Learning disability and Northern Ireland: Achieving proportionate universalism through administrative data research

Final Report

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Ulster University
Professor Jamie Murphy (PI)
Dr Lisa Hanna-Trainor
Dr Orla McBride
Professor Mark Shevlin
Dr Laurence Taggart
University of Bristol
Professor Pauline Heslop

Mencap Northern Ireland
Mary Anne Webb
Public Health England
Professor Gyles Glover
Positive Futures
Agnes Lunny
ARC Northern Ireland
Leslie-Anne Newton
Department of Health
Darren McCaw

Health & Social Care NI
Alyson Dunn
Valerie McConnell
Lorna Conn
Briege Quinn
Melissa McGuigan
Lynda Johnson
Compass Advocacy Network
Janet Schofield

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The Administrative Data Research Network takes privacy protection very seriously. All information that directly identifies individuals will be removed from the datasets by trusted third parties, before researchers get to see it. All researchers using the Network are trained and accredited to use sensitive date safely and ethically, they will only access the data via a secure environment, and all of their findings will be vetted to ensure they adhere to the strictest confidentiality standards.

Executive Summary

Background

Proposals for the 2021 Northern Ireland (NI) Census indicated that NI citizens will, for the first time, be able to explicitly report that they (or members of their household) live with a learning disability. Given that, at present, there is no central register detailing the actual number of individuals with a learning disability in NI, this future Census data, supplemented by a variety of other Census metrics and data from an array of other NI administrative data sources (that contain important information on e.g. housing, family, employment, education, health, income, services and supports), will have the potential to transform our understanding of learning disability at a population level and, more importantly, our ability to more effectively respond to the needs of those with learning disability. In anticipation of, and in preparation for this new and improved national data on learning disability, the current study, which commenced during the proposal/planning stage of the 2021 Census and under the auspices of the UK's Administration Data Research Partnership, aimed to access and analyse existing administrative data relating to learning disability in NI, from 2007 and 2011, in order to highlight the availability, utility and import of learning disability data in NI, and to promote and stimulate future use of this administrative data in the region.

The findings of the study reveal much about the current state of play in NI regarding administrative data and learning disability. While there is much to be positive and optimistic about, there are also notable challenges and obstacles that will need to be overcome if we are to truly realise the potential of our existing and future administrative data. Among other things the study findings have revealed (i) the value and potential of Census data, alone, in identifying and locating individuals with learning disability in NI, and describing much about the socio-economic, health, education and demographic characteristics of the learning disability population, (ii) the limitations of poorly defined/designed Census survey questions and the importance of survey item specificity for accurately recording learning disability prevalence, (iii) the immense value of disability-focussed household survey data obtained using probability-based sampling methods and its potential to contextualise and amplify the findings from Census data, (iv) the presence of, but, inaccessibility to, a variety of important Northern Ireland administrative data resources that have the potential to transform our understanding of important learning disability issues relating to e.g. health, service use, medication use, education and employment, and finally (v) the importance of administrative data awareness and timely use of data by all. It is hoped that the findings will aid researchers, policy makers, service commissioners and practitioners in all sectors in the years to come.

Methodology

Three primary sources of data were accessed and analysed for the current study: (1) data from the 2011 Census, (2) data from the NI General Registrar Office, and (3) data from the 2007 NI Survey of Activity Limitation and Disability (NISALD). The study also used NI Settlement Band data and linked data from the NI Multiple Deprivation Measure. Access to the data from the first two sources was provided by the Administrative Data Research Centre – NI (ADRC-NI; now the Administrative Data Research NI - ADR NI), part of a recent UK-wide initiative funded by the Economic and Social Research Council (ESRC) to increase use of administrative data sources and linkages for research purposes. The data from these sources was linked by the Northern Ireland Statistics and Research Agency (NISRA) Research Support Unit (RSU) team, tested for potential disclosure problems, de-identified and, made available to the research team in a secure setting at NISRA headquarters in Belfast. The NISALD data (private households only), collected by NISRA in 2006-2007, was sourced from the UK data archive (UK Data Archive Study Number 7236). Ethical approval for this study was obtained from the Ulster University Research Ethics Committee, and the Administrative Data Research Network.

Key findings

Prevalence

National learning disability prevalence based on 2011 Census crude learning disability indicator

- The prevalence of learning disability within the overall Census population = 2.2%
- The prevalence of learning disability among those aged 15 years or younger = 3.8%
- The prevalence of learning disability among those aged 16 years or over = 1.7%

Prevalence within communal establishments

- The prevalence of learning disability among those aged 15 years or younger = ~13.1%
- The prevalence of learning disability among those aged 16 years or over = ~13.9%.

Prevalence within private households

- The prevalence of learning disability among those aged 15 years or younger = 3.8%.
- The prevalence of learning disability among those aged 16 years or over = 1.5%.

Prevalence by Health & Social Care Trust

- *Overall prevalence of learning disability ranged from 1.9% (Northern HSCT) to 2.5% (Belfast HSCT)*
- *Prevalence among those aged 15 years or younger ranged from 3.2% (Southern HSCT) to 4.8% (Belfast HSCT)*
- *Prevalence among those aged 16 years or over ranged from 1.5% (Northern HSCT) to 2% (Belfast & Western HSCTs)*

National learning disability prevalence based on the more explicitly defined measure of intellectual disability contained within the 2007 Northern Ireland Survey of Activity Limitations and Disability (NISALD)

- The prevalence of learning disability within the overall NISALD sample = 0.5%
- The prevalence of learning disability among those aged 15 years or younger = 1.3%

- The prevalence of learning disability among those aged 16 years or over = 0.3%

Socio-economic and demographic characteristics of NI's learning disability population

- According to the Census data, over 60% of those reporting a learning disability were male.
- In relation to age, learning disability was more common among those aged 15 years or younger. While 29% of those who had a learning disability in addition to at least one other health condition were under 16 years of age, 50% of those who reported learning disability as their only health condition were under 16 years of age.
- From the Census data, learning disability status was associated with greater deprivation. Among those reporting a learning disability as their only health condition, 12.7% were in the first decile (i.e. most deprived) while 7.6% were in the 10th decile (least deprived). Among those reporting learning disability with at least one other health condition, 15.1% were in the first multiple deprivation index decile while 5.9% were in the 10th. Over 39% of those with a learning disability within the Belfast HSCT area were in the first multiple deprivation index decile.
- The majority of those with a learning disability, either as a single health condition, or, comorbidly with other health conditions, were neither living as part of a couple nor living alone
- Regarding activity limitation, the majority (52%) of those with a learning disability as a single condition indicated that their day-to-day activities were not limited, while a minority (19%) indicated that their day-to-day activities were limited a lot. Conversely, 68% of those with a learning disability comorbidly with at least one other health condition indicated that their day-to-day activities were limited a lot while only 12% indicated that their day-to-day activities were not limited.
- Within the overall Census sample, 1.3%-1.4% respectively of those with a learning disability, either as a single health condition, or, comorbidly with other health conditions, identified as non-white (=1.1% prevalence of learning disability among non-white ethnic population in NI).
- Over 35% of those with a learning disability, either as a single health condition, or, comorbidly with other health conditions resided within the Belfast Metropolitan Urban Area while over 23% of those with a learning disability, either as a single health condition, or, comorbidly with other health conditions resided in a small village, hamlet or the open countryside.

General health and comorbidity status of NI's learning disability population

Learning disability as a single health condition

- Compared to those reporting good or very good general health, those who had bad or very bad general health were over 3.5 times more likely to be non-white.
- Compared to those reporting good or very good general health, those who had bad or very bad general health were over 2.5 times more likely to live in areas of most extreme deprivation (i.e. the first and second multiple deprivation index deciles).
- Those whose day to day activities were 'limited a little' were over 4.5 times more likely to have bad or very bad health, while those whose day to day activities were

'limited a lot' were over 22.5 times more likely to have bad or very bad health compared to those reporting good or very good general health.

Learning disability with at least one other health condition

- Compared to those reporting good or very good general health, those who had bad or very bad general health were more likely to be female.
- Compared to those reporting good or very good general health, those who had bad or very bad general health were over 5.5 times more likely to reside in a private household.
- Compared to those living a small village, hamlet or open countryside, those living in the Belfast metropolitan urban area, a medium sized town, a small town, or a village, were more likely to have bad or very bad health.
- Compared to those reporting good or very good general health, those who had bad or very bad general health were significantly more likely to live in more deprived areas (i.e. within the first seven multiple deprivation index deciles).
- Those individuals whose day to day activities were 'limited a little' were over 2 times more likely to have bad or very bad health, while those whose day to day activities were 'limited a lot' were over 18 times more likely to have bad or very bad health compared to those reporting good or very good general health

Health condition comorbidity under 16 years

- Among those with a learning disability in this age group, the most commonly co-occurring health conditions were communications difficulties (66.4%), mobility issues (33.4%), 'other' health conditions (26.2%) and respiratory problems (23.7%).
- Compared to those under aged 16 years who had multiple health conditions not including learning disability, a higher proportion of those under aged 16 years who had multiple health conditions including learning disability experienced memory loss (1.6% v 4.5% respectively), communications difficulties (17.1% v 66.4% respectively), and mental health problems (5.3% v 15.6% respectively).

Health condition comorbidity over 15 years

- Among those with a learning disability in this age range, the most commonly co-occurring health conditions were communications difficulties (53.2%), mobility issues (52.1%), mental health problems (45.7%), memory loss (25.2%) and respiratory problems (24%).
- Compared to those over aged 15 years who had multiple health conditions not including learning disability, a higher proportion of those over aged 15 years who had multiple health conditions including learning disability experienced memory loss (12.4% v 25.2% respectively), communications difficulties (5.5% v 53.2% respectively), mental health problems (25.7 v 45.7 respectively) and blindness or visual impairment (9.6% v 10.9% respectively).

Mortality and cause of death among NI learning disability population

- Overall, 4.8% of individuals who identified the presence of a learning disability during the 2011 Census died between March 2011 and December 2015. Among those without a learning disability at the 2011 Census, 3.7% died during this period.
- Among those who died and where learning disability was recorded as their only health condition at the 2011 Census, circulatory system complications were the most common cause of death (22%), followed by respiratory system complications (16.5%), then neoplasms (13.2%).
- Among those who died and where learning disability was recorded as one of a number of health conditions at the 2011 Census, circulatory system complications were the most common cause of death (19.2%), followed by nervous system complications (16.1%), then respiratory system complications (14%).
- Compared to those in the NI population who did not identify the presence of a health condition at the 2011 Census, those individuals who indicated that learning disability was one of a number of underlying health conditions had the highest risk of death between March 2011 and December 2015. These individuals were almost six times more likely to die (OR=5.87, 95%CI=5.82-5.92) compared to the large majority of the NI population who were free from health conditions at the last Census. In comparison, those who had multiple health conditions excluding learning disability at the 2011 Census were approximately three times more likely to die during this period (OR=3.38, 95%CI=3.36-3.40).

Employment among NI learning disability population (see Appendix 4)

- In the overall population and among those aged 16 years or over, 18.8% of individuals who reported the presence of a learning disability at the 2011 Census also indicated that they were in paid employment. Among the remainder of the NI working-age population, regardless of health condition status, 55% indicated that they were in paid employment.
- The top five areas of employment among those who reported the presence of a learning disability at the 2011 Census were 1. Sales and retail assistants (10.9%), 2. Employment in areas including farming, gardening, carpentry, labouring, goods handling and storage, and shelf filling (8.2%), 3. Associate professional and technical occupations (6.6%), 4. Kitchen and catering assistants (4.3%), 5. Domestic cleaning (3.8%).
- Mode of employment was notably influenced by both sex and settlement band. For example, of the most common modes of employment, a higher proportion of females were employed as care assistants and home carers, waiting staff, or kitchen catering assistants. A higher representation of males was evident within all remaining modes of employment. In relation to farming, gardening, carpentry, labouring, shelf-filling, or goods handling and storage, 92.7% of jobs were held by male respondents. In relation to settlement band (i.e. city, town, rural), 70.3% of individuals with a learning disability who worked in farming or gardening, and 55.6% of those who worked as a labourer resided in a rural area. Over 50% of those who worked as a waiter/waitress, handling goods, office administration, or associate professional/technical occupations resided in a city.

Conclusions & implications of study findings

A burgeoning international research literature continues to detail the extreme disadvantages that are disproportionately faced by those in society with a learning disability. Worryingly, this extreme population-specific disadvantage is further and significantly compounded by the fact that those with a learning disability, in many countries, remain unseen. Learning disability specifically, at a population level, has either remained unrecorded and undetected or has been camouflaged/hidden/buried within general health data, that have referred to limitations in day-to-day activities or inability to work as a result of health problems or disability. We hope that these findings will (i) highlight the availability, utility and import of learning disability data in NI, (ii) promote and stimulate future use of this data in the region, (iii) incentivise those in power to facilitate NI data custodians to share/link available learning disability relevant data where possible and (iv) lay some useful foundations for the more advanced and sophisticated learning disability statistical modelling that will be possible in the years to come and the policy changes that will emerge as a consequence.

Report structure

This report comprises seven separate sections. A summary of each section is detailed below.

Section 1 *Background to the study*: Section 1 provides a background to the study including (i) the policy context of the research and the critical issue of national level health surveillance for learning disability in NI, (ii) an overview of the historical context of learning disability data, its collection and use in NI, (iii) an overview of the improving status of disability assessment within the Northern Ireland Census and the implications of this for future recording and understanding of learning disability in NI, (iv) important information pertaining to the definition of, and terminology relating to, intellectual/learning disability both internationally and in relation to NI specifically and finally (iv) the main aims and objectives of the study.

Section 2 *Study methodology:* Section 2 provides a general overview of the methods underpinning the study. Specifically, a description of the administrative data bodies responsible for facilitating the current research (the Administrative Data Research Partnership (ADRP) & the Northern Ireland Mortality Study (NIMS)) will be provided. Section 2 describes (i) the various data sources accessed for the current study, (ii) the data linkages completed by NISRA/NIMS to facilitate the analyses and (iii) the data access restrictions that emerged during the project.

The report is partitioned into four separate analysis sections (Sections 3-6), each pertaining to specific project objectives.

Section 3. *Learning disability prevalence and demography using Census 2011 and NISRA generated settlement band data:* Section 3 provides overall NI prevalence findings for learning disability according to the 2011 Census data and profiles the demography of the learning disability population using a range of Census based socio-economic metrics (sex, age, multiple deprivation indices, residential status, living arrangements, ethnicity, settlement area, and health-related limitations associated with disability) To provide a more regional assessment of learning disability, Section 3 will also provide prevalence findings and profile the demography of the learning disability population in relation to the five NI Health and Social Care Trusts.

Section 4. *Learning disability health status, socio-demographic risk, and comorbidity status using Census 2011 data:* Using the 2011 Census general health question, Section 4 profiles the general health of the learning disability population of NI and identify the main socio-demographic indicators of poor health among this population using indicators detailed in Section 3. Using the ten health conditions from Q23 of the 2011 Census, Section 4 also compares and contrasts the comorbidity profiles of those with and without a learning disability, firstly throughout NI, and secondly, in relation to the five NI Health and Social Care Trusts.

Section 5. *Learning disability mortality and cause of death using Census 2011 and NI General Registrar Office data:* Using linked data from the 2011 Census and the NI General Registrar

Office (death records from March 2011-December 2015), Section 5 (i) details the distribution of deaths in NI over a 5-year period, (ii) reports the proportion of deaths occurring amongst the learning disability population during this time, (iii) reports mortality rates per 100,000 person-years for the learning disability population during this time, (iv) reports the main causes of death for the learning disability population during this time and (v) compares and contrasts likelihood of death among the learning disability population with the rest of the NI population.

Section 6. *Learning disability prevalence and demography using the NI Survey of Activity Limitation and Disability data*: Using more explicit population-based data on learning disability, Section 7 compares the prevalence of learning disability generated from the 2011 Census data with the prevalence estimate of learning disability generated from the NISALD data to assess how survey item specificity affects learning disability prevalence estimation. Section 7 also reports the socio-demographic and health-related characteristics of those individuals who endorsed the learning disability item from the 2007 NISALD survey. In doing this, we wanted to profile the NI learning disability population using the more explicit and specific descriptor of 'intellectual disability', and, in so doing, provide a benchmark against which the more explicit 2021 Census data relating to learning disability can be measured in the future.

Each analysis section will include (i) a reminder of the section aims and focus (ii) an overview of the evidence base and supporting literature underpinning the analyses, (iii) a summary of the methods, data and analyses used, (iv) a comprehensive set of analytic findings accompanied by tabled counts and population proportions displayed using bar charts, and (v) a brief discussion of findings.

Section 7. *Conclusions & implications of study findings*: To conclude, in Section 7, a general discussion and details relating to the project consortium's interaction and correspondence with NISRA and the NI Census 2021 team regarding future learning disability assessment is provided.

Section 1 Background to the study

1.1. Learning disability and health inequality

Evidence indicates that people with a learning disability in the UK have higher rates of obesity, respiratory disease, some cancers, diabetes, osteoporosis, epilepsy, mental health problems and dementia [1-2]. Moreover, it is estimated that people with a learning disability in the UK will die 20 years earlier and are 58 times more likely to die prematurely [3]. While having a diagnosis of a learning disability is central to the health inequalities experienced by this group, other social and economic factors have also been evidenced to compound this vulnerability and disadvantage (e.g. ethnic minority and low socio-economic status) [4]. Specifically, such factors have been evidenced to compromise health care access for people with learning disability (e.g. breast and cervical screening, female vaccination for HPV [5]). Furthermore, the learning disability population is less likely to get the benefits of the annual health checks and various treatments they need [6-7]. These factors contribute to preventable ill health, poor quality of life and potentially, premature death' [6-7].

Recently, a 'Research and Information Service Paper' submitted to the Northern Irish Assembly [9] noted that "…according to a review conducted by Marmot in 2010 [8], health inequalities are avoidable and socially unjust….In order to reduce the steepness of the social gradient in health…actions must be universal, but with a scale and intensity proportionate to the level of disadvantage. Therefore, policies and strategies should target action at those experiencing greater social and economic disadvantage. This approach is termed 'proportionate universalism' [9] and it requires multi-agency working across local and central government, and the voluntary and private sectors" [10]. Worryingly, the health, social and economic inequality experienced by individuals with learning disability in the UK represents one of the most overlooked humanitarian failings of UK society [11-14, 3].

Importantly however, the evidence base that has begun to catalogue this inequity has introduced a real opportunity to begin to tackle the problem [2,4, 15-16]. While a UK evidence base now grows and while the first 'green shoots' of action are beginning to emerge, individuals with learning disability in NI remain largely unseen. At present there is no central register detailing the actual number of individuals with learning disability in NI. As a consequence, it is extremely difficult to evaluate the form, context or degree of inequality that may be experienced by this group. This in turn makes it challenging to tailor or to target services or to monitor health in terms of health inequalities for this population. However, while NI may not have a central register detailing the number of individuals with learning disability, population level data relating to learning disability, although crude, has been collected and available for analysis, but, has been somewhat overlooked.

1.2. Population level data relating to learning disability in Northern Ireland

In 2010, Fujiura and colleagues [17], in a paper entitled 'Make measurable what is not so' espoused a 'what gets counted gets done' philosophy and contested that the essential issues relating to the statistical monitoring of disability generally and learning disability ('intellectual disability') more specifically in the population are 'those of recognition by national statistical systems and, once recognised, definition' (p.244).

Reviewing twelve nations (Brazil, China, Egypt, Germany, India, Ireland, Japan, Nigeria, NI, Russia, South Africa, United States of America (USA)) with respect to their disability surveillance, the authors recognised NI as one of three countries (incl. Republic of Ireland and USA) that possessed the closest approximation of a national surveillance system upon which learning disability benchmarking could be built. Second only to the USA, NI possessed the most sources of general disability data and learning disability approximators/identifiers (within e.g. census, household probability surveys, administrative/service registries) in addition to important accompanying socio-econometric data (e.g. housing, family, employment, education, health, income, social participation, services and supports) critical for effective learning disability social/health/education policy generation and implementation.

Sadly however, NI's potential as a learning disability national surveillance pioneer was never realised. Although a handful of reports [18-19] produced crude and mixed estimates of the prevalence of ID in NI (e.g. 1-3% using the standard internationally cited population prevalence of ID as a guide [20-21], or 0.4% - 0.8% based on a variety of other NI administrative data sources e.g. NI GP register data, NI Health & Social Care Trust data, NI Housing Executive data), little additional investigation of extant population data has been conducted since this 2010 review to determine the characteristics of individuals with learning disability in NI, or where learning disability is most prevalent in the region. This is somewhat surprising, particularly given (i) the revised health and disability content that emerged in the NI 2011 Census and (ii) the detailed disability household probability survey data that informed the content of that Census – The 2007 Northern Ireland Survey on Activity Limitation and Disability (NISALD) [22]. These data sources together have had the potential to produce comparable estimates of the prevalence of learning disability in NI and to facilitate general modelling of the spatial distribution and socio-economic characteristics of learning disability in NI for nearly 10 years, however, the data, for some reason, has remained virtually unused.

1.3. Census recording of disability and ID in NI

Population level recording of disability in NI has slowly been improving. In 1991 the NI Census afforded citizens the opportunity to officially record whether they or members of their household had 'any long-term illness, health problem or handicap which [limited] [their] daily activities or the work [they could] do'. In 2001 this question was amended to 'any long-term illness, health problem or disability….'. While neither datum afforded an opportunity to explore the precise nature of disability or any direct information about citizens with ID specifically in NI, they no less paved the way for more refined measurement of disability in future NI Census data sweeps. Informed by the NISALD (which surveyed the NI population in relation to 15 distinct disabilities in 2007 and was intended to supplement and inform the 2011 Census data) the 2011 NI Census introduced 12 specific health condition categories including one that specified 'A learning difficulty, an intellectual difficulty, or a social or behavioural difficulty'. While this Census item may have been crude (e.g. the category referred to intellectual difficulty rather than intellectual disability and subsumed intellectual difficulty with learning difficulties and social and behavioural difficulties), it, for the first time, offered NI citizens with a learning disability an opportunity to officially report, albeit indistinctly, their disability status.

Notably however, while inclusion of persons with disabilities into data collection systems in NI improved, the critical matter of disability definition and learning disability specification remained unresolved. This, reassuringly, soon seems set to change. NI Census proposals for 2021 [23] indicated that NI citizens will be afforded the opportunity to officially and specifically report the presence of 'An intellectual or learning disability (for example Down syndrome)'. Moreover, specific separate options to also record 'A learning difficulty (for example dyslexia)' and/or 'Autism or Asperger syndrome' will further enhance the specificity and improve the measurement of learning disability in the next NI Census. Supplemented by a variety of other Census metrics and linkage to data from an array of other NI administrative data sources capturing important information on e.g. housing, family, employment, education, health, income, services and supports (generated from e.g. Department of Health & Social Services & Public Safety, Department of Economic Development, Department of Education etc.) NI may soon be able to both effectively recognise and define learning disability at a population level, but also, begin to more effectively respond to the needs of those with learning disability as a consequence. Critically however, the data that becomes available must first be used and used moreover in a timely and effective manner.

1.4. A note on definitions & the use of language

The definition and description of intellectual/learning disability is a critical issue that must be acknowledged and carefully navigated when exploring data and the evidence base relating to intellectual/learning disability.

Understanding Disability

Health and disability are complex concepts. They are dynamic, multi-dimensional and ever-changing [24-25]. In 1946, the World Health Organisation defined health as a 'state of complete physical, mental and social wellbeing and not simply the absence of disease or infirmity'. More than 70 years on, this initial definition is considered basic, even idealistic and unobtainable. As a consequence, more 'modest' definitions of health e.g. the idea of 'achieving personal potential' have been proposed [26]. Our understanding of disability too is changing and evolving and the role of physical and social barriers relating to disability are now more widely recognized and acknowledged [27].

Disability is now viewed as an umbrella term encompassing 'impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal)'. Thus, we now understand much better that individuals with disabilities are diverse and heterogeneous [25]. More consideration has also been given to the wider determinants of health. The WHO state that the social determinants of health are 'the conditions in which people are born, grow, live, work and age'. An individual's circumstances can be greatly impacted by the distribution of power, resource and money at a local, national and global level and these social determinants of health (employment, exclusion, public health access, gender equity) are largely responsible for health inequalities experienced disproportionately by those with disabilities [28].

Understanding the terminology

There have been many discrepancies in both research and clinical practice relating to the description and definition of learning disability. In the United Kingdom (UK) (England, Scotland, Wales and Northern Ireland) the most common term used is ‘learning disability’. Across Europe (including the Republic of Ireland) and in Canada the term ‘intellectual disability’ is used. In the United States of America (USA) the term ‘mental retardation’ was used until recently when they changed to the term ‘intellectual disability’. In Australia, they refer to ‘developmental-disabilities’.

The World Health Organisation (WHO) defines an learning disability as a ‘significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence)’. They state that this results in ‘reduced ability to cope independently (impaired social functioning)’, and that it begins ‘before adulthood, with a lasting effect on development’ [28]. Similarly, the UK Government White Paper ‘Valuing People: a new strategy for learning disability for the 21st Century’ [29] defined an ID as the presence of:

- a significantly reduced ability to understand new or complex information or to learn new skills;
- a reduced ability to cope independently
- an impairment that started before adulthood, with a lasting effect on development (pp.14).

This definition is also acknowledged by the British Psychological Society (BPS) who state that a learning disability includes ‘significant impairment of intellectual functioning’; as well as ‘significant impairment of adaptive/social functioning’. They also acknowledge that the ‘age of onset is before adulthood’ (pp.4) [30].

The Royal Mencap Society, a UK-based charity who work with people with learning disabilities, state that people with profound and multiple learning disability need ‘full-time help with every aspect of their lives – including eating, drinking, washing, dressing and toileting’. They acknowledge that an individual with learning disability will have a ‘reduced intellectual ability and difficulty with everyday activities’, which in turn will affect them for their entire life. People with a learning disability tend ‘to take longer to learn’ and they require ‘support to develop new skills, understand complicated information and interact with other people’. The use of terms such as Mild, Moderate, Severe and Profound are also employed to identify disability severity and can vary depending on who uses them (e.g. support organisations) and the context. These terms usually relate to the level of support need required by an individual [31]. Although there is some debate around the terminology and classification of learning disability, it is widely accepted that a person with a learning disability finds it more difficult than others to understand, learn and communicate.

Describing Intellectual Disability

There are also a number of different sub-classifications with regard to learning disability. However, there are discrepancies between these categories among the different ID associations. The WHO list four different sub-classifications of learning disability: Mild, Moderate, Severe and Profound. Although the British Psychological Society (BPS) utilise the same descriptive categories there is some confusion surrounding the quoted IQ ranges of these categories. The BPS recommends 'that decisions involving sub classification of 'learning disability' should refer to both intellectual and to adaptive/social functioning'. They consider it 'good practice to refer to the levels of support required' [30] (pp.8). This is important as the classification is limited unless it helps people and guides support services to meet the needs of people within each category of learning disability.

The WHO's International statistical classification of diseases and related health problems (10th revised edition) (ICD-10) define four degrees of learning disability: mild (an IQ of 50-70), moderate (an IQ of 35-49), severe (an IQ of 20-34) and profound (an IQ of less than 20). This classification has been criticised though, with claims that it does not account for any measure of social or adaptive functioning. It is also argued that IQ scores are uncertain and subjective in practice and are not fixed throughout life. Many health care professionals acknowledge that these classifications create unnecessary labels that inevitably describe people inaccurately. There is also further confusion when comparing these labels between and within countries. For example, within the UK, the classifications of mild and moderate learning disability/difficulty have different meanings across education and health care.

In 2015, NHS England outlined that in terms of intellectual functioning, a learning disability is conventionally defined as an IQ score in the region of 70 or below [32]. However, they acknowledged that the cut-off figure of 70 is not always appropriate, as the results of a recognized IQ test require skilled interpretation. Those with a learning disability will also have significant difficulties in social and/or adaptive functional including but not limited to language, interpersonal skills and activities of daily living. The level of support required will depend on individual factors, including the severity of their learning disability, which can range from someone with a mild or moderate learning disability to someone with a severe of profound learning disability. The extent and nature of a person's learning disability can be determined by the presence of a single major genetic or environmental cause or by multiple factors interacting with educational and social opportunities that facilitate learning and the development of functional and social skills [32].

Disability vs Difficulty

The term 'intellectual disability', although the international standard for describing an individual with reduced intellectual functioning, is not commonly used within the UK in health and social care settings. Within the practice environment, learning disability is used more frequently and Disability services across the UK use the term learning disability [33]. However, in the UK, there is also a distinction to be made between "disability" and "difficulty". According to the British Institute of Learning Disabilities (BILD), many people find the term ‘learning disability’ confusing due to the array of explanations about what exactly a learning disability is. Therefore, in the UK learning disability and learning difficulty are often interchanged within the health and social care world. In fact, BILD report that people with a learning disability prefer to use the term learning difficulties [34].

Within the UK education system, the term ‘learning difficulty’ includes children and young people who have a specific range of ‘learning difficulties’ (for example dyslexia) but who do not necessarily have significant general impairment of intelligence. Special Educational Need (SEN) provision in the UK also use the terms Moderate, Severe and Profound and Multiple to relate to the severity of a learning difficulty [35]. Children and young people who have SEN do not necessarily have a disability; likewise, some disabled children and young people do not have special educational needs, although there can be a lot of overlap between the two groups.

A child or young person has SEN if they need additional support because they find it more challenging to learn than other children or young people of the same age. Examples of special educational needs include: Specific learning difficulties, such as Dyslexia and Attention Deficit Hyperactivity Disorder; Speech, language and communication needs; Behavioural, emotional and social difficulties; Autistic spectrum conditions; Moderate, profound and multiple difficulties; and Multi-sensory impairment. Whereas disability is a physical or mental impairment that has a substantial or long-term effect on an individual’s ability to carry out normal day to day activities. Those with the most complex needs can require support from specialist services as they may need help with their health, education, physical, intellectual, emotional, social or behavioural development.

1.5. Policy context relating to learning disability and administrative data - in NI and beyond

At national (UK) and local (NI) levels, policy has been acknowledging the need for improved visibility of people with learning disabilities within health service data for some time, however, to date, no clear, concrete steps on how to do this have been declared.

International Policy and Key Drivers

In 2006, the United Nations (UN) published the Convention on the Rights of Persons with Disabilities (CRPD) [36]. The purpose of the treaty is to protect and promote the full enjoyment of human rights by people with any form of disability. It emphasised that everyone is equal under the law and that the principles of respect, non-discrimination, inclusion, participation, equality and accessibility are afforded to all. The UK adopted the treaty in 2009. By following CRPD, the UK agreed to protect and promote the human rights of all disabled people, including: eliminating disability discrimination; enabling disabled people to live independently within their communities; ensuring an education system which is inclusive of all; ensuring disabled people are protected from all forms of exploitation, violence and abuse. The UN reviewed the UK’s implementation of the treaty in 2017 and published a number of recommendations including:

- To recognise and enforce the rights of disabled people to live independently, be included in the community, and choose where they live and who they live with
- To ensure that social security policies protect the income of disabled people and their families, allowing for the extra costs that come with disability
- To remove barriers to ensure that disabled people can access decent work and equal pay
- To take action to combat any negative or discriminatory stereotypes or prejudice against disabled people in public and the media
- To ensure disabled people have equal rights to justice by providing appropriate legal advice and support
- To involve disabled people and disabled people's organisations in planning and implementing all laws and policies affecting disabled people
- To incorporate CRPD into domestic law to ensure that people can take legal action if their rights have been breached

In 2011, the WHO published their 'World Report on Disability' [37], which aimed to provide governments and civil society with a comprehensive description of the importance of disability as well as make recommendations for action at national and international levels. They focused on measures to improve accessibility and equality of opportunity; as well as promoting participation and inclusion with the drive to increase respect for the autonomy and dignity of all persons with a disability. The report included a number of recommendations which would remain valid until 2021, at which time the WHO planned to review the progress made. The recommendations included:

1. Enabling access to all mainstream policies, systems and services
2. Investing in specific programmes and services for people with disabilities
3. Adopting a national disability strategy and plan of action
4. Involving people with disabilities
5. Improving human resource capacity
6. Providing adequate funding and improving affordability
7. Increasing public awareness and understanding of disability
8. Improving disability data collection
9. Strengthening and supporting research on disability

One key recommendation advocated for an improvement in the collection of disability-related data. The report acknowledged the importance of different types of population level data including, Census data, large-scale surveys, and administrative datasets. It highlighted the need to improve national disability statistics as well as improving the comparability of data gathered at national and international levels. The report also suggested further work to develop appropriate tools to fill the research gaps that currently exist including: improving the validity of estimates; gaining a clearer understanding of people in their environments; as well as understanding the lived experiences of people with disabilities and their interrelationships in order to develop a true epidemiology of disability.

UK Policy and Key Drivers

In 2001, the UK Government published a White Paper 'Valuing People: A New Strategy for Learning Disability for the 21st Century' [38]. It aimed to set out how the Government would provide opportunities for children and adults with learning disabilities and their families to live full and independent lives as part of their local communities. The report put forward four key principles including: Legal and Civil Rights; Promoting Independence; Having a Choice; and Inclusion. The report noted the underdevelopment of national data available on learning disabilities issues and indicated that the Department of Health would undertake work to improve its data collection in the field of learning disability; however, no key recommendations surrounding the collation and use of data within learning disabilities were put forward.

In 2008, the Government commissioned an independent inquiry into access to healthcare for people with learning disabilities, led by Sir Jonathon Michael. The report followed the publication by Mencap of 'Death by Indifference' [39], which described the experiences of six people who died whilst under the care of the NHS. The inquiry's findings were based on public consultation, a review of the research and evidence gathered from witnesses and stakeholders. They made ten recommendations, including one regarding data: - *All healthcare organisations, including the Department of Health should ensure that they collect the data and information necessary to allow people with learning disability to be identified by the health service and their pathways of care tracked*.

The inquiry acknowledged the importance of data and information systems and the fact that regarding learning disabilities and hospital admissions, data was almost non-existent. They recommended improving data collection in order to allow people with learning disabilities to be identified within health service data. However, the report stopped short of detailing how such measures should and could be implemented.

The Winterbourne Review was carried out in 2014 and focussed on transforming the commissioning of services for people with learning disabilities and/or autism [40]. The report made ten recommendations in a number of key areas including:

- Strengthening Rights
- Commissioning
- Closures
- Building Capacity in Communities
- Holding People to account

The report specifically mentioned that all recommendations should be accompanied by improved collection and publication of performance data, including data on admissions, duration of stay and transfers. It acknowledged that individual commissioners should be held to account by NHS England but stopped short of suggesting a strategy for how this could be implemented.

The Northern Ireland Policy Context

At a local level, the Bamford Review, undertaken in 2003, focused on Mental Health and Learning Disability in Northern Ireland [41]. The Department of Health, Social Services and Public Safety (DHSSPS) initiated the wide-ranging independent review to focus on the law, policy and provision affecting people with mental health needs or a learning disability in Northern Ireland. It followed similar reviews across England and Scotland. The exercise was overseen by a Steering Committee comprised of representatives from professional and other interested groups in the areas of mental health and learning disability. The review consisted of a number of interlinked papers, which comprised of policy, service recommendations and legislation.

The Equal Lives Report (2005) brought equality for learning disabilities to the fore and was a key direction-setting report [42]. The review was based on five core values with which all policy and service developments were to be underpinned. The values offered guidance for future developments for those with a learning disability irrespective of age, gender, severity of disability or complexity of need. The five core values included:

- **Citizenship** – People with a learning disability are individuals first and foremost and each has a right to be treated as an equal citizen
- **Social Inclusion** – People with a learning disability are valued citizens and must be enabled to use mainstream services and be fully included in the life of the community
- **Empowerment** – People with a learning disability must be enabled to actively participate in decisions affecting their lives
- **Working Together** – Conditions must be created where people with a learning disability, families and organisations work well together in order to meet the needs and aspirations of people with a learning disability
- **Individual Support** – People with a learning disability will be supported in ways that take account of their individual needs and help them to be as independent as possible

(pp.7)

The report also proposed 12 core objectives on which future policy for improving the lives of people with a learning which to be based. A number of recommendations were also put forward in the report, in relation to a variety of areas including: Children, Young People and their Families; Fuller Lives; Accommodation and Support; Health and Wellbeing; Mental Health and Challenging behaviours; Growing Older; Ensuring Personal Outcomes; Enabling and Managing Change. Only one of the recommendations noted the issue of data. It called for improvements to be made in how people with a learning disability are identified within GP practices. A number of other references to data were made throughout the report noting the need for improved data on people with learning disabilities in order to accurately assess numbers, needs and services for this population. However, no detailed plan on the collecting of this data was suggested.

In 2011, the Minister for Health, Social Services and Public Safety in NI announced a review of the provision of health and social care services across the region. The review aimed to put forward a number of recommendations to shape the future of services across

NI and provide a plan for implementation. John Compton, the then Chief Executive of the Health and Social Care Board (HSCB) led a newly formed independent review panel, who engaged widely with the public, clinical and professional leaders, as well as health and social care organisations and stakeholders from the community, voluntary, private and independent sectors. The work resulted in the publication of Transforming Your Care: A Review of Health and Social Care in Northern Ireland [43]. The review identified twelve major principles for change, which were to underpin the shaping of a future model proposed for health and social care. These principles included:

1. Placing the individual at the centre of any model by promoting a better outcome for the service user, carer and their family
2. Using outcomes and quality evidence to shape services
3. Providing the right care in the right place at the right time
4. Population-based planning of services
5. A focus on prevention and tackling inequalities
6. Integrated care – working together
7. Promoting independence and personalisation of care
8. Safeguarding the most vulnerable
9. Ensuring sustainability of service provision
10. Realising value for money
11. Maximising the use of technology
12. Incentivising innovation at a local level

One principle highlighted the need to maximise the use of technology. The report acknowledged that within the health and social care systems huge amounts of data are collected. However, the collation, linkage and analysis of this data has been very poor. They acknowledged that data needed to be used in more effective ways to ensure that it is translated into information that can be utilised in service planning. The report proposed using GP data as a building block to collate population level data, which would be stored in data warehouses. This data warehouse would protect patient confidentiality and provide timely, anonymised patient-based data and information for purposes other than direct clinical care, including; planning and commissioning, public health and research, clinical auditing and governance, benchmarking and performance improvement. However, the report lacked any real detail on data linkage and who would act as custodian for the data (pp.121).

In 2011, the DHSSPSNI published the Learning Disability Service Framework, a document containing 34 standards developed to protect and improve the quality of health and social care services in NI, ensuring that all services are safe, effective and focussed on the patient. Although none of the standards directly related to data, the document acknowledged the importance of timely, accurate information and data being provided in order to support decision-making and service improvement. The standards, each have key performance indicators, and data sources were identified to monitor the progress of each of the indicators. No specific mention is given to improving these data sources and a major limitation to the successful adherence of the standard would be poor data being available to measure the performance indicators [44].

Following, the Bamford Review report, a range of Departmental Action Plans were published including Bamford Action Plan 2009-2011 and Bamford Action Plan 2012-2015 [45, 46]. The 2009-2011 Plan set out the Executive's commitment across Departments to improve the mental health and well-being of the population of NI, as well as to improve services for those with a mental health need or a learning disability in line with the policy laid out in Delivering the Bamford Vision. A Mental Health Action Plan was created that included the theme of Providing Better Services to meet People's Needs. One of the key actions was to improve information systems on the provision and use of mental health and learning disability services. A proposal was made to extend an already existing database of inpatient records for learning disability facilities to include users of community-based services. However, no further information was given. The 2012-2015 Action Plan followed on from the work addressed in the 2009-2011 Plan, as well as addressing issues which had not been considered by the Bamford Review but fell under the remit of the review. However, the only mention of data within the 2012-2015 Action Plan was for further data sharing between Department of Education and the Department of Employment and Learning regarding Career Services for young people [45, 46].

In line with the commitments put forward by the UN Convention on the Rights of People with Disabilities, the NI Executive published a departmental Autism Strategy and Action Plan to address the needs of people with autism, their families and carers throughout their lives. The Strategy was a requirement of the NI Autism Act 2011 and outlines the eleven key themes within which sixteen strategic priorities are defined in relation to the future development and delivery of services for those with autism. The key themes included: Awareness; Accessibility; Children, Young People and Family; Health and Wellbeing; Education; Transitions; Employability; Independence, Choice and Control; Access to Justice; Being Part of the Community and Participation and Active Citizenship. The report outlined the poor data that currently exists on people with Autism and acknowledges, through a key action, the need to collect better data on the prevalence of autism in NI including details of age, gender and co-occurring conditions for people with autism, in order to assist with the planning and commissioning of services in the future for people with Autism.

