the Committee's best wishes for the success of this project. When it has been completed, would you kindly notify the Committee of the outcome.

Yours sincerely

✓
Secretary of the Jersey Ethics Committee
Lay member (Chaplain)

direct dial: +44 (0)1534 442377
email: ma.turner@health.gov.je

NOTE: Approval of the HSSD Ethics Committee is valid for 3 years from date of this letter

Appendix 1.6 – McMahon et al. (2018) – Professional collaboration in searching the literature for an ill-defined concept

Professional collaboration in searching the evidence for an ill-defined concept

Martin McMahon

Division of Health Research, Lancaster University, Lancaster, UK Email:
m.mcmahon2@lancaster.ac.uk

Chris Hatton

Division of Health Research, Lancaster University, Lancaster, UK

Simon Alberici

Department of Health and Social Services, States of Jersey, St Helier, UK

Abstract

This paper outlines the inter-professional collaboration of the authors, a PhD student, his supervisor and an information professional, to systematically search the literature for an ill- defined concept. The research question posed for the scoping literature review indicated that the topic, the subjective socio-economic status and health of adults with intellectual disabilities, was rare. The need for a methodological search process was therefore identified and successfully carried out. The paper presents an analysis of the processes and the collaboration involved in developing a successful search strategy. The resulting transformative learning by the researcher of the professional practice of the information specialist illuminates their facilitating and supportive role in advancing health related research.

Keywords: database searching; information skills; literature searching; PhD thesis; review, scoping review

Introduction

This study outlines the interprofessional collaboration of the researchers (MMcM & CH) and an information scientist (SA) to systematically search the literature for an ill-defined concept in the absence of known evidence. The search was conducted to form a scoping review by the first author as a part fulfilment of his alternative format PhD programme. In the absence of known previous research that had explicitly addressed the topic of the review, the need for a systematic search process was identified and successfully carried out. This study explores the collaboration between the researchers and the information scientist to develop a search strategy and identify relevant research to include in the scoping review. Focusing on the role of the information scientist as facilitator and educator, the development of the systematic search involving the collaborative knowledge and skills of the researchers and the information scientist are outlined and reflected upon.

Background context

The past decade has seen a significant increase in students undertaking PhDs through publication or in alternative formats insofar as students do not produce a large single monograph, rather they publish multiple peer review manuscripts throughout their studies that assemble into an interrelated coherent thesis upon completion. Traditional PhDs have a literature review chapter that synthesises existing scholarship known about the studies' topic. Whilst this is incorporated in alternative format routes, systematic reviews and their familial equivalents (e.g. rapid reviews and scoping reviews) are now becoming a principal method for students of alternative format PhDs to conduct a comprehensive and structured literature search to justify that their research is theoretically grounded and necessary whilst contributing originality within the specific arena (Moher, Stewart & Shekelle, 2015). There are many advantages of this alternative formative approach. By virtue of following a systematic searching process, the potential of bias is minimised and the search process can be replicated. Following a systematic search process is an important starting point for many student PhD researchers. Nonetheless, many difficulties present themselves. Firstly, such reviews are complex to undertake and

there is an established evidence base supporting insufficient rigour in many peer-reviewed publications involving systematic literature searching (Koffel, 2015). Secondly, inexperienced students often will not have the general research skills to administer all aspects of a systematic search strategy. Conducting such reviews has generally been perceived to be a post-doctoral skill. Finally, such searches are labour-intensive requiring at least two to three people and the involvement of an information science specialist. This can be further complicated when the PhD student is trying to add originality to their work and examine an ill-defined concept within their field of study. The absence of known research that had explicitly addressed the first author's PhD topic 'is subjective socio-economic status a discrete correlate of health in individuals with intellectual disabilities?' from the outset, reinforced the need for a systematic search process. This was achieved through the interprofessional collaboration of researchers and an information science specialist.