In 2014, the Donaldson Report was published, entitled, The Right Time, The Right Plan: An Expert Examination of the Application of Health and Social Care Governance Arrangements for Ensuring the Quality of Care Provision in Northern Ireland [47]. The report put forward ten recommendations including:

1. Coming together for world class care
2. Strengthened commissioning
3. Transforming your care – action not words
4. Self-management of chronic disease
5. Better regulation
6. Making incident reports really count
7. A beacon of excellence in patient safety

8. System-wide data and goals
9. Moving to the forefront of new technology
10. A much stronger patient voice (pp.44)

The report acknowledged the uncertainties about the reliability of mortality data, as well as the fact that within healthcare systems, data systems are weak and proper goals for improvement are lacking. However, although their recommendations highlighted the need for improved data in order to provide up-to-date information for service provision and commissioning, no clear strategy on how to achieve this was developed [47].

In 2016, a ten-year approach to transforming health and social care was launched (*Health and Wellbeing 2026: Delivering Together*) [48]. The plan was the response to the Bengoa Report, tasked with considering the best configuration of health and social care services in NI [49]. The Report acknowledged the change required in order to support everyone to lead long, healthy and active lives, including;

- Building capacity in communities and in prevention to reduce inequalities and ensure the next generation is healthy and well;
- Providing more support in primary care to enable more preventive and proactive care, and earlier detection and treatment of physical and mental health problems;
- Reforming our community and hospital services so that they are organised to provide care when and where it is needed;
- Organising ourselves to deliver by ensuring that the administrative and management structures make it easier for staff to look after the public, patients and clients.

The report outlined the approach to be taken in order to achieve these changes. This included;

- Partnership Working
- Improving Quality and Safety
- Investing in our Workforce
- Leadership and Culture
- E-health and Care

Within e-health and care, the report acknowledged the need to make better use of technology and data. It highlighted that across the HSC there are too many different systems which makes it difficult to link data and focus on the service user. They acknowledged the major undertaking to consolidate the data systems, however, the report did not suggest a plan or timeframe to implement these proposed changes.

In 2018, the All-Party Group on Learning Disability (APGLD) published its ‘Priority Issues for People with a Learning Disability in Northern Ireland [50]. Set up in 2009, the group comprised of MLAs across the political parties and supported by a number of voluntary and community sector organisations, as well as parents and people with learning disabilities. In keeping with the standards set out in the UNCRPD, the APGLD aims to promote a better understanding of the issues that face a person with a learning disability and their family, as well as influence policy, legislation and service development to improve the lives of people with a learning disability in NI and ensure their inclusion within society (Mencap, 2018). The document outlines ten priority issues including;

1. Policy Implementation
2. Advocacy
3. Data
4. Housing
5. Service Provision
6. Sleep-ins
7. Social inclusion
8. Education
9. Early intervention
10. Personal Independence Payments

Regarding data, the document acknowledges the general lack of disaggregated in NI amongst the LD population. The APGLD call for improved collection and data sharing across government departments and HSCTs in order to strategically and effectively plan to meet the level of need.

1.6. Project aims and objectives

Recognising the inherent complexities and challenges associated with intellectual/learning disability description, definition and measurement and in anticipation of, and in preparation for, NI's new and improved Census 2021 data on learning disability, the current study aimed to (i) highlight the availability, utility and import of learning disability data in NI and (ii) promote and stimulate future use of this data in the region. These aims were addressed through eight objectives:

i. Introduce NI learning disability stakeholders to NI administrative data, its use and potential.
ii. Using the crude learning disability indicator from the 2011 Census estimate the overall prevalence of learning disability for (a) the entire population, (b) those residing in private households and those residing in communal establishments and (c) those aged 15 years or younger and those aged 16 years or over - at both a national and regional level.
iii. Using the crude learning disability indicator from the 2011 Census profile the learning disability population of NI in relation to an array of socio-economic and demographic indicators, again at both a national and regional level.
iv. Using the crude learning disability indicator from the 2011 Census profile and predict general health and health condition comorbidity status for the learning disability population of NI at both a national and regional level.
v. Using General Registrar Office mortality data, linked to the 2011 Census, estimate the rate and cause of mortality for the learning disability population of NI.
vi. Using the crude learning disability indicator from the 2011 Census detail the educational status and employment status (stratified by gender and settlement band) of the adult learning disability population of NI (see Appendix 3).

vii. Using the more explicitly defined learning disability indicator from the 2007 NISALD, estimate the overall prevalence of learning disability for (a) the entire population, and (b) those aged 15 years or younger and those aged 16 years or over. Also, compare the prevalence estimate of learning disability generated from the 2011 Census data with the prevalence estimate of learning disability generated from the NISALD data to assess how survey item specificity affects learning disability prevalence estimation.

viii. Finally, to better understand the origins and decision making surrounding the new learning disability survey content, set to be introduced in the forthcoming 2021 Northern Ireland Census, the project team explored the rationale and methodology employed by the Northern Ireland Census team relating to 2021 disability and health condition assessment.

Section 2 Study methodology

This section provides a general overview of the methods underpinning the study. Specifically, a description of the administrative data organisations responsible for facilitating the current research (Administrative Data Research Northern Ireland (ADR-NI) & the Northern Ireland Mortality Survey (NIMS)) will be provided. This section will also describe (i) the various data sources accessed for the current study, (ii) the data linkages and access restrictions that emerged during the project.

2.1. The Administrative Data Research Northern Ireland and the Northern Ireland Mortality Study (NIMS) (see O'Reilly et al. [1, 2])

The Administrative Data Research Northern Ireland (ADR NI) represents a partnership between academia (Queen's University Belfast and Ulster University) and the Northern Ireland Statistics and Research Agency (NISRA). Along with ADR Scotland and ADR Wales, it is one of three national partnerships in the UK coordinated by a UK-wide Strategic Hub which also includes a partnership with the Office for National Statistics (ONS). The overarching aims of this Administrative Data Research Partnership are to facilitate safe and secure access for accredited researchers to administrative data in the UK predominantly in order to help inform and evaluate government policy decisions. While the current study was originally approved as an ADR NI project, it was initiated and completed as a Northern Ireland Mortality Study (NIMS) project due to the unforeseen impacts of the digital economy act (see Section 2.4 and Appendix 5). Access to the administrative data for the current project (2011 Census data & General Registrar Office mortality data) therefore was facilitated by the NIMS in 2017. NIMS is a census-based administrative data linkage study developed and managed by NISRA. It comprises the enumerated Northern Ireland (NI) 2011 Census population linked with subsequently registered deaths. A sister project of the Northern Ireland Longitudinal Study (NILS) [3], the goal of these projects is to provide a mechanism for understanding the population health dynamics of Northern Ireland equivalent to that provided by the ONS Longitudinal Study (ONS-LS) which has, for the past 30 years, fulfilled this function for England and Wales.

The data from these sources was linked by the NISRA RSU team (see proposed data linkages in section 2.4), tested for potential disclosure problems, de-identified and, made available to the research team in a secure setting at NISRA headquarters in Belfast.

2.2. Data sources used in the current study

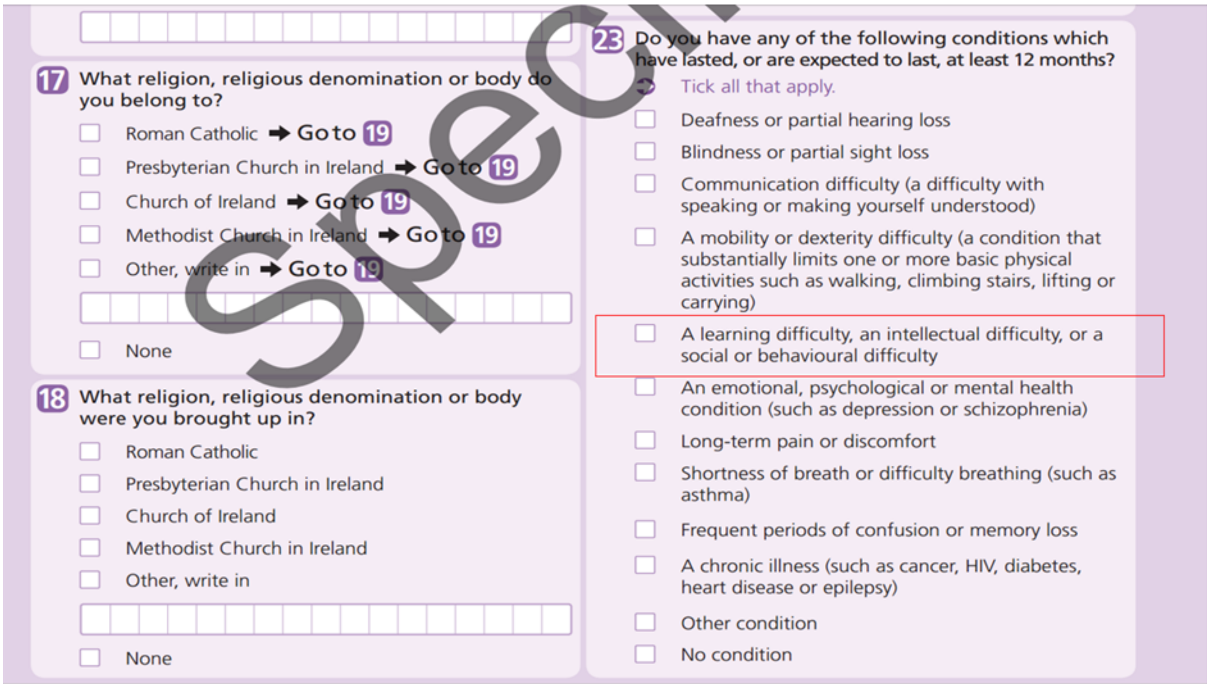
Census 2011

Census data was obtained from 1,723,180 residents (98.8% of entire population), of which 1,702,217 lived in private households and 20,963 lived in communal establishments. The Census form indicated that the householder (the person who owned or rented the accommodation and was responsible for paying the household bills) was responsible for ensuring that the questionnaire was completed and returned, although it did not provide instructions as to who should complete the separate sections of the Census form relating to each individual household member. It was generally assumed, however, that parents would have completed the individual forms on behalf of younger children while older children would have self-reported.

Intellectual/Learning Disability

At the 2011 Census, individuals were asked whether they had any of a list of health conditions (see Census 2011 Q23 in Figure 2.1.) which had lasted or were expected to last, at least 12 months. There was also an option to report no health conditions. One of these health condition categories afforded respondents an opportunity to record the presence of 'A learning difficulty, an intellectual difficulty, or a social or behavioural difficulty'. While this census item may have been crude (e.g. the category referred to intellectual difficulty rather than disability and subsumed intellectual difficulty with learning difficulties and social and behavioural difficulties), it, for the first time, offered NI citizens with an ID an opportunity to officially record, albeit indistinctly, their disability status.

Figure 2.1. Question 23 health conditions list from the 2011 Census



17 What religion, religious denomination or body do you belong to?

☐ Roman Catholic ➔ Go to **19**
☐ Presbyterian Church in Ireland ➔ Go to **19**
☐ Church of Ireland ➔ Go to **19**
☐ Methodist Church in Ireland ➔ Go to **19**
☐ Other, write in ➔ Go to **19**
☐ None

18 What religion, religious denomination or body were you brought up in?

☐ Roman Catholic
☐ Presbyterian Church in Ireland
☐ Church of Ireland
☐ Methodist Church in Ireland
☐ Other, write in
☐ None

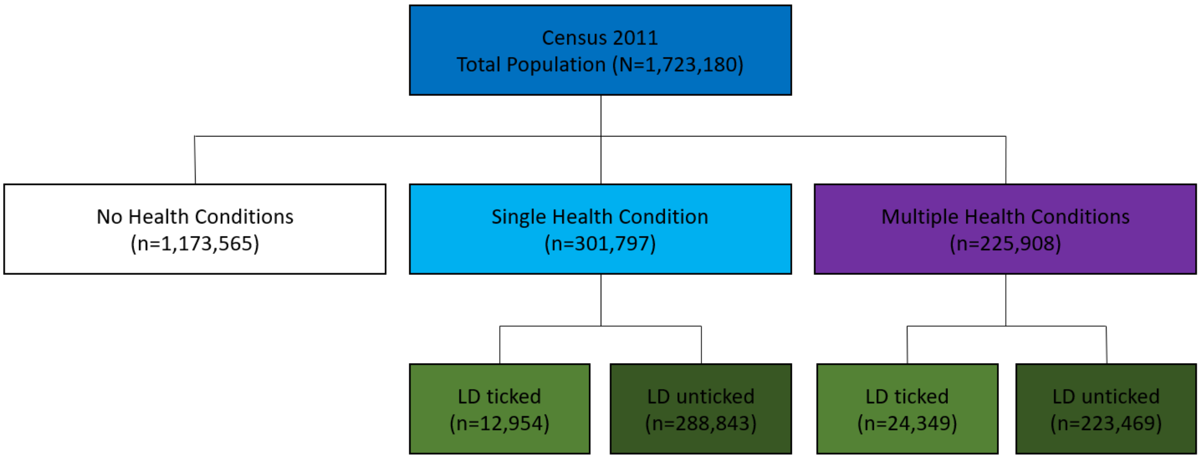
23 Do you have any of the following conditions which have lasted, or are expected to last, at least 12 months?

Tick all that apply.

☐ Deafness or partial hearing loss
☐ Blindness or partial sight loss
☐ Communication difficulty (a difficulty with speaking or making yourself understood)
☐ A mobility or dexterity difficulty (a condition that substantially limits one or more basic physical activities such as walking, climbing stairs, lifting or carrying)
☐ A learning difficulty, an intellectual difficulty, or a social or behavioural difficulty
☐ An emotional, psychological or mental health condition (such as depression or schizophrenia)
☐ Long-term pain or discomfort
☐ Shortness of breath or difficulty breathing (such as asthma)
☐ Frequent periods of confusion or memory loss
☐ A chronic illness (such as cancer, HIV, diabetes, heart disease or epilepsy)
☐ Other condition
☐ No condition

To attain the most effective classification of intellectual/learning disability (i.e. given that respondents may have identified learning disability as a single health condition or along with one or more health conditions), a 5-category health conditions variable, generated using the 12-category health conditions list from Question 23 in the 2011 Census was created and framed all analyses for the current study (1=no health conditions present; 2=a single learning disability condition present; 3=a single health condition present other than learning disability; 4=multiple health conditions present including learning disability and 5=multiple health conditions present not including learning disability (see Figure 2.2.).

Figure 2.2. Breakdown of 2011 Census population in relation to no, single, multiple, health condition status



LD = Learning disability indicator

From an overall population sample of 1,723,180, 17.5% indicated the presence of a single health condition while 13% indicated the presence of at least two co-occurring health conditions. Among those with a single health condition 4.3% indicated that this condition was a learning disability while among those with two or more health conditions, 10.8% indicated that one of these conditions included learning disability.

Other Census 2011 variables

In order to describe the socio-economic and demographic characteristics of the learning disability population of Northern Ireland a variety of socio-economic, demographic, and area level variables were targeted: In our analyses, age was categorised into seven age bands (0-15 years, 16-24, 25-34, 35-44, 45-54, 55-64, 65 years+). Sex was categorised as (1) male or (2) female. Living status was represented by three categories: (1) lives alone, (2) lives in a couple, (3) other. Ethnicity (an 11-category item in the Census – Q16) was dichotomised as (1) non-white, (2) white. Activity limitations (Are your day-to-day activities limited because of a health problem or disability which has lasted, or is expected to last, at least 12 months? Census – Q22) was represented by three categories: (1) Not limited, (2) Limited a little, (3) Limited a lot. A dichotomous residence variable was used to denote residence in (1) a private household or (2) a communal establishment. Deprivation was measured using the NI Multiple Deprivation Measure 2010 (NIMDM) scores [4]. Scores range from most deprived (1) to least deprived (10). Eight settlement bands ranging from the largest, the Metropolitan Area of Belfast (comprising ca. 580,000 people); to a band representing settlements of less than 1000 people and open countryside were used. Finally, the Northern Ireland Health and Social Care Trusts (HSCTs) were each represented; (1) Belfast HSCT (2) Northern HSCT (3) South Eastern HSCT (4) Southern HSCT and (5) Western HSCT.

General Registry Office data

Data detailing all deaths occurring between March 2011 and December 2015 in Northern Ireland for the total population (N=1,723,180) were included. Data detailing cause specific mortality were also included - Neoplasms (International Classification of Disease (ICD) C00-D48); Circulatory system (ICD 10 I00-I99); Respiratory system (ICD 10 J00-j99); Nervous system (ICD 10 G00-H95); Digestive system (ICD 10 K00-N93); Genito-urinary (ICD 10 K00-N93); Diabetes mellitus (ICD 10 K00-N93); Congenital malformations (ICD 10 Q00-Q99); and Obesity.

NI Multiple Deprivation Measure 2010 (NIMDM)

Deprivation was measured using NI Multiple Deprivation Measure 2010 (NIMDM) scores [5]. The NIMDM measures deprivation on seven domains: health; income; employment; education skills and training; proximity to services; living environment; and crime and disorder. Weighted scores are derived by calculating the number of people experiencing each type of deprivation in a Super Output Area (SOA; M = 2035 residents). Scores range from most deprived (1) to least deprived (10). In this analysis, we utilised the Multiple (summary) Deprivation indicator.

NISRA generated settlement band data

Although there is no universally agreed definition of what constitutes an ‘urban’ or ‘rural’ area, the official classification in Northern Ireland uses an approach based on population size, density and access to services to group small population tracts of about 300 people into eight settlement bands ranging from the largest, the Metropolitan Area of Belfast (comprising ca. 580,000 people); to a band representing settlements of less than 1000 people and open countryside (Bands include: Belfast Metropolitan Urban Area; Derry Urban Area; Large Town; Medium Town, Small Town; Int Intermediate Settlement; Village; Small Village, Hamlet & Open Countryside). Respondents were allocated to settlement bands based on place of residence on Census day. Settlement bands in the current study either retained the original eight category structure or were re-categorised into three similarly sized groups; urban – comprising the largest two cities; intermediate – combining large, medium, and small towns and intermediate areas, and rural as above.

Northern Ireland Survey of Activity Limitation and Disability (NISALD)

The NISALD was conducted by the Northern Ireland Statistics and Research Agency (NISRA) during 2006-2007. The survey aimed to provide an up-to-date, accurate picture of the prevalence and circumstances of adults and children living with a disability in Northern Ireland. Although the NISALD comprised two strands i.e. (1) private households and (2) communal establishments (excluding places of detention and military establishments), only data and findings from the private household strand have been released publicly and, as such, the current study relates to disability and activity limitations within *private households* in Northern Ireland only.

There was no comprehensive register of people with disabilities in Northern Ireland (i.e. no sampling frame) from which to sample potential respondents for the NISALD survey. To overcome this obstacle, NISRA selected a random sample of 12,000 households from the

Northern Ireland Valuation and Lands Agency Database, which contains a record of all domestic households in Northern Ireland, to serve as the study sampling frame. Selected households were posted an advanced letter which contained detailed information about the NISALD, its purpose, and that their household would be contacted in due course with respect to potential participation. Of the initial sample of 12,000 households, 10,984 (84% of random sample) were eligible addresses. Subsequently, NISRA contacted each eligible household to conduct a screening exercise with one member of the household (largely via telephone, but also via face-to-face interview if requested or if the household did not have a telephone) during which information was requested on each member living in the household. Information sought included: basic demographic information on each member of the household, as well as the presence and level of difficulty associated with 15 disabilities or activity limitations (in accordance World Health Organisation (WHO) International Classification of Functioning, Disability and Health (ICF) [12]) that had lasted or were expected to last 6 months (see Table 1).

In total, 23,689 screening interviews were conducted with 18,517 adults and 5,172 children in eligible households. Individuals within the household who reported: (1) more than one mild limitation that affected activities sometimes; (2) at least one mild limitation that affected activities often; or (3) one or more moderate/severe limitation (n=4,185; 3,865 adults and 320 children), were considered as having some medical, social or environmental factor that affected their ability and therefore were deemed eligible to complete a questionnaire designed to further assess the nature of their activity limitations and disability.

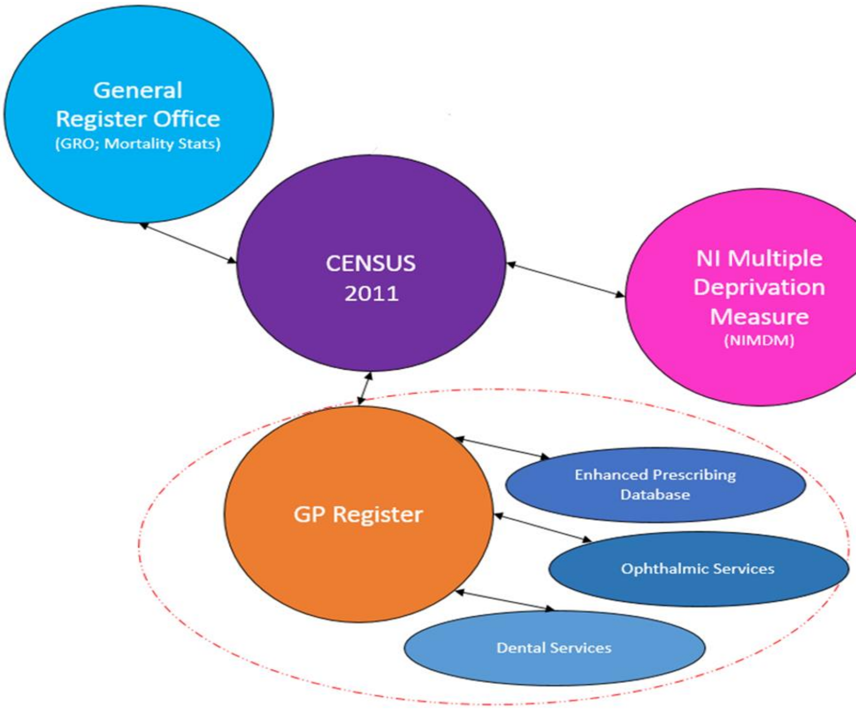
Multiple members of the same household could complete this questionnaire if they met the eligibility criteria, which was conducted via face-to-face interviewing in the respondent's own home. Adult and child versions of the main questionnaire were largely similar with only minor amendments to wording for children. All interviews for respondents aged 15 years or younger were conducted in proxy form with the parent or guardian.

The main questionnaire collected information on: how the disability or activity limitation affected daily life; use of aids, specialised equipment or medication; management of disabilities; supports and care needed/received; general health; use of health and social care services; education; employment and training; social participation, leisure and attitudes of others; transport and travel; housing; crime and fear of crime; additional costs relating to living with a disability (e.g. goods, services, equipment or medication), income and benefits; and general background information. Approximately 85% of those who were eligible and invited to participate in the main interview did so (n=3,543; 3,262 adults and 281 children). Data from NISALD is available for researchers to access via the UK Data Service, study number 7236 (https://beta.ukdataservice.ac.uk/datacatalogue/studies/study?id=7236).

2.3. Proposed data linkage & access restrictions

Data sources originally targeted for the current study included the NI Census 2011, the NI Multiple Deprivation Measure (NIMDM) 2010, the Enhanced Prescribing Database (EPD), the Dental Payment System, the Ophthalmic Claim System (OCS), and the NI Death Register (see Figure 2.3.). However, due to data access restrictions relating to the Digital Economy Act (see Appendix 5), all data accessible via the GP Register (i.e. the Enhanced Prescribing Database; the Dental Payment System; the Ophthalmic Claim System) were denied to the project team. Planned analyses and interrogation of data therefore relating to e.g. medical treatments/prescriptions and health care service utilisation among the learning disability population of Northern Ireland were not possible (see also Section 7.3).

Figure 2.3. Original proposed administrative data linkage plan for study



Section 3 Learning disability prevalence and demography using Census 2011 data

3.1. Aims: To provide an overall NI prevalence estimate for learning disability according to the 2011 Census data and profile the demography of the learning disability population using a range of Census based socio-economic metrics. To provide prevalence estimates and profile the demography of the learning disability population in relation to the five NI Health and Social Care Trusts.

3.2. Background

According to most recent meta-analysis findings, the prevalence of learning disability ranges from 0.05 – 1.55% globally [1]. Reviewing 20 studies (from Australia, Canada, China, Denmark, Finland, India, Norway, Taiwan & Sweden), McKenzie and colleagues showed that learning disability prevalence was highly variable. Estimates based on studies using child/adolescent data ranged from 0.22 % to 1.55 % [2, 3] while estimates based on studies using adult data ranged from 0.05 % to 0.8 % [4, 5]. Estimates based on data that included both children/adolescents and adults ranged from 0.10 % to 1.30 % [6, 7]. Regarding prevalence over time, seven studies provided estimates across multiple years [2, 8-13]. Of these, one study revealed an increase over time [11], three reported decreasing prevalence [8, 12-13], while three identified no time trend [8, 10, 2].

The authors partly attributed this variability in prevalence to heterogeneity in study settings, methodologies, and case definitions. Specifically, studies tended to vary in data source i.e. administrative data (e.g. health, education, social services data or data form national registries) or national household survey data. Moreover, administrative data-based studies were distinct from studies based on national household survey data in relation to intellectual disability classification. Classification of learning disability in administrative data-based studies tended to be determined by clinical diagnosis, a recognized classification system (ICD; DSM; AAMR), psychological assessments, use of learning disability services, legal definition, and/or receipt of special education. However, learning disability classification in studies based on national household survey data tended to be based on survey questions (all slightly different) designed to ascertain the presence of learning disability.

Prevalence estimation of learning disability in NI

The evidence base relating to learning disability prevalence estimation in Northern Ireland is limited. McVeigh noted that there is currently no comprehensive database for recording the number of people with a learning disability in NI [14]. However, a number of estimates have been derived from a variety of sources and range from ~0.4% based on GP records, to ~0.5% based on Health and Social Care Trust data, to 2.2% based on crude learning disability data from the NI Census (partly the focus of this study). Prior to the 2011 Census, the Bamford Action Plan (2009-2011) [15], using accepted prevalence rates of 1%-2% derived from national and international studies, estimated that approximately 26,500 (~1.5%) people were living with a learning disability in NI at this time. As described earlier, in

2011, the Census for NI introduced a new question that examined the nature of citizens' long-term health conditions. This question asked if individuals had any of a defined list of conditions, (which had lasted or were expected to last, at least 12 months). The list included blindness; deafness; communication difficulties; difficulties with mobility or dexterity; emotional psychological or mental health conditions; long term pain or discomfort; shortness of breath or difficulty breathing; frequent periods of confusion or memory loss; chronic illness; and a category that included having a learning difficulty, an intellectual difficulty, and a social or behavioural difficulty. The choice of terminology and collation of the terms used in the NI census in 2011 were determined by the Northern Ireland Survey of Activity Limitation and Disability (NISALD), which was conducted in 2006-2007 [16]. Although it was not possible to replicate the protocol from this survey in a single census question, the census team hoped to align the response categories in the census question with the list of activity limitations and disabilities used in NISALD, to allow for future work on modeling the spatial distribution of people with particular activity limitations and disabilities [16]. McVeigh reported that on Census Day 2011, 2.22% of the resident population of NI reported having a learning difficulty, an intellectual difficulty, or a social or behavioural difficulty' [14].

After the 2011 Census, a number of other NI administrative data-based estimates were derived, firstly from GP records data and secondly from Health and Social Care Trusts data. GP services in NI undertake Directed Enhanced Services (DES) for people with learning disability and as part of this they produce a return for the Health and Social care Board. In 2013, 7,198 (~0.4% of NI population) individuals were registered as having an learning disability with their GP practices [17-18]. In 2016, Swann et al. reported on figures generated by the Department for Health and Social Services and Public Safety in NI (DHSSPS). These figures were based on individuals with learning disability who had been in contact with one of the 5 Health and Social Care Trusts (HSCT) in NI. DHSSPS recorded and reported 8,738 persons with learning disability throughout NI (~0.5% of NI population), a number that was consistent with GP estimates gathered in 2012/2013. Both GP services and Dentists across NI are required to keep a record of patients with a learning disability. Likewise, the Health and Social Care Trusts across NI also keep records of those with a specific learning disability who are in receipt of a day care, day opportunity placement and/or those accessing respite services. However, it is widely acknowledged that there is a hidden or unseen population of people with learning disability in NI who are not in receipt of specific disability services and are therefore not included in these numbers.

How does NI population data relating to learning disability compare with the rest of the UK and the Republic of Ireland?

There are a number of large population-based datasets available in the UK, which can be used to help estimate the prevalence of learning disability. These include the Labour Force Survey, the British Household Panel Survey (BHPS), the English Longitudinal Study of Ageing, the National Survey of the Mental Health of Children and Adolescents in England and Wales, the Great Britain Child Mental Survey, the Psychiatric Morbidity Survey, the Continuous Household Survey and the Health Survey for England. However, not all of these datasets cover the four nations of the United Kingdom, and the methods for identifying learning disability are not standardized across the datasets.

Census questions across the different nations of the UK and in the Republic of Ireland also differ. Disability questions in the English and Welsh Censuses in 2011 only asked if individuals were limited in their day-to-day activities due to a health condition or disability but did not ask for any further clarification on the type of health condition or disability [19]. In England and Wales, 8.5% of the population reported their daily activities were 'limited a lot' and 9.4% were 'limited a little' due to a health problem or disability [19].

Unlike England and Wales, Scotland and the Republic of Ireland included specific questions on learning disability within their 2011 Census surveys. The Irish census question on disability, from 2011, includes a separate and specific item for intellectual disability [20]. The number of people who reported an intellectual disability in the Irish Census in 2011 was 57,709 (or 1.3% of the resident population). Of those who stated that they had an intellectual disability, 81.3% indicated the presence of a second disability; the most common of which was a difficulty with learning, remembering or concentrating, which was reported by 70.3% of intellectual disability respondents [21]. The 2011 Census in Scotland introduced a question on disability, separating the disability element of the question into Learning Disability (for e.g. Down's Syndrome), Learning Difficulty (for e.g. dyslexia) and Developmental disorder (for e.g. Autistic Spectrum Disorder or Asperger's Syndrome). On Census day 2011, 26,300 people in Scotland reported that they had a learning disability (0.5% of the total population). Of those who reported having a learning disability, over 20% also reported that they had a developmental disorder. The majority of the Scottish LD population were male (57.5%) [22].

Recognising change and exploiting the extant data

While the crude learning disability survey item contained in the Northern Ireland 2011 Census may have lacked the specificity of those used in both the Scottish and Irish Censuses, it was certainly superior to the disability survey questions used in the 2011 Censuses in England and Wales. Moreover, the 2011 question afforded a greater opportunity to approximate learning disability prevalence than that afforded by the 2001 NI Census disability survey question ('any long-term illness, health problem or disability….'). While previous studies have reported the 2.2% prevalence of learning disability in NI, as derived from this crude 2011 Census survey question, little more, it seems, has been done with the data. This is surprising given that the Census data affords an opportunity to consider learning disability prevalence, not just for the overall population, but for those living in communal establishments as well as private households, those within specific age ranges, and within specific geographical regions of the country. Moreover, the Census is rich with socio-economic, health, education, employment and household data that can be exploited to reveal much about those who indicated the presence of 'A learning difficulty, an intellectual difficulty, or a social or behavioural difficulty' in NI in 2011.

3.3. Methods

Measures

The variables used in in the current set of analyses largely comprise those derived from the 2011 Census data (N=1,723,180).

Learning disability: To frame the analyses a 5-category health conditions variable, generated using the 12-category health conditions list from Question 23 in the 2011 Census was employed (1=no health conditions present; 2=a single learning disability condition present; 3=a single health condition present other than learning disability; 4=multiple health conditions present including learning disability and 5=multiple health conditions present not including learning disability; see Section 2.3.).

Socio-economic, demographic, and area level variables: In this analysis, age was categorised into seven age bands (0-15 years, 16-24, 25-34, 35-44, 45-54, 55-64, 65 years+). Gender was categorised as (1) male or (2) female. Living status was represented by three categories: (1) lives alone, (2) lives in a couple, (3) other. Ethnicity was dichotomised as (1) non-white, (2) white. Activity limitations was represented by three categories: (1) Not limited, (2) Limited a little, (3) Limited a lot. A dichotomous residence variable was used to denote residence in (1) a private household or (2) a communal establishment. Deprivation was measured using NI Multiple Deprivation Measure 2010 (NIMDM) scores [23]. Scores range from most deprived (1) to least deprived (10). Eight settlement bands ranging from the largest, the Metropolitan Area of Belfast (comprising ca. 580,000 people); to a band representing settlements of less than 1000 people and open countryside were used. Finally, the Northern Ireland Health and Social Care Trusts (HSCTs) were each represented; (1) Belfast HSCT (2) Northern HSCT (3) South Eastern HSCT (4) Southern HSCT and (5) Western HSCT [24].

3.4. Analysis

Using the learning disability indicator from the 2011 Census health conditions list, a crude learning disability prevalence estimate was recorded for (i) the entire Northern Ireland population, (ii) those aged 16 years or above and those aged 15 years or younger and (iii) those residing in private households and those residing in communal establishments. The five category health conditions variable was used to stratify each of the socio-economic and demographic indicators to profile and to compare and contrast the demography of the learning disability population with the rest of the population of Northern Ireland. Finally, prevalence estimates and demography profiles were generated for the five Northern Ireland HSC Trusts.

3.5. Results

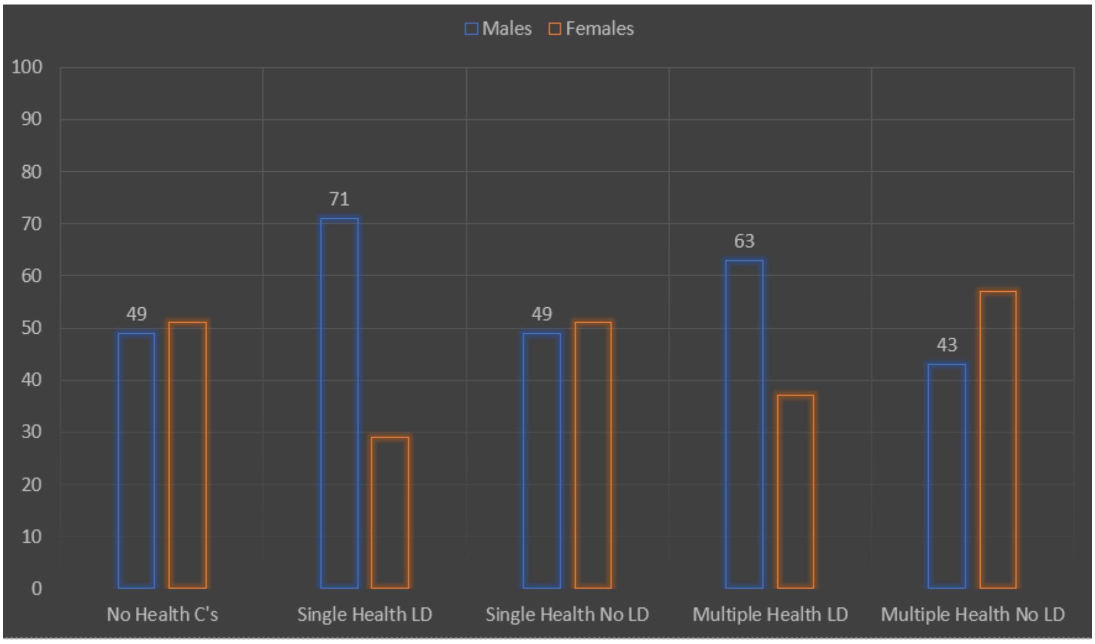
Learning disability prevalence

Within the overall Census sample, 37,303 (**2.2%**) respondents indicated the presence of ‘A learning difficulty, an intellectual difficulty, or a social or behavioural difficulty’. Among those aged 15 years or younger (n=355,784), 13,572 (**3.8%**) indicated the presence of ‘A learning difficulty, an intellectual difficulty, or a social or behavioural difficulty’. Among those aged 16 years or over (n=1,367,396), 23,731 (**1.7%**) indicated the presence of 'A learning difficulty, an intellectual difficulty, or a social or behavioural difficulty'. Among those aged 15 years or younger living in private households (n=355,430), 13,530 (**3.8%**) indicated the presence of 'A learning difficulty, an intellectual difficulty, or a social or behavioural difficulty'. Among those aged 16 years or over living in private households (n=1,346,787), 20,871 (**1.5%**) indicated the presence of 'A learning difficulty, an intellectual difficulty, or a social or behavioural difficulty'. Among those aged 15 years or younger living in a communal establishment (n=312-330; low cell counts in this age category precluded a calculation of the actual total), 42 (**12.7% - 13.5%**) indicated the presence of 'A learning difficulty, an intellectual difficulty, or a social or behavioural difficulty'. Among those aged 16 years or over living in a communal establishment (n=2,0633-20,651), 2,860 (**13.8% - 13.9%**) indicated the presence of 'A learning difficulty, an intellectual difficulty, or a social or behavioural difficulty'.

Sex & age

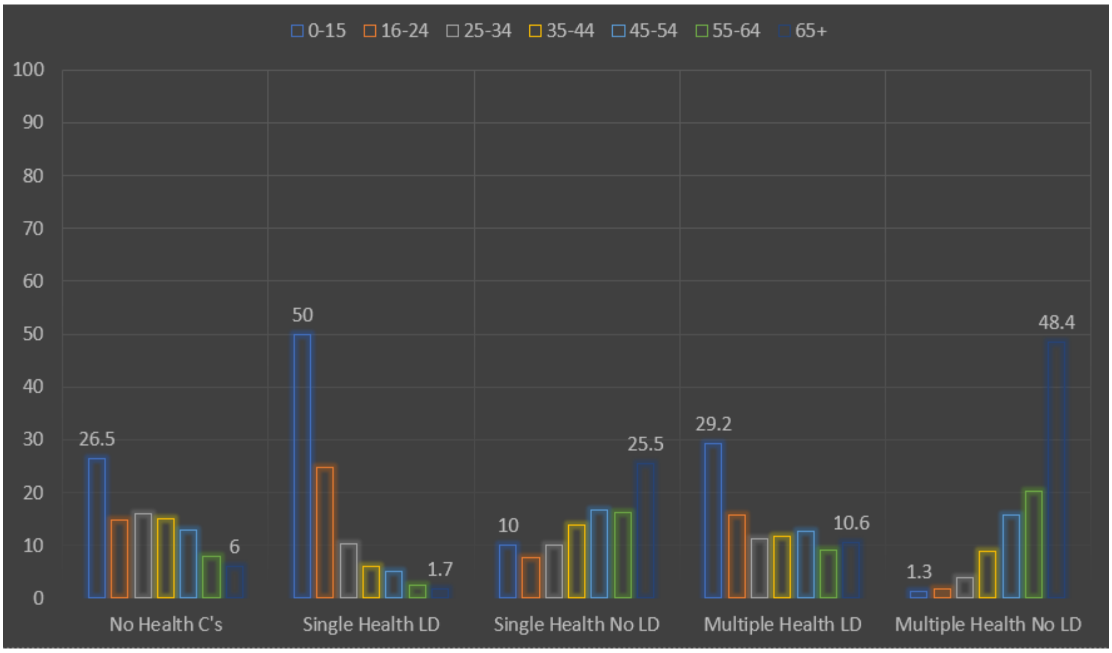
Within the overall Census sample (see Table 3.1. in Appendix 1 and Figure 3.1.), **learning disability was more common among male members of the population**. A significantly higher proportion of those with a learning disability, either as a single condition, or, comorbidly with other health conditions, identified as male (71% and 63% respectively). In contrast, relatively equal numbers of males and females experienced a single health condition other than learning disability, while a higher proportion of females experienced multiple health conditions excluding learning disability (57%).

Figure 3.1. Sex distribution by LD status for **total Census** sample (N=1,723,180)



In relation to age (see Table 3.1. in Appendix 1 and Figure 3.2.), **learning disability was more common among those aged 15 years or younger**. While 29% of those who had a learning disability in addition to at least one other health condition were under 16 years of age, **50% of those who reported learning disability as their only health condition were under 16 years of age**. Conversely, the majority of those who reported the presence of a single health condition other than learning disability, and those reporting multiple health conditions excluding learning disability were in the highest age bracket (65 years +; 25% & 48% respectively).

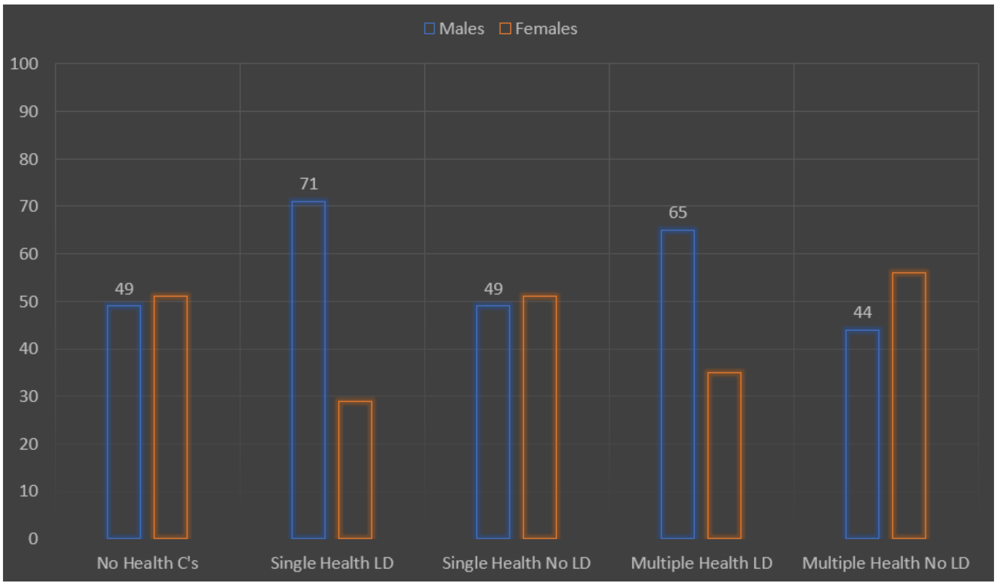
Figure 3.2. Age distribution by LD status for **total Census** sample (N=1,723,180)



Sex-age distribution by residence

Within the Census household subsample (see Table 3.2. in Appendix 1 and Figure 3.3a.), **a significantly higher proportion of those with a learning disability also identified as male** (as a single condition = 71%, or, comorbidly with other health conditions = 65%).

Figure 3.3a. Sex distribution by LD status for total Census **household** sub-sample (N=1,702,217)



Within the communal establishments subsample, however, while more males reported learning disability as a single health condition (61%), more females reported learning disability with other health conditions (52%; see Table 3.2. in Appendix 1 and Figure 3.3b). Regarding age (see Table 3.2. in Appendix 1 and Figures 3.4a & 3.4b), **learning disability was again more common among those aged 15 years or younger in the household subsample** (as a single condition = 51%, or, comorbidly with other health conditions = 32%).

Figure 3.3b. Sex distribution by LD status for total Census **communal establishments** sub-sample (N=20,963)

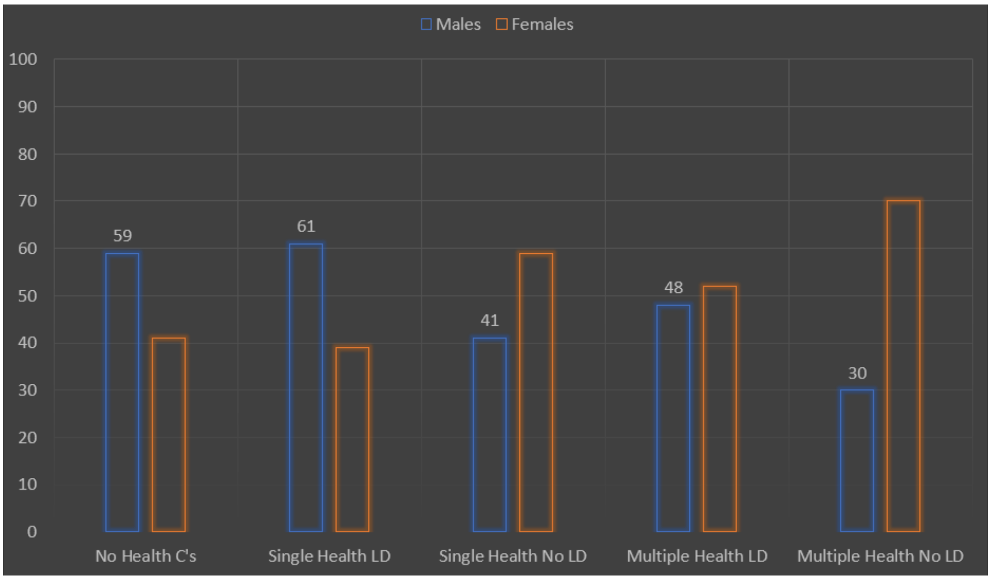
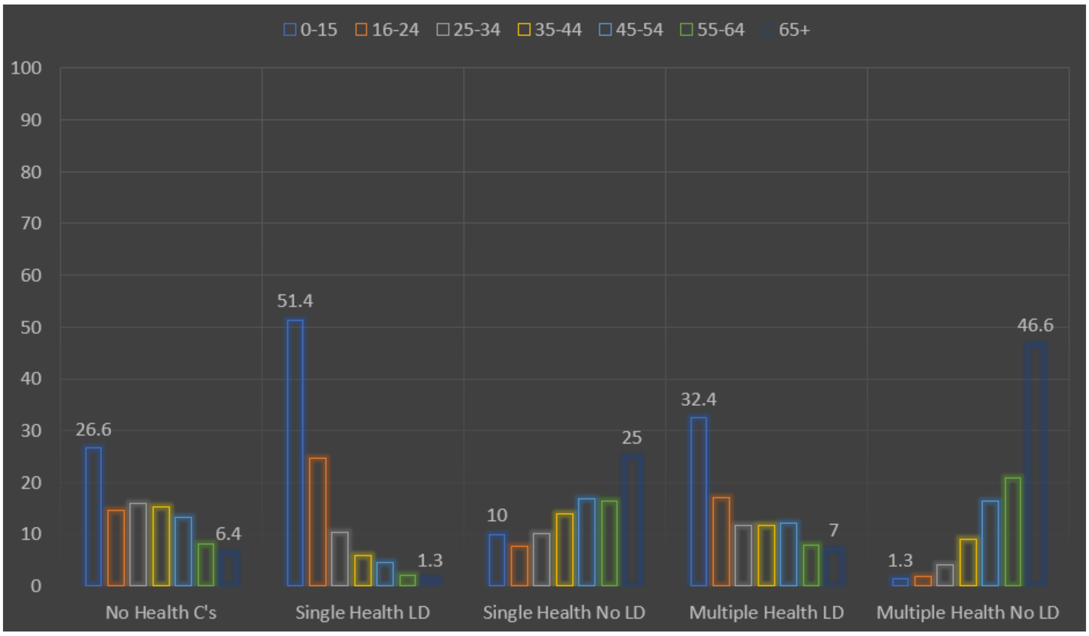
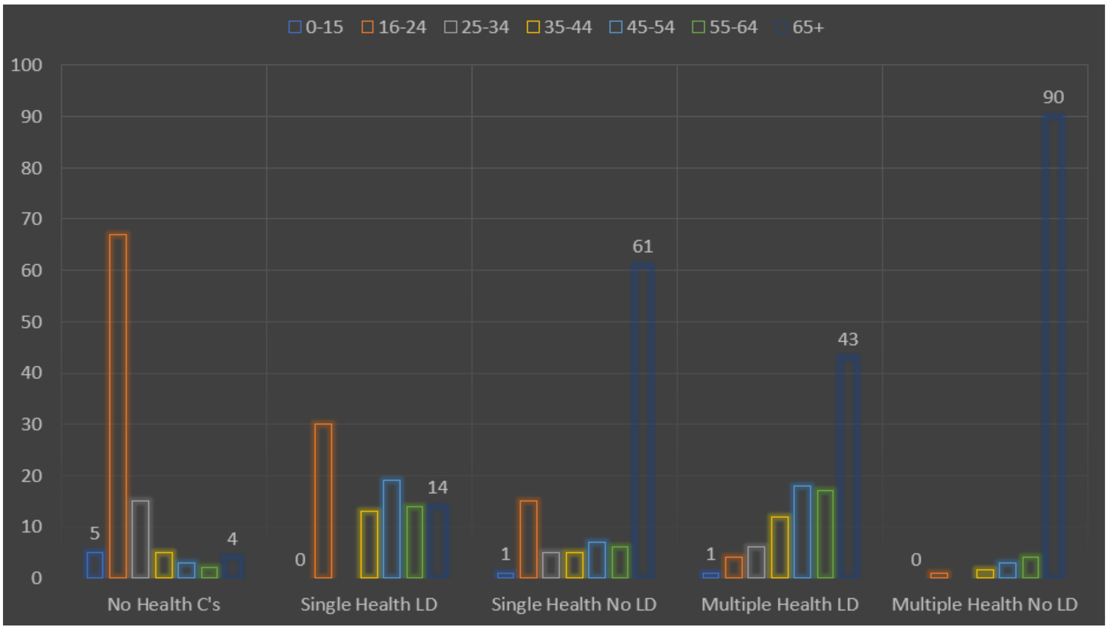


Figure 3.4a. Age distribution by LD status for total Census **household** sub-sample (N=1,702,217)



However, within the communal establishments subsample, the majority of those reporting a learning disability with (an)other health condition(s) were aged 65 years or over (43%), while the majority of those who reported learning disability only were aged 16 – 24 years. The majority of those who reported the presence of a single health condition other than learning disability, and those reporting multiple health conditions excluding learning disability were in the highest age bracket (65 years +) within both the household (25% & 47% respectively) and, much more pronouncedly, within the communal establishments subsample (61% & 90% respectively).

Figure 3.4b. Age distribution by LD status for total Census **communal establishments** sub-sample (N=20,963)



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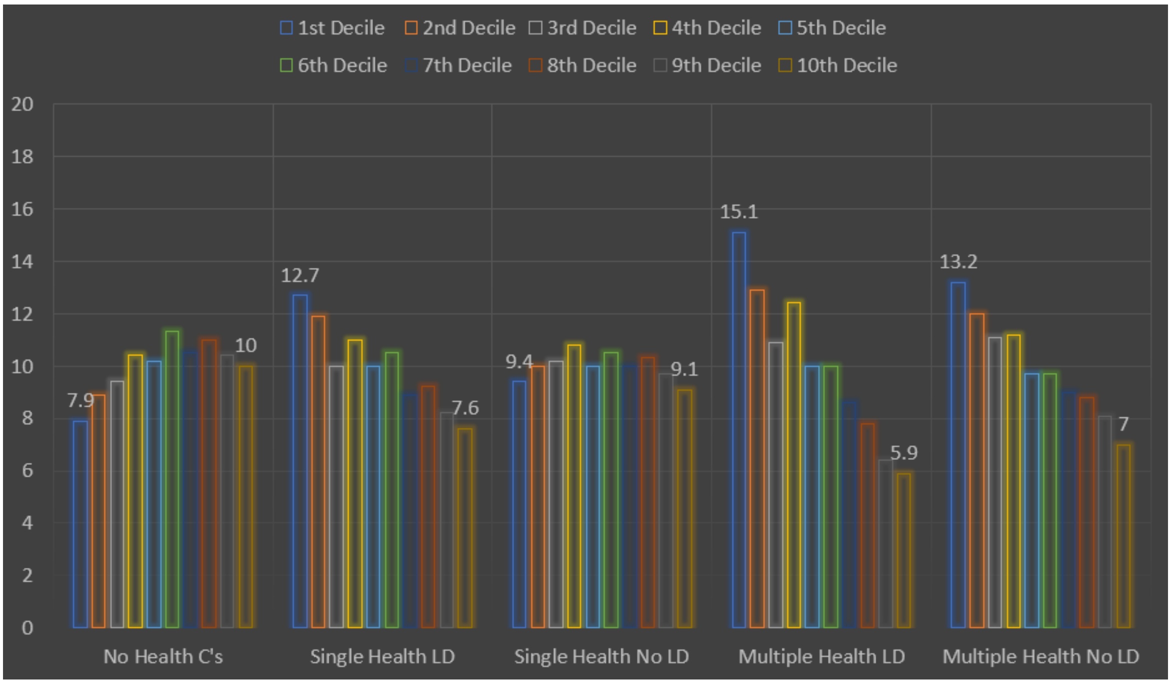
Deprivation

Within the overall Census sample, **learning disability status was associated with greater deprivation** (see Table 3.3. in Appendix 1 and Figure 3.5). Multiple deprivation indices were generally normally distributed among those in the population without an underlying health condition and among those who reported a single health condition other than learning disability (i.e. the majority of people in these groups had a mid-range, 3rd – 8th decile, multiple deprivation index). **The multiple deprivation index distributions for the remaining three groups however** (i.e. those who reported learning disability as their only health condition; those who reported learning disability in addition to at least one other condition; and those with multiple morbidities excluding learning disability) **were positively skewed with the highest proportion of these groups characterised by a first or second decile multiple deprivation index and the lowest by a 9th or 10th decile index**. Among those reporting a learning disability only, 12.7% were in the first decile while 7.6% were in the 10th decile. Among those reporting learning disability with at least one other health condition, 15.1% were in the first multiple deprivation index decile while 5.9% were in the 10th.

Figure 3.5. NIMDM decile by LD status for total Census sample (N=1,723,180)



Living arrangements & Disability Limitation

Within the overall Census sample the majority of those with a learning disability, either as a single health condition, or, comorbidly with other health conditions, were neither living as part of a couple nor living alone (see Table 3.4. in Appendix 1 and Figure 3.6)**.** Overall, 89% of those with a learning disability as a single condition were classified as 'other' while 73% of those with a learning disability comorbidly with at least one other health condition were classified as 'other'. It is worth recapping here however that the proportions of these groups that were under 16 years of age was 50% and 29% respectively therefore 'other' status for many will have been attributable to dependent status and familial context.

Regarding activity limitation (see Table 3.4. in Appendix 1 and Figure 3.7), **the majority (52%) of those with a learning disability as a single condition indicated that their day-to-day activities were not limited while a minority (19%) indicated that their day-to-day activities were limited a lot**. Moreover, the proportion of those in this group indicating that their day-to-day activity was limited a lot was also higher than that observed for a single health condition other than learning disability (16%). **Conversely, 68% of those with a learning disability comorbidly with at least one other health condition indicated that their day-to-day activities were limited a lot while only 12% indicated that their day-to-day activities were not limited**. This activity limitations profile was similar for those with multi-morbidity excluding learning disability. Once again however, the age profile of these groups must be considered.

Figure 3.6. Living status by LD status for total Census sample (N=1,723,180)

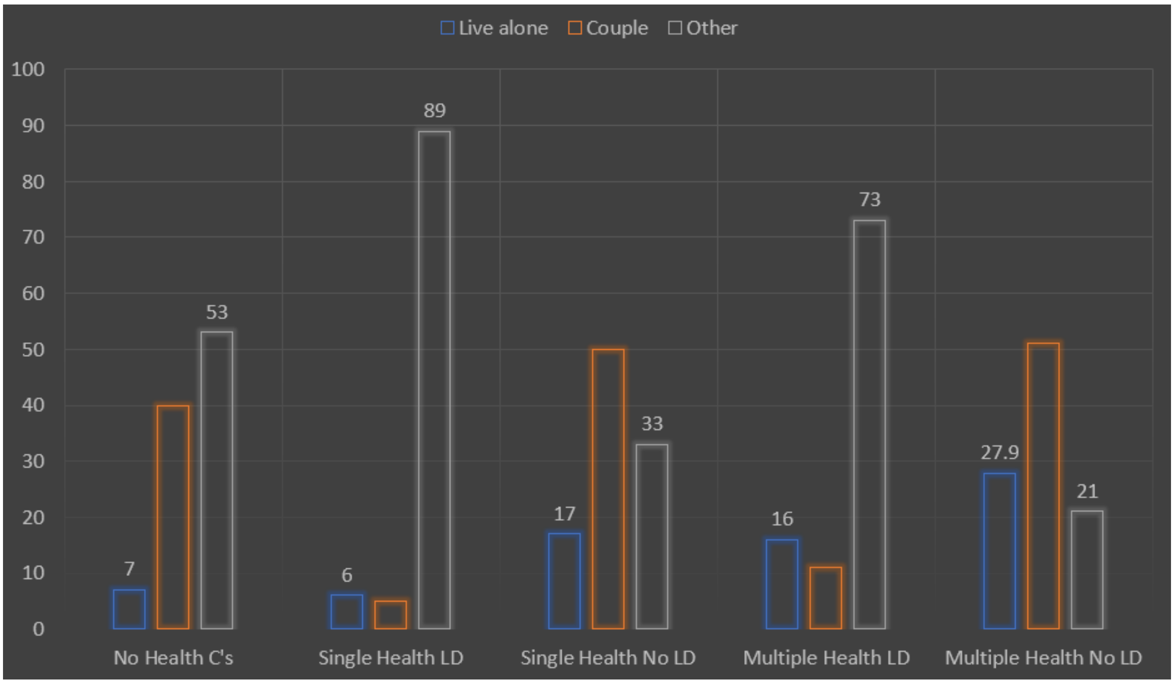


Figure 3.7. Activity limitation by LD status for total Census sample (N=1,723,180)

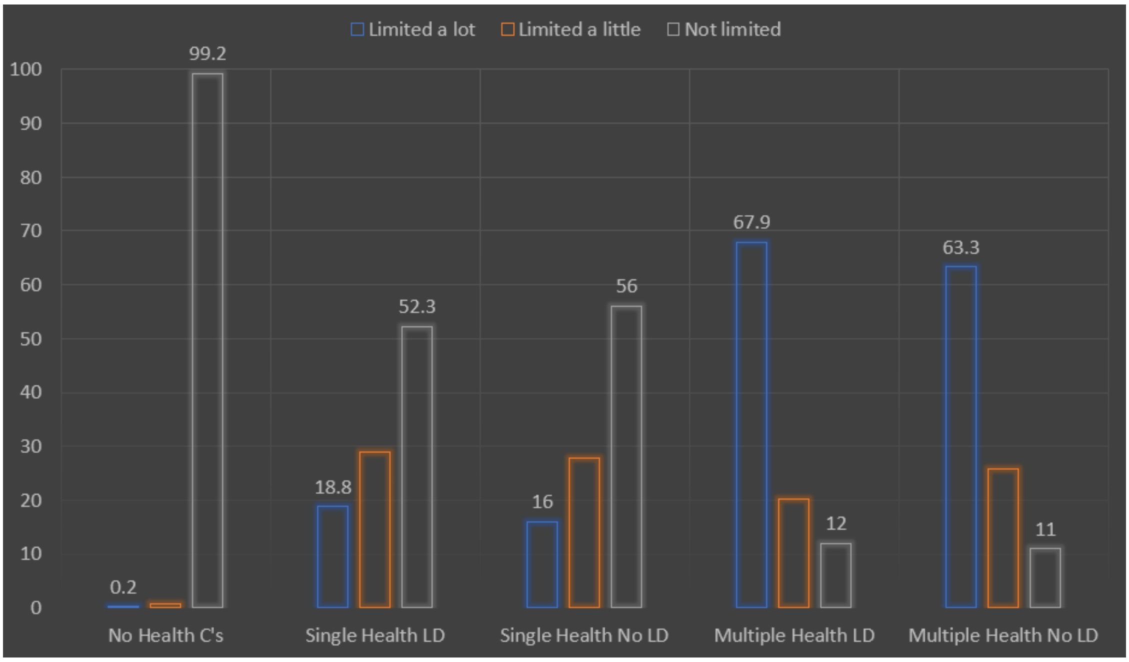
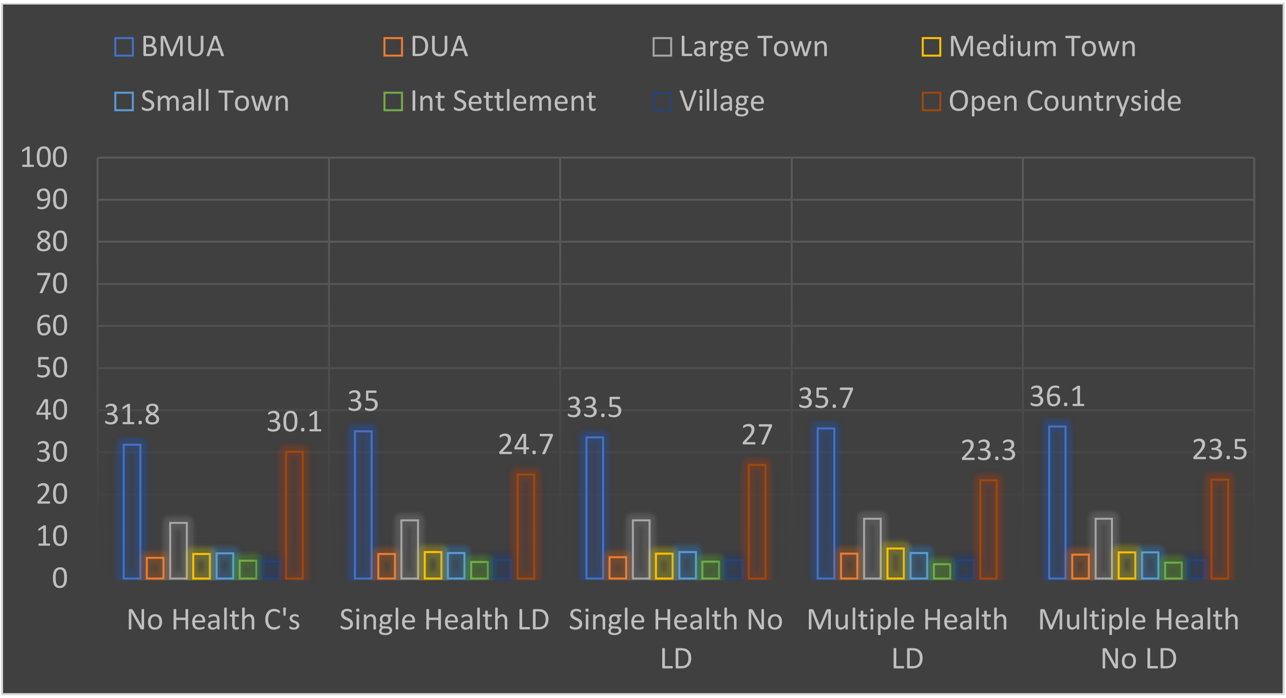


Figure 3.8 Settlement band residence by LD status for total Census sample (N=1,723,180)



BMUA=Belfast Metropolitan Urban Area; DUA=Derry Urban Area; Int Settlement= Intermediate Settlement; SV, H&OC=Small Village, Hamlet & Open Countryside; LD=Learning Disability indicator

Ethnicity & Settlement Band

Within the overall Census sample, 1.3%-1.4% respectively of those with a learning disability, either as a single health condition, or, comorbidly with other health conditions, identified as non-white (see Table 3.5. in Appendix 1), while 2.1% of those without a health condition and 0.6% of those with multiple health conditions identified as non-white. Regarding settlement band, the proportions of each health condition category subpopulation residing in each of the eight settlement bands were relatively equal (see Table 3.5. in Appendix 1 and Figure 3.8). Over 50% of each health condition category subpopulation resided either within the Belfast Metropolitan Urban Area or a small village, hamlet or the open countryside.

Learning disability prevalence and demography by Health and Social Care Trust

Learning disability prevalence by Health and Social Care Trust

Belfast HSCT: Within the Belfast HSCT population (N=319,233), 8,066 (2.5%) respondents indicated the presence of ‘A learning difficulty, an intellectual difficulty, or a social or behavioural difficulty’. Among those aged 15 years or younger (n=60,018), 2,897 (4.8%) indicated the presence of ‘A learning difficulty, an intellectual difficulty, or a social or behavioural difficulty’. Among those aged 16 years or over (n=259,215), 5,169 (2%) indicated the presence of ‘A learning difficulty, an intellectual difficulty, or a social or behavioural difficulty’.

Northern HSCT: Within the Northern HSCT population (N=437,648), 8,482 (1.9%) respondents indicated the presence of ‘A learning difficulty, an intellectual difficulty, or a social or behavioural difficulty'. Among those aged 15 years or younger (n=90,006), 3,143 (3.5%) indicated the presence of 'A learning difficulty, an intellectual difficulty, or a social or behavioural difficulty'. Among those aged 16 years or over (n=347,642), 5,339 (1.5%) indicated the presence of 'A learning difficulty, an intellectual difficulty, or a social or behavioural difficulty'.

South Eastern HSCT: Within the South Eastern HSCT population (N=330,009), 7,282 (2.2%) respondents indicated the presence of 'A learning difficulty, an intellectual difficulty, or a social or behavioural difficulty'. Among those aged 15 years or younger (n=67,036), 2,906 (4.3%) indicated the presence of 'A learning difficulty, an intellectual difficulty, or a social or behavioural difficulty'. Among those aged 16 years or over (n=262,973), 4,376 (1.7%) indicated the presence of 'A learning difficulty, an intellectual difficulty, or a social or behavioural difficulty'.

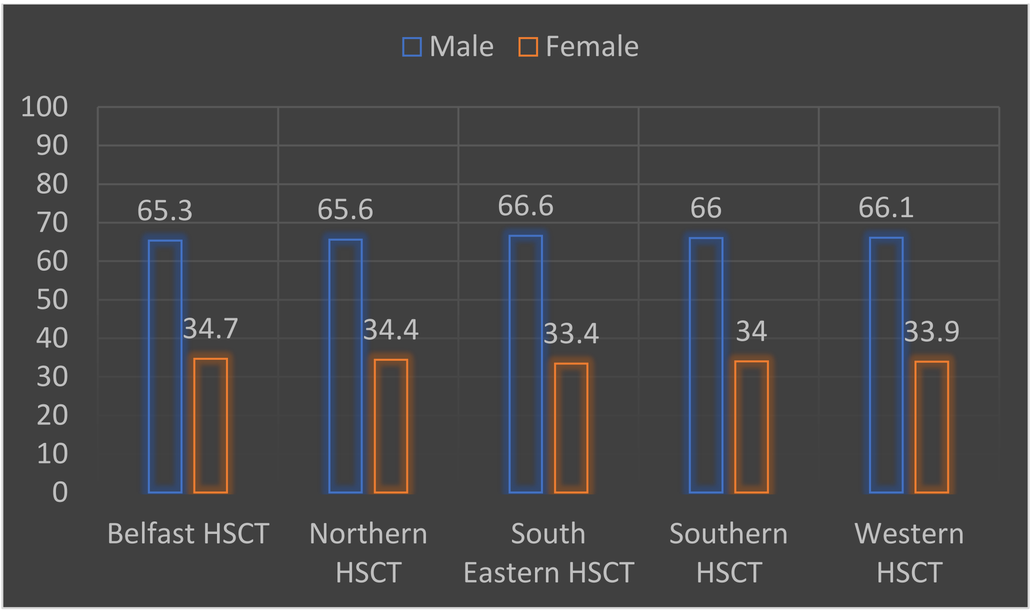
Southern HSCT: Within the Southern HSCT population (N=338,157), 6,688 (2%) respondents indicated the presence of 'A learning difficulty, an intellectual difficulty, or a social or behavioural difficulty'. Among those aged 15 years or younger (n=75,729), 2,395 (3.2%) indicated the presence of 'A learning difficulty, an intellectual difficulty, or a social or behavioural difficulty'. Among those aged 16 years or over (n=262,428), 4,293 (1.6%) indicated the presence of 'A learning difficulty, an intellectual difficulty, or a social or behavioural difficulty'.

Western HSCT: Within the Southern HSCT population (N=273,378), 6,474 (2.4%) respondents indicated the presence of 'A learning difficulty, an intellectual difficulty, or a social or behavioural difficulty'. Among those aged 15 years or younger (n=59,810), 2,154 (3.6%) indicated the presence of 'A learning difficulty, an intellectual difficulty, or a social or behavioural difficulty'. Among those aged 16 years or over (n=213,568), 4,320 (2%) indicated the presence of 'A learning difficulty, an intellectual difficulty, or a social or behavioural difficulty'.

Learning disability demography by Health and Social Care Trust

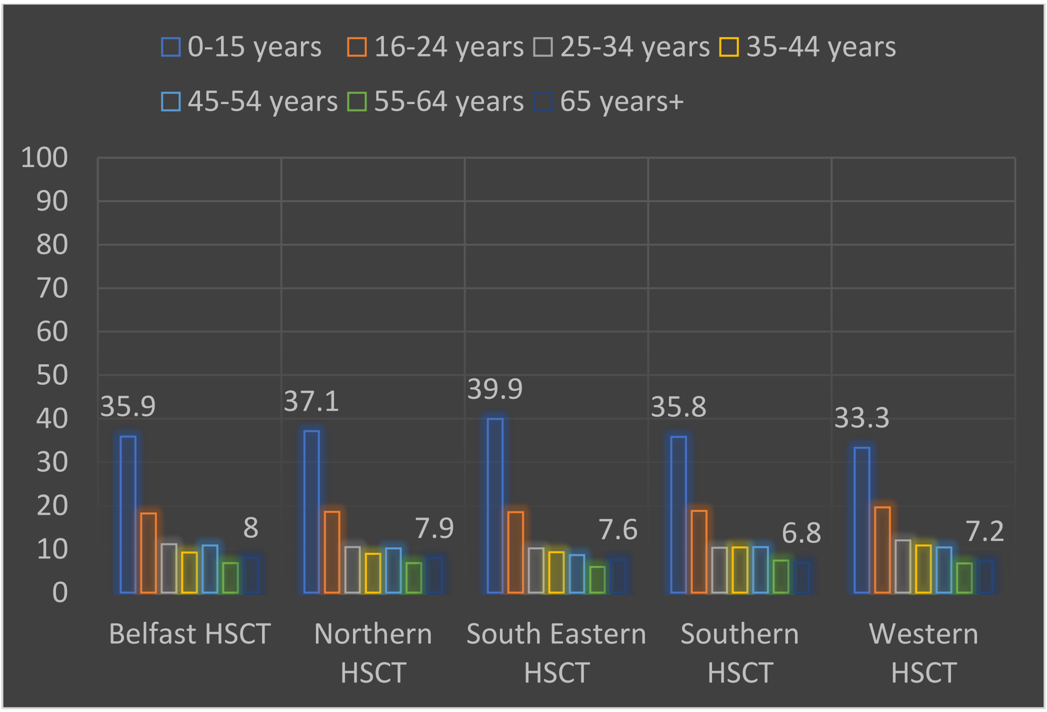
To summarise the demography of the learning disability populations in each of the five HSC Trusts, Figures 3.9 – 3.12 provide a breakdown of each demographic indicator in relation to overall learning disability (i.e. these figures are not stratified by single or multiple health condition status; also see Tables 3.6a-3.6e in Appendix 1). Regarding gender (see Figure 3.9), the proportion of individuals with a learning disability identifying as male across the trusts ranged from 65.3% (Belfast HSCT) to 66.6% (Eastern HSCT).

Figure 3.9. Sex distribution by LD status across 5 NI-HSCTs



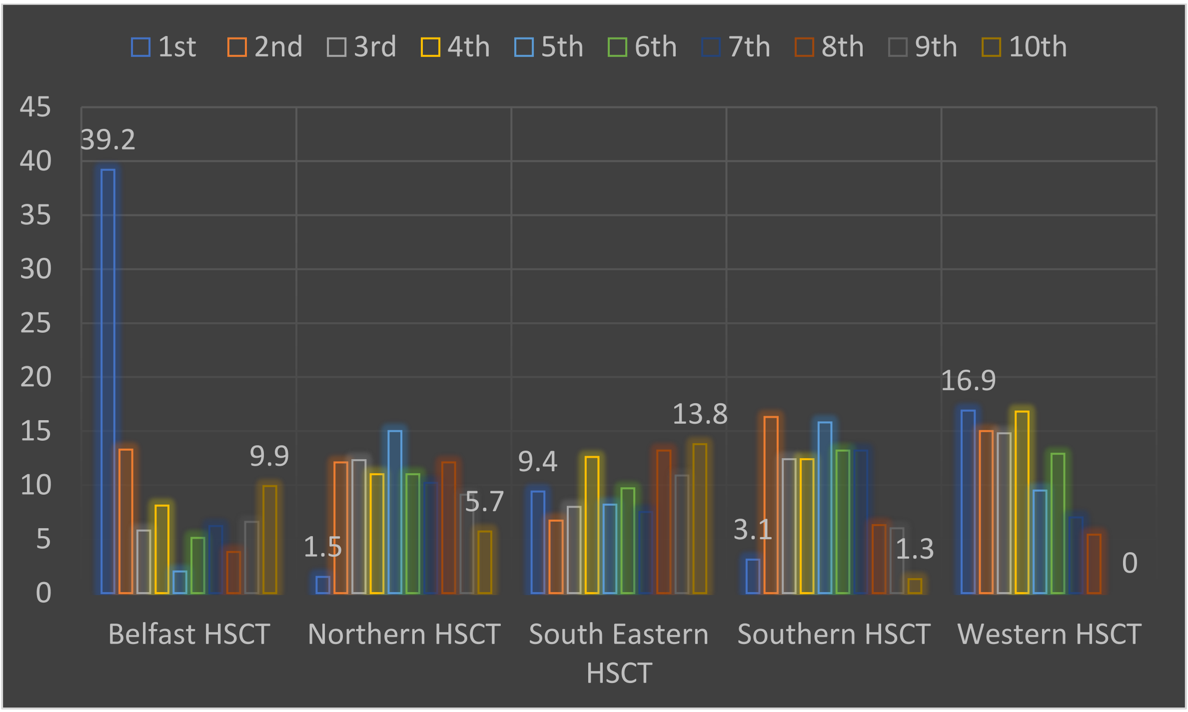
Regarding age (see Figure 3.10), the proportion of individuals with a learning disability aged 0-15 years across the trusts ranged from 33.3% (Western HSCT) to 39.9% (South Eastern HSCT)

Figure 3.10. Age distribution by LD status across 5 NI-HSCTs



Regarding deprivation (see Figure 3.11), 39.2% of the learning disability population within the Belfast HSCT were classified in the most extreme deprivation index. Multiple deprivation at this level for each of the remaining four trusts ranged from 1.5% (Norther HSCT) to 16.9% (Western HSCT). While deprivation was more evenly distributed among the learning disability populations in the Northern and South Eastern HSCTs, higher proportions of the learning disability populations in the Belfast, Southern and Western HSCTs were characterised by more severe deprivation.

Figure 3.11. NIMDM decile by LD status across 5 NI-HSCTs



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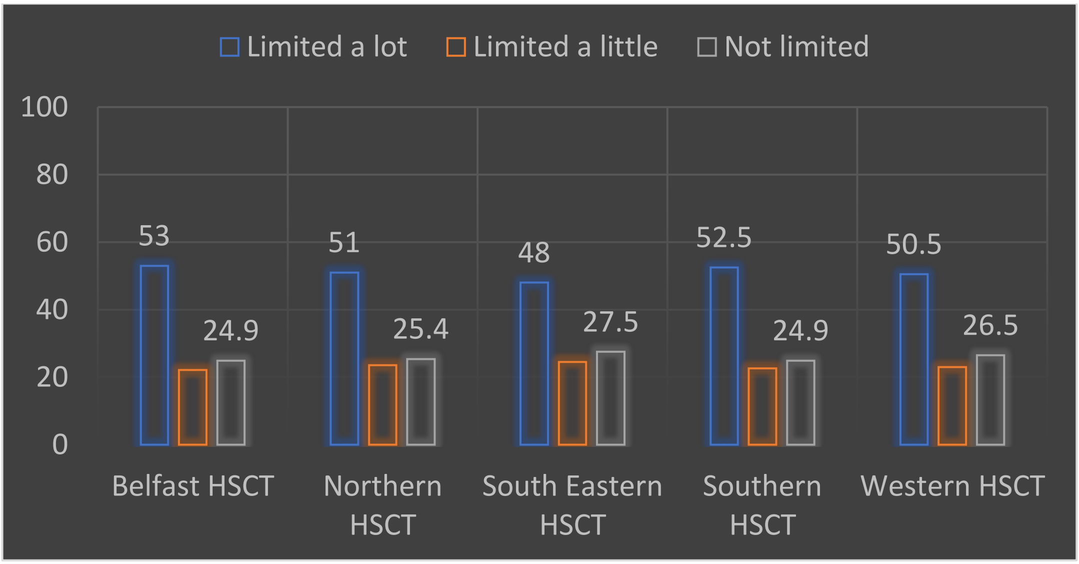
Regarding activity limitation (see Figure 3.12), the proportion of individuals with a learning disability across the trusts who indicated that their daily activities were ‘limited a lot’ ranged from 48% (South Eastern HSCT) to 53% (Belfast HSCT).

Figure 3.12. Activity limitation by LD status across 5 NI-HSCTs



Regarding ethnicity and residence status, the proportion of individuals with a learning disability who identified as belonging to a non-white ethnic group across the trusts ranged from 0.9% (Northern HSCT) to 1.9% (Belfast HSCT). Regarding residence status, the proportion of individuals with a learning disability who resided in a communal establishment across the trusts ranged from 6.7% (Southern HSCT) to 8.7% (South Eastern HSCT).

Tabled counts used to generate all figures in this section can be found in **Appendix 1.**

3.6. Overview

The prevalence of learning disability within the overall 2011 Census population was 2.2%. This estimate is notably higher than the 0.05 – 1.55% estimates that have been reported in the most recent international meta-analysis findings [1]. Moreover, the 3.8% prevalence rate for children and the 1.7% rate for adults identified using the 2011 Census data far exceed those reported for children (0.22%-1.55%) and adults (0.05%-0.8%) in other international studies [1]. This however was not surprising. The learning disability indicator in the 2011 Census lacked specificity and was inclusive of conditions that were distinct from (although likely to be highly associated with) learning disability. Citizens were afforded an opportunity in this Census to identify the presence of 'A learning difficulty, an intellectual difficulty, or a social or behavioural difficulty'. Problematically, the framing of this survey question referred to intellectual difficulty rather than disability and subsumed intellectual difficulty with learning difficulties and social and behavioural difficulties. This is likely to have been the primary reason for the inflated prevalence estimates in the current study. It is notable that in the 2011 Censuses in both Scotland and Ireland, where learning disability measurement was much more specific and explicit, prevalence estimates (Scotland 0.5%; Ireland 1.3%) were more consistent with international rates. It is also notable that in the Scottish Census, over 20% of those reporting an intellectual disability also reported that they had a developmental disorder, while in Ireland, over 70% of those reporting an intellectual disability also reported learning difficulties. It is highly likely therefore that respondents in the NI 2011 Census may have been signalling the presence of an array of conditions and disabilities when responding to this single health condition survey question. Importantly, however, while these various conditions and disabilities may often co-occur, they are often also likely to be entirely distinct and to manifest in isolation from one another.

While these survey item specificity issues therefore limit the interpretability of the findings regarding learning disability identification and prevalence estimation in Northern Ireland, they were widely recognised and acknowledged by the research team at the outset of the current study. It is important to note, therefore, that in anticipation of the improvements in learning disability assessment due to be implemented in the next NI Census (NI citizens will be afforded the opportunity to officially and specifically record the presence of 'An intellectual or learning disability (for example Down syndrome)' and specific separate options to also record 'A learning difficulty (for example dyslexia)' and/or 'Autism or Asperger syndrome') a key aim of the current study was to demonstrate how the Census database could be used, not only to calculate learning disability prevalence, but also, to describe the social, economic and demographic characteristics of this population.

Those indicating the presence of ‘A learning difficulty, an intellectual difficulty, or a social or behavioural difficulty’ in NI in 2011 were more likely to be male and under the age of 16 years, findings very much consistent with the extant evidence base relating to learning disability [1]. Within the overall Census sample, learning disability status was associated with greater deprivation. Among those reporting a learning disability as their only health condition, 12.7% were in the first NIMDM decile (i.e. most deprived) while 7.6% were in the 10th NIMDM decile (least deprived). Among those reporting learning disability with at least one other health condition, 15.1% were in the first NIMDM index decile while 5.9% were in the 10th. Over 39% of those with a learning disability within the Belfast HSCT area were in the first NIMDM index decile. Again, these findings were not unexpected. Learning disability has repeatedly been shown to be associated with social deprivation in the research literature. For example, in a study based on data from educational records of over 5 million English children aged 7-15 years, lower household socio-economic position was associated with increased rates of identification of intellectual and developmental disabilities especially less severe forms of intellectual disability [25]. Moreover, in a Scottish study of patients who had face-to-face contact with community learning disability psychiatric services over 1 year, 52% lived in the most deprived Scottish Index of Multiple Deprivation (SIMD) decile, while 90.5% lived in the lowest 5 deciles. Compared with the general population, there were significantly more patients than expected living in the most deprived decile and in the most deprived 5 deciles [26].

Regarding activity limitation, the majority (52%) of those with a learning disability as a single condition indicated that their day-to-day activities were not limited while a minority (19%) indicated that their day-to-day activities were limited a lot. Conversely, 68% of those with a learning disability comorbidly with at least one other health condition indicated that their day-to-day activities were limited a lot while only 12% indicated that their day-to-day activities were not limited. It would seem that this difference was likely a consequence of the multi-morbidity and older age profile of the latter group. However, given that the Census data did not afford an opportunity to classify respondents in relation to the severity of their learning disability, activity limitation may also have been a consequence of undetected variation in disability severity among these groups. Notably however, in an investigation of activity limitation among individuals with mild intellectual disability or moderate intellectual disability, Kottorp, Bernspång, and Fisher indicated that he overall activities of daily living motor and activities of daily living process hierarchies of skill item difficulties remained stable between groups. Although participants with moderate learning disability had more difficulty overall with activities of daily living motor and activities of daily living process skills, they were able to carry out some of these activities equally as well as participants with mild learning disability [27]. If activity limitation among those with a learning disability is therefore attributable to other comorbid health conditions, then assessments of health condition comorbidity is critical (see Section 4).