Literature review

The aim of this study was to explore this interprofessional collaboration in conducting a scoping review. The brief literature review presented here serves to identify and focus the research question of the scoping review. Intellectual disability is characterised by a significantly reduced ability to learn new skills and understand complex information (impaired intelligence) with a reduced ability to manage independently (social functioning), which started before adulthood and has a lasting effect on development. Individuals with intellectual disabilities have greater health needs, out of proportion of the general population and die on average 20 years before their non- intellectual disability peers (O'leary, Cooper & Hughes-McCormack, 2018). Conventional socio-economic status factors such as education, occupation and income have a profound influence on how long a person will live and how healthy a life they will have. This socio-economic gradient has a strong evidence base, and these objective socio-economic factors have been consistently shown to be deeply patterned and predictive of mortality and morbidities in the general population (Marmot et al., 2010). Nonetheless, as individuals with intellectual disabilities are generally at the lower spectrum of the socio-economic continuum

with most individuals being unemployed, poorly educated and having marginal income due to their limited earning power, the use of conventional objective measures in this population is questionable. Recent research has considered the notion of subjective socio-economic status – a personal sense of their place in society and also referred to as socio-economic position or subjective social status – as being a more robust measure of socio-economic status. Significantly, an established evidence base and recent meta-analysis now support that this may be a more robust measure than crude objective measures of socio-economic status by measuring its association with health (Cundiff & Matthews, 2017). Nevertheless, what we know about subjective socio-economic status and health is largely based upon empirical studies concerning the general population and therefore this scoping review set out to address our research question concerning its relationship with health in adults with intellectual disabilities.

Research methods

Consistent with our research objectives, the use of a scoping review was warranted to systematically search the available research evidence and establish a comprehensive and in-depth overview of this topic area. We followed Arksey and O'Malley's (2005) existing methodological framework that identifies five stages in the scoping review process: identifying the research question; identifying relevant studies; study selection; charting the data; and collating, summarising and reporting the results. To formulate a search for the research question, the PICO model (Richardson, Wilson, Nishikawa & Hayward, 1995) was deemed unsuitable as our question did not easily categorise into the elements of Patient/Population/Problem, Intervention, Comparison and Outcome and did not fit with our overall objective of scoping the literature for a broad concept. Subsequently, we follow the principle of search planning and created four components that were representative of our research question:

1. People with intellectual disabilities

2. Subjective socio-economic status

3. Health status

4. Objective social factors

Four databases were used in our search process: Cumulative Index to Nursing and Allied Health Literature [CINAHL], MEDLINE, PsycINFO and the Web of Science (SCI-EXPANDED, SSCI and A&HCI). Terminology and vocabulary surrounding intellectual disability are complicated and distinctive depending on the date, causation and location of use. For scientific purposes, intellectual disability is now internationally recognised; however, the use of mental retardation and learning disability whilst synonymous with intellectual disability are still used. Recognising such difficulties, a pearl harvesting methodology was followed. In the case of intellectual disability, Sandieson, Kirkpatrick, Sandieson and Zimmerman (2010) have advanced information retrieval techniques insofar as they have created a pearl-harvested synonym ring for intellectual and developmental disabilities. This is a set of keyword search terms specific to certain databases. The function of creating a synonym ring makes the keywords explicit to other authors, and subsequently, it allows other authors to build upon the original synonym ring if new terms are identified, or to exclude terms to attune the search. Synonym rings were not available for the three other components of our research question. In terms of subjective socio-economic status and health status, we followed the pearl growing and pearl building process (Booth, 2008) to identify keyword searches that were representative of the components under consideration. This was underpinned by firstly collecting and analysing keywords from a representative sample of articles to create our pearls and through using the specific thesaurus functionality in CINAHL, MEDLINE, PsycINFO and the Web of Science. The final process involved repeating the searches and refining the search terms before an exhaustive set of pearl grown terms were identified. Our final component, objective social factors existed by virtue of being the contrast of the previous two components. We were ambivalent about this, as though use was not being made of the PICO search framework,

this fourth component clearly identified with the 'C' – Comparison of the framework, so held some potential value; equally the 'C' is often omitted when using this

framework, as this potential is not always fulfilled, rendering it superfluous or damaging. Initially we formed the opinion that the terms we had for this component would increase recall at the cost of precision, so excluded it. However, a recent meta-analysis (Cundiff & Matthews, 2017) identified objective social factors as a correlate to subjective social status and set out a search set to describe this same component. We tested it and found that it focused our final sets favourably, so included it to represent our final component. After creating search sets for each database, we set an inclusion criterion that specified that research needed to be peer-reviewed, in the English language, be published since 1990 and concern adult individuals with intellectual disabilities.