Within the overall Census sample, 1.3%-1.4% respectively of those with a learning disability, either as a single health condition, or, comorbidly with other health conditions, identified as non-white. Within those who identified as non-white in the 2011 NI Census this translates into a 1.1% prevalence rate, notably lower than the 2.2% for the overall NI population. This again was not inconsistent with previous findings. In Emerson's analysis of children in England, minority ethnic status was, in general, associated with lower rates of identification of intellectual and developmental disabilities [25]. Finally, over 35% of those with a learning disability, either as a single health condition, or, comorbidly with other health conditions resided within the Belfast Metropolitan Urban Area while over 23% of those with a learning disability, either as a single health condition, or, comorbidly with other health conditions resided in a small village, hamlet or the open countryside. Capturing the settlement area and distribution of the learning disability population has notable benefits [28]. Traditionally, living in rural areas has been considered advantageous because of a stronger sense of community, supportive social networks and economic restructuring [29-30]. Physical health has also been found to be better in urban areas [31]. However, living in a rural area does not guarantee these benefits and it may have its own drawbacks including social exclusion, stigma and loss of independence. Rural residents have been found to be disadvantaged in relation to service access and use [32].

The lack of specificity in the 2011 Census survey item relating to learning disability certainly limits the accuracy with which learning disability prevalence can be estimated and the level of socio-economic and demographic description that can be achieved with the Census data. Fortunately, however, the NI Census of 2011 was preceded and informed by a national random probability household disability survey in 2007 that asked participants to separately report the presence of 'a learning difficulty', 'an intellectual difficulty' or 'a social or behavioural difficulty'. The data from this survey afforded a valuable opportunity to, not only, compare the prevalence estimates of learning disability identified here with those derived from a more explicit and specific measure, but to model the demography and geography of this population also using a more specific measure. This work is reported in Section 6.

Section 4 Learning disability health status, socio-economic/demographic risk, and comorbidity using Census 2011 data

4.1. Aims: Using the 2011 Census general health question, this section will profile the general health of the learning disability population of Northern Ireland and identify the main socio-demographic indicators of poor health among this population using indicators detailed in Section 3. Using the ten health conditions from Q23 of the 2011 Census, this section will also compare and contrast the comorbidity conditions of those with and without a learning disability, firstly throughout Northern Ireland, and secondly, in relation to the five Northern Ireland Health and Social Care Trusts.

4.2. Background

The poor health profile of individuals with a learning disability in comparison to those in the non-disabled population is well documented and acknowledged [1-2]. The learning disability population have early mortality [1], increased incidence of respiratory disease [3-4], gastrointestinal cancers [5-6] and heart disease [7-8]; as well as higher rates of chronic illness including obesity, [9-10] diabetes [11-12], and epilepsy [13-14]. People with learning disability are also at adverse risk of minor health problems including digestive, reflux and swallowing issues [15-16] and eyesight, ear, nose and throat problems [14, 16]. Mental health issues [17-18] and age-related health issues such as dementia [19-20] have also increased in the learning disability population. These secondary chronic illnesses result in a population who are more likely to be sedentary and less likely to eat a healthy balanced diet necessary to achieve optimum health [21-23].

Morbidity and Secondary Health Conditions

Increased longevity amongst the learning disability population has led to a rise in secondary conditions such as obesity and Type 2 diabetes as well as an increased prevalence in a number of chronic illnesses including sensory problems, epilepsy, swallowing issues, stomach problems, hypertension, arthritis and musculoskeletal complaints including osteoporosis [22, 24, 15]. According to Rimmer and Rowland [25], people with learning disability report fewer 'healthier days' than those in the general population and the quality of life of the ID population is greatly impacted by their physical health and by levels of self-determination [26].

People with learning disability are at a greater risk of developing both Type 1 and Type 2 diabetes, due in part to a number of genetic factors, commonly prescribed psychotropic medications, poor diet and nutrition and a sedentary lifestyle [27-30]. However exact figures for the number of people with learning disability who have diabetes are unknown. Poorly managed or untreated type 2 diabetes is a significant concern within the learning disability community and can lead to serious complications including stroke, blindness, renal failure, heart attacks and amputation [31, 26, 32].

Epilepsy is the most common co-morbid health condition experienced by the learning disability population and the prevalence rate has been reported as at least twenty times higher than for the general population [31, 33]. The incidence of epilepsy increases with the level of learning disability and with age [34]. A study by McCarron et al. found that older people with ID were less likely to be receiving antiepileptic medication to control seizures [35]. However, Crawley reported that the drugs normally used to control seizures can have numerous side-effects, leading to increased risk of challenging behaviour among the ID population [36].

Obesity is considered one of the most prevalent and preventable health conditions among people with learning disability [37-39]. There is a lot of debate as to whether the prevalence of obesity is higher or lower in the learning disability population compared to general population [24, 37, 40-41]; however there is clear evidence that people with learning disability are more susceptible to being overweight or obese due in part to genetic predisposition (Prader-Willi syndrome and Down syndrome) [24, 42]; medication use that causes weight gain [37, 43] ; poor diet and lifestyle factors including sedentary behaviour [21, 44-45]; age and severity of ID [40,41].

Digestive, reflux and swallowing issues (dysphagia) are all common among the learning disability population, most notably among those with severe ID [15, 16]. Diseases such as gastro-oesophageal reflux disease (GORD) are more prevalent in those who use anticonvulsant drugs, those with cerebral palsy and those with an IQ less than 35 [46].

Poor communication is recognized as a significant barrier for people with learning disability especially when accessing healthcare services (GP services, hospital acute, preventative screening services, psychiatric, preventative screening services) [31, 47, 48]. Therefore, resulting in difficulties in health assessments, diagnosis, treatment and the provision of care [49, 50].

As people with learning disability age, conditions associated with older age (like memory loss) become more prevalent [51]. Recent studies have reported increased risk of dementia among the ID population and those with Down syndrome have a well-established genetic risk of Alzheimer’s disease [52, 53]. The aging profile of the learning disability population is unique and diseases such as dementia are found in the learning disability population from a younger age [54].

Emerson and Baines reported that 40% of those with learning disability have a hearing impairment; and that people with learning disability were 8-200 times more likely to have vision impairment when compared to the general population [33]. Bland et al., reported that eyesight problems accounted for 53% of illness among people with learning disability [16]. Concerns around the access to and frequency of eye tests have been acknowledged in the literature [55,56]. Better health education is required to support those with learning disability and their families and carers to access services and support effective communication [57].

Truesdale and Brown reported that the exact prevalence of mental ill-health among the learning disability population remains unknown [31]. Deb et al., [18] found higher rates of mental among the ID population when compared to the general population and a review by Buckles et al., (2013) reported prevalence rates of between 13.9% and 75.2% in the learning disability population [58]. Anxiety, depression, schizophrenia and other psychiatric diagnoses are all reported high among the learning disability population [31]. This high prevalence of mental ill-health has a major impact on the 'general wellbeing' and quality of life of those both those with learning disability and their carers [59].

The health profile of those with learning disability is complex and their access and ability to navigate health services can have a significant impact on the diagnosis and treatment of a wide variety of chronic health conditions. In order for services to appropriately assess, treat and manage those with learning disability, a better understanding of learning disability is required. Reasonable adjustments are necessary to facilitate access to services and an accurate count of the numbers of people with learning disability accessing and requiring services is vital. Therefore, in order to effectively understand the health of the learning disability population, it is vital that we can, not only, accurately count the numbers of people with ID in the UK but capture their broader health condition/comorbidity status also.

4.3. Methods

Measures

The variables used in in the current set of analyses largely comprise those derived from the 2011 Census data (N=1,723,180).

Learning disability: To frame the analyses the 5-category health conditions variable, generated using the 12-category health conditions list from Question 23 in the 2011 Census was employed (1=no health conditions present; 2=a single learning disability condition present; 3=a single health condition present other than learning disability; 4=multiple health conditions present including learning disability and 5=multiple health conditions present not including learning disability; see Section 2.3.).

General Health: A five category general health variable with response options 'Very Good', 'Good', 'Fair', 'Bad' and 'Very bad' (Census question = How is your health in general?) was recoded into a 3-category variable denoting (1) Good/Very Good, (2) Fair and (3) Bad/Very Bad.

Comorbidity: Self-reported health over the 12 months prior to the census was measured using a question probing the presence of chronic health problems ('Do you have any of the following conditions which have lasted or are expected to last, at least twelve months') for which respondents ticked all items applying to them from a list comprising 'deafness/partial hearing loss'; 'blindness/partial sight loss; communication difficulty'; 'a mobility/dexterity difficulty'; 'a learning/intellectual difficulty or social/behavioural difficulty'; 'emotional, psychological or mental health difficulties'; 'long-term pain/discomfort'; 'shortness of breath/breathing difficulties'; 'frequent periods of confusion/memory loss'; 'a chronic illness'; or 'other conditions'. Responses were used to determine patterns of long-term ill-health.

Socio-economic, demographic, and area level variables: In this analysis, age was categorised into seven age bands (0-15 years, 16-24, 25-34, 35-44, 45-54, 55-64, 65 years+). Gender was categorised as (1) male or (2) female. Ethnicity was dichotomised as (1) non-white, (2) white. Activity limitations was represented by three categories: (1) Not limited, (2) Limited a little, (3) Limited a lot. A dichotomous residence variable was used to denote residence in (1) a private household or (2) a communal establishment. Deprivation was measured using NI Multiple Deprivation Measure 2010 (NIMDM) scores [5]. Scores range from most deprived (1) to least deprived (10). Eight settlement bands ranging from the largest, the Metropolitan Area of Belfast (comprising ca. 580,000 people); to a band representing settlements of less than 1000 people and open countryside were used. Finally, the Northern Ireland Health and Social Care Trusts (HSCTs) were each represented; (1) Belfast HSCT (2) Northern HSCT (3) South Eastern HSCT (4) Southern HSCT and (5) Western HSCT.

4.4. Analysis

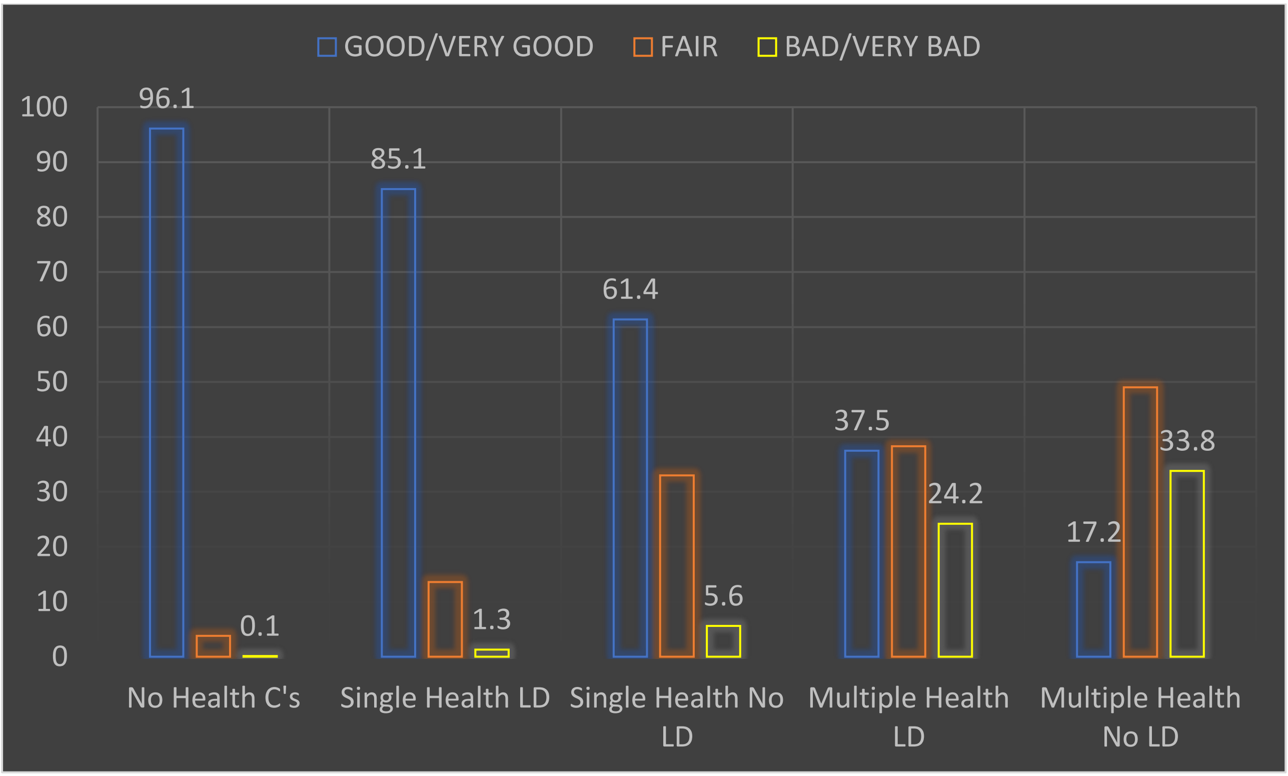
First, the distribution of general health was plotted for the 5-categories of the health conditions variable (1=no health conditions present; 2=a single learning disability condition present; 3=a single health condition present other than learning disability; 4=multiple health conditions present including learning disability and 5=multiple health conditions present not including learning disability). Second, using the recoded 3-category general health variable as an outcome variable, with Good/Very Good as the reference category, five multinomial regression analyses were conducted. Each regression analysis focussed on one of the five categories of the health conditions variable and included gender, age, ethnicity, residential status, settlement area, multiple deprivation score, and activity limitations as categorical predictor variables. Third, using the 12-category health conditions list from Question 23 of the Census, comorbidity profiles for each condition were generated for (i) all those aged 15 years or younger who reported multiple conditions with or without a learning disability and (ii) all those aged 16 years or older who reported multiple conditions with or without a learning disability. Finally, health condition comorbidity for each of the Census health conditions among the learning disability populations of each of the five health and social care trusts was assessed.

4.5. Results

Distribution of general health

Overall, the majority of those who indicated that they had no health conditions and those who reported the presence of a single health condition, also reported that their general health was either good or very good (see Figure 4.1). Over 60% of individuals in each of these three groups reported at least good general health. Among those who indicated the presence of multiple health conditions, 37.5% of those with a learning disability and 17.2% of those without a learning disability also reported that their general health was good or very good. Conversely, 24.2% of those with a learning disability and 33.8% of those without a learning disability reported that their general health was bad or very bad.

Figure 4.1. General health by learning disability status for total Census sample (N=1,723,180)



Socioeconomic and demographic predictors of poor general health

Learning disability as a single health condition

Compared to those reporting good or very good general health, those who had bad or very bad general health were over 3.5 times more likely to be non-white (OR=3.59; 95% CI=1.22-10.53), and over 2.5 times more likely to live in the most deprived areas (OR for first MDM decile = 3.98, 95% CI=1.61-9.82; OR for second MDM decile = 2.73, 95% CI=1.09-6.87). Poor health among this group was also significantly predicted by activity limitation. Those whose day to day activities were 'limited a little' were over 4.5 times more likely to have bad or very bad health (OR=4.68, 95%CI=2.50-8.74), while those whose day to day activities were 'limited a lot' were over 22.5 times more likely to have bad or very bad health (OR=22.78, 95%CI=12.93-40.12) compared to those reporting good or very good general health (see Table 4.1 in Appendix 2).

Learning disability with at least one other health condition

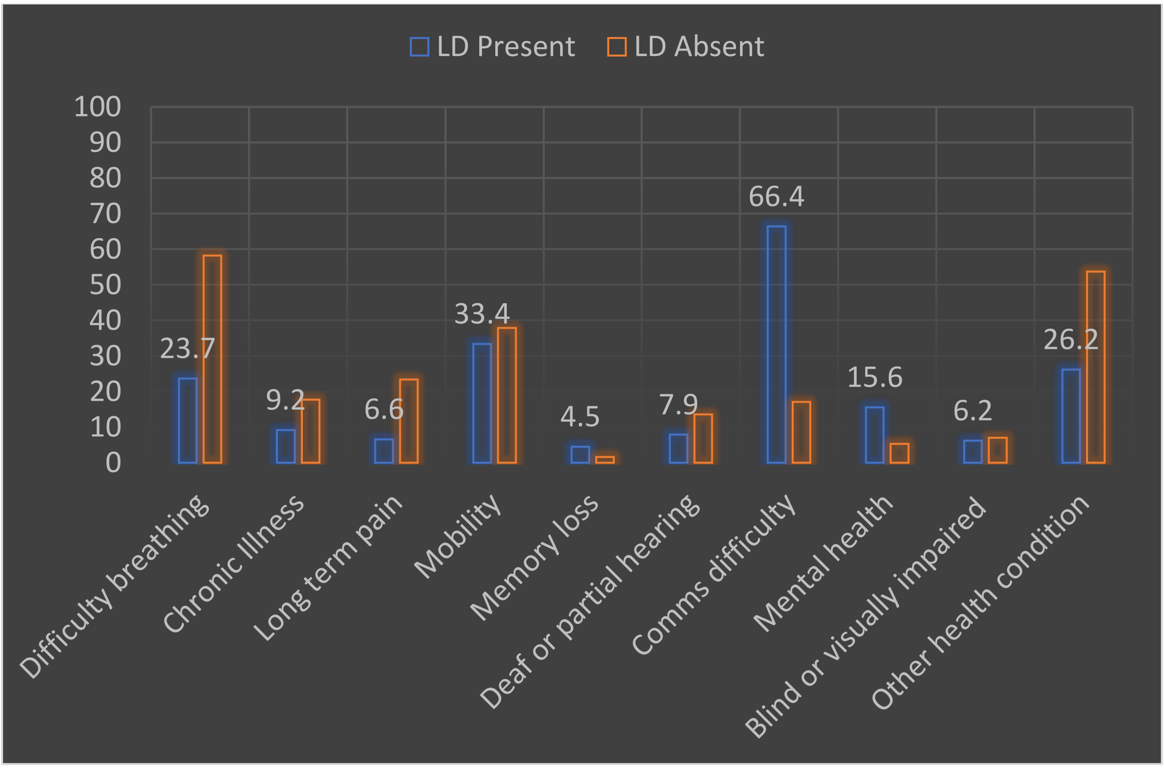
Compared to those reporting good or very good general health, those who had bad or very bad general health were more likely to be female (OR=1.10, 95%CI=1.01-1.19) and were over 5.5 times more likely to reside in a private household (OR=5.88, 95%CI=5.00-6.67). Poor health among this group was also significantly predicted by settlement area. Compared to those living a small village, hamlet or open countryside, those living in the Belfast metropolitan urban area (OR=1.28, 95%CI=1.14-1.43), a medium sized town (OR=1.30, 95%CI=1.10-1.54), a small town (OR=1.20, 95%CI=1.01-1.43), or a village

(OR=1.23, 95%CI=1.00-1.50), were more likely to have bad or very bad health. Poor health was also significantly predicted by deprivation across the first seven MDM indices (1st index OR=2.78, 95%CI=2.29-3.38; 7th index OR=1.29, 95%CI=1.05-1.60). Finally, those whose day to day activities were 'limited a little' were over 2 times more likely to have bad or very bad health (OR=2.15, 95%CI=1.73-2.68), while those whose day to day activities were 'limited a lot' were over 18 times more likely to have bad or very bad health (OR=18.48, 95%CI=15.29-22.32) compared to those reporting good or very good general health (see Table 4.1 in Appendix 2).

Comorbidity 15 years or younger

Figure 4.2a shows the proportion of each multiple health condition group (i.e. with and without learning disability), below the age of 16 years, that reported 10 other health conditions (as listed in Q23 of the 2011 Census - difficulty breathing, chronic illness, long term pain, mobility, deafness or partial hearing, communications difficulty, mental health, blindness or visual impairment and 'other' health condition). Among those with a learning disability in this age group, the most commonly co-occurring health conditions were communications difficulties (66.4%), mobility issues (33.4%), 'other' health conditions (26.2%) and respiratory problems (23.7%). Compared to those under aged 16 years who had multiple health conditions not including learning disability, a higher proportion of those under aged 16 years who had multiple health conditions including learning disability experienced memory loss (1.6% v 4.5% respectively), communications difficulties (17.1% v 66.4% respectively), and mental health problems (5.3% v 15.6% respectively).

Figure 4.2a. Comorbidity 15 years or younger (LD absent n=2,814) (LD present n=7,119)



Comorbidity 16 years or older

Figure 4.2b shows the proportion of each multiple health condition group (i.e. with and without learning disability), over aged 15 years. Among those with a learning disability in this age range, the most commonly co-occurring health conditions were communications difficulties (53.2%), mobility issues (52.1%), mental health problems (45.7%), memory loss (25.2%) and respiratory problems (24%). Compared to those over aged 15 years who had multiple health conditions not including learning disability, a higher proportion of those over aged 15 years who had multiple health conditions including learning disability experienced memory loss (12.4% v 25.2% respectively), communications difficulties (5.5% v 53.2% respectively), mental health problems (25.7 v 45.7 respectively) and blindness or visual impairment (9.6% v 10.9% respectively).

Figure 4.2b. Comorbidity 16 years or older (LD absent n=220,655) (LD present n=17,230)

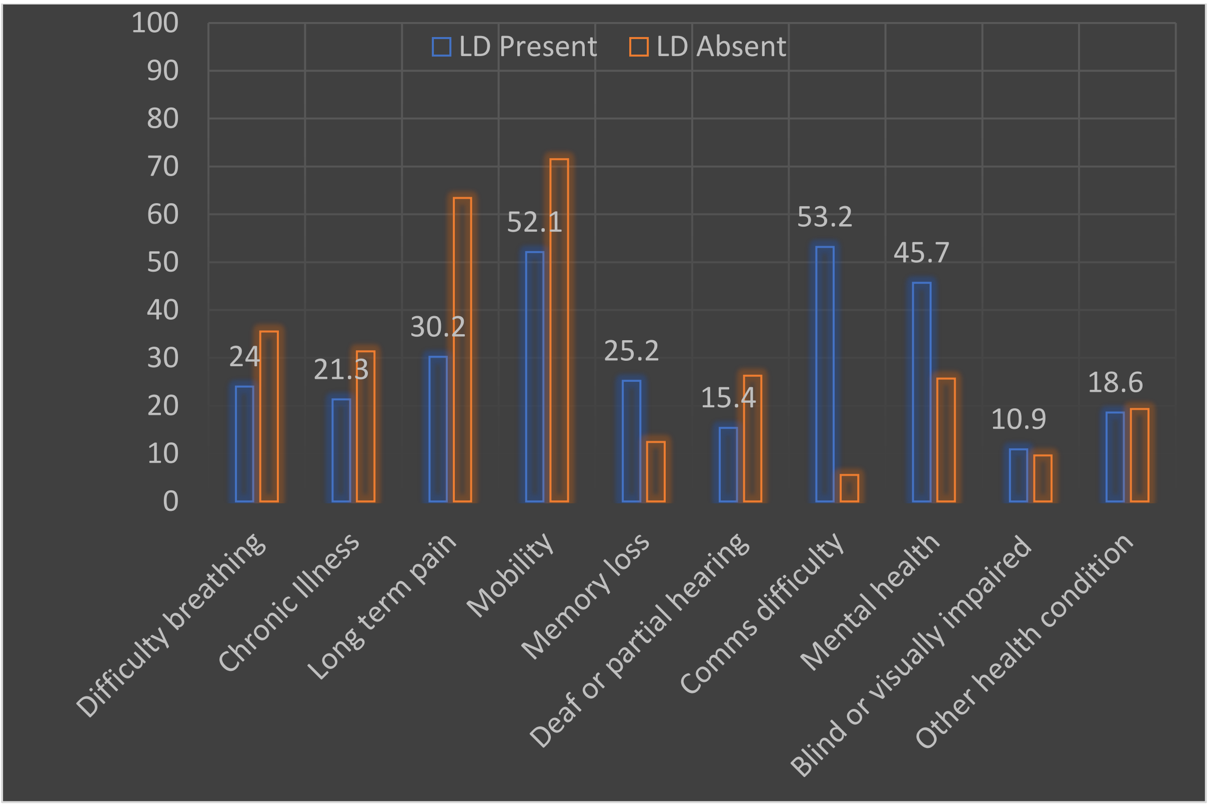
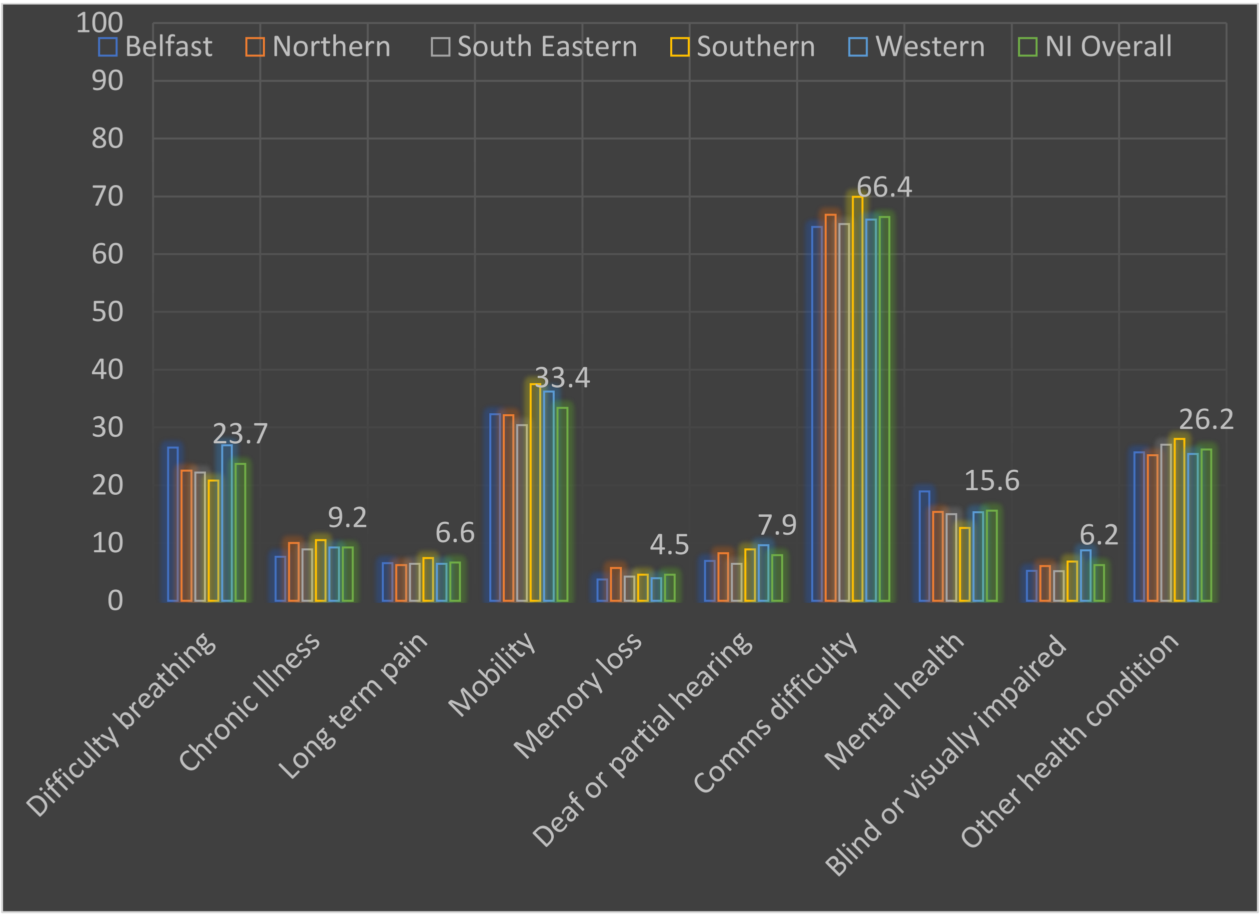


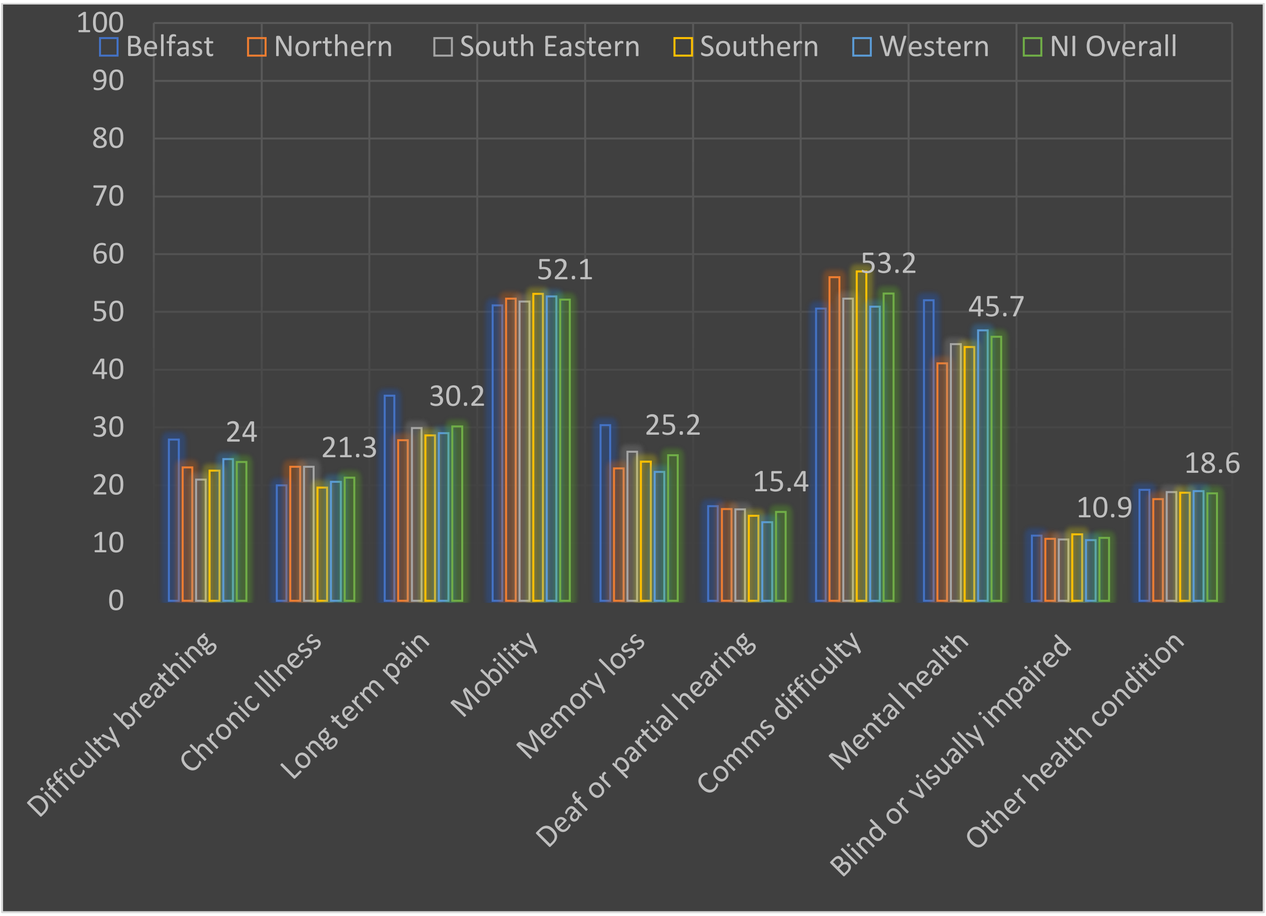
Figure 4.3a. Comorbidity 15 years or younger LD Multiple Conditions by NI-HSCT



Comorbidity under 16 years by NIHSCT

Figure 4.3a shows the frequency of co-occurrence for each health condition among all those below the age of 16 years who reported multiple health conditions including learning disability in each of the 5 Health and Social Care Trusts and in NI overall. Compared to levels recorded for this population nationally, the occurrence of (i) respiratory problems was higher in the Western and Belfast HSCT areas (ii) chronic illnesses was higher in the Southern and Northern HSCT areas, (iii) long-term pain was higher in the Southern HSCT area, (iv) mobility was higher in the Western and Southern HSCT areas, (v) memory loss was higher in the Northern HSCT area, (vi) deafness or hearing impairment was higher in the Western, Southern and Northern HSCT areas, (vii) communications difficulties in the Southern and Northern HSCT areas, (viii) mental health problems was higher in the Belfast HSCT area, (ix) blindness or visual impairment was higher in the Western HSCT area, and (x) ‘other’ health condition was higher in the Southern HSCT area. The Southern and Eastern HSCT was the only trust that had levels of comorbidity that were lower than the national rates across all ten health condition categories.

Figure 4.3b. Comorbidity over 15 years LD Multiple Conditions by NI-HSCT



Comorbidity over 15 years by NIHSCT

Figure 4.3b shows the frequency of co-occurrence for each health condition among all those below the age of 16 years who reported multiple health conditions including learning disability in each of the 5 Health and Social Care Trusts and in NI overall. Compared to levels recorded for this population nationally, the occurrence of (i) respiratory problems was higher in the Western and Belfast HSCT areas (ii) chronic illnesses was higher in the South-Eastern and Northern HSCT areas, (iii) long-term pain was higher in the Belfast HSCT area, (iv) mobility was higher in the Western, Southern and Northern HSCT areas, (v) memory loss was higher in the South Eastern and Belfast HSCT areas, (vi) deafness or hearing impairment was higher in the South Eastern and Northern HSCT areas, (vii) communications difficulties was higher in the Southern and Northern HSCT areas, (viii) mental health problems was higher in the Western and Belfast HSCT areas, (ix) blindness or visual impairment was higher in the Southern and Belfast HSCT areas, and (x) 'other' health condition was higher in the Wester, Southern, South Eastern and Belfast HSCT areas.

4.6. Overview

With the caveat that the Census learning disability indicator was recognised to lack specificity (see Section 3), it was notable that in the current findings, those who identified learning disability as a single health condition, generally reported good or very good health. Over 85% of individuals in this group indicated that their general health was either good or very good, compared to only 1.3% who indicated that their general health was either bad or very bad. Conversely, only 37.5% of those who had multiple health conditions including learning disability, indicated that their general health was either good or very good, compared to over 37% who indicated that their general health was either bad or very bad. While the older age profile of the latter group will obviously have contributed to this difference, it seems that the presence of learning disability alone may not necessarily translate into poor general health, but that accompanying comorbidity associated with learning disability may. Given the array of conditions that were reported by those who identified the presence of a learning disability this would seem understandable.

Regarding socio-economic and demographic risk for poor health, those few who identified learning disability as a single health condition and also reported their general health to be bad or very bad, were more likely to identify as non-white and live in the first and second most deprived NIMDM deciles. While social gradients and ethnic disparities relating to self-reported general health, have been widely recognised and evidenced in the research literature generally [60-63], the influence of these factors on the health and well being of the learning disability population specifically has also been well evidenced [64-68]. Those whose learning disability was accompanied by at least one other health condition, and also reported their general health to be bad or very bad, were more likely to be female, reside in a private household rather than a communal establishment, live in a particular settlement area, and in the first seven most deprived NIMDM deciles.

The most commonly co-occurring health conditions for individuals with a learning disability above and below age 15 years were communication difficulties (66.4% & 53.2% respectively), mobility issues (33.4% & 52.1% respectively) and respiratory problems (23.7% & 24% respectively). For those aged 16 years and older, mental health problems were present for over 45% of individuals while memory loss was evident for over 25%. In order to understand the health burden for the learning disability population, it is imperative to recognize the range of factors (genetic/biological, individual lifestyle, accessibility and socio-economic, cultural and environmental) that determine the health outcomes of people with learning disability [69]. There are a number of broad classes of determinants of the health inequalities which affect those with learning disability. These inequalities start early in life and result from the interaction between multiple processes. These inequalities are also, in principle, amenable to intervention [33, 70].

Specific Genetic and Biological Factors Associated with ID

The first is the increased risk associated with the specific genetic and biological causes of learning disability. A number of previous studies have focused on the increased risk of certain health conditions that are associated with a number of syndromes associated with learning disability. In 2009, Tyrer and McGrother reported that people with moderate and profound learning disability are more likely to die from congenital abnormalities when compared to the general population [7]. There is also a link between the increased risk of congenital heart disease in those with Down’s syndrome and Williams syndrome [71, 72].

People with learning disability may also have syndrome-related conditions that result in difficulty eating or swallowing, dental problems, reduced mobility, bone demineralization, gastro-oesophageal reflux, arthritis, decreased muscle tone and progressive cervical spine degeneration [69]. Adults with Prader-Willis syndrome have higher incidence of hypothalamic disorders and there is increased risk of endocrine problems in children with Prader-Willis syndrome [73-74].

There is also an increased risk of mental health problems and challenging behaviours being displayed among those with specific conditions such as Lesch-Nyhan syndrome, Autism spectrum disorders, Rett syndrome, Fragile-X syndrome, William's syndrome, Riley-Day syndrome, Cornelia de Lange syndrome, Prader-Willis syndrome and Velocardiofacial syndrome [33, 75, 76]. A study by Head et al., noted the increased risk for cognitive decline, dementia and Alzheimer disease in those with Down's syndrome [77].

Secondary health conditions such as obesity have been found to be more prevalent among people with Down syndrome, Prader-Willis syndrome, Cohen syndrome and Bardet-Biedl syndrome [78, 79]. Finally, Taggart and Cousins acknowledged that those with ID who are frequently prescribed psychotropic and anti-seizure medications on a long-term basis have a higher risk of developing osteoporosis [69, 80].

Personal Health Risks and Lifestyle / Behaviours

Personal health risks and behaviours including poor diet and sedentary lifestyle are another key determinant of the health of those with learning disability. According to Haverman et al. these lifestyle factors disproportionately increase the health burden of older people with learning disability [81]. Recent research has highlighted that individuals with learning disability are also more likely to have unhealthy diets, lower levels of physical activity and are prescribed high levels of psychotropic medication; consequently, leading to a higher risk of obesity [82, 83].

A study by Hanna et al., found that few people with learning disability eat a balanced diet and their family/paid carers have limited/poor knowledge about the appropriate recommendations on dietary intake [21]. Slevin et al., reported that young people with learning disability, when compared to their non-disabled peers, had poorer diets, consumed more fatty and sugary foods, were significantly obese, and engaged in lower levels of physical activity [84]. These behaviours can lead in later life to increased risk of serious health conditions including Type 2 diabetes, coronary heart disease, certain cancers and even premature death [69, 85-87].

Conclusion

The overall life expectancy of people with ID is increasing [88] but throughout their lifespan their health remains poorer than that of the general population [87]. The United Nations Convention on the Rights of Persons with Disabilities (2007) recognizes that 'person with disabilities should have the same right to the highest attainable standard of healthcare without discrimination'. The policy states that 'early identification and intervention' are priority and that services should be 'designed to minimize and prevent further disability'. As with many other countries throughout the world, the UK and Northern Ireland in particular is struggling to ensure that those with ID receive the same quality of healthcare as their non-disabled peers [69]. The inequalities faced by people with ID are due in part to the complex health profile of this population.

Section 5 Learning disability mortality and cause of death using Census 2011 and Northern Ireland General Registrar Office data

5.1. Aims: Using linked data from the 2011 Census and the Northern Ireland General Registrar Office (death records from March 2011-December 2015), this section will (i) detail the total number of deaths occurring during this study period, and the characteristics (age, sex, health condition status) of NI citizens who died; (ii) describe the main causes of death for individuals with a learning disability who died during the study period; and (iii) calculate the age and sex-adjusted risk of dying during the follow-up period for those individuals with a learning disability (with and without comorbid health conditions) compared to other members of the general population.

5.2. Background

In 2010, Emerson and Baines reported that the rate of mortality among adults with moderate to severe learning disability was three times higher than the mortality rate for the general population [1]. Moreover, mortality rates were higher among young adults, women and those with Down syndrome. A 'Confidential Inquiry Report into the Premature Deaths of People with Learning Disabilities' reviewed the deaths of 247 people with learning disabilities in England between 2010-12 and found the median age of death for males in the UK to be 17% lower than the general population and 25% lower for females [2]. Despite evidence that the learning disability population is living longer [3], and that those individuals with a mild learning disability are expected to live equally as long as their non-disabled peers [4-6], the increased illness burden for this population is indisputable and attributable to multiple sources. A recent study by Glover and colleagues found that, overall, people with an learning disability in the UK are dying on average 15-20 years sooner compared to those without an learning disability, and often, from causes that are commonly preventable, (an observation echoed by others including the WHO, 2011 and the Disability Rights Commission, 2006)[7]. The poor health profile associated with learning disability, to a substantial extent, is avoidable [8, 9]. In 2010, Glover and Ayub utilised information from death certificates to ascertain the age and cause of death for people with learning disability, who died in England between 2004 and 2008. They found that all individuals with a definite or possible learning disability died younger than those without an learning disability. Focusing on cause of death, two notable preventable causes were highlighted as both common amongst the learning disability population and affected most people with learning disability; epilepsy or convulsion (13%) and lung problems, caused by solids or liquids going down the wrong way (14%). The study found that the major causes of mortality in adults with learning disability were respiratory diseases (52% - compared to 26% in the general population); circulatory diseases (12% - compared with 29% in the general population) and infectious and parasitic diseases (6.2% - compared to 4% in the general population) [10].

According to the British Lung Foundation (2019) there are over 40 different conditions which can affect the lungs and/or airways and impact on a person's ability to breathe. These include: lung disease, asthma, pneumonia, COPD (chronic obstructive pulmonary disease), cystic fibrosis, pulmonary vascular disease and bronchiectasis. Hollins et al. (1998) reported that respiratory disease (pneumonia specifically) accounted for 46.6% of deaths in people with learning disability [11]. This finding was later supported by Patja et al. who reported that respiratory disease accounted for 36.3% of deaths among people with learning disability [12]. More recently, Hosking et al. reported that deaths from pneumonia and aspiration pneumonia were ten times more common among the learning disability population, when compared to the general population [13].

A number of other studies have revealed other major causes of death among the learning disability population. For example, in 2017, Esbensen et al. reported on findings from a longitudinal study, from 1988-2007, and indicated that cardiovascular problems accounted for 40.5% of deaths among people with Down syndrome [14]. In 2014, Heslop et al. reported that circulatory disease was the leading underlying cause of death among people with learning disability [2]. Moreover, a recent systemic review by O'Leary et al. reported that circulatory diseases were a leading cause of death among the learning disability population alongside respiratory illness; they acknowledged a greater emphasis on congenital heart disease rather than ischaemia when comparing those with learning disability to the general population [15].

Cancer is another leading cause of death among people with learning disability [2, 7, 13], although the learning disability population have a varied cancer profile when compared to that of the general population. Heslop et al., [16] reported higher prevalence of cancers of the stomach, oesophagus and gallbladder in the learning disability population, with a lower prevalence rate of the cancers more commonly found in the general population, including lung, breast and prostate [16, 7, 17]. The difference in the cancer profile of the learning disability population can be attributed to a range of factors including; lower smoking rates and lower life expectancy (a reduced risk of living to an age where they become at risk of certain cancers) [17, 15]. People with learning disability also have higher rates of the Helicobacter Pylori infection, a risk factor for stomach and bowel cancers; which has been linked to a history of institutionalization, high incidence of peptic ulcers and poor awareness among frontline staff [1, 18, 19].

Taken together these findings reveal a growing evidence base that is critical to informing and aiding service delivery, and practice in all sectors in the UK and beyond. In Northern Ireland, however, this information has been lacking and at present there is limited information relating to rates or causes of mortality for the learning disability population. Again, this is surprising given the availability of the Northern Ireland General Registrar Office database on mortality and the Census learning disability indicator from the 2011 Census. Linking these data affords a valuable opportunity to begin to learn about mortality and its causes among a population that is widely recognised as particularly vulnerable in relation to early and avoidable death.

5.3. Methods

The Northern Ireland Mortality Study (NIMS; see general methods section 2) is a prospective record linkage study, based on Census returns for the whole enumerated population, to which subsequent registered deaths have been linked. This forms a longitudinal study, with

94% of all deaths occurring in the six-year post-census period linked to a census return. These data were anonymised, held in a safe setting by NISRA and made available to the research team for this study.

For the current set of analyses, demographic characteristics included age-group (10 categories ranging from 0-9 years, 10-17 years, 18-24 years, and then 10 year age bands up to 85 years+), sex and learning disability status (see general methods section 2). Cause specific mortality included Neoplasms (International Classification of Disease (ICD) C00-D48); Circulatory system (ICD 10 I00-I99); Respiratory system (ICD 10 J00-j99); Nervous system (ICD 10 G00-H95); Digestive system (ICD 10 K00-N93); Genito-urinary (ICD 10 K00-N93); Diabetes mellitus (ICD 10 K00-N93); Congenital malformations (ICD 10 Q00-Q99); and Obesity.

5.4. Analysis

As outlined in the previous section, several studies in other countries have attempted to identify how rates and patterns of mortality for individuals with learning disability differ to the rest of the population using a variety of different methods, including the calculation of life expectancy tables and standardised mortality ratios (10,11). In comparison to other studies, the data available in this study was limited in terms of the short follow-up period between the Census and the end of observation period in the NIMS (58 months spanning from March 2011 to December 2015), coupled with the relatively small size of the population of Northern Ireland (~1.7 million people) and low numbers of deaths occurring during this period. There were also problems in relation to the sizeable proportion of missing data for ICD codes relating to cause of death for those NI citizens who died during this observation period (~15% of all deaths records did not have a corresponding ICD code for main cause of death). Moreover, perhaps due to the nature of the learning disability indicator in the Census, the age-sex population profile of those citizens reporting a learning disability compared to those who did not (see Figure 5.1 in Appendix), was considerable younger and the short observation period meant that there was limited time to 'observe' deaths in this group of interest in the population. Our study team anticipates that, as the NIMS study observation period is extended beyond 2015 in the future, this will provide a better opportunity to conduct more robust analyses to fully explore the rates and cause of death among people with learning disability, compared to their counterparts in the general population. For the purposes of this study, we adopted a more descriptive approach to: (1) identify the total number of deaths occurring between March 2011 and December 2015 in Northern Ireland for age, sex, learning disability status and year of death; (2) describe the main causes of death, where available, for the five health condition groups, and (3) maximise the information available during the observation period to calculate the age and sex-adjusted risk of 'surviving' (i.e. not dying) during the follow-up period for the 5 health condition categories (1=no health conditions present; 2=a single learning disability condition present; 3=a single health condition present other than learning disability; 4=multiple health conditions present including learning disability and 5=multiple health conditions present not including learning disability).

5.5. Results

Table 5.1. shows the total number of deaths occurring between March 2011 and December 2015 in Northern Ireland for age, sex, learning disability status and year of death. Deaths were relatively equally distributed across the five years (note: only ten months of data included for 2010 due to Census occurring in March 2011). Overall, a higher proportion of females died during period, while over 65% of deaths occurred among those aged 75 years or older. Overall, 4.8% of those with a learning disability died during this period while 3.7% of those without a learning disability died.

Table 5.1. Composition of population and deaths studied via the 2011 Census, Northern Ireland linked to NI General Registrar Office (GRO) death records March 2011-December 2015 – the Northern Ireland Mortality Study (NIMS)

2011 NI Census full population	**Count**	**Total number of deaths (March 2011-December 2015)**
Total population	1,723,180	63,555
Age groups (years)		
0-9	219460	95 (0.1%)
10-17	184206	176 (0.3%)
18-24	159468	281 (0.4%)
25-34	229621	580 (0.9%)
35-44	240492	1413 (2.2%)
45-54	241182	3432 (5.4%)
55-64	189719	6928 (10.9%)
65-74	142918	12981 (20.4%)
75-84	85251	20940 (32.9%)
85+	30863	16729 (36.3%)
Gender		
Male	836,828	30,225 (47.6%)
Female	886,352	33,330 (52.4%)
Learning Disability (LD) status		
With LD	37,303	1803 (2.8%)
No LD	1,685,877	61752 (97.2%)
Year of death		
2011		8969 (14.1%)
2012		13362 (21.0%)
2013		13666 (21.5%)
2014		13417 (21.1%)
2015		14141 (22.3%)

Table 5.2 displays the number of deaths among those without a health condition, those with/without a learning disability as a single health condition, and those with multiple health conditions with/without learning disability. Of those individuals who indicated they

had a LD at the 2011 Census and who died during the follow-up period (n=1803), the majority (95%) had multiple health conditions.

Table 5.2 Death status as of 31st December 2015 by health condition status at 2011 NI Census (N=1,723,180)

	No health condition	Single health condition		Multiple health conditions		Total population
	(n=1,173,565)	LD indicator endorsed (n=12,954)	LD indicator not endorsed (n=288,843)	LD indicator endorsed (n=24,349)	LD indicator not endorsed (n=223,469)	(N=1,723,180)
Dead	9,335	91	15,668	1,712	36,749	63,555
Alive	1,164,230	12,863	273, 175	22,637	186,720	1,659,625

LD=Learning disability health condition indicator

Table 5.3 presents a cross-tabulation for main cause of death (ICD code) by health condition status for all individuals who died during the observation period. As previously stated, main cause of death was missing for ~15% of all death records (categorised as not classified/ICD code not provided in Table 5.3). Moreover, due to the small number of deaths occurring in the LD single health condition (n=91), it was only possible to report counts for the main cause of death for 62.6% of individuals in this group. Caution is advised in attempting to determine patterns of the most commonly reported main cause of death across the five health condition groups due to the relatively small numbers of deaths in the categories where the LD indicator was endorsed. This noted, circulatory problems, respiratory problems, and nervous system problems were frequently reported as the main cause of death for those with LD, but these causes of death were also evident in the health condition groups not experiencing a LD.

Table 5.3. Main cause of death by 31st December 2015 by health condition status at 2011 NI Census (n=63,555)

ICD code for main cause of death	No health condition	Single health condition		Multiple health conditions	
	(n=9,335)	LD indicator endorsed (n=91)	LD indicator not endorsed (n=15,668)	LD indicator endorsed (n=1,712)	LD indicator not endorsed (n=36,749)
C00-D48 Neoplasms	4,165	12	5,522	12	8,882
I00-I99 Circulatory system	2,233	20	4,054	328	10,181
J00-j99 Respiratory system	605	15	1,837	238	6,292
G00-H95 Nervous system	236	10	731	275	2,209
K00-N93 Digestive system	434	*	743	74	1710
N00-N99 Genito-urinary	106	*	330	39	999
E10-E14 Diabetes mellitus	39	*	163	**	573
Q00-Q99 Congenital malformations	14	*	**	63	48
Obesity	11	*	*	*	31
Not classified	62	*	128	22	431
Other – ICD Codes not provided	1,430	**	2,160	**	5,393

LD=Learning disability health condition indicator; *=Cell count less than 10; ** Cell count not reported to prevent totalling within columns

Following this exploratory and descriptive analysis, the next stage was to calculate the rate of ‘survival’ for each of the health conditions, that is, what was the likelihood of death occurring during the observation period for members of the health condition group. The results of the Cox’s regression analysis are presented in Table 5.4. Cox’s regression compares the hazard (as ratios) of the health condition groups, but also accounting the individual’s age and sex, which is important because the age and sex profile of these health conditions differed by age and sex. The unadjusted model results (middle column) indicate that, in comparison to the no health condition reference group, all of the other groups, except the single health conditions LD not endorsed group, had an increased probability of dying during the observation period. The adjusted model results (right hand column, Table 5.5) indicate that, after accounting for the individual’s age and sex, members of the single health condition categories were between 2 and 2.5 times the odds of death occurring during the observation period, compared to the reference group. The odds of death occurring were higher for the multiple health conditions groups, and greatest for the group of individuals who experienced LD with comorbid health conditions.

Table 5.4. Odds ratios for likelihood of death by 31st December 2015, by 2011 NI Census Health Condition Status, unadjusted and adjusted for sex and age in 2011

Health condition status	Unadjusted Model Odds Ratio (95% CI)	Adjusted Model (Age & Sex) Odds Ratio (95% CI)
No health conditions (Reference category)		
Single health condition: LD indicator endorsed	6.987 (6.961-7.012) **	2.072 (0.013) **
Single health condition: LD indicator not endorsed	0.883 (0.678-1.089)	2.514 (0.105) **
Multiple health conditions: LD indicator endorsed	9.143 (9.092-9.194) **	5.871 (5.820-5.922) **
Multiple health conditions: LD indicator not endorsed	22.556 (22.532-22.579) **	3.380 (3.357-3.404) **

**p<0.001

5.6. Overview

The availability of linked mortality records to the 2011 Census provided a unique opportunity to conduct an exploratory investigation, over a relatively short period of time, as to the risk of death among individuals living in NI who self-reported a learning disability compared to other individuals in the population, including those with non-learning disability related health conditions and 'healthy' individuals. During the 58-month observation period, 1803 or 4.8% of individuals who self-reported a learning disability at the 2011 Census died. The vast majority of these individuals (95%) had comorbid health conditions. When comparing across the observed health condition groups, the probability of dying during the observation period was greatest for individuals who had a learning disability in combination with other health conditions, even after adjusting for age and sex. Given issues relating to the quality of death records in identifying main cause of death for all citizens, it was difficult to identify meaningful differences between the health condition groups in relation to the main cause of death; however, complications relating to circulatory, respiratory and nervous system problems were frequently recorded among those individuals with a self-reported learning disability who died during this period.

Looking to the future, it seems highly likely that improvements in the 2021 Census question in relation to the classification of intellectual disability, coupled with anticipated extension of the observation period of death records in the NIMS, will facilitate a more detailed exploration of administrative data to assess, using more robust statistical methods, the excess risk of death experienced by those with an LD compared to their counterparts in the general population. In particular, it is anticipated that the 2021 Census will permit a retrospective 're-classification' of the learning disability indicator into more nuanced categories (e.g. Down’s syndrome, autism, etc.), which would be helpful in facilitating comparisons to previous studies which have routinely demonstrated an excess risk of premature death among people with LD due to health-related complications. This novel methodological work, in addition to the extension of the observation period for experiencing death since the 2011 Census via the NIMS, would provide an ideal opportunity to establish a more robust evidence base in Northern Ireland as to how the life expectancy of people living here with a LD differs to that of the general population, as well as, hopefully, providing a greater insight into the health comorbidities they experience that influences and increases their risk of experiencing a shorter than expected life.

Section 6 Learning disability prevalence and demography using the Northern Ireland Survey of Activity Limitation and Disability data

6.1. Aims: This final analytic section will compare the prevalence estimate of intellectual disability generated from the 2011 Census data with the prevalence estimate of intellectual disability generated from the Northern Ireland Survey of people with Activity Limitations and Disability (NISALD) data to assess how survey item specificity affects intellectual disability prevalence estimation. This section will also report the socio-demographic and health-related characteristics of those individuals who endorsed the intellectual difficulty item from the 2007 NISALD survey. In doing this, we wanted to profile the Northern Irish learning disability population using a more explicit and specific descriptor of 'intellectual disability', and, in so doing, provide a benchmark against which the more explicit 2021 Census data relating to intellectual disability can be measured in the future.

6.2. Background

Intellectual disability classification in studies based on national household survey data tended to be based on survey questions (all slightly different) designed to ascertain the presence of intellectual disability. Variation in the format and content of these survey questions, particularly in studies based in the same country and administered during the same time, have returned varying intellectual disability prevalence estimates. For instance, where intellectual disability prevalence estimates were derived from adult participant responses to two separate Canadian national household surveys that used different questions to ascertain the presence of intellectual disability, prevalence varied from 0.2% in one survey (survey question = 'Do you have autism or any other developmental disorder such as Down's syndrome, Asperger's syndrome, or Rett syndrome') to 0.5% in the other (survey question = 'Has a doctor, psychologist or other health professional ever said that you had a developmental disability or disorder (examples provided)') [1]. Moreover, where intellectual disability prevalence estimates were generated using child/adolescent participant data from two separate longitudinal US national household surveys (1997 – 2008; 2001 – 2011) that also used different questions to ascertain the presence of intellectual disability, prevalence varied from less than 0.4% in one study (survey question = 'Has a doctor or health professional ever told you that [survey child] has any of the following conditions? (included—autism, mental retardation)' [2] to greater than 0.6% in the other (survey question = 'What caused disability/limitation? (options included mental retardation)' [3].

While poorer classification of intellectual disability has notable effects on prevalence estimation, it has also been shown to dramatically influence assessments of related morbidity. For instance, Lin and colleagues [4] employed three algorithms (broad, intermediate & narrow) to vary the sensitivity/specificity of intellectual disability classification. They found that using the narrow algorithm classified substantially more individuals with psychiatric co-morbidities than using the intermediate algorithm. These findings provided useful evidence of how intellectual disability mis/classification might disrupt or compromise our assessment of other factors that are important in attaining a clearer understanding of the epidemiology of intellectual disability.

6.3. Method

Data sources

2007 Northern Ireland Survey of people with Activity Limitations and Disability (NISALD)

The NISALD [5] was conducted by the Northern Ireland Statistics and Research Agency (NISRA) during 2006-2007. The survey aimed to provide an up-to-date, accurate picture of the prevalence and circumstances of adults and children with a disability in Northern Ireland. Although the NISALD comprised of two strands i.e. (1) private households and (2) communal establishments (excluding places of detention and military establishments), only data and findings from the private household strand have been released publicly and, as such, the current study relates to disability and activity limitations within private households in Northern Ireland only.

There was no comprehensive register of people with disabilities in Northern Ireland (i.e. no sampling frame) from which to sample potential respondents for the NISALD survey. To overcome this obstacle, NISRA selected a random sample of 12,000 households from the Northern Ireland Valuation and Lands Agency Database, which contains a record of all domestic households in Northern Ireland, to serve as the study sampling frame. Selected households were posted an advanced letter which contained detailed information about the NISALD, its purpose, and that their household would be contacted in due course with respect to potential participation. Of the initial sample of 12,000 households, 10,984 (84% of random sample) were eligible addresses. Subsequently, NISRA contacted each eligible household to conduct a screening exercise with one member of the household (largely via telephone, but also via face-to-face interview if requested or if the household did not have a telephone) during which information was requested on each member living in the household. Information sought included: basic demographic information on each member of the household, as well as the presence and level of difficulty associated with 15 disabilities or activity limitations (in accordance World Health Organisation (WHO) International Classification of Functioning, Disability and Health (ICF) 16) that had lasted or were expected to last 6 months (see Table 6.1).

In total, 23,689 screening interviews were conducted with 18,517 adults and 5,172 children in eligible households. Individuals within the household who reported: (1) more than one mild limitation that affected activities sometimes; (2) at least one mild limitation that affected activities often; or (3) one or more moderate/severe limitation (n=4,185; 3,865 adults and 320 children), were considered as having some medical, social or environmental factor that affected their ability and therefore were deemed eligible to complete a questionnaire designed to further assess the nature of their activity limitations and disability.

Multiple members of the same household could complete this questionnaire if they met the eligibility criteria, which was conducted via face-to-face interviewing in the respondent’s own home. Adult and child versions of the main questionnaire were largely similar with only minor amendments to wording for children. All interviews for respondents aged 15 years or younger were conducted in proxy form with the parent or guardian.

The main questionnaire collected information on: how the disability or activity limitation affected daily life; use of aids, specialised equipment or medication; management of disabilities; supports and care needed/received; general health; use of health and social care services; education; employment and training; social participation, leisure and attitudes of others; transport and travel; housing; crime and fear of crime; additional costs relating to living with a disability (e.g. goods, services, equipment or medication), income and benefits; and general background information. Approximately 85% of those who were eligible and invited to participate in the main interview did so (n=3,543; 3,262 adults and 281 children). Data from NISALD is available for researchers to access via the UK Data Service, study number 7236 (https://beta.ukdataservice.ac.uk/datacatalogue/studies/study?id=7236).

2011 Census

The Census aimed to collect information on all residents of NI (N=1,744,966) living in both private households (N=1,723,942) and communal establishments (N=21,024). Census data was not obtained for 21,786 residents, reducing the population to 1,723,180 (98.8% of entire population), of which 1,702,217 lived in private households and 20,963 lived in communal establishments. Those living in communal establishments were excluded from the analytical sample. The Census form indicates that the householder (the person who owns or rents the accommodation and is responsible for paying the household bills) is responsible for ensuring that the questionnaire is completed and returned although it does not provide instructions as to who should complete individual parts of the Census form. However, it is generally anticipated that parents would complete the individual forms on behalf of younger children while older children may complete on their own behalf. In the 2011 Census, individuals were asked whether they had any of a list of health conditions (see Table 6.1) which have lasted, or are expected to last, at least 12 months. There was also an option to report no health conditions.

Key differences in the methodologies of the 2007 NISALD and the 2011 Census in relation to measuring the prevalence of disability and other health conditions in NI are summarised in Table 6.1. For the purposes of this investigation, the most notable difference between the two sources relates to the separation of intellectual difficulty from learning difficulty and social or behavioural difficulty in the NISALD, compared to the aggregation of these three conditions in the 2011 Census. Thus, the NISALD presents a unique opportunity to isolate those individuals who have an intellectual difficulty or developmental delay.

Table 6.1. Overview of the content, phrasing, and mode of administration of questions used to ascertain the presence of disability and other health conditions in the 2007 Northern Ireland Survey on Activity Limitations and Disability and the 2011 Northern Ireland Census

	2007 Northern Ireland Survey on Activity Limitations and Disability	**2011 Census**
Method of administration	(telephone and face-to-face interview)	(paper based self-report)
Introductory statement/question	*The survey is only interested in difficulties or activity limitations that have lasted or are expected to last 6 months or more. Do you/any of the people in your household have any difficulty…*	*Do you have any of the following conditions which have lasted, or are expected to last, at least 12 months?*
Hearing	Hearing, cannot hear at all or use a hearing aid?	Deafness or partial hearing loss
Vision	Seeing, cannot see at all or wear glasses or contact lenses to assist their vision?	Blindness or partial sight loss
Communication	Speaking or making themselves understood, cannot speak at all or use aids or specialised equipment to assist them to communicate? Do not include children who cannot yet speak unless there is a specific problem.	Communication difficulty (a difficulty with speaking or making yourself understood)
Mobility	Mobility difficulties for example moving about, walking, climbing stairs; are not mobile at all or use specialised equipment or have personal support services such as a home help or personal assistant to help them to be mobile?	A mobility or dexterity difficulty (a condition that substantially limits one or more basic physical activities such as walking, climbing stairs, lifting or carrying)
Dexterity	Dexterity difficulties (by that I mean lifting, carrying, grasping or holding objects); cannot lift, carry, grasp or hold at all; or use specialised equipment to help them with these actions?	

Learning difficulty/disability	**A difficulty learning for example at school, college, work or in other places. This may be due to a condition such as dyslexia or Attention Deficit Hyperactivity Disorder or it may not have a name.**	**A learning difficulty, an intellectual difficulty, or a social or behavioural difficulty**
	An intellectual difficulty or developmental delay. This may not have a name but include things like Down's syndrome, autism, Fragile X Syndrome and other conditions.	
	A social or behavioural difficulty, for example difficulty making friends or aggressive outbursts etc. These may be associated with conditions such as autism, Attention Deficit Hyperactivity Disorder, Asperger's Syndrome or may have no apparent cause or name.	
Pain or discomfort	Long-term pain or discomfort that is always present or reoccurs from time to time or take medication to manage any long-term pain or discomfort?	Long-term pain or discomfort
Shortness of breath	Shortness of breath or difficulty breathing or use specialised equipment such as a nebuliser, oxygen concentrator or cylinder or ventilator to assist with breathing?	Shortness of breath or difficulty breathing (such as asthma)
Confusion	Frequent periods of confusion or difficulty remembering things? These difficulties may be associated with diseases such as Alzheimer's, dementia or as a result of a brain injury or stroke?	Frequent periods of confusion or memory loss

Long-term health conditions	Any of the following long-term conditions that have lasted or are expected to last 6 months or more and that have been diagnosed by a health professional: asthma or severe allergies; heart condition or disease; kidney condition or disease; cancer; diabetes; epilepsy; Cerebral Palsy; Spina Bifida; Cystic Fibrosis; muscular dystrophy; multiple sclerosis; migraines; paralysis of any kind; missing or malformed arms, legs, fingers or toes; complex medical care needs; or other.	A chronic illness (such as cancer, HIV, diabetes, heart disease or epilepsy)
Brain damage	Any difficulty carrying out everyday activities as a result of a head injury, stroke or any other sort of brain damage?	NA
Other conditions	Any other difficulties or limitations because of a physical condition, mental health condition or health problem that we have not already covered?	Other condition
No conditions	NA	No condition

6.4. Data analysis

As a preliminary step, we compared the 2007 NISALD and the 2011 Census in relation to the distribution of age, sex, region (Nomenclature of Territorial Units for Statistics (NUTS)), and disability (both in terms of distinct disabilities categories and the overall number of health conditions reported). Differences were tested using a Chi-squared, taking the census as the theoretical distribution. This provided an initial test as to how comparable the 2007 NISALD (survey sample) was to the general population (2011 Census). Next, we estimated and compared the prevalence and 95% confidence intervals of any learning difficulty, intellectual difficulty, and/or social-behavioural difficulty across the two sources. To achieve comparability with the 2011 Census, for this step, a binary variable was generated to represent endorsement/experiences across the three individual categories (i.e., any learning difficulty, intellectual difficulty and/or social/behavioural difficulty) in the 2007 NISALD. And fourth, given that the 2007 NISALD contained a detailed breakdown of the learning difficulty, intellectual difficulty, and/or social/behavioural difficulty item (unlike the 2011 Census), we estimate the socio-demographic and health characteristics associated with experiencing any intellectual difficulty.

6.5. Results

Comparability of NISALD and 2011 Census

The 2007 NISALD and the 2011 Census had similar distributions for sex, age, and region; standardised difference scores for these comparisons were all <0.10 (see Table 6.2), suggesting no meaningful differences in the distribution of these characteristics between the two data sources.

The medium effect size of >0.5 for number of health conditions indicates that the 2007 NISALD and the 2011 Census differed considerably in relation to the number of health conditions experienced. Specifically, the 2007 NISALD had a higher percentage of individuals with no disability/health conditions and a higher percentage of individuals with multiple comorbid health conditions, when compared to the 2011 Census.

Table 6.2. Comparison of the sex, age, geographical, and health-related distribution of the general population sample recruited in the 2007 Northern Ireland Survey on Activity Limitations and Disability compared to the 2011 Northern Ireland Census.

Socio-demographic and health characteristics		2007 NISALD All (N=23,689)		2011 Census All (N=1,702,217)		Standardized differences
		N	%	N	%	
Sex	Male	11,492	48.5	827,932	48.6	0.002
	Female	12,190	51.5	874,285	51.4	
Age (years)	0-15 years	5,192	21.9	355,430	20.9	0.066
	16-24 years	3,176	13.4	202,794	11.9	
	25-34 years	2,972	12.6	228,377	13.4	
	35-44 years	3,506	14.8	239572	14.1	
	45-54 years	3,102	13.1	240,001	14.1	
	55-64 years	2,628	11.1	188,582	11.1	
	65-74 years	1,860	7.9	141,259	8.3	
	75+ years	1,222	5.2	106,202	6.2	
Region	Belfast	3,422	14.4	254,631	15.0	0.0338
	Outer Belfast	5,135	21.7	371,176	21.8	
	East	5,666	23.9	420,515	24.7	
	North	3,862	16.3	267,788	15.7	
	West/South	5,604	23.7	384,315	22.6	
Number of health conditions	None	19,513	82.3	1,168,020	68.7	0.510
	One	816	3.4	297,950	17.5	
	Two	912	3.9	103,200	6.1	
	Three	757	3.2	67,135	3.9	
	Four or more	1,691	7.2	65,912	3.8	

Prevalence of learning difficulty, intellectual difficulty and/or social/behavioural difficulty in the general population

The prevalence of experiencing any learning difficulty, intellectual difficulty, and/or social/behavioural difficulty in the NISALD was lower than that obtained via the 2011 Census (1.6% vs. 2.0%). Of the three conditions, based on the NISALD data alone (comparable estimates for the 2011 Census were not available), the prevalence was highest for any learning difficulty, followed by social or behavioural difficulty, and then intellectual difficulty (see Table 6.3).

Table 6.3. Comparison of the prevalence of learning difficulty, intellectual difficulty and/or a social or behavioural difficulty (LD) in the general population of Northern Ireland: data from the 2007 Northern Ireland Survey on Activity Limitations and Disability and the 2011 Northern Ireland Census

		2007 NISALD		2011 Census	
		Overall (N=23,689) 0-15 years (n=5,172) 16 years + (n=18,517)		Overall (N=1,770,217) 0-15 years (n=355,430) 16 years + (n=1,346,787)	
Disability		n	Prevalence (95% CI)	n	Prevalence (95% CI)
A learning difficulty, intellectual disability **and/or** a social or behavioural difficulty	Overall	389	1.6% (1.5-1.8)	34,401	2.0% (2.0-2.0)
	0-15 years	186	3.6% (3.1-4.1)	13,530	3.8% (3.8-3.8)
	16 years +	203	1.1% (.9-1.3)	20,871	1.5% (1.5-1.5)
Any intellectual difficulty	Overall	130	0.5% (0.4-0.7)	NA	NA
	0-15 years	67	1.3% (1.0-1.6)	NA	NA
	16 years +	63	0.3% (0.3-0.4)	NA	NA
Any learning difficulty	Overall	298	1.3% (1.1-1.4)	NA	NA
Any social or behavioural difficulty	Overall	176	0.7% (0.6-0.9)	NA	NA

Correlates of learning difficulty, intellectual difficulty and/or social/behavioural difficulty in the general population

As presented in Table 6.4, there was little difference in the sex distribution of any learning difficulty, intellectual difficulty and/or social/behavioural difficulty between the 2007 NISALD and the 2011 Census (standardised difference score <0.01), with approximately 70% of those satisfying this indicator being male.

Small-to-medium effect sizes were evident for the other characteristics. Specifically, a higher percentage of younger people (0-15 years) with any learning difficulty, intellectual difficulty and/or social/behavioural in NISALD compared to the Census. Higher percentages of individuals with any learning difficulty, intellectual difficulty and/or social/behavioural difficulty in NISALD lived outside the Belfast/Outer Belfast area, were not economically active, and had a greater number of health conditions, compared to those in the 2011 Census.

Table 6.4. Comparison of the socio-demographic and health-related characteristics of individuals reporting any learning difficulty, intellectual difficulty and/or a social or behavioural difficulty (LD) in the general population of Northern Ireland: data from the 2007 Northern Ireland Survey on Activity Limitations and Disability and the 2011 Northern Ireland Census.

		Learning difficulty, intellectual difficulty and/or a social or behavioural difficulty (LD)				Standardized differences
		2007 NISALD (n=389)		2011 Census (n=34,401)		
		N	%	N	%	
Sex	Male	260	66.8	23,108	67.2	0.007
	Female	129	33.2	11,293	32.8	
Age	0-15 years	186	47.8	13,530	39.3	0.247
	16-24 years	58	14.9	6,800	19.8	
	25-34 years	26	6.7	3,880	11.3	
	35-44 years	45	11.6	3,260	9.5	
	45-54 years	37	9.5	3,230	9.4	
	55+years	36	9.5	3,701	10.7	
Region*	Belfast	50	12.9	6,333	18.4	0.181
	Outer Belfast	77	19.8	6,897	20.0	
	East	90	23.1	7,959	23.1	
	North	80	20.6	5,564	16.2	
	West/South	92	23.6	7,379	21.4	
Economic activity	Active	40	10.3	5,751	16.7	0.312
	Inactive	127	32.6	13,609	39.6	
	Other	36	9.3	1,511	4.4	
	Not working age	186	47.8	13,530	39.3	
General health*	Very good	92	23.7	7,456	21.7	0.174
	Good	115	29.6	11,505	33.4	
	Fair	76	19.5	9,906	28.8	
	Bad	33	8.5	3,796	11.0	
	Very bad	16	4.1	1,738	5.1	
Number of health conditions	One	73	18.8	12,526	36.4	0.444
	Two	84	21.6	7,462	21.7	
	Three	67	17.2	5,277	15.3	
	Four or more	165	42.4	9,136	26.6	

*Note. Percentages do not total 100 due to minimal levels of missing data

Socio-demographic and health-related characteristics of intellectual difficulty

Finally, we focused on the 2007 NISALD data only to identify the characteristics of individuals reporting any intellectual difficulty (see Table 6.5 for prevalence and 95% confidence intervals). The majority of individuals surveyed with an intellectual difficulty (overall and in both age categories) were male, living outside Belfast and the Outer Belfast area, had a severe intellectual difficulty, had multiple comorbid health conditions (communication difficulties were highly prevalent, as were learning difficulties and other social/behavioural difficulties) but, in general, self-reported that their health was good or very good. A higher proportion of those age 16 years or over resided in the East or West and South NUTS regions of Northern Ireland and reported difficulties with vision, chronic illness and head injury compared to those aged 0-15 years. A higher proportion of those age 0-15 years resided in the Outer Belfast or North NUTS regions of Northern Ireland and reported social or behavioural difficulties compared to those aged 16 years or over.

Table 6.5. Socio-demographic and health-related characteristics of individuals reporting any **intellectual difficulty** in NISALD (n=130)

Socio-demographic characteristics		Prevalence (95% CI)		
		Overall	0-15 years	16 years +
Age	0-15 years	51.5% (42.6-60.1%)	-	-
	16-24 years	20.0% (13.5-27.9%)	-	-
	25-34 years	6.9% (3.2-12.7%)	-	-
	35-44 years	6.2% (2.7-11.8%)	-	-
	45-54 years	12.2% (7.2-19.2%)	-	-
	55+ years	3.1% (0.8-7.7%)	-	-
Sex	Male	69.2% (60.5-77.0%)	70.1% (57.7-80.7%)	68.3% (55.3-79.4%)
	Female	30.8 (23.0-39.5%)	29.9% (19.3-42.3%)	31.7% (20.6-44.7%)
Region	Belfast	6.9% (3.2-12.7%)	7.5% (2.5-16.6%)	6.3% (1.8-15.5%)
	Outer Belfast	20.0% (13.5-27.9%)	22.4% (13.1-34.2%)	17.5% (9.1-29.1%)
	East	26.9% (19.5-35.4%)	22.4% (13.1-34.2%)	31.7% (20.6-44.7%)
	North	16.9% (10.9-24.5%)	20.9% (11.9-32.6%)	12.7% (5.6-23.5%)
	West and South	29.3% (21.6-37.8%)	26.9% (16.8-39.1%)	31.7% (20.6-44.7%)
Disability and other health-related characteristics				
Severity of intellectual disability	Mild	6.2% (2.7-11.8%)	3.0% (0.4-10.4%)	9.5% (3.6-19.6%)
	Moderate	28.4% (20.9-37.0%)	34.3% (23.2-46.9%)	22.2% (12.7-34.5%)
	Severe	65.4% (56.5-73.5%)	62.7% (50-74.2%)	68.3% (55.3-79.4%)
General health*	Very good	27.4% (19.5-36.6%)	33.3% (21.7-46.7%)	20.8% (10.8-34.1%)
	Good	43.4% (34.1-53.0%)	40.0% (27.6-53.5%)	47.2% (33.3-61.4%)
	Fair	24.8% (17.1-33.8%)	23.3% (13.4-36.0%)	26.4% (15.3-40.3%)
	Bad/Very bad	4.4% (1.5-10%)	3.3% (0.4-11.5%)	5.7% (1.2-15.7%)
Health conditions (any)	Sight	10.0% (5.4-16.5%)	4.5% (0.9-12.5%)	15.9% (7.9-27.3%)
	Hearing	11.5% (6.6-18.3%	10.4% (4.3-20.3%)	12.7% (5.6-23.5%)
	Communication	50.0% (41.1-58.9%)	47.8% (35.4-60.3%)	52.4% (39.4-65.1%)
	Mobility	23.1% (16.1-31.3%)	20.9% (11.9-32.6%)	25.4% (15.3-37.9%)
	Dexterity	29.2% (21.6-37.8%)	25.4% (15.5-37.5%)	33.3% (22.0-46.3%)
	Pain	8.5% (4.3-14.6%)	7.5% (2.5-16.6%)	9.5% (3.6-19.6%)
	Chronic Illness	45.6% (36.6-54.3%)	41.8% (29.8-54.5%)	49.2% (36.4-62.1%)

	Breathing	10.8% (6.0-17.4%)	14.9% (7.4-25.7%)	6.3% (1.8-15.5%)
	Learning difficulty	70.7% (62.2-78.4%)	68.7% (56.2-79.4%)	73.0% (60.3-83.4%)
	Social or behavioural difficulty	53.7% (44.1-61.8%)	62.7% (50.0-74.2%)	42.9% (30.5-56.0%)
	Memory	15.4% (9.7-22.8%)	10.4% (4.3-20.3%)	20.6% (11.5-32.7%)
	Emotional, psychological or mental health condition	20.0% (13.5-27.9%)	19.4% (10.8-30.9%)	20.6% (11.5-32.7%)
	Head Injury	3.8% (1.3-8.7%)	1.5% (0.00-8.0%)	6.3% (1.8-15.5%)
Number of health conditions	One	3.8% (1.3-8.7%)	4.5% (0.9-12.5%)	3.2% (0.4-11.0%)
	Two	15.4% (9.7-22.8%)	13.4% (6.3-24.0%)	17.5% (9.1-29.1%)
	Three	20.0% (13.5-27.9%)	22.4% (13.1-34.2%)	17.5% (9.1-29.1%)
	Four or more	60.7% (51.8-69.2%)	59.7% (47.0-71.5%)	61.9% (48.8-73.9%)

*Note. Percentages do not total 100 due to minimal levels of missing data

6.6. Overview

Survey comparisons of sex, age, geographic, and health-related distributions

Relating to sex, age and geographic location, the NISALD delivered an accurate and reliable representation of the Northern Ireland population (as enumerated in the 2011 Census). Standardised difference scores for these comparisons were all <0.10. A key advantage of national survey programmes, such as NISALD, is that samples are carefully constructed to be statistically representative of the whole population and quality control is generally of a high standard [6]. The representativeness of the NISALD data therefore, based on these key demographic characteristics, was not unexpected. However, there was a notable difference in relation to the distributions of number of health conditions between data sets. A higher proportion of the NISALD sample (82.3%) indicated an absence of household disability compared with Census household data (disability absence = 68.7%). A higher proportion of the NISALD sample also reported the presence of four or more disabilities (7.2%) compared with Census household data (>4 disabilities = 3.8%). While the higher degree of specificity of health condition classification in the NISALD may have accounted for these differences, there is evidence that the distribution of health status responses may be influenced by mode of administration [7, 8]. For instance, it may have been the case that the crude self-report in the Census was not picking up the more serious health conditions that the detailed face-to-face/telephone interview was capturing by providing respondents with an opportunity for clarification. This means that the NISALD might have obtained a more complete and accurate distribution of health limitations when compared to the Census.

Intellectual disability prevalence estimate comparisons between the 2011 Census data and the NISALD data

Satisfied that the data from both sources could be reliably compared, our findings indicated that intellectual disability, as crudely approximated by the recoded 2007 NISALD data and the 2011 Census data, returned an overall prevalence rate of 1.6 – 2%. For those aged 0-15 years, prevalence estimates were 3.6 and 3.8% respectively, and for those aged 16 years or older, prevalence estimates were 1.1 and 1.5% respectively.

While these estimates were within range of some internationally cited population prevalence estimates of 1-3% [9, 10] they were generally above those cited in the most recent meta-analysis of international intellectual disability prevalence estimation (0.05 – 1.55%) [11]. However, extricated from 'learning difficulty' and 'social or behavioural difficulty', intellectual disability alone returned an overall prevalence rating of 0.5% (0-15 years = 1.3%; 16 years or over = 0.3%) which was more consistent with McKenzie's meta-analysis estimate range. More importantly however, these estimates were consistent with those derived from studies in McKenzie's meta-analysis that employed survey questions as the mode of intellectual disability classification (estimates ranged from ~0.2 - ~1%). While a high proportion of these individuals also recorded the presence of a learning difficulty (70%) or a social or behavioural difficulty (54%), these data suggested that, when defined and distinguished from other forms of disability, intellectual disability specifically in Northern Ireland, as recorded within private households, may be less prevalent than has previously been suggested/reported [12].

Notably, this 0.5% prevalence estimate was also consistent with estimates derived from other Northern Ireland administrative data sources (e.g. Northern Ireland GP register data, Northern Ireland Health & Social Care Trust data, Northern Ireland Housing Executive data) [13] and with the most widely used estimate of the number of adults in England known to have an intellectual disability [14]. Derived from GP registers in the National Health Service (NHS), 0.5% (n=206,132) of patients were identified as having an intellectual disability in England in 2013 (N=53.3m) (these data however were restricted to individuals over 18 years of age, were under-representative of people with mild learning disabilities and included those living in residential settings – three important distinctions from the NISALD data).

Using the 2011 Census general population base (i.e. N=1,770,217) and the prevalence of intellectual disability of 0.5% (95%CI 0.4-0.7%), a crude approximation (based on 2011 Census general household population figures and an unchanged prevalence of intellectual disability between 2007 and 2011) is that between 7,081 and 12,392 individuals living in private households in Northern Ireland met the NISALD criterion for an intellectual disability in 2011. Given, however, the limitations of the NISALD data (detailed in limitations section below) and the many barriers and obstacles individuals with intellectual disability commonly face in accessing timely, appropriate and effective health care [15-23] we believe the estimates derived from our data analysis and the English GP register data in 2013, while consistent, are likely to be underestimates.

Intellectual disability subsample comparisons of sex, age, geographical, economic-activity and health-related distributions from both surveys, as derived from the 2011 Census and NISALD Census-comparator items.