Results

Our search returned 1345 potential articles for inclusion. There were imported into Covidence, a web-based software platform aimed at supporting the proficient production of systematic reviews. A further nine articles were sourced through alternative sources. After de-duplication, we had 1098 articles for inclusion. These were independently title and abstract screened by the first and second author. After title and abstract screening, 18 of these articles were identified as warranting full-text screening. The primary reason for excluding articles was due to the absence of an identifiable indicator that related to subjective socio-economic status. Of the 18 articles, there were no research studies that had a principal objective to specifically consider the relationship between subjective socio-economic status and health in individuals with intellectual disabilities. Consequently, it was necessary to consider the derivatives of findings that were not the primary objective of the intended research. Nonetheless, within these articles, a number of patterns began to appear that were not entirely obvious at the outset and from the final search set of seven articles the following two themes were explored: (1) subjective socio-economic status indicators; and (2) the relationship between subjective socio-economic status and health. Whilst the end result of this scoping review is not the primary aim of this study, its implication for practice is.

Implication for practice

As noted in the introduction, the use of systematic and scoping reviews is becoming a more common journey for PhD students. However, it cannot be assumed that the PhD student will have acquired or developed the research skills needed to lead the review, calling instead for interprofessional collaboration. The concept of interprofessional collaboration (Reeves, Pelone, Harrison, Goldman & Zwarenstein, 2017) has arisen from the need for disciplines to shift the focus towards mutual partnerships and sharing of speciality-specific knowledge. Yet prior to undertaking this review as a health professional and research student, the need for non-clinical interprofessional collaboration was not fully appreciated, and indeed was considered questionable. With respect to the many initiatives in university libraries to provide guidance and assistance to students in the literature searching, the implications of this observation are potentially far reaching. It is undisputed that students should be developing their information literacy skills from the outset of their Bachelor's degree, and these skills should progress in tandem with their graduate and post-graduate education. However, this is all too often overlooked in reality and underlying this may be (to some extent) the student's questioning the need to develop their skills and/or to request help from a non-clinical (or non-subject specialist), or indeed a graduate or professional questioning the need for some form of interprofessional collaboration. As the collaboration experienced in the conduct of the systematic search described in this study has consequently displaced the first author's (the PhD student) original understanding that surrounded his questionable need for these skills, it is worthwhile considering the level of learning and education that has occurred in respect of information science searching and retrieval in more detail. Whilst the information specialist's skills were positively exploited and harvested in this scoping review search, rather than being a passive provider of information in this endeavour, the information specialist did not merely complete the systematic search; working collaboratively and strategically they translated their knowledge and skills into a comprehensible approach to facilitate the researchers' learning and development. As a consequence, the evolution for information specialists from 'evidence locators' and "resource providers" to being quality literature filterers,

critical appraisers, educators, disseminators, and even change managers' (Beverley, Booth & Bath, 2003, p. 65) was fully realised. The implications of this were considered by the researcher to be significant. First, as a developing researcher having positively experienced the influence that information specialists have in systematic search strategies, there is a greater understanding of how this is the first step into evidence-based health care. Secondly, having been exposed to and actively participated in the 'pearl growing', 'pearl building' and 'pearl harvesting' methodological approach, the researcher has acquired a new confidence in their ability to undertake a comprehensive systematic search. The skill of using this approach cannot be underestimated in the light of the narrow arena that the researchers work in. Taken together, these implications for practice suggest that through early interprofessional collaboration, information scientists cannot only influence specific research outcomes, and they can also influence developing researchers who expect to shape their scientific discipline. Logically, this can only have a positive impact on patient outcomes.

Conclusion

The role of the information science specialist in this scoping review process was critical. Without their involvement, this review would not have been as successful. This review was positive insofar as we identified some key themes within the search results that we did not fully appreciate from the outset. In addition, a by-product of this collaboration emerged as a deeper level of learning and development occurred. This is almost certainly as a result of a hidden transformative learning process whereby through exposure and active participation the researcher transformed their understanding of information science, which encouraged a revised belief system that guided and will continue to guide future behaviours. Finally, a key message is the need for information specialists to collaborate with early stage PhD students across all disciplines. They are the future of their discipline and the collaborations of the future.

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