Using the cruder classification of intellectual disability from the Census, it was clear that the ID subsample distributions of age and geographical location, shown to be comparable at an overall population level, were, in this context, statistically different. In fact, sex was the only variable that did not statistically differ between intellectual disability subsamples when the data was framed using the classification of intellectual disability from the Census. While the differences in general health between subsamples were negligible, notable disparities between the number of health conditions were evident. Lin and colleagues [4], demonstrated how more precise classification of intellectual disability resulted in the identification of higher rates of comorbidity. While the cruder classification of intellectual disability in this analytic step my likely have affected comorbidity comparisons between data sources, it would seem logical that the greater level of specificity in each of the other NISALD health conditions also influenced findings.

Socio-demographic and health-related characteristics of those individuals who endorsed the more specific intellectual difficulty item from the 2007 NISALD survey

Using the explicit intellectual disability indicator from the NISALD data it was possible to more accurately locate the regions in Northern Ireland where individuals with intellectual disability live and to describe Northern Ireland's intellectual disability population in relation to several important socio-demographic and health related characteristics. Compared to the NISALD measure of intellectual disability, the 2011 Census recorded a larger proportion of the population with intellectual disability in two of the five NUTS regions and a lower proportion intellectual disability in the remaining three regions. Notable differences were evident in relation to Belfast (NISALD intellectual disability =6.9% versus Census '11=15%) and in relation to Western and Southern Northern Ireland (NISALD ID=29.3% versus Census '11=22.6%). The NISALD intellectual disability indicator also returned a much younger age profile and suggested a more severe morbidity/comorbidity profile compared to the 2011 Census data.

While a minimum prevalence rate of 10% was evident for all but one (long-term pain) of the 13 health conditions, communication difficulties (50%), and chronic illness (45.6%) (in addition to learning difficulty and social and behavioural difficulty) were particularly prevalent. These rates are not unexpected. Poor communication is recognized as a significant barrier for people with intellectual disability [24-27] while increased longevity amongst the intellectual disability population has led to a rise in secondary conditions such as obesity and Type 2 diabetes as well as an increased prevalence in a number of chronic illnesses [28-30].

A notable advantage of the NISALD was its supplementary data on disability severity. While distinguishing intellectual disability from learning difficulties and social and behavioural difficulties is critical for defining, locating and responding to intellectual disability effectively, qualifiers of 'mild', 'moderate', and 'severe' are commonly employed by health care practitioners to indicate the level of support that is required by individuals with varying levels of intellectual impairment [31]. NISALD therefore afforded an opportunity to recognise that over 65% of those with an intellectual disability in Northern Ireland experienced severe impairment.

Limitations

Several important limitations must be acknowledged in relation to the proposed findings. First and most importantly, the current set of analyses were restricted to people living in private households. This means that individuals in residential care were excluded. Given their residential status we also suspect that our findings will be heavily weighted towards younger people with intellectual disability.

Second, as is commonly the case with national survey programmes and the investigation of low prevalence phenomena, the number of people with intellectual disability in the NISALD data (n=130) limited our analyses e.g. half of the intellectual disability sample was under 15 years of age therefore more in-depth analyses of e.g. health indicators and economic activity known to be age variant, were restricted.

Third, while the NISALD data offered a more explicit measure of intellectual disability, compared to the 2011 Census, it was not without its own definition complications. The NISALD intellectual disability item explicitly referred to an intellectual ‘difficulty’ rather than ‘disability’ and included autism as an exemplar condition which was also included as a condition under the social or behavioural difficulty item. The precise interpretation of this intellectual disability indicator by respondents therefore was unknown and may have influenced item endorsement.

These findings clearly highlight the importance of definition and specificity in the detection and classification of intellectual disability in the general population. They also reveal the value of supplementing Census data with high quality national survey data. Given, however, that household probability survey sampling will almost certainly under detect phenomena such as intellectual disability, it can be expected that the prevalence estimate of 0.5% reported here will fall short of the Census household prevalence rate in 2021 (although census returns may also under-report).

Section 7. *Conclusions & implications of study findings*

The following study had two broad but specific aims. The first of these was to highlight the availability, utility and import of learning disability data in NI. To achieve this, it was important, not only, to access and analyse whatever administrative data was available/accessible in NI, but also to attempt to understand the origins and history of the data, and to highlight the utility of the data to key NI learning disability stakeholders. It became clear during the project that important population data on learning disability in NI existed but had remained unused or overlooked. Ensuring that key stakeholders were introduced to these data and involved in exploring their origins, helped raise awareness about the data's existence, potential and utility, but also laid the groundwork for achieving the second aim of the project. The second aim was to promote and stimulate future use of learning disability data in the region. To achieve this aim, it was important, not only, to record and highlight what was conducted during the project and how, but to record also the various queries, discussion points and observations made by the consortium over the lifetime of the project (e.g. in relation to the history and 'evolution' of the disability content of the NI Censuses and the design and administration of the next Census in 2021). Moreover, it was important to catalogue the various obstacles and challenges that the consortium encountered along the way and the communications it had with the NI Census Team and the Northern Ireland Statistics and Research Agency (NISRA) in seeking to better understand NI data. In doing so this section highlights what was learned during the project and some of the issues that will need to be addressed if the potential of future learning disability data in NI is to be fully realised.

7.1. Showcasing what is possible with administrative data in NI

Over the course of the project, while data from a number of administrative data resources remained inaccessible to the team, researchers successfully accessed and analysed data from various sources to demonstrate data utility in a number of important areas, such as learning disability prevalence calculation, demography and health profiling, and mortality risk/cause estimation (see Section 3-5). Specifically, researchers successfully accessed and analysed data from the 2011 Census to *approximate* the prevalence of learning disability (i) for the overall population, (ii) for distinct age groups, (iii) for those who lived in private households and communal establishments, and (iv) for each of the five NI Health and Social Care Trusts. Using the Census data, coupled with NI multiple deprivation measure data, and NI settlement band data, the demography and health status of the learning disability population of NI was also profiled at both a national and regional level. Moreover, using Census data linked to General Registrar's Office data, the rate and cause of mortality for the learning disability population of NI were estimated.

At the outset of the project, however, it was clear to the consortium that the 2011 NI Census item relating to learning disability lacked specificity. Because of this, the consortium recognised from the beginning that the prevalence rates produced using this item would likely be higher than those recorded in other countries where more explicit, clearly defined learning disability Census survey items had been used (e.g. Scotland, Republic of Ireland), and, that an accurate and robust analysis of learning disability prevalence in NI, based on the 2011 Census data, would be unattainable. It was also clear that any analyses that attempted to explore the demography, health and/or mortality status of the learning disability population using this item would be affected by this specificity issue. While important variation in prevalence therefore was identified, particularly between the younger and older members of the NI population, and between those in different health and social care trusts, the ambiguity and lack of specificity in the Census item likely returned figures that captured much more than learning disability alone. Moreover, while the demography, education, employment, and deprivation profiles that were produced were consistent with what was expected for a learning disability population, again the specificity issue compromised interpretation. Had the 2011 NI Census contained a more explicit and specific survey item relating to learning disability, such as those included in the 2011 Scottish and Irish Censuses, the current findings may have allowed the consortium to confidently report the prevalence of learning disability in NI for the first time, to reveal important regional and age related variations in expression and prevalence of learning disability and to accurately describe the learning disability population, at an individual, spatial and contextual level. Regrettably, the survey item used in the 2011 NI Census ('A learning difficulty, an intellectual difficulty, or a social or behavioural difficulty') prohibited this. Referring to intellectual difficulty rather than intellectual disability and subsuming intellectual difficulty with learning difficulties and social and behavioural difficulties this survey item lacked specificity and introduced notable complications for Census respondents and researchers alike. However, the crude framing of learning disability in the 2011 Census afforded the consortium a valuable opportunity to explore and learn about how disability assessment had evolved over previous NI Censuses, and, more importantly, to discover valuable data that was central to the design of the 2011 Census, but had been overlooked by researchers for almost 10 years prior to the beginning of the current project.

7.2. Data discovery during the project

One of the earliest queries by the consortium related to the origins and design of the 2011 Census survey item relating to learning disability. Upon reviewing the proposal and planning documentation for the 2011 Census, it became clear that the survey item used in the 2011 NI Census was a composite of three conditions that had originally been framed separately in a national household probability survey that had in turn been commissioned and designed specifically to inform the health condition/disability content of the 2011 Census (i.e. NISALD, 2007). Sourcing and accessing this significantly underutilised data afforded an opportunity, not only, to estimate the prevalence and variation of learning disability in NI using a more explicit learning disability survey item (see Section 6), but to reveal the value and potential of such survey data in supplementing and enhancing future Census data also. The data from this survey produced prevalence estimates that were much more consistent with (i) internationally cited population prevalence estimates of learning disability and (ii) studies that employed explicit survey questions as the mode of learning disability classification. Moreover, the data from this survey afforded an opportunity to reveal the degree to which learning disability co-occurred, not only, with learning difficulties and social or behavioural difficulties but with an array of health conditions/disabilities that were more explicitly described and detailed compared to the Census conditions they were intended to inform. Most notably however the NISALD data highlighted the value of supplementing Census data with high quality national survey data. Such data can ‘supercharge’ and contextualise Census findings with information on how disability or activity limitation affect daily life; use of aids, specialised equipment or medication; management of disabilities; supports and care needed/received; general health; use of health and social care services; education; employment and training; social participation, leisure and attitudes of others; transport and travel; housing; additional costs relating to living with a disability (e.g. goods, services, equipment or medication), income and benefits; and general background information. Given the additional contextual value of such a data resource it is hoped that Census 2021 will also be accompanied and supplemented by its own NISALD. While this may be challenging to deliver, the consortium believes it to be a critical data resource worth pursuing and securing. To this end, during the project, the consortium explored whether NISRA had intentions to collect similar data to coincide with the 2021 Census (see consortium memo to NISRA in Appendix 5).

Moreover, the data sources accessed in the current project represent only a few of the administrative data resources that provide information on the landscape of learning disability in NI. Ultimately, it would be important to strive towards collating and combining all available and relevant information at a regional-level to ensure that prevalence estimates of learning disability in NI are as accurate as possible. Indeed, there has been a surge in the use of the ‘capture-recapture method’ in epidemiological research in recent years for this specific purpose [1]. Although not without limitations [2], capture-recapture techniques have been used in attempts to estimate or adjust for the extent of incomplete ascertainment of cases (e.g. for specific health conditions or diseases such as alcohol use problems [3], using information from overlapping lists of cases derived from distinct sources. Whilst this method may well offer a potentially useful avenue for future intellectual disability research in NI, the potential utility of the capture-recapture method would largely depend on gaining access to data relating to the prevalence of intellectual disability from multiple different government and community/voluntary services and agencies (e.g. GP registers, Health and Social Care Trust data; community day service attendance; residential care homes and sheltered accommodation), which has historically proven difficult in an NI context.

7.3. Data access challenges

An important limitation of the current project (and one that will continue to undermine future administrative data research in NI if unaddressed) related to data accessibility. Data sources originally targeted for the current study included the Enhanced Prescribing Database (EPD), the Dental Payment System (DPS), and the Ophthalmic Claim System (OCS). However, due to data access restrictions relating to the Digital Economy Act (see Appendix 5), all data accessible via the GP Register (i.e. the EPD, DPS and OCS) became unavailable to the project team. Planned analyses and interrogation of data therefore relating to medical treatments/prescriptions and health care service utilisation among the learning disability population of Northern Ireland were not possible. For example, the team had originally proposed to conduct specific and tailored analyses of NI prescription data to investigate (i) the psychopharmacological treatment of the learning disability population in NI (e.g. how prevalent and in what context are certain antipsychotics prescribed for individuals with a learning disability?) and (ii) vaccination uptake/compliance among the learning disability population in NI (e.g. ethnic minority and low socio-economic status have each been evidenced to reduce health care access for LD individuals such as breast and cervical screening, female vaccination for HPV). Sadly, while these data exist, these important data linkages and analyses could not be demonstrated.

Access to such health and service use data is critical for the exploration of the health needs of the learning disability population. Deficiencies relating to access to health education, health promotion and screening, access to care, consent and overt discrimination can all negatively impact on the health of the learning disability population. A number of organizational barriers to accessing healthcare services, include, but are not limited to scarcity of services; physical barriers to access; failure to adequately provide reasonable adjustments due to lack of awareness of communication and literacy difficulties associated with learning disability; negative attitudes among healthcare staff and risk of diagnostic overshadowing. The current data access and linkage restrictions in NI therefore will need to be resolved in order to optimise the utility and potential of the new and improved future Census data on learning disability. During the project, the consortium explored whether NISRA could offer any clarity or assurances that such data linkage would be possible in time for the release of the next Census data in 2021 (see consortium memo to NISRA in Appendix 6).

7.4. Improving and promoting use of administrative data in the future

Given (i) the specificity complications of the extant 2011 Census learning disability survey item, (ii) the data access and linkage restrictions imposed by the Digital Economy Act, that currently prohibit important health and service use related analyses in NI, and (iii) the new and improved learning disability survey content that is to be included in the next NI Census; it became clear that the value of the current project lay not necessarily in what the consortium could learn about learning disability from extant administrative data in NI, but instead, what it could learn about administrative data utility and potential in time for the next NI Census. The consortium therefore attempted not only to demonstrate some of the linkages and analyses that are possible with administrative data relating to learning disability, but to highlight a range of issues faced by the consortium over the lifetime of the project that will hopefully help to improve and promote use of administrative data in the future (i.e. aim #2).

Four queries relating to the inclusion, framing and collection of learning disability data in the NI Censuses (past and future) arose over the course of the project. In an attempt to seek clarification on each, and to highlight important issues relating to future Census data collection, the consortium initiated correspondence with the Northern Ireland Census team (correspondence included in Appendix 6). Specifically, the consortium was interested to know more about (1) the origins and 'evolution' of the disability content in the Northern Ireland Censuses, (2) why learning disability is being framed/assessed in the forthcoming 2021 Census in the way that it is, (3) how the Census Team intend to ensure the correct and complete enumeration of individuals with learning disability living in particular residences and communal establishments on Census day and (4) how the Census Team aim to support individuals with learning disability to manage the changes in mode of administration of the 2021 Census. The background to and rationale for these specific queries is detailed here.

The first query related to the origins and history of the disability survey items in the 2011 Census. This served to (a) provide an evidence base relating to the design features and decision making surrounding the disability content of the NI 2011 Census (particularly the learning disability content), (b) track the origins and change of this content and (c) provide some clarity on the rationale behind disability assessment in general, and learning disability more specifically, in the NI Censuses.

1. Nature of long-term health conditions question in 2011 Census in Northern Ireland

A significant change to the content of the 2011 Census was the addition of a question to collect data on the ‘nature of any long-term health conditions’ experienced by the people of Northern Ireland [4]. This new question was piloted in the 2007 Census Test questionnaire as a ‘long-standing health conditions’ question and comprised seven response categories including ‘*a learning difficulty*’ [5]. Despite the 2007 Census Test Evaluation indicating that the new question used language that was too complex and imposed a high cognitive burden on respondents [6], the question was subsequently expanded in the 2009 Census Rehearsal to cover 12 categories, and the response category for ‘*a learning difficulty*’ was extended to cover ‘*a learning difficulty, an intellectual difficulty, or a social or behavioural difficulty*’. Evidence from the 2011 Census proposal document [7] suggests the expanded question was “*intended to align the response categories in a census question, as far as possible, with the list of activity limitations and disabilities used in NISALD [2006-07 Northern Ireland Survey of Activity Limitation and Disability] [7, p.43].* Unlike the NISALD which assessed in detail the public’s experiences of a learning difficulty, an intellectual difficulty and/or a social or behavioural difficulty, the 2011 Census combined these health conditions into a single tick-box response [of note, the only other health conditions to be combined in the Census were mobility and dexterity issues – both of which were assessed separately in NISALD]. The following query was put to the NI Census Team.

Query 1: What was the rationale for combining the long-term health conditions of ‘*a learning difficulty, an intellectual difficulty, or a social or behavioural difficulty’* into a single response category in the 2011 NI Census?

The second query related to the change in learning disability assessment in the forthcoming 2021 Census. NI Census proposals for 2021 indicated that NI citizens will be afforded the opportunity to officially and specifically report the presence of ‘An intellectual or learning disability (for example Down syndrome)’. Moreover, specific separate options to also record ‘A learning difficulty (for example dyslexia)’ and/or ‘Autism or Asperger syndrome’ will further enhance the specificity and improve the measurement of learning disability in the next NI Census. This query served to secure clarification on and document the rationale and specific decision-making surrounding the particular design features and formatting of this new Census disability content.

2. Nature of long-term health conditions question in 2021 Census in Northern Ireland

The 2021 Census Topic Consultation for NI [8] process reaffirmed the importance of collecting health data in the Census, but also highlighted the need to collect additional information on the nature of long-term health conditions experienced by the population. At that time, it was proposed to conduct "*further research and testing to see whether these needs can be accommodated within the confines of the Census*" (p.11). The 2017 Census Test questionnaires [9] included an extended question on the nature of long-term health conditions question (Q15) which disaggregated intellectual or learning disability from a learning difficulty and Autism or Asperger's Syndrome. In addition, the learning difficulty category was supported by an example of dyslexia or ADHD, whereas the intellectual disability category contained Down's Syndrome as an example. It is was reported that "*the response categories have been updated to take account of changing user needs and to streamline with international definitions to promote standardisation. In particular, a new separate category has been included for Autism or Asperger syndrome to develop a baseline on the prevalence of these conditions"* [10, p.31]. The following query was put to the NI Census Team.

Query 2: What was the rationale for the change in the measurement of learning difficulty and intellectual disability in the 2021 Census?

The third query related to a more practical issue relating to the administration of the next Census. Specifically, the consortium wished to establish (i) whether the Census Team were aware of the various supported living settings that commonly characterise the residential status of individuals with a learning disability in NI and (ii) whether all individuals with a learning disability in NI would be adequately supported to complete the Census and enumerated correctly.

3. Communal Establishments in 2021 NI Census

The 2021 Census Proposals Document [10] outlined plans to produce a complete census address register of every household and communal establishment in NI, using data from a range of sources including the POINTER address register, public bodies and a range of organisations. Although the definition for large communal establishments is clear, and there are plans to have a dedicated team of communal establishment enumerators to manage this sector, concerns were raised by members of our consortium regarding the definition of smaller communal establishments (e.g. supported living arrangements / shared lives services (people with a learning disability living on a long term basis, with individuals / families, other than their own family) / short break services to include family settings) and the correct and complete enumeration of individuals with learning disability living in such communal establishments on Census day. The following query was put to the NI Census Team.

Query 3: What processes are in place to ensure that individuals with learning disability living in all types of residence will be enumerated correctly on Census day 2021?

The fourth and final query also related to a more practical/logistical issue relating to the administration of the next Census. Specifically, the consortium, in recognition of the move to online Census completion for the next Census, sought to establish what considerations had been given and preparations made to support members of the population with a learning disability to successfully complete the 2021 Census.

4. Mode of administration in 2021 Census in NI

The 2021 Census Proposal Document [10] outlined ambitious plans for the Census to be conducted predominantly online; specifically, it is anticipated that 90% of households will receive an initial contact letter with a unique code to complete the Census online, and there is a target for 60% of households to return their data electronically. Although there are provisions for a range of support services to assist the public with this change in mode of administration before the Census (e.g. Stakeholder Engagement and Communication Strategies) and on Census day (e.g. contact centre; online webchat help facilities), concerns were raised by members of our consortium as to the ability of individuals with a range of difficulties associated with learning disability, and in particular those who are living in smaller communal establishments, to be able to navigate these changes. The following query was put to the NI Census Team.

Query 4: What considerations have been given to supporting individuals with learning disability to manage the changes in mode of administration of the Census?

The responses to these queries and a number of follow-up queries are detailed in Appendix 6. It is hoped that this exchange proves useful both to those responsible for the correct enumeration of the NI learning disability population at the next Census (and for future Censuses) and those who might continue this research once the new Census data (and other administrative data sources) becomes available. Early signs are positive, in that the NI Census Team have already begun to engage with project partners to ensure that the learning disability population will be adequately supported at the next Census (see Census Team correspondence with Positive Futures in Appendix 8).

7.5. Conclusion

A burgeoning international research literature continues to detail the extreme disadvantages that are disproportionately faced by those in society with a learning disability. Worryingly, this extreme population-specific disadvantage is further and significantly compounded by the fact that those with a learning disability, in many countries, remain unseen. Learning disability specifically, at a population level, has either remained unrecorded and undetected or has been camouflaged/hidden/buried within general health data, that have referred to limitations in day-to-day activities or inability to work as a result of health problems or disability.

The future import and potential of the sources of data outlined in the current project for informing the assessment of need of people with learning disabilities, healthcare planning and government policy in NI therefore cannot be understated. The United Nations Convention on the Rights of People with Disabilities requires States Parties to commit to the collection of appropriate information, including statistical and research data to enable them to formulate and implement policies to give effect to the Convention [11]. According to Glover [12] ‘if an issue is both visible and quantifiable in official statistics, it becomes much harder for public bodies locally and nationally to ignore.’ (p.15). In other countries, data linkage approaches have provided the basis for the type of service use and needs assessment work that is fundamental to reviewing healthcare policy [e.g. 13, 14]. Once Northern Ireland’s new and improved Census 2021 learning disability indicator comes ‘on line’, a variety of other administrative data resources hopefully will unlock the full policy potential of this more explicit and specific learning disability measure (e.g. national mortality statistics, health service data, education data).

We hope that these findings will (i) highlight the availability, utility and import of learning disability data in NI, (ii) promote and stimulate future use of this data in the region, (iii) incentivise those in power to facilitate NI data custodians to share/link available learning disability relevant data where possible and (iv) lay some useful foundations for the more advanced and sophisticated learning disability statistical modelling that will be possible in the years to come and the policy changes that will emerge as a consequence.

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Appendices

Appendix 1: Tabled information for Section 3

Table 3.1. Sex and age distribution by LD status for total Census sample (N=1,723,180)

		No health conditions n=1,173,565	Single health Condition		Multiple health Condition		Total N=1,723,180
			LD indicator endorsed n=12,954	LD indicator not endorsed n=288,843	LD indicator endorsed n=24,349	LD indicator not endorsed n=223,469	
Sex	Male	575,052	9,142	140,169	15,425	97,040	836,828
	Female	598,513	3,812	148,674	8,924	126,429	886,352
Age	0-15 years	310,756	6,453	28,642	7,119	2,814	355,784
	16-24 years	174,133	3,210	22,282	3,819	3,906	207,350
	25-34 years	187,803	1,322	29,082	2,731	8,683	229,621
	35-44 years	177,553	782	39,742	2,818	19,597	240,492
	45-54 years	153,858	656	48,464	3,092	35,112	241,182
	55-64 years	94,877	311	47,106	2178	45,247	189,719
	65 years+	74,585	220	73,525	2,592	108,110	259,032

LD = Learning Disability

Table 3.2. Sex and age distribution by LD status for household sub-sample (N=1,702,217) and communal establishments sub-sample (N=20,963)

		No health conditions		Single health Condition				Multiple health Conditions				
		n=1,173,565		LD indicator endorsed n=12,954		LD indicator not endorsed n=288,843		LD indicator endorsed n=24,349		LD indicator not endorsed n=223,469		Total N=1,723,180
		HH n=1,168,020	COM n=5,545	HH n=12,526	COM n=428	HH n=285,424	COM n=3,419	HH n=21,875	COM n=2,474	HH n=214,372	COM n=9,097	
Sex	Male	571,773	3,279	8,880	262	138,766	1,403	14,228	1,197	94,285	2,755	836,828
	Female	596,247	2,266	3,646	166	146,658	2,016	7,647	1,277	120,087	6,342	886,352
Age	0-15 years	310,486	270	6,436	17	#	#	7,094	25	#	#	355,784
	16-24 years	170,421	3,712	3,083	127	#	#	3,717	102	#	#	207,350
	25-34 years	186,984	819	1,293	29	28,909	173	2,587	144	8,604	79	229,621
	35-44 years	177,291	262	728	54	39,569	173	2,532	286	19,452	145	240,492
	45-54 years	153,682	176	573	83	48,235	229	2,657	435	34,854	258	241,182
	55-64 years	94,777	100	252	59	46,897	209	1,755	423	44,901	346	189,719
	65 years+	74,379	206	161	59	71,433	2,092	1,533	1,059	99,955	8,155	259,032

HH=Household; COM=Communal Establishment; # = information has been suppressed as values would be disclosive

Table 3.3. NIMDM decile by LD status for total Census sample (N=1,723,180)

		No health conditions n=1,173,565	Single health Condition		Multiple health Condition		Total N=1,723,180
			LD indicator endorsed n=12,954	LD indicator not endorsed n=288,843	LD indicator endorsed n=24349	LD indicator not endorsed n=223,469	
MDM	1ST	93,004	1,645	27,281	3,670	29,592	155,192
	2ND	105,013	1,542	28,794	3,136	26,928	165,413
	3RD	109,985	1,281	29,501	2,644	24,890	168,301
	4TH	122345	1431	31,054	3,011	24,922	182,763
	5TH	120154	1303	28,749	2,429	21,653	174,288
	6TH	133138	1366	30,289	2,445	21,699	188,937
	7TH	122687	1159	28,920	2,102	20,164	175,032
	8TH	129431	1190	29,785	1,897	19,663	181,966
	9TH	121659	1057	28,098	1,571	18,115	170,500
	10TH	116149	980	26,372	1,444	15,843	160,788

MDM=Multiple Deprivation Measure; 1st – 10th = MDM deciles where 1st = highest deprivation index and 10th = lowest deprivation index

Table 3.4. Living status and activity limitation by LD status for total Census sample (N=1,723,180)

		No health conditions n=1,166,372	Single health Condition		Multiple health Condition		Total N=1,700,378
			LD indicator endorsed n=12,516	LD indicator not endorsed n=285,279	LD indicator endorsed n=21,870	LD indicator not endorsed n=214,341	
Living arrangements	Lives alone	81,473	703	48,377	3,466	59,828	193,847
	In a couple	469,255	672	143,693	2,379	110,181	726,180
	Other	615,644	11,141	93,209	16,025	44,332	780,351
		n=1,173,565	n=12,954	n=288,843	n=24349	n=223,469	N=1,723,180
Disability	Limited a lot	2,111	2,435	46,291	16,542	141,533	208,912
	Limited a	7,720	3,743	80,698	4,882	57,374	154,417
	Not limited	1,163,734	6,776	16,1854	2,925	24,562	1,359,851

Table 3.5. Ethnicity and Settlement band residence by LD status for total Census sample (N=1,723,180)

			No health conditions n=1,162,852	Single health Condition		Multiple health Condition		Total N=1,708,825
				LD indicator endorsed n=12,824	LD indicator not endorsed n=286,925	LD indicator endorsed n=24,021	LD indicator not endorsed n=222,203	
Ethnicity		White	1,137,865	12,660	283,794	23,683	220,962	1,678,964
		Non-white	24987 (2.1%)	164 (1.3%)	3,131 (1.1%)	338 (1.4%)	1241 (0.6%)	29,861
			n=1,173,565	n=12,954	n=288,843	n=24349	n=223,469	N=1,723,180
Settlement	City	BMUA	369,794	4,488	96,097	8,565	80,314	559,258
		DUA	54,409	745	14,567	1,422	12,670	83,813
	Town	Large Town	153,082	1,771	39,636	3,405	31,599	229,493
		Medium	67,878	806	17,038	1,704	13,675	101,101
		Small Town	69,278	787	17,991	1,467	13,745	103,268
	Rural	Int Settlement	48,495	496	11,565	828	8,372	69,756
		Village	48,195	558	12,450	1,035	9,587	71,825
		SV,H&OC	349,721	3,173	77,581	5,595	52,241	488,311
	XXX		12,713	130	1,918	328	1,266	16,355

BMUA=Belfast Metropolitan Urban Area; DUA=Derry Urban Area; Int Settlement= Intermediate Settlement; SV,H&OC=Small Village, Hamlet & Open Countryside; LD=Learning Disability indicator; XXX=unclassified

Table 3.6a. Belfast HSCT (N=319,233)

		Single Condition LD indicator endorsed n=2645		Multiple Condition LD indicator endorsed n=5421		Total LD N=8,066	
		n	%	n	%	n	%
Sex	Male	1852	70.0%	3419	63.1%	5271	65.3
	Female	793	30.0%	2002	36.9%	2795	34.7
Age	0-15 years	1335	50.5%	1562	28.8%	2897	35.9
	16-24 years	616	23.3%	851	15.7%	1467	18.2
	25-34 years	322	12.2%	576	10.6%	898	11.1
	35-44 years	150	5.7%	589	10.9%	739	9.2
	45-54 years	129	4.9%	742	13.7%	871	10.8
	55-64 years	50	1.9%	495	9.1%	545	6.8
	65 years+	43	1.6%	606	11.2%	649	8.0
MDM	1ST	925	35.0%	2235	41.2%	3160	39.2
	2ND	338	12.8%	733	13.5%	1071	13.3
	3RD	154	5.8%	317	5.8%	471	5.8
	4TH	200	7.6%	451	8.3%	651	8.1
	5TH	62	2.3%	97	1.8%	159	2.0
	6TH	150	5.7%	263	4.9%	413	5.1
	7TH	169	6.4%	334	6.2%	503	6.2
	8TH	114	4.3%	191	3.5%	305	3.8
	9TH	220	8.3%	310	5.7%	530	6.6
	10TH	313	11.8%	490	9.0%	803	9.9
Ethnicity	White	2591	98%	5320	98.1%	7911	98.1%
	Non-White	54	2%	101	1.9%	155	1.9%
Disability	Limited a lot	485	18.3%	3789	69.9%	4274	53.0
	Limited a little	763	28.8%	1016	18.7%	1779	22.1
	Not limited	1397	52.8%	616	11.4%	2013	24.9
Residence	Household	2573	97.3%	4927	90.9%	7500	93.0
	Com-Est.	72	2.7%	494	9.1%	566	7.0
Employment	Working	467	17.7%	481	8.9%	948	11.7
	Unemployed	143	5.4%	142	2.6%	285	3.5
	Student	274	10.4%	352	6.5%	626	7.8
	Retired	29	1.1%	508	9.4%	537	6.7
	Sick/Disabled	236	8.9%	2054	37.9%	2290	28.4
	Homekeeper	47	1.8%	54	1.0%	101	1.3
	Other	114	4.3%	268	4.9%	382	4.7
	XX	1335	50.5%	1562	28.8%	2897	35.9

Table 3.6b. Northern HSCT (N=437,648)

		Single Condition LD indicator endorsed n=3009		Multiple Condition LD indicator endorsed n=5473		Total LD N=8482	
		n	%	n	%	n	%
Sex	Male	2124	70.6%	3440	62.9%	5564	65.6
	Female	885	29.4%	2033	37.1%	2918	34.4
Age	0-15 years	1503	50.0%	1640	30.0%	3143	37.1
	16-24 years	734	24.4%	841	15.4%	1575	18.6
	25-34 years	287	9.5%	605	11.1%	892	10.5
	35-44 years	180	6.0%	581	10.6%	761	8.9
	45-54 years	171	5.7%	691	12.6%	862	10.2
	55-64 years	79	2.6%	494	9.0%	573	6.8
	65 years+	55	1.8%	621	11.3%	676	7.9
MDM	1ST	44	1.5%	84	1.5%	128	1.5
	2ND	352	11.7%	672	12.3%	1024	12.1
	3RD	332	11.0%	715	13.1%	1047	12.3
	4TH	318	10.6%	612	11.2%	930	11.0
	5TH	442	14.7%	831	15.2%	1273	15.0
	6TH	330	11.0%	603	11.0%	933	11.0
	7TH	292	9.7%	571	10.4%	863	10.2
	8TH	378	12.6%	647	11.8%	1025	12.1
	9TH	319	10.6%	454	8.3%	773	9.1
	10TH	202	6.7%	284	5.2%	486	5.7
Ethnicity	White	2978	99%	5429	99.2%	8407	99.1%
	Non-White	31	1%	44	0.8%	75	.9%
Disability	Limited a lot	601	20.0%	3727	68.1%	4328	51.0
	Limited a	896	29.8%	1102	20.1%	1998	23.6
	Not limited	1512	50.2%	644	11.8%	2156	25.4
Residence	Household	2903	96.5%	4876	89.1%	7779	91.7
	Com-Est.	106	3.5%	597	10.9%	703	8.3
Employment	Working	526	17.5%	505	9.2%	1031	12.2
	Unemployed	164	5.5%	142	2.6%	306	3.6
	Student	311	10.3%	333	6.1%	644	7.6
	Retired	34	1.1%	539	9.8%	573	6.8
	Sick/Disabled	319	10.6%	1984	36.3%	2303	27.2
	Homekeeper	29	1.0%	68	1.2%	97	1.1
	Other	123	4.1%	262	4.8%	385	4.5
	XX	1503	50.0%	1640	30.0%	3143	37.0

Table 3.6c. South Eastern HSCT (N=330,009)

		Single Condition LD indicator endorsed n=2754		Multiple Condition LD indicator endorsed n=4528		Total LD N=7,282	
		n	%	n	%	n	%
Sex	Male	1980	71.9%	2870	63.4%	4850	66.6
	Female	774	28.1%	1658	36.6%	2432	33.4
Age	0-15 years	1444	52.4%	1462	32.3%	2906	39.9
	16-24 years	648	23.5%	702	15.5%	1350	18.5
	25-34 years	268	9.7%	474	10.5%	742	10.2
	35-44 years	163	5.9%	512	11.3%	675	9.3
	45-54 years	125	4.5%	498	11.0%	623	8.6
	55-64 years	62	2.3%	371	8.2%	433	5.9
	65 years+	44	1.6%	509	11.2%	553	7.6
MDM	1ST	245	8.9%	440	9.7%	685	9.4
	2ND	170	6.2%	316	7.0%	486	6.7
	3RD	204	7.4%	381	8.4%	585	8.0
	4TH	318	11.5%	601	13.3%	919	12.6
	5TH	218	7.9%	379	8.4%	597	8.2
	6TH	265	9.6%	443	9.8%	708	9.7
	7TH	222	8.1%	324	7.2%	546	7.5
	8TH	399	14.5%	562	12.4%	961	13.2
	9TH	319	11.6%	475	10.5%	794	10.9
	10TH	394	14.3%	607	13.4%	1001	13.8
Ethnicity	White	2730	99.1%	4470	98.7%	7200	98.9%
	Non-White	24	0.9%	58	1.3%	82	1.1%
Disability	Limited a lot	473	17.2%	3020	66.7%	3493	48.0
	Limited a	837	30.4%	949	21.0%	1786	24.5
	Not limited	1444	52.4%	559	12.3%	2003	27.5
Residence	Household	2660	96.6%	3987	88.1%	6647	91.3
	Com-Est.	94	3.4%	541	11.9%	635	8.7
Employment	Working	465	16.9%	447	9.9%	912	12.5
	Unemployed	167	6.1%	128	2.8%	295	4.1
	Student	274	9.9%	325	7.2%	599	8.2
	Retired	37	1.3%	439	9.7%	476	6.5
	Sick/Disabled	231	8.4%	1494	33.0%	1725	23.7
	Homekeeper	36	1.3%	55	1.2%	91	1.3
	Other	100	3.6%	178	3.9%	278	3.8
	XX	1444	52.4%	1462	32.3%	2906	39.9

Table 3.6d. Southern HSCT (N=338,157)

		Single Condition LD indicator endorsed n=2243		Multiple Condition LD indicator endorsed n=4445		Total LD N=6,688	
		n	%	n	%	n	%
Sex	Male	1582	70.5%	2833	63.7%	4415	66.0
	Female	661	29.5%	1612	36.3%	2273	34.0
Age	0-15 years	1114	49.7%	1281	28.8%	2395	35.8
	16-24 years	550	24.5%	708	15.9%	1258	18.8
	25-34 years	208	9.3%	484	10.9%	692	10.3
	35-44 years	162	7.2%	534	12.0%	696	10.4
	45-54 years	111	4.9%	590	13.3%	701	10.5
	55-64 years	63	2.8%	429	9.7%	492	7.4
	65 years+	35	1.6%	419	9.4%	454	6.8
MDM	1ST	65	2.9%	140	3.1%	205	3.1
	2ND	337	15.0%	750	16.9%	1087	16.3
	3RD	266	11.9%	562	12.6%	828	12.4
	4TH	250	11.1%	582	13.1%	832	12.4
	5TH	356	15.9%	700	15.7%	1056	15.8
	6TH	315	14.0%	569	12.8%	884	13.2
	7TH	312	13.9%	573	12.9%	885	13.2
	8TH	150	6.7%	274	6.2%	424	6.3
	9TH	151	6.7%	250	5.6%	401	6.0
	10TH	41	1.8%	45	1.0%	86	1.3
Ethnicity	White	2213	98.7%	4373	98.4%	6586	98.5%
	Non-White	30	1.3%	72	1.6%	102	1.5%
Disability	Limited a lot	477	21.3%	3031	68.2%	3508	52.5
	Limited a	633	28.2%	879	19.8%	1512	22.6
	Not limited	1133	50.5%	535	12.0%	1668	24.9
Residence	Household	2183	97.3%	4056	91.2%	6239	93.3
	Com-Est.	60	2.7%	389	8.8%	449	6.7
Employment	Working	341	15.2%	429	9.7%	770	11.5
	Unemployed	123	5.5%	123	2.8%	246	3.7
	Student	247	11.0%	293	6.6%	540	8.1
	Retired	35	1.6%	361	8.1%	396	5.9
	Sick/Disabled	264	11.8%	1673	37.6%	1937	29.0
	Homekeeper	25	1.1%	49	1.1%	74	1.1
	Other	94	4.2%	236	5.3%	330	4.9
	XX	1114	49.7%	1281	28.8%	2395	35.8

Table 3.6e. Western HSCT (N=273,378)

		Single Condition LD indicator endorsed n=2169		Multiple Condition LD indicator endorsed n=4305		Total LD N=6,474	
		n	%	n	%	n	%
Sex	Male	1524	70.3%	2754	64.0%	4278	66.1
	Female	645	29.7%	1551	36.0%	2196	33.9
Age	0-15 years	1022	47.1%	1132	26.3%	2154	33.3
	16-24 years	603	27.8%	668	15.5%	1271	19.6
	25-34 years	213	9.8%	557	12.9%	770	12.0
	35-44 years	117	5.4%	585	13.6%	702	10.8
	45-54 years	117	5.4%	556	12.9%	673	10.4
	55-64 years	55	2.5%	381	8.9%	436	6.7
	65 years+	42	1.9%	426	9.9%	468	7.2
MDM	1ST	347	16.0%	748	17.4%	1095	16.9
	2ND	327	15.1%	645	15.0%	972	15.0
	3RD	313	14.4%	645	15.0%	958	14.8
	4TH	339	15.6%	747	17.4%	1086	16.8
	5TH	214	9.9%	400	9.3%	614	9.5
	6TH	295	13.6%	543	12.6%	838	12.9
	7TH	156	7.2%	290	6.7%	446	7.0
	8TH	136	6.3%	211	4.9%	347	5.4
	9TH	-	-	-	-	-	-
	10TH	-	-	-	-	-	-
Ethnicity	White	2150	99.1%	4254	98.8%	6404	98.9%
	Non-White	19	0.9%	51	1.2%	70	1.1
Disability	Limited a lot	382	17.6%	2887	67.1%	3269	50.5
	Limited a	592	27.3%	895	20.8%	1487	23.0
	Not limited	1195	55.1%	523	12.1%	1718	26.5
Residence	Household	2097	96.7%	3870	89.9%	5967	92.2
	Com-Est.	72	3.3%	435	10.1%	507	7.8
Employment	Working	337	15.5%	378	8.8%	715	11.0
	Unemployed	164	7.6%	155	3.6%	319	4.9
	Student	261	12.0%	309	7.2%	570	8.8
	Retired	19	0.9%	315	7.3%	334	5.2
	Sick/Disabled	212	9.8%	1710	39.7%	1922	29.7
	Homekeeper	29	1.3%	64	1.5%	93	1.4
	Other	125	5.8%	242	5.6%	367	5.7
	XX	1022	47.1%	1132	26.3%	2154	33.3

Appendix 2: Tabled information for Section 4

Count data for **Figure 4.1**

	No health conditions n=1,173,565	Single health Condition		Multiple health Condition	
		LD indicator endorsed n=12,954	LD indicator not endorsed n=288,843	LD indicator endorsed n=24,349	LD indicator not endorsed n=223,469
General health Good/Very Good	1,117,016	10,919	176,070	9,003	38,262
General health Fair	44,508	1,742	94,700	9,203	108,878
General health Bad/Very Bad	1,328	163	16,155	5,815	75,063
Missing	10,713	130	1,918	328	96,484

Count data for **Figure 4.2a**

	Breath	Illness	Pain	Mobility	Memory	Deafness	Comms	Mental	Blindness	Other
LD endorsed	1,687	655	468	2,379	319	564	1,862	4,729	6,008	6,677
LD not endorsed	1,638	496	659	1,067	46	382	1,512	482	149	198

Count data for **Figure 4.2b**

	Breath	Illness	Pain	Mobility	Memory	Deafness	Comms	Mental	Blindness	Other
LD endorsed	1,687 4,134	655 3,672	468 5,212	2,379 8,969	319 4,341	564 2,653	1,862 3,209	4,729 9,171	6,008 7,882	6,677 1,882
LD not endorsed	1,638 7,830	496 69,393	659 139,873	1,067 157,838	46 27,404	382 58,052	1,512 42,659	482 12,035	149 56,629	198 21,246

Count data for **Figure 4.3a**

	Breath	Illness	Pain	Mobility	Memory	Deafness	Comms	Mental	Blindness	Other
Belfast	414	118	102	505	58	107	1010	295	81	401
Northern	369	164	101	526	94	134	1096	253	98	414
South Eastern	325	130	94	445	62	93	953	219	75	395
Southern	267	135	95	481	58	114	895	162	87	359
Western	305	104	72	410	44	109	747	173	98	287

Count data for **Figure 4.3b**

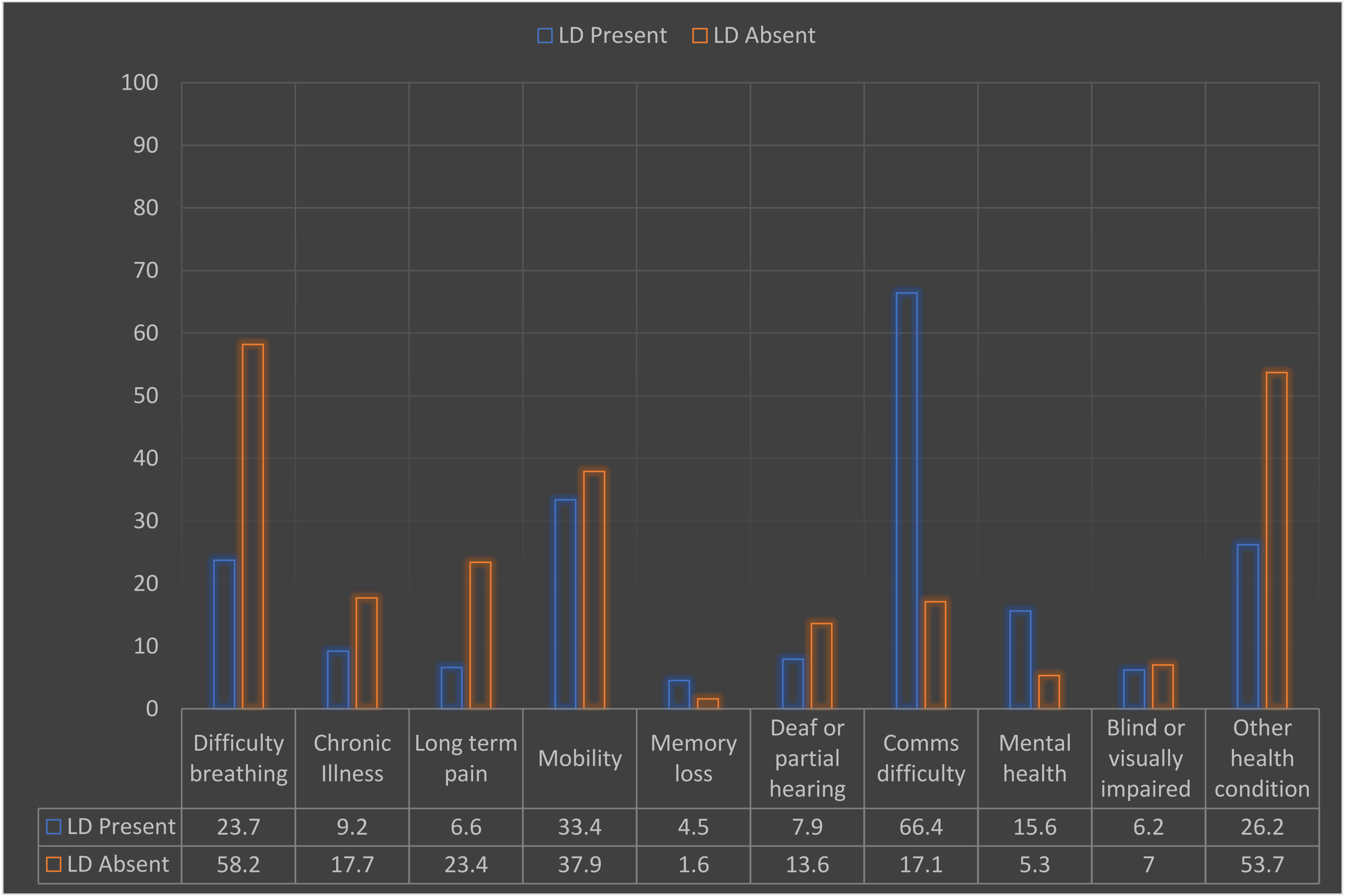
	Breath	Illness	Pain	Mobility	Memory	Deafness	Comms	Mental	Blindness	Other
Belfast	1,078	773	1,371	1,973	1,175	633	1,953	2,006	436	740
Northern	884	891	1,064	2,006	876	608	2,146	1,577	412	675
South Eastern	644	712	916	1,588	790	484	1,602	1,306	324	577
Southern	711	619	904	1,680	762	465	1,805	1,390	364	591
Western	778	654	920	1,672	708	433	1,614	1,486	332	602

Table 4.1 Socio-economic and demographic indicators of poor (bad/very bad) general health. Reference category = good/very good general health

	No health conditions		**Single health condition**				**Multiple health condition**			
	n=1,173,565		LD indicator endorsed n=12,954		LD indicator not endorsed n=288,843		LD indicator endorsed n=24,349		LD indicator not endorsed n=223,469	
	OR	(95% CI)	OR	(95% CI)	OR	(95% CI)	OR	(95% CI)	OR	(95% CI)
Male	**1.23**	**(1.10-1.37)**	.87	(.62-1.22)	.98	(.94-1.02)	**.91**	**(.84-.99)**	**.93**	**(.90-.96)**
(Sex – Reference Category = Female)										
0-15 years	**.24**	**(.19-.30)**	**.11**	**(.05-.21)**	**.29**	**(.26-.33)**	**.04**	**(.03-.04)**	**.33**	**(.29-.38)**
16-24 years	**.33**	**(.26-.42)**	**.15**	**(.07-.32)**	**.58**	**(.53-.64)**	**.08**	**(.07-.09)**	**.73**	**(.66-.82)**
25-34 years	**.43**	**(.35-54)**	**.29**	**(.14-.61)**	.94	(.87-1.01)	**.16**	**(.14-.20)**	**1.34**	**(1.24-1.44)**
35-44 years	**.64**	**(.52-.78)**	.61	(.30-1.25)	**1.35**	**(1.27-1.43)**	**.33**	**(.28-.39)**	**1.76**	**(1.66-1.85)**
45-54 years	**.74**	**(.61-.90)**	.82	(.40-1.67)	**1.66**	**(1.57-1.75)**	**.46**	**(.39-.55)**	**2.32**	**(2.22-2.42)**
55-64 years	1.1	(.90-1.34)	1.00	(.45-2.25)	**1.68**	**(1.59-1.78)**	**.56**	**(.47-.68)**	**2.13**	**(2.05-2.22)**
(Age – Reference Category = 65 years +)										
Non-White	**3.09**	**(2.43-3.94)**	**3.59**	**(1.22-10.53)**	**1.65**	**(1.37-1.99)**	1.34	(.97-1.84)	**1.40**	**(1.15-1.70)**
(Ethnicity – White)										
Communal Est	**3.01**	**(1.81-5.00)**	.68	(.34-1.37)	.76	(.66-.87)	**.17**	**(.15-.20)**	**.60**	**(.56-.64)**
(Residence – Reference Category = Household)										
BMUA	**1.49**	**(1.27-1.75)**	.89	(.54-1.46)	**1.19**	**(1.12-1.25)**	**1.28**	**(1.14-1.43)**	**1.22**	**(1.17-1.27)**
DUA	.80	(.59-1.08)	.60	(.26-1.39)	1.04	(.95-1.34)	1.11	(.92-1.34)	.99	(.92-1.07)
Large Town	**1.39**	**(1.15-1.68)**	.90	(.51-1.60)	**1.16**	**(1.09-1.23)**	1.07	(.93-1.22)	**1.14**	**(1.09-1.20)**
Medium Town	1.09	(.84-1.43)	.67	(.31-1.45)	**1.09**	**(1.01-1.19)**	**1.30**	**(1.10-1.54)**	1.03	(.96-1.10)
Small Town	**1.36**	**(1.06-1.76)**	.97	(.46-1.04)	1.03	(.94-1.12)	**1.20**	**(1.01-1.43)**	1.01	(.94-1.08)
Int Settlement	**1.43**	**(1.06-1.93)**	1.39	(.59-3.26)	**1.14**	**(1.03-1.26)**	.95	(.75-1.20)	**1.15**	**(1.06-1.24)**
Village	1.30	(.96-1.76)	1.98	(.96-4.08)	**1.22**	**(1.11-1.34)**	**1.23**	**(1.00-1.50)**	**1.12**	**(1.03-1.21)**
(Settlement - Reference Category = Small village, hamlet and open countryside)										
1st decile	**4.98**	**(3.77-6.57)**	**3.98**	**(1.61-9.82)**	**4.34**	**(3.93-4.78)**	**2.78**	**(2.29-3.38)**	**3.86**	**(3.60-4.15)**
2nd decile	**3.65**	**(2.74-4.86)**	**2.73**	**(1.09-6.87)**	**3.16**	**(2.86-3.50)**	**1.88**	**(1.54-2.29)**	**2.86**	**(2.67-3.07)**
3rd decile	**2.62**	**(1.94-3.54)**	1.83	(.70-4.81)	**2.69**	**(2.43-2.97)**	**1.62**	**(1.32-1.99)**	**2.29**	**(2.13-2.46)**
4th decile	**2.31**	**(1.71-3.13)**	1.60	(.59-4.35)	**2.34**	**(2.11-2.59)**	**1.61**	**(1.31-1.97)**	**2.17**	**(2.02-2.33)**

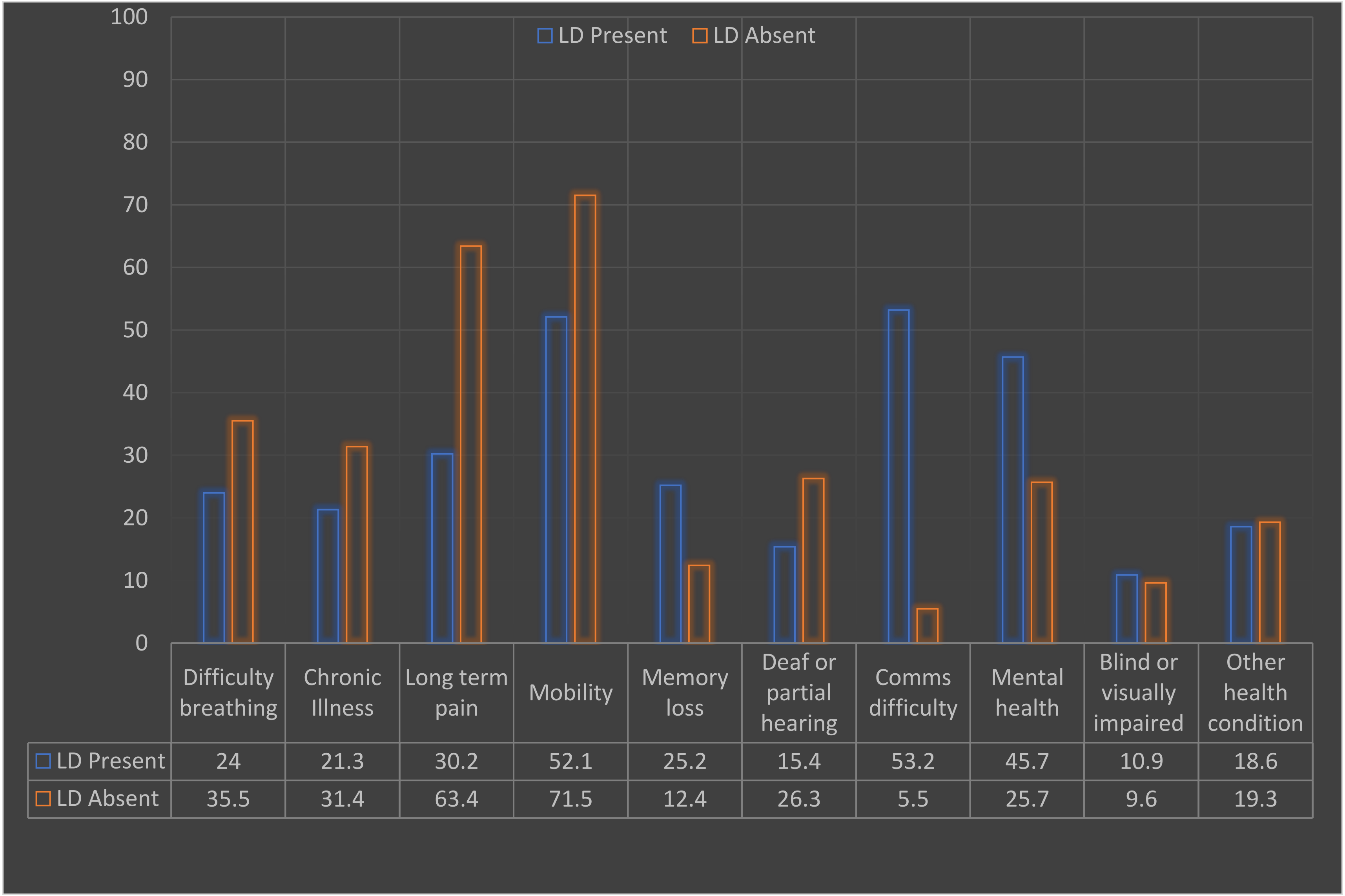
5th decile	**1.57**	**(1.13-2.17)**	2.20	(.85-5.69)	**2.03**	**(1.83-2.56)**	**1.28**	**(1.04-1.57)**	**1.89**	**(1.75-2.03)**
6th decile	**2.29**	**(1.70-3.10)**	2.37	(.92-6.13)	**1.89**	**(1.70-2.10)**	**1.41**	**(1.15-1.74)**	**1.83**	**(1.71-1.97)**
7th decile	**2.01**	**(1.48-2.73)**	1.51	(.56-4.10)	**1.80**	**(1.62-2.00)**	**1.29**	**(1.05-1.60)**	**1.61**	**(1.49-1.73)**
8th decile	**2.00**	**(1.47-2.70)**	.57	(.17-1.94)	**1.58**	**(1.42-1.76)**	1.13	(.91-1.41)	**1.47**	**(1.36-1.58)**
9th decile	1.31	(.94-1.81)	.29	(.06-1.47)	**1.25**	**(1.12-1.40)**	1.01	(.81-1.27)	**1.24**	**(1.16-1.34)**
(MDM – Reference Category = 10th decile)										
Limited a lot	**177.85**	**(151.09-209.34)**	**22.78**	**(12.93-40.12)**	**176.96**	**(165.19-189.57)**	**18.48**	**(15.29-22.32)**	**138.76**	**(129.31-148.9)**
Limited a little	**13.81**	**(10.94-17.43)**	**4.68**	**(2.50-8.74)**	**9.60**	**(8.92-10.33)**	**2.15**	**(1.73-2.68)**	**6.08**	**(6.08-7.04)**
(Disability – Reference Category = Not limited)										

Figure 4.2a Comorbidity under 16 years (LD absent n=2,814) (LD present n=7,119)



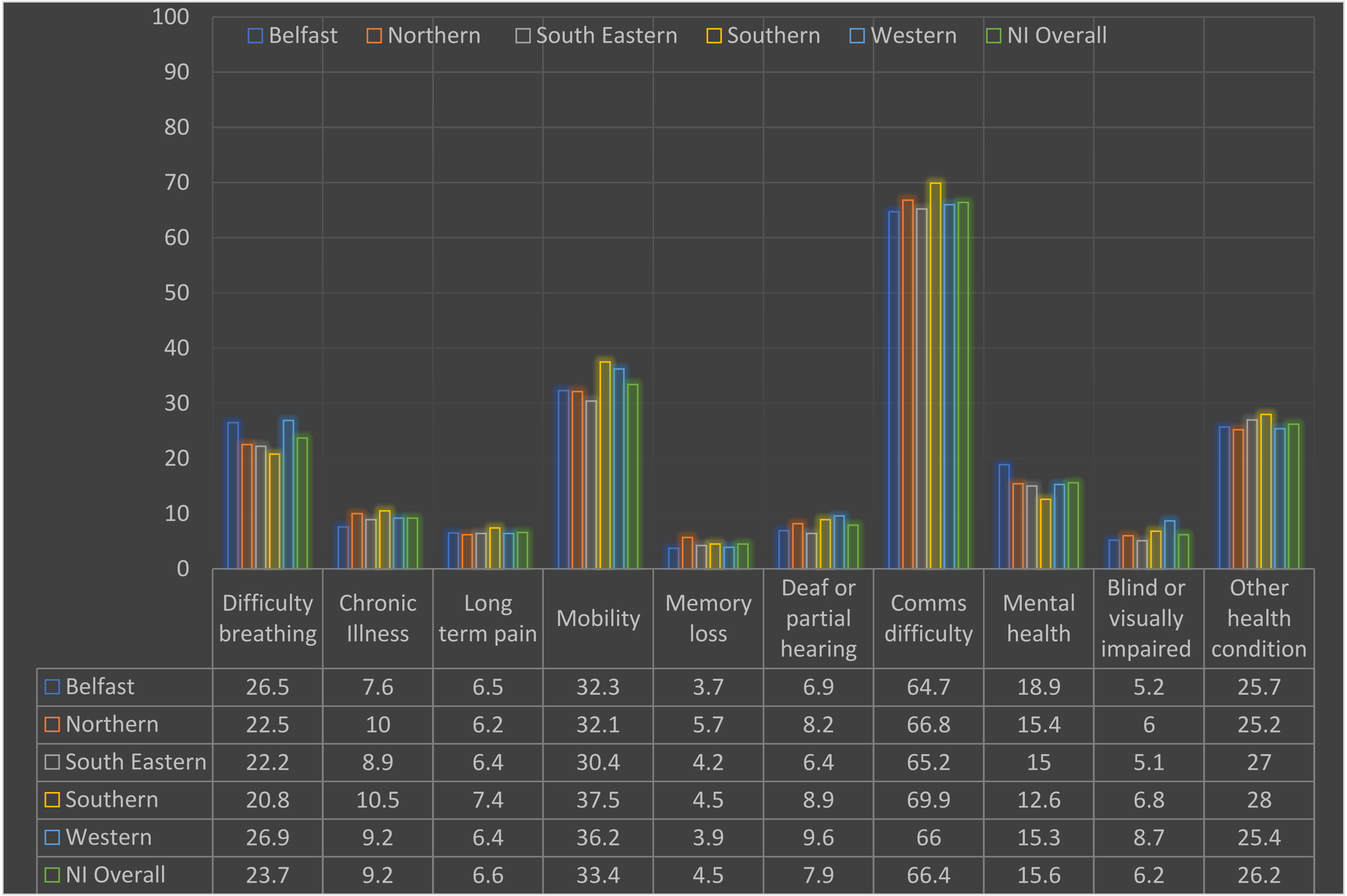
	Difficulty breathing	Chronic Illness	Long term pain	Mobility	Memory loss	Deaf or partial hearing	Comms difficulty	Mental health	Blind or visually impaired	Other health condition
LD Present	23.7	9.2	6.6	33.4	4.5	7.9	66.4	15.6	6.2	26.2
LD Absent	58.2	17.7	23.4	37.9	1.6	13.6	17.1	5.3	7	53.7

Figure 4.2b Comorbidity over 15 years (LD absent n=220,655) (LD present n=17,230)



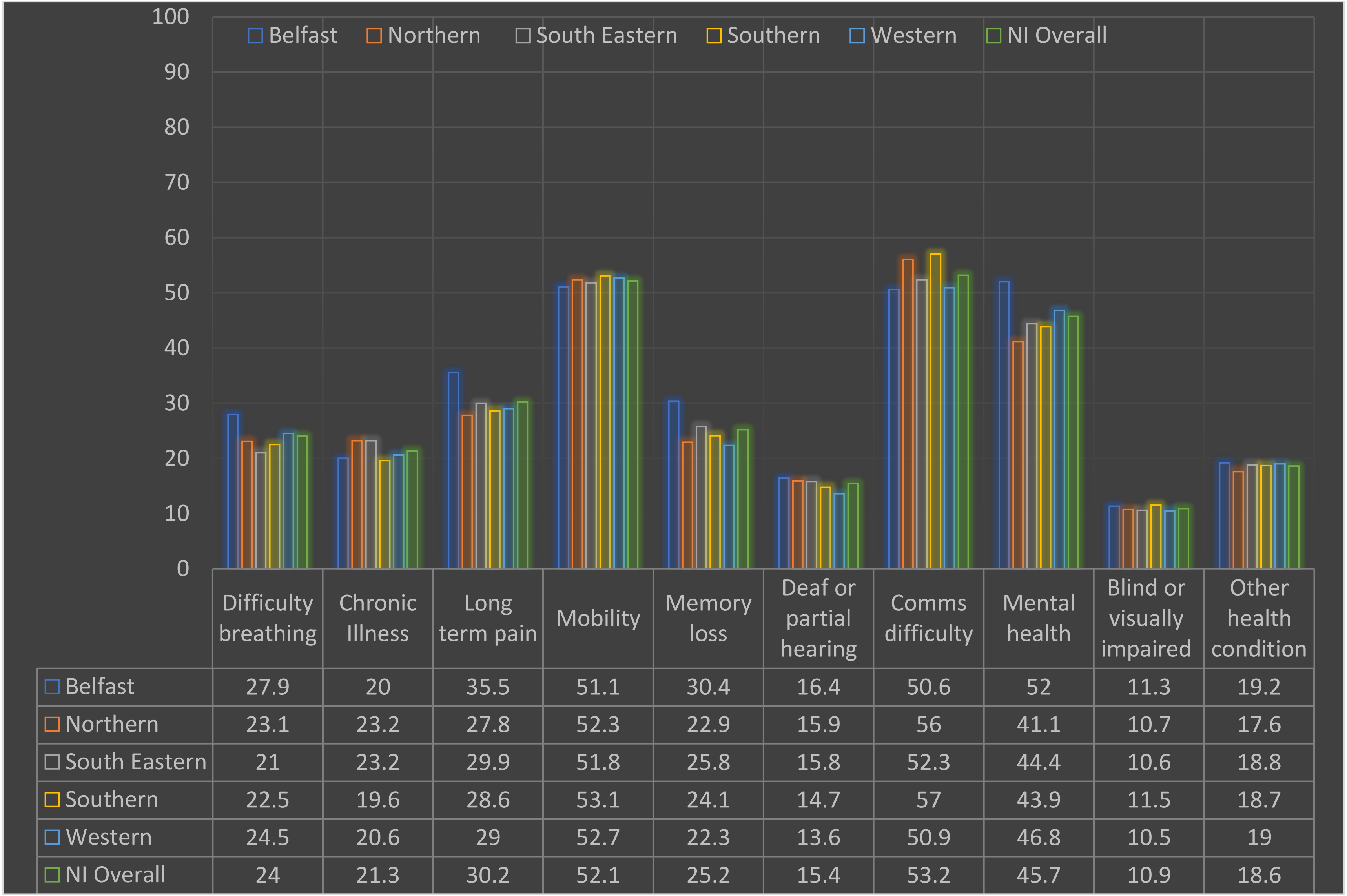
	Difficulty breathing	Chronic Illness	Long term pain	Mobility	Memory loss	Deaf or partial hearing	Comms difficulty	Mental health	Blind or visually impaired	Other health condition
☐ LD Present	24	21.3	30.2	52.1	25.2	15.4	53.2	45.7	10.9	18.6
☐ LD Absent	35.5	31.4	63.4	71.5	12.4	26.3	5.5	25.7	9.6	19.3

Figure 4.3a Comorbidity under 16 years LD Multiple Conditions by NI-HSCT



	Difficulty breathing	Chronic Illness	Long term pain	Mobility	Memory loss	Deaf or partial hearing	Comms difficulty	Mental health	Blind or visually impaired	Other health condition
☐ Belfast	26.5	7.6	6.5	32.3	3.7	6.9	64.7	18.9	5.2	25.7
☐ Northern	22.5	10	6.2	32.1	5.7	8.2	66.8	15.4	6	25.2
☐ South Eastern	22.2	8.9	6.4	30.4	4.2	6.4	65.2	15	5.1	27
☐ Southern	20.8	10.5	7.4	37.5	4.5	8.9	69.9	12.6	6.8	28
☐ Western	26.9	9.2	6.4	36.2	3.9	9.6	66	15.3	8.7	25.4
☐ NI Overall	23.7	9.2	6.6	33.4	4.5	7.9	66.4	15.6	6.2	26.2

Figure 4.3b Comorbidity over 15 years LD Multiple Conditions by NI-HSCT



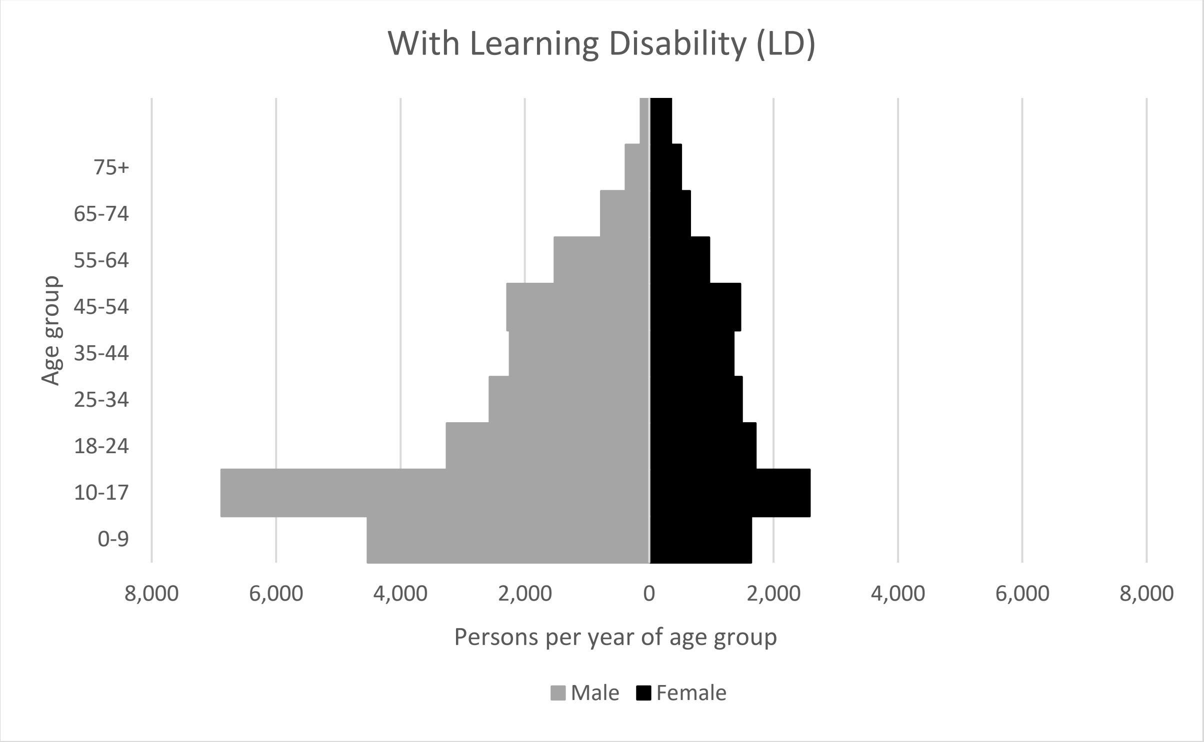
	Difficulty breathing	Chronic Illness	Long term pain	Mobility	Memory loss	Deaf or partial hearing	Comms difficulty	Mental health	Blind or visually impaired	Other health condition
□ Belfast	27.9	20	35.5	51.1	30.4	16.4	50.6	52	11.3	19.2
□ Northern	23.1	23.2	27.8	52.3	22.9	15.9	56	41.1	10.7	17.6
□ South Eastern	21	23.2	29.9	51.8	25.8	15.8	52.3	44.4	10.6	18.8
□ Southern	22.5	19.6	28.6	53.1	24.1	14.7	57	43.9	11.5	18.7
□ Western	24.5	20.6	29	52.7	22.3	13.6	50.9	46.8	10.5	19
□ NI Overall	24	21.3	30.2	52.1	25.2	15.4	53.2	45.7	10.9	18.6

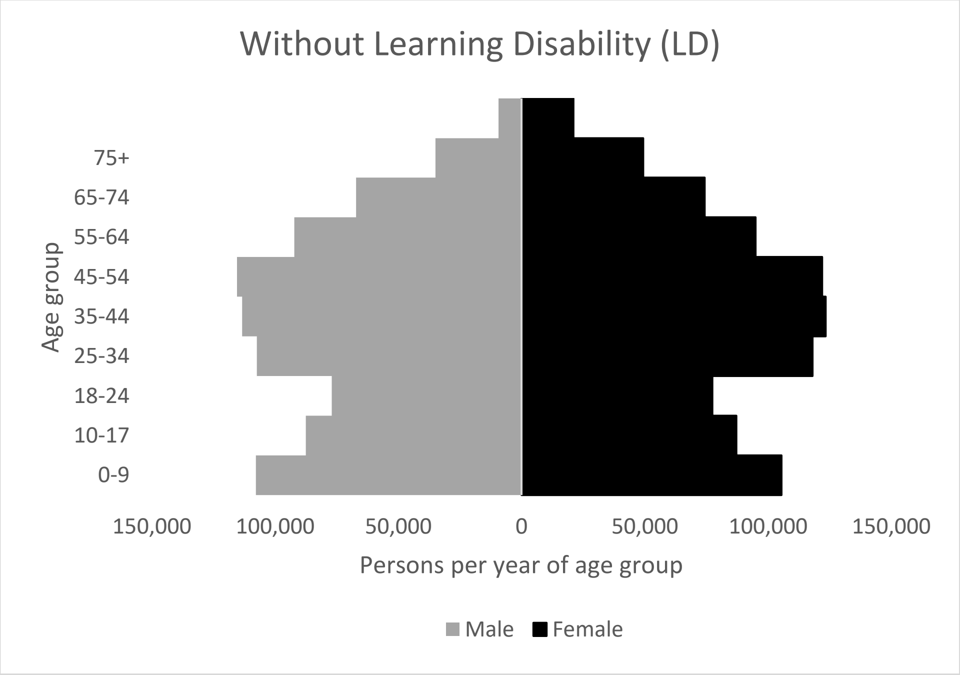
Appendix 3

Count data for **Figure 5.1**

	Male		Female	
Age	With LD	Without LD	With LD	Without LD
0-9	4527	107833	1641	105459
10-17	6880	87507	2583	87236
18-24	3257	77049	1713	77449
25-34	2565	107444	1488	118124
35-44	2244	113421	1356	123471
45-54	2283	115395	1465	122039
55-64	1522	92202	967	95028
65-74	775	67103	656	74384
75+	514	44307	867	70426
Total	24567	812261	12736	873616

Figure 5.1. Population pyramids for people with and without learning disability. 2011 Census, Northern Ireland





Appendix 4

Learning disability education and employment using Census 2011 and NISRA generated settlement band data

Aims: Although not the focus of the current project, the following analyses were conducted to demonstrate the utility of the education and employment data contained within the 2011 Census for describing and locating attainment and activity in these important areas. This section will detail the educational status and employment status of the adult learning disability population of Northern Ireland. Using educational qualification attainment data from the 2011 Census, this section will report the overall and gender specific attainment of a range of secondary and higher-level educational qualifications for learning disability adults in Northern Ireland. Using employment data from the 2011 Census, Section 6 will also (i) determine the proportion of the learning disability population of Northern Ireland who reported that they were in paid employment at the 2011 Census, (ii) identify the most common areas/types of employment reported by the learning disability population of Northern Ireland, (iii) identify gender distributions for these main employment areas and (iv) using settlement band data from the Land and Property Service data, identify settlement distributions for these main employment areas (i.e. city, town, rural).

Background: Swann et al., (2016) indicated that those with learning disability are twice as likely to not be attending some form of education, training or employment as those in the general population. Focusing on employment, Mencap (2012) reported that only 17% of people with learning disability are in paid employment; that's compared to 80% of the general population and 46% of people with 'other' disabilities (Swann et al., 2016). Similarly, Emerson and Hatton (2008) reported 83% of people with learning disability in England of working age were unemployed.

Education: Regarding educational qualifications (see Table 7 and Figure 9), other than category B (NVQ Level 1, Foundation GNVQ, Basic Skills), fewer of those with a learning disability had a qualification in each of the remaining qualification categories compared to the rest of the population. The most commonly attained qualification for both females (11%) and males (10%) with a learning disability was category A (1-4 O Levels/CSE/GCSEs (any grades), Entry Level, Foundation Diploma). With the exception of categories E (Apprenticeship) and I (VQ Level 4-5, HNC, HND, RSA Higher Diploma, BTEC Higher Level), a higher proportion of females than males with a learning disability had a qualification in each of the remaining qualification categories.

Employment: Regarding employment status, within the overall Census sample the majority of those with a learning disability, either as a single health condition, or, comorbidly with other health conditions, were either unclassified (50% and 29% respectively) or were classified as sick or disabled (10% and 37% respectively; see Table 6 and Figure 8)**.** Once again, however, it is worth recapping here that the proportions of these groups that were under 16 years of age was 50% and 29% respectively therefore these individuals will have been restricted to the latter categories (Other & XX). Conversely, the majority of those who reported the presence of a single health condition other than learning disability, and those reporting multiple health conditions excluding learning disability were classified either as working or retired. The proportion of those with a learning disability as a single health condition that was classified as 'working' was 17% while the proportion of those with multiple health conditions including learning disability was 9%. Overall, among those with a learning disability, 12% were in employment. The learning disability subpopulations also had the fewest 'home keepers' and 'retirees' but the highest proportions of students. Again, this will likely have been largely attributable to the age profile of these groups.

Mode of employment was notably influenced by both sex and settlement band. For example, of the most common modes of employment, a higher proportion of females were employed as care assistants and home carers, waiting staff, or kitchen catering assistants. A higher representation of males was evident within all remaining modes of employment. In relation to farming, gardening, carpentry, labouring, shelf-filling, or goods handling and storage, 92.7% of jobs were held by male respondents. In relation to settlement band (i.e. city, town, rural), 70.3% of individuals with a learning disability who worked in farming or gardening, and 55.6% of those who worked as a labourer resided in a rural area. Over 50% of those who worked as a waiter/waitress, handling goods, office administration, or associate professional/technical occupations resided in a city.

Table 6.1a.

		No health conditions		Single health Condition				Multiple health Conditions				
		n=1,173,565		LD indicator endorsed n=12,954		LD indicator not endorsed n=288,843		LD indicator endorsed n=24,349		LD indicator not endorsed n=223,469		Total N=1,723,180
		Female n=598,513	Male n=575,052	Female n=3,812	Male n=9,142	Female n=148,674	Male n=140,169	Female n=8,924	Male n=15,425	Female n=126,429	Male n=97,040	
Qual	A	146,465	138,076	485	1,025	35,287	30,580	890	1,398	20,139	14,376	388,721
	B	37,322	35,792	309	588	9,085	7,482	490	800	5,335	3,534	100,737
	C	203,788	164,648	448	800	41,024	32,855	607	878	19,102	12,597	476,747
	D	66,531	57,860	239	450	16,555	13,183	424	623	9,294	6,674	171,833
	E	3,397	51,631	-	174	1,059	15,520	-	439	1,030	12,409	85,718
	F	112,609	87,726	250	356	20,115	16,936	294	388	7,893	5,898	252,465
	G	50,062	48,475	137	228	11,151	10,722	204	300	5,318	5,063	131,660
	H	94,625	74,269	151	195	16,397	15,297	210	289	6,054	5,475	212,962
	I	20,780	25,180	45	111	4,479	5,739	88	146	2,136	2,532	61,236
	J	75,891	42,030	73	56	18,278	11,662	209	200	11,261	6,040	165,700
	K	65,243	67,878	190	350	18,512	19,158	402	675	12,523	11,739	196,670

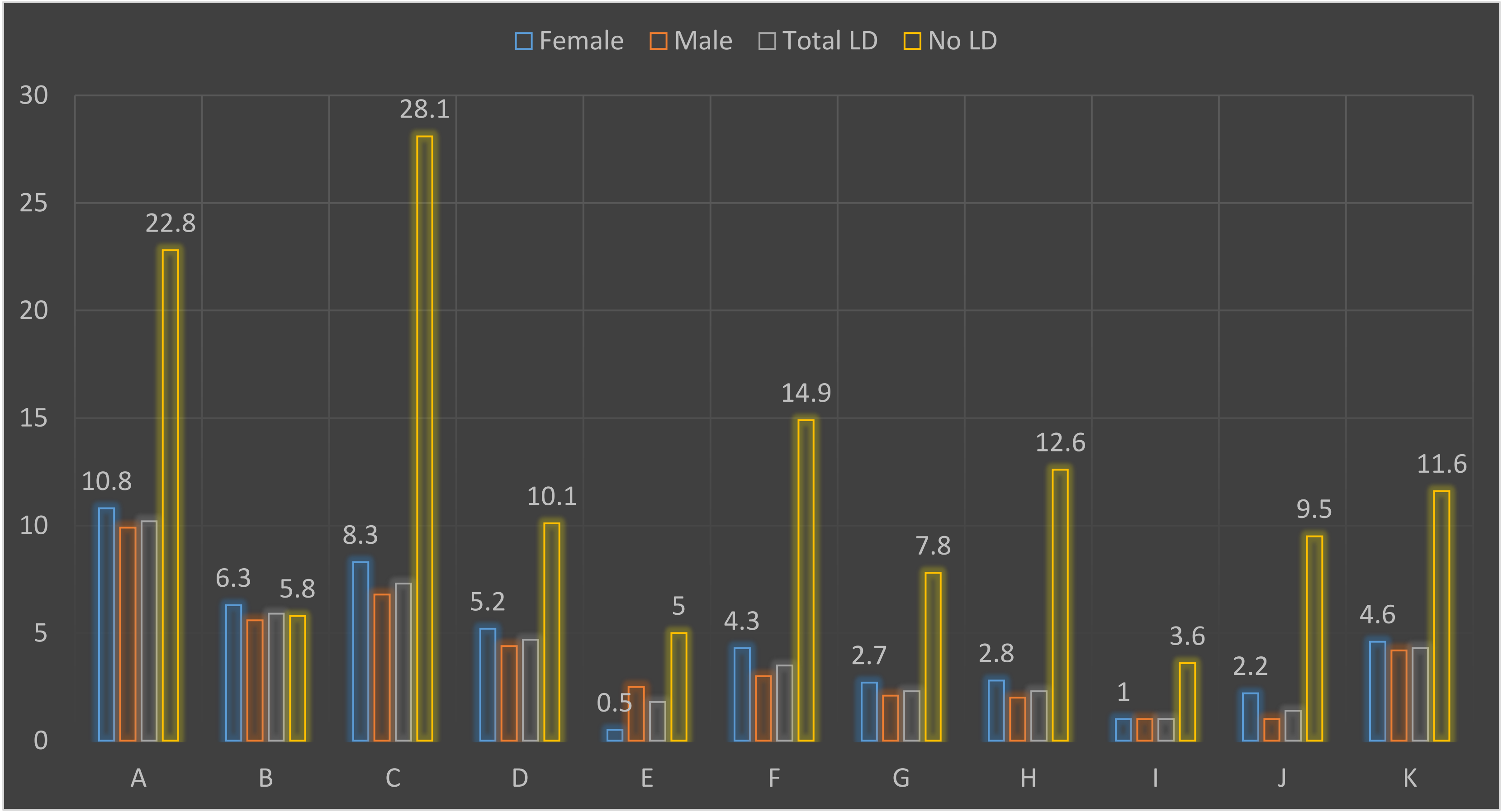
A=1-4 O Levels/CSE/GCSEs (any grades), Entry Level, Foundation Diploma; **B=**NVQ Level 1, Foundation GNVQ, Basic Skills; **C=**NVQ Level 1, Foundation GNVQ, Basic Skills; **D=**NVQ Level 2, Intermediate GNVQ, City and Guilds Craft, BTEC First/General Diploma, RSA Diploma; **E=**Apprenticeship; **F=**2+ A Levels/VCEs, 4+ AS Levels, Higher School Certificate, Progression/Advanced Diploma; **G=**NVQ Level 3, Advanced GNVQ, City and Guilds Advanced Craft, ONC, OND, BTEC National, RSA Advanced Diploma; **H=**Degree (BA, BSc), Higher Degree (MA, PhD, PGCE); **I=**NVQ Level 4-5, HNC, HND, RSA Higher Diploma, BTEC Higher Level; **J=**Professional Qualifications (Teaching, Nursing, Accountancy); **K=**Other Vocational/Work-Related Qualifications. Attainment of multiple qualifications means rows and columns do not match totals.

Table 6.1b.

Qualification		LD indicator endorsed			LD indicator not endorsed
		Female n=12,736	Male n=24,567	Total n=37,303	Total n=1,685,877
A	1-4 O Levels/CSE/GCSEs (any grades), Entry Level, Foundation Diploma	1,375 (10.8%)	2,423 (9.9%)	3,798 (10.2%)	384,923 (22.8%)
B	NVQ Level 1, Foundation GNVQ, Basic Skills	799 (6.3%)	1,388 (5.6%)	2,187 (5.9%)	98,550 (5.8%)
C	5+ O Level (Passes)/CSEs (Grade 1)/GCSEs (Grades A*-C), School Certificate, 1 A Level/2-3 AS Levels/VCEs, Higher Diploma	1,055 (8.3%)	1,678 (6.8%)	2,733 (7.3%)	474,014 (28.1%)
D	NVQ Level 2, Intermediate GNVQ, City and Guilds Craft, BTEC First/General Diploma, RSA Diploma	663 (5.2%)	1,073 (4.4%)	1,736 (4.7%)	170,097 (10.1%)
E	Apprenticeship	59 (0.5%)*	613 (2.5%)	672 (1.8%)	85,046 (5.0%)
F	2+ A Levels/VCEs, 4+ AS Levels, Higher School Certificate, Progression/Advanced Diploma	544 (4.3%)	744 (3.0%)	1,288 (3.5%)	251,177 (14.9%)
G	NVQ Level 3, Advanced GNVQ, City and Guilds Advanced Craft, ONC, OND, BTEC National, RSA Advanced Diploma	341 (2.7%)	528 (2.1%)	869 (2.3%)	130,791 (7.8%)
H	Degree (BA, BSc), Higher Degree (MA, PhD, PGCE)	361 (2.8%)	484 (2.0%)	845 (2.3%)	212,117 (12.6%)
I	VQ Level 4-5, HNC, HND, RSA Higher Diploma, BTEC Higher Level	133 (1.0%)	257 (1.0%)	390 (1.0%)	60,846 (3.6%)
J	Professional Qualifications (Teaching, Nursing, Accountancy)	282 (2.2%)	256 (1.0%)	538 (1.4%)	159,660 (9.5%)
K	Other Vocational/Work-Related Qualifications	592 (4.6%)	1,025 (4.2%)	1,617 (4.3%)	195,053 (11.6%)

% = proportion of subpopulations with specified qualification. Attainment of multiple qualifications means rows and columns do not match totals. *Does not include values omitted due to low cell count

Figure 6.1.



A=1-4 O Levels/CSE/GCSEs (any grades), Entry Level, Foundation Diploma; **B**=NVQ Level 1, Foundation GNVQ, Basic Skills; **C**=NVQ Level 1, Foundation GNVQ, Basic Skills; **D**=NVQ Level 2, Intermediate GNVQ, City and Guilds Craft, BTEC First/General Diploma, RSA Diploma; **E**=Apprenticeship; **F**=2+ A Levels/VCEs, 4+ AS Levels, Higher School Certificate, Progression/Advanced Diploma; **G**=NVQ Level 3, Advanced GNVQ, City and Guilds Advanced Craft, ONC, OND, BTEC National, RSA Advanced Diploma; **H**=Degree (BA, BSc), Higher Degree (MA, PhD, PGCE); **I**=NVQ Level 4-5, HNC, HND, RSA Higher Diploma, BTEC Higher Level; **J**=Professional Qualifications (Teaching, Nursing, Accountancy); **K**=Other Vocational/Work-Related Qualifications

Table 6.2.

		No health conditions n=1,173,565	Single health Condition		Multiple health Condition		Total N=1,723,180
			LD indicator endorsed n=12,954	LD indicator not endorsed n=288,843	LD indicator endorsed n=24,349	LD indicator not endorsed n=223,469	
Employment	Working	607,162	2,181	117,307	2,275	35,169	764,094
	Unemployed	53,122	777	11,549	703	3,826	69,977
	Student	58,433	1,386	7,534	1,626	1,613	70,592
	Retired	80,064	154	76,479	2,171	111,368	270,236
	Sick/Disabled	4,915	1,270	24,893	8,962	55,248	95,288
	Homekeeper	38,907	169	11,928	295	5,396	56,695
	Other	20,206	564	10,511	1,198	8,035	40,514
	XX	310,756	6,453	28,642	7,119	2,814	355,784

XX = Unclassified

Figure 6.2a.

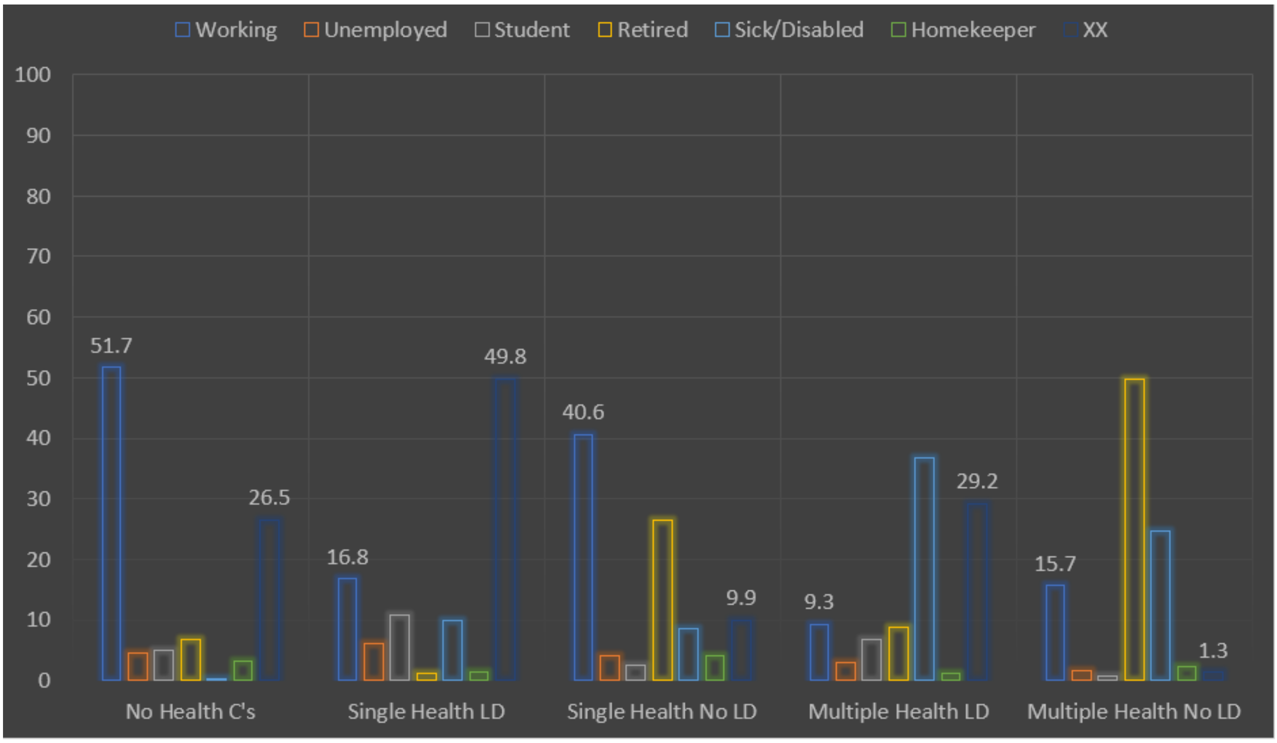


Figure 6.2b.

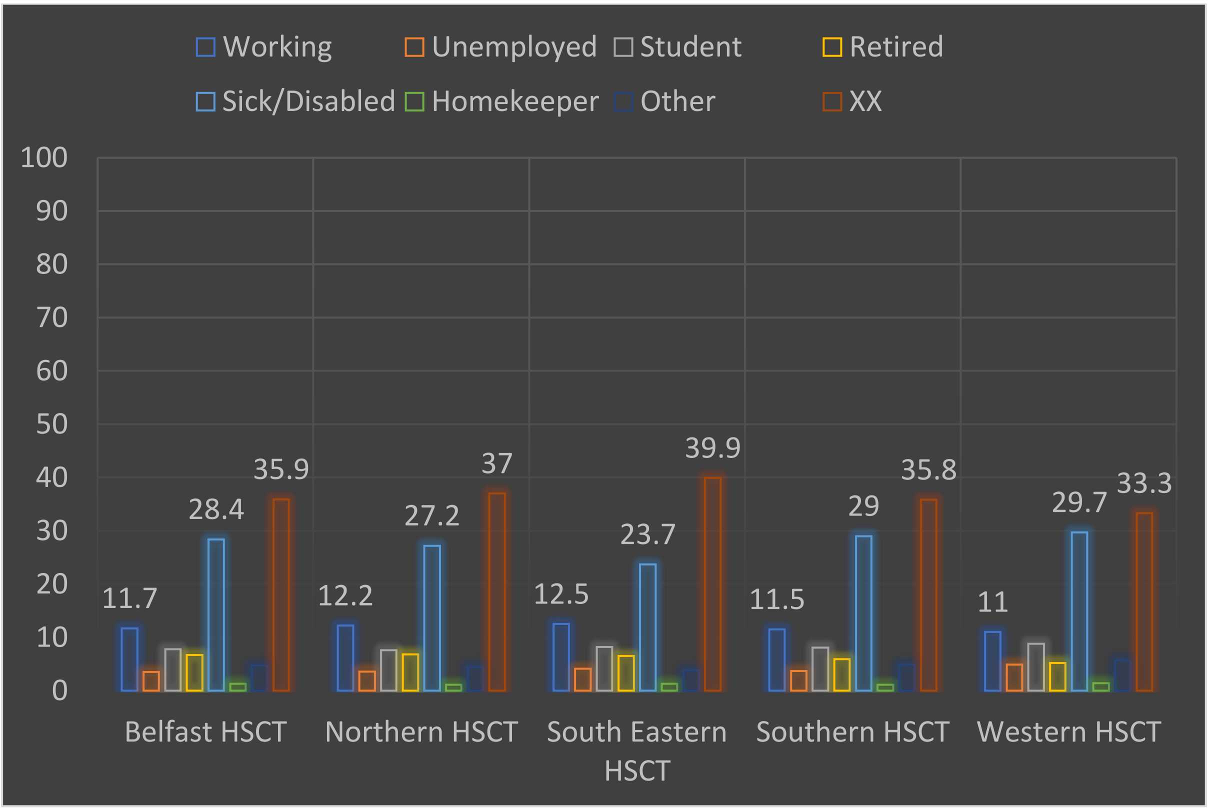


Table 6.3a.

Employment Category	Employment Type	Counts (%)	Male%	Female%	Male Counts	Female Counts
		Total (n=4,456)	%	%	n	n
1	Corporate managers and directors	85 (1.9%)	81.2%	18.8%	69	16
2	Associate professional and technical occupations	292 (6.5%)	71.2%	28.8%	208	84
3	Civil Service administrative officers and assistants	60 (1.3%)	66.7%	33.3%	40	20
4	General office assistants/clerks	64 (1.4%)	56.3%	43.8%	36	28
5	Farmers	56 (1.2%)				*
6	Gardeners and groundsmen/women	52 (1.2%)				*
7	Carpenters and joiners	65 (1.4%)				*
8	Chefs cooks	75 (1.7%)	70.7%	29.3%	53	22
9	Care assistants and home carers	79 (1.8%)	29.1%	70.9%	23	56
10	Sales and retail assistants	487 (10.9%)	57.3%	42.7%	279	208
11	Labourers in building and woodworking trades	54 (1.2%)				*
12	Other goods handling and storage occupations	76 (1.7%)				*
13	Kitchen & Catering Assistants	192 (4.3%)	46.4%	53.6%	89	103
14	Waiters/Waitresses	43 (1%)	30.2%	69.8%	13	30
15	Cleaners Domestic	168 (3.8%)	53.0%	47.0%	89	79
16	Shelf Fillers	61 (1.4%)				
5-7,11-12 & 16 Combined		364 (8.2%)	92.7%	7.3%	337	27
NOT AGED 16-74 or UNABLE TO CODE		1,087 (24.4%)				

Because counts for females were too low (*) for categories 5-7,11-12 & 16, these categories were combined to facilitate gender comparison.

Table 6.3b.

Employment Category	Employment Type	Counts (%)	Settlement Band %			Settlement Band Counts*		
		Total (n=4,456)	City	Town	Rural	City	Town	Rural
1	Corporate managers and directors	85 (1.9%)	43.5%	16.5%	40.0%	37	14	34
2	Associate professional and technical occupations	292 (6.5%)	54.2%	16.3%	29.5%	158	48	86
3	Civil Service administrative officers and assistants	60 (1.3%)						
4	General office assistants/clerks	64 (1.4%)						*
3&4 Combined		124 (2.3%)	51.6%	25.0%	23.4%	64	64	31
5	Farmers	56 (1.2%)				*	*	
6	Gardeners and groundsmen/women	52 (1.2%)						
5&6 Combined		108 (2.4%)	16.7%	13.0%	70.3%	18	18	14
7	Carpenters and joiners	65 (1.4%)	32.8%	25.0%	42.2%	21	16	27
8	Chefs cooks	75 (1.7%)	42.7%	30.7%	26.7%	32	23	20
9	Care assistants and home carers	79 (1.8%)	42.3%	23.1%	34.6%	33	18	27
10	Sales and retail assistants	487 (10.9%)	44.1%	28.2%	27.6%	215	136	135
11	Labourers in building and woodworking trades	54 (1.2%)	22.2%	22.2%	55.6%	12	12	30
12	Other goods handling and storage occupations	76 (1.7%)	50.7%	20.0%	29.3%	38	15	22
13	Kitchen & Catering Assistants	192 (4.3%)	47.1%	27.7%	25.1%	90	53	48
14	Waiters/Waitresses	43 (1%)	52.4%	23.8%	23.8%	22	10	10
15	Cleaners Domestic	168 (3.8%)	45.2%	30.1%	24.7%	76	51	41
16	Shelf Fillers	61 (1.4%)	39.7%	25.2%	35.2%	24	15	21
NOT AGED 16-74 or UNABLE TO CODE		1,087 (24.4%)						

*Counts calculated using percentages. Counts were calculated using percentages and may therefore differ from the total due to rounding.

Appendix 5

PHASE II ADRC-NI RESEARCH – LEGAL BASIS FOR PROCESSING

Phase II of the ESRC investment in ADRC-NI began on 1st October 2018. The contracts with both of the Northern Ireland universities and NISRA are based on the delivery of Strategic Impact Programmes (SIPs) and the research projects contained within them for delivery over the 30 month period from October 2018 to March 2021.

There are generally two elements to ADRC-NI projects:

(i) The sharing of directly identifiable information for the purposes of linking two or more datasets together. This is completed by the Trusted Third Party (TTP) on behalf of the researcher; and
(ii) the subsequent linkage of personal non-identifiable data using the linkages created at stage (i).

This note sets out arrangements for the handling of Phase II ADRC-NI projects in the context of the recent Digital Economy Act (2017). Phase I applications approved before May 2018 will be handled separately.

Digital Economy Act (2017) – research clauses (sections 64-73)

The research clauses of the Digital Economy Act 2017 (sections 64-73) were commenced across the UK on 1st May 2018. In the absence of an Executive the research clauses were commenced in Northern Ireland via agreement from the Secretary of State. The associated Codes of Practice for the research clauses detailing how the provisions are to be delivered were published in August 2018.

The Digital Economy Act (DEA) research clauses enable the sharing of personally identifiable data held by public bodies for research. As the new clauses are generic in nature, they bring about a sea change in the range of data that can now be processed for research purposes. The legislation is ground-breaking and supports research that is in the public interest enabling a wide range of public authorities to share and integrate data for research. The law gives a power to public bodies to disclose personal data for research to an accredited third party processor (in this case, NISRA) who links, de-identifies and makes the data available to an accredited researcher for an accredited research project. The regulator/accreditor for these functions will be the UK Statistics Authority.

For Data Custodians, the law also creates a criminal offence, with up to 6 months imprisonment, if personal data are disclosed by researchers, data linkers etc. In time, the new law will industrialise the scale and nature of data linkage research in Northern Ireland and across the UK (enabling the linking of, for example, education, justice, or social welfare data). That said, it is the express will of Parliament that the DEA research clauses enable data linkage for research involving most public bodies but **not those public bodies providing health and adult social care services** (sections 65.4, 73.2 (see below)).

Digital Economy Act (Section 64.1)

Information held by a public authority in connection with the authority's functions may be disclosed to another person for the purposes of research which is being or is to be carried out.

Digital Economy Act (Section 65.4)

> *In its application to a public authority with functions relating to the provision of health services or adult social care, section 64 does not authorise the disclosure of information held by the authority in connection with such functions.*

Digital Economy Act (Section 73.2)

> *A person is not a public authority for the purposes of this Chapter if the person—*
>
> *(a) only has functions relating to the provision of health services,*
>
> *(b) only has functions relating to the provision of adult social care, or*
>
> *(c) only has functions within paragraph (a) and paragraph (b).*

NISRA is seeking clarification from the UK Statistics Authority but presently 'functions relating to the provision of health services' is interpreted as public bodies wholly or majority funded by DoH. This means that research projects which require the linkage of data from a "health body" to a "non-health body" cannot be performed under the research clauses of the DEA.

At the same time, the Digital Economy Act repealed four NI Assembly Orders made under section 49 of the Statistics and Registration Services Act (2007). This means that the previous legislative context that supported Phase 1 ADRC research is no longer available.

Position going forward

Although the Phase II SIPs are living documents and may not deliver the projects exactly as currently listed, they do contain projects which link "health" and "non-health" datasets. The DEA research clauses cannot be used as the legal gateway for this research. One alternative option for researchers wishing to link health data to Registrar General (RG) data (Census/GRO) is to use the long-standing Northern Ireland Longitudinal Study (NILS) project which is managed under the Census Act (NI) 1969 legislation. In summary, projects have different pathways as follows:

ADRC-NI projects

- "Non-Health" data projects: Projects requiring "non-health data" proceed under processes laid out under the Digital Economy Act 2017 research clauses.

- “Health” only data projects: Projects requiring only “health data” proceed under the Honest Broker Service processes.
- “Health” and RG data projects: Projects requiring “health” and RG data (e.g. Census/GRO data) proceed under Northern Ireland Longitudinal Study processes under the Census Act (NI) 1969.
- “Health” linked to other NICS departmental datasets: There is currently no legal gateway in Northern Ireland for projects using a combination of “health” and other public-body data.

ADRC-NI projects should be submitted through RSU in NISRA in the first instance. RSU staff will work with researchers to prepare new projects for the appropriate approval panel. Agreement will be required from all data providers before a project can be reviewed at either the UK Statistics Authority Research Accreditation Panel (DEA-centric) or the NILS Approval Group.

NISRA has attempted to explain a complex legal landscape in an accessible manner in this guidance. If not clear, feedback as to how to further clarify is welcome.

Siobhan Carey, Registrar General & NISRA Chief Executive

Appendix 6

Ulster University

RESEARCH BRIEFING MEMO

Ulster University is currently undertaking an Economic and Social Research Council (ESRC)-funded research project entitled, "**Learning Disability and Northern Ireland: Achieving proportionate universalism through administrative data research**"**.** This memo aims to (1) provide a brief overview of the project background and aims, and (2) request a response in relation to several administrative data-related challenges encountered by our Consortium during this project.

Overview of project background and aims

People with a Learning Disability (LD) represent one of the most vulnerable and disadvantaged groups in Northern Ireland (NI) [1]. Evidence suggests that inequity often exists and persists among this population because they remain unseen [2]. At present there is no central register detailing the actual number of individuals with LD in NI. As a consequence, it is not possible to evaluate the form, context or degree of inequality that may be experienced by this group. This in turn makes it difficult to tailor, target services or to monitor health in terms of health inequalities for this population. Recently, a 'Research and Information Service Paper' submitted to the Northern Irish Assembly [3] noted that "...according to a review by Marmot in 2010 [4], health inequalities are avoidable and socially unjust...[and]...in order to reduce the steepness of the social gradient in health...actions must be universal, but with a scale and intensity proportionate to the level of disadvantage. Therefore, policies and strategies should target action at those experiencing greater social and economic disadvantage. This approach is termed 'proportionate universalism' [5] and it requires multi-agency working across local and central government, and the voluntary and private sectors" [6]. To begin to pursue and achieve proportionate universalism for the LD population of NI, this project aims to source and exploit extant administrative/population level data to (i) provide a geographical map of LD in NI; (ii) profile the demography of the LD population using a range of socio-economic metrics; (iii) profile morbidity and comorbidity of health care problems among the LD population using Census health metric data; (iv) exploit NI Mortality data to explore the causes and contexts of death among the NI LD community and (v) stimulate and facilitate 'proportionate universalism' across the region through multi-agency collaboration across local and central government, and the voluntary and private sectors. **Additionally, our project included an important legacy objective - to facilitate and expedite ongoing data sharing negotiations to secure LD relevant administrative data in NI in the future.**

Administrative data-related issues encountered during the project

Our consortium would welcome and appreciate any information from NISRA in relation to two main queries that have arisen over the course of this project.

5. NISALD 2007

The response categories of the 'nature of long-term health conditions' question in the 2011 Census was intended to align to, as far as possible, the list of activity limitations and disabilities used in the NI Survey on Activity Limitations and Disability (NISALD) [7], a major survey of disability that was conducted by NISRA during 2006-07. The NISALD aimed to provide an up-to-date, accurate picture of the prevalence and circumstances of children and adults living with a disability in NI, including those living in private households and communal establishments. The 2011 Census proposals document [8] indicated that, "*together with further methodological work, it should therefore be possible to use NISALD and the Census to model the spatial distribution of people with particular activity limitations and disabilities*" (p.43). Although one main NISALD bulletin was published that documented the prevalence of disability among children and adults living in **private households** in NI [7], ambitious plans to publish additional bulletins on (i) the detailed characteristics of individuals with disability (e.g. the use of aids, equipment or medication; links between various types of disabilities and the severity of impact on the individual); (ii) the circumstances of people with disabilities, their experiences and any barriers they face in using services and participating in society; and (iii) prevalence rates amongst children and adults living in communal establishments (e.g. residential and care homes, long-stay hospitals) in NI, were not realised. Our consortium were advised that the lack of additional analysis of the NISALD data was because the "*communal establishment strand of the survey resulted in data that was not wholly representative of the population living in private and NHS communal establishments, so the series of bulletins originally promised could not be completed and the communal establishment data was not submitted to the UK Data Archive*" [9]. Given this difficulty, it was not possible to comprehensively model the spatial distribution of people with LD (or other disabilities) in NI using these two data resources. Our Consortium are mindful that the 2021 NI Census will, for the first time, afford citizens with a LD in NI the opportunity to report their specific disability status (the 2017 Census Test questionnaires [10] differentiated intellectual or learning disability from a learning difficulty and Autism or Asperger's Syndrome. In addition, the learning difficulty category was supported by an example of dyslexia or ADHD, whereas the intellectual disability category contained Down's Syndrome as an example). In so doing, NI Census 2021 will afford NI its greatest opportunity to date to recognise, respond to and resolve the many challenges that the NI LD community so commonly face. However, collection of nationally representative survey data on disability in NI (such as the NISALD) will be vital to ensure that the research, policy and practice 'potential' of the new Census LD indicator can be realised/ 'unlocked'.

Query 1: Does NISRA have plans to conduct another NISALD in the future and/or can our Consortium help in some way to lobby for such a survey?

Dear Professor Murphy,

In relation to your question "Does NISRA have plans to conduct another NISALD in the future and/or can our Consortium help in some way to lobby for such a survey?"

The drivers for another NISALD will be considered in the context of the development of a new Disability Strategy, which is referenced in paragraph 4.2.6 of the New Decade, New Approach document. The availability of resources to conduct a survey of this scale will be an important factor in deciding the way forward.

Thanks,

[removed]

[removed] | Professional Services Unit | Department for Communities
Level 6 | Causeway Exchange | 1-7 Bedford Street | Belfast | BT2 7EG
Contact: * [removed]

6. Challenges relating to linkage of Census data to health and social care data

This research project received approval from the Administrative Data Research Network (ADRN) Approvals Panel (PROJ-099) in May 2016, followed by an ESRC-funding awarded in December 2016, and ADRN project approval agreements were completed in May 2017. Our Consortium subsequently received notification from NISRA in relation to delays regarding data acquisition for our project. We were advised that these delays related to the implementation of the Digital Economy Act (2017) and we were encouraged to proceed with a staged approach to data acquisition for the project. This involved re-applying for permission to secure the 2011 Census data with linkage to the General Registrar Office's Mortality Statistics (i.e., the NI Mortality Study or NIMS) via the NIMS Research Advisory Group (RAG) in July 2017. This request was approved in November 2017 (PROJ-114). After a pause in the project (01-11-2018 – 01-06-2019) in February 2019, our Consortium was advised further that legal issues relating to the gateway for linking 'Health' and 'Census and Vital Statistics or Non-Health' data remained unresolved, and that it would not be possible to secure linkage of identified Health and Social Care (HSC) data for the entire Census population (as per original application - PROJ-099). Our Consortium was offered a few workaround options by NISRA and communications lines were opened with the funding body ESRC to consider the acceptability/feasibility of these options. The most viable option was to conduct the linkage of Census and HSC data via the NI Longitudinal Study (NILS) mechanism, which provides researchers with access to 28% of the NI population. Ultimately, a new application for permission to secure data linkage for this project via NILS was submitted in September 2019 and a no-cost funding extension was granted by the ESRC on 17-10-19.

Our Consortium would like to take this opportunity to express our gratitude to the NISRA team for their solution focussed support during this time. We are also eager to re-iterate the importance of being able to apply for and secure access to population data which facilitate the analysis of health and non-health related data. This is especially important given the proposed changes to the 2021 Census which will, for the first time, collect population-level data on experiences of intellectual disability separately from a learning, social or behavioural difficulty.

Query 2*:* Can NISRA offer any assurances that linkage of administrative HSC data (and other 'non-health' data) to the 2021 Census will be possible?

I look forward to receiving your response,

On behalf of the Project Consortium, Professor Jamie Murphy

School of Psychology
H258 I Cromore Road I BT52 1SA
T: +44(0)2871675283
E: ja.murphy@ulster.ac.uk W: www.ulster.ac.uk

References

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5 The Marmot Review (2010) Fair Society, healthy lives (Executive Review) p 10.

6 The Marmot Review (2010) Fair Society, healthy lives (Executive Review) p 12.

7 Northern Ireland Statistics and Research Agency, The Prevalence of Disability and Activity Limitations amongst adults and children living in private households in Northern Ireland: First report from the Northern Ireland Survey of people with Activity Limitations and Disabilities. 2007: Belfast, Northern Ireland. Sourced from: https://beta.ukdataservice.ac.uk/datacatalogue/studies/study?id=7236 (accessed on 16/9/2019).

8 https://www.nisra.gov.uk/sites/nisra.gov.uk/files/publications/2011-census-proposals-document.pdf

9 Personal communication with NISRA (August 2019)

10 https://www.nisra.gov.uk/sites/nisra.gov.uk/files/publications/2017-census-test-questionnaire-version-1.PDF

Appendix 7

RESEARCH BRIEFING MEMO 9-1-2020 (with Census Team response on 12-2-2020 in yellow)

Ulster University is currently undertaking an Economic and Social Research Council (ESRC)-funded research project entitled, "**Learning Disability and Northern Ireland: Achieving proportionate universalism through administrative data research**" (ES/P002293/1)**.** This memo aims to (1) provide a brief overview of the project background and aims, and (2) request additional information relating to the inclusion, framing and collection of learning disability (LD) data in the 2011 and 2021 Census.

Overview of project background and aims

People with a LD represent one of the most vulnerable and disadvantaged groups in Northern Ireland (NI) [1]. Evidence suggests that inequity often exists and persists among this population because they remain unseen [2]. At present there is no central register detailing the actual number of individuals with LD in NI. As a consequence, it is not possible to evaluate the form, context or degree of inequality that may be experienced by this group. This in turn makes it difficult to tailor, target services or to monitor health in terms of health inequalities for this population. Recently, a 'Research and Information Service Paper' submitted to the Northern Irish Assembly [3] noted that "...according to a review by Marmot in 2010 [4], health inequalities are avoidable and socially unjust...[and]...in order to reduce the steepness of the social gradient in health...actions must be universal, but with a scale and intensity proportionate to the level of disadvantage. Therefore, policies and strategies should target action at those experiencing greater social and economic disadvantage. This approach is termed 'proportionate universalism' [5] and it requires multi-agency working across local and central government, and the voluntary and private sectors" [6]. To begin to pursue and achieve proportionate universalism for the LD population of NI, this project aims to source and exploit extant administrative/population level data to (i) provide a geographical map of LD in NI; (ii) profile the demography of the LD population using a range of socio-economic metrics; (iii) profile morbidity and comorbidity of health care problems among the LD population using Census health metric data; (iv) exploit NI Mortality data to explore the causes and contexts of death among the NI LD community and (v) stimulate and facilitate 'proportionate universalism' across the region through multi-agency collaboration across local and central government, and the voluntary and private sectors.

Request for information relating to the collection of LD data in the Census

Four queries relating to the inclusion, framing and collection of LD data in the NI Censuses have arisen over the course of the project (each one is outlined below). Our consortium would welcome and appreciate any information in relation to these queries in order to assist us in the completion of our project aims.

1. Nature of long-term health conditions question in 2011 Census in Northern Ireland

A significant change to the content of the 2011 Census was the addition of a question to collect data on the 'nature of any long-term health conditions' experienced by the people of Northern Ireland [7]. This new question was piloted in the 2007 Census Test questionnaire as a 'long-standing health conditions' question and comprised seven response categories including '*a learning difficulty*' [8]. Despite the 2007 Census Test Evaluation indicating that the new question used language that was too complex and imposed a high cognitive burden on respondents [9], the question was subsequently expanded in the 2009 Census Rehearsal to cover 12 categories, and the response category for '*a learning difficulty*' was extended to cover '*a learning difficulty, an intellectual difficulty, or a social or behavioural difficulty*'. Evidence from the 2011 Census proposal document [10] suggests the expanded question was "*intended to align the response categories in a census question, as far as possible, with the list of activity limitations and disabilities used in NISALD [2006-07 Northern Ireland Survey of Activity Limitation and Disability] [10, p.43].* Unlike the NISALD which assessed in detail the public's experiences of a learning difficulty, an intellectual difficulty and/or a social or behavioural difficulty, the 2011 Census combined these health conditions into a single tick-box response [of note, the only other health conditions to be combined in the Census were mobility and dexterity issues – both of which were assessed separately in NISALD].

Query 1: What was the rationale for combining the long-term health conditions of '*a learning difficulty, an intellectual difficulty, or a social or behavioural difficulty'* into a single response category in the 2011 NI Census?

I do not have any specific rationale for the combination of those specific categories but it appears that we aimed to replicate the assessment protocol used in the 2006-2007 NISALD survey (as you had identified) as closely as possible. However, we were unable to do so exactly using a single question within the 2011 Census Questionnaire. This was identified within the 2011 Census proposals document for which I have provided the wording and the source of this information below;

Nature of long-term health conditions
3.63 A new question is proposed that will examine the nature of respondents' long-term health conditions.

3.64 A major survey of disability (The Northern Ireland Survey of Activity Limitation and Disability, NISALD) was conducted in 2006-2007. It is not possible to replicate the assessment protocol used in that survey in a single census question. However, it is intended to align the response categories in a census question, as far as possible, with the list of activity limitations and disabilities used in NISALD. Together with further methodological work it should therefore be possible to use NISALD and census results to model the spatial distribution of people with particular activity limitations and disabilities.

Source; https://www.nisra.gov.uk/sites/nisra.gov.uk/files/publications/2011-census-proposals-document.pdf

Census testing prior to 2011 also indicated that only ten respondents (1.1%) found the long standing conditions question difficult to answer. Four of these ten respondents were unsure as to which category to select and suggested that further categories be added (See page 30 on the 2006 Omnibus survey). As a response to this last issue additional categories were provided in 2011 including

- Communication difficulty
- Long term pain or discomfort
- Shortness of Breath
- Frequent periods of confusion or memory loss
- A chronic illness

2. Nature of long-term health conditions question in 2021 Census in Northern Ireland

The 2021 Census Topic Consultation for NI [11] process reaffirmed the importance of collecting health data in the Census, but also highlighted the need to collect additional information on the nature of long-term health conditions experienced by the population. At that time, it was proposed to conduct "*further research and testing to see whether these needs can be accommodated within the confines of the Census*" (p.11). The 2017 Census Test questionnaires [12] included an extended question on the nature of long-term health conditions question (Q15) which disaggregated intellectual or learning disability from a learning difficulty and Autism or Asperger's Syndrome. In addition, the learning difficulty category was supported by an example of dyslexia or ADHD, whereas the intellectual disability category contained Down's Syndrome as an example. It is was reported that "*the response categories have been updated to take account of changing user needs and to streamline with international definitions to promote standardisation. In particular, a new separate category has been included for Autism or Asperger syndrome to develop a baseline on the prevalence of these conditions" [13, p.31].*

Query 2*:* What was the rationale for the change in the measurement of learning difficulty and intellectual disability in the 2021 Census?

In 2015 NISRA conducted a topic consultation where users identified a need for the continued use of the long term conditions question used in 2011. Data on long term conditions have been widely used in academic research and resource allocation by central government and as such NISRA intends to continue to collect information about long-term health problems or disability and the nature of long-term conditions in the 2021 Census. (source see page 15 of topic consultation paper; https://www.nisra.gov.uk/sites/nisra.gov.uk/files/publications/2021-census-topic-consultation-for-northern-ireland-document.pdf)

The 2021 Census proposals document provides further information on why the categories were expanded for 2021. The response categories were updated to take account of changing user needs. In particular, a new separate category has been included for Autism or Asperger syndrome to develop a baseline on the prevalence of these conditions within Northern Ireland. This approach was taken after user engagement by the Census content team. (Source; see page 31 of the 2021 Census proposals document)

3. Communal Establishments in 2021 NI Census

The 2021 Census Proposals Document [13] outlined plans to produce a complete census address register of every household and communal establishment in NI, using data from a range of sources including the POINTER address register, public bodies and a range of organisations. Although the definition for large communal establishments is clear, and there are plans to have a dedicated team of communal establishment enumerators to manage this sector, concerns were raised by members of our consortium regarding the definition of smaller communal establishments (e.g. supported living arrangements / shared lives services (people with a learning disability living on a long term basis, with individuals / families, other than their own family) / short break services to include family settings) and the correct and complete enumeration of individuals with LD living in such communal establishments on Census day.

Query 3*:* What processes are in place to ensure that individuals with LD living in all types of residence will be enumerated correctly on Census day 2021?

Work has been conducted to ensure that the census can be completed by anyone within NI. As with the 2011 Census, the census office aims to provide online help and a helpline in 2021 to ensure that anyone who is having difficulty to complete the census can receive the assistance or guidance that they need. While the aim is to have as many forms collected online as possible, a paper questionnaire is available to anyone who lacks access to the internet or who are unable to complete the electronic questionnaire. Carers are also duty bound to assist an individual in completing their Census form as the completion of the Census is seen as a legal obligation.

4. Mode of administration in 2021 Census in NI

The 2021 Census Proposal Document [13] outlined ambitious plans for the Census to be conducted predominantly online; specifically, it is anticipated that 90% of households will receive an initial contact letter with a unique code to complete the Census online, and there is a target for 60% of households to return their data electronically. Although there are provisions for a range of support services to assist the public with this change in mode of administration before the Census (e.g. Stakeholder Engagement and Communication Strategies) and on Census day (e.g. contact centre; online webchat help facilities), concerns were raised by members of our consortium as to the ability of individuals with a range of difficulties associated with LD, and in particular those who are living in smaller communal establishments, to be able to navigate these changes.

Query 4: What considerations have been given to supporting individuals with LD to manage the changes in mode of administration of the Census?

See above. Extensive testing of the systems in place has also been completed within the Census office on both the paper and electronic questionnaires. Work also is currently underway to test the response rates and data received from the Census rehearsal conducted in 2019 to ensure that there are no barriers to any individual within Northern Ireland as they attempt to complete the Census questionnaire.

I look forward to receiving your response,

On behalf of the Project Consortium, Professor Jamie Murphy

School of Psychology
H258 I Cromore Road I BT52 1SA
T: +44(0)2871675283
E: ja.murphy@ulster.ac.uk W: www.ulster.ac.uk

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FOLLOW-UP Correspondence 3-3-2020 (with Census Team response on 27-3-2020 in yellow)

Dear [redacted],

Thank you for replying to our queries regarding the inclusion, framing and collection of learning disability data in the NI Censuses. Thank you also for inviting us to seek further information. We would like to seek further detail/clarification on some of the responses that you have provided.

Dear Jamie,

I would just like to respond to each query in turn (response in blue) although I would like to combine my response for query 3 and 4 together.

In relation to Q1 and Q2, our research is partly attempting to understand and describe the history of learning disability recognition and recording in the NI Censuses. Our consortium therefore wishes to be clear on how and why learning disability specifically was introduced as it was in the 2011 Census and how and why it has been explicitly revised/framed in the forthcoming 2021 Census.

Query 1: *What was the rationale for combining the long-term health conditions of 'a learning difficulty, an intellectual difficulty, or a social or behavioural difficulty' into a single response category in the 2011 NI Census?*
In your response, you state that you 'do not have' a specific rationale for the combination of learning difficulty, intellectual difficulty, and social or behavioural difficulty into a single health condition item in the 2011 Census. Can you please clarify if this response means (i) that you are personally not aware of a rationale that might have informed the combination of these separate conditions or (ii) that no rationale informed this decision.

I can confirm that I personally am not aware of a rationale that might have informed the combination of these separate conditions, this decision predates most of the staff who currently work within Census. However, I have been able to locate some internal papers that suggest that its development may have been informed by the 'Study of people with Activity Limitations and Disabilities' – NISALD'. While it appears some of the categories from the NISALD were combined, where possible the NI census question covers a number the health conditions examined through this study. The definition of disability for the purposes of the NISALD was based on the concepts of the International Classification of Functioning, Disability and Health (ICF) and as such, by aligning with these categories it would still allow for international comparisons to be made.

Query 2: *What was the rationale for the change in the measurement of learning difficulty and intellectual disability in the 2021 Census?*
In response to our second query you refer us to 'The 2021 Census proposals document' and highlight the content within the document that partially explains why autism/Asperger syndrome has been included in the 2021 Census. We are specifically interested in the rationale for the explicit and separate framing and inclusion of the (i) learning difficulty category and (ii) the intellectual disability category. Moreover, we would like to know why these categories were framed using the exemplars dyslexia or ADHD for learning difficulty, and Down's Syndrome specifically for intellectual disability.

This change from the 2011 format was as a result of work that Census Office undertook with a range of Topic Experts and Stakeholders ranging from the 2015 Topic Consultation through to 2019. The decision (and agreement of the Topic Expert group) was arrived at on advice that that these conditions often co-occur in one person and also that there was value in splitting 'intellectual disability' from 'learning difficulties' as they require different types of interventions/future-service-provision – this would improve the data quality and enhance the user understanding of the outputs (by including the examples given). In particular, although ADHD was initially included as an example of a Learning Difficulty, it was later removed and 'dyslexia' retained. In the same way, 'Down syndrome' was included as an example of an Intellectual or Learning Disability. These exemplar changes would also have been informed by previous question design/layout testing and learning.

While working with the stakeholder groups it was noted that there was a need for a good indicator of the number of people with Autism (or Asperger) to develop a baseline to help them gain an understanding of autism (or Asperger's) prevalence in Northern Ireland- one of the chief drivers for this is the Autism Act NI 2011 which specifically asks for the prevalence of autism in the population.

Query 3: *What processes are in place to ensure that individuals with LD living in all types of residence will be enumerated correctly on Census day 2021?*
You state in response to our third query that (i) 'Work has been conducted to ensure that the census can be completed by **anyone** within NI', (ii) 'the census office aims to provide online help and a helpline in 2021 to ensure that **anyone** who is having difficulty to complete the census can receive the assistance or guidance that they need', (iii) 'the aim is to have as many forms collected online as possible', (iv) 'a paper questionnaire is available to **anyone** who lacks access to the internet or who are unable to complete the electronic questionnaire' and (v) 'Carers are also duty bound to assist an individual in completing their Census form as the completion of the Census is seen as a legal obligation'. Our Consortium wish to know how and in what way the specific needs of individuals with a **learning/intellectual disability** in NI, and their carers, have been assessed/considered in relation to the five points outlined in your reply.

NISRA jointly with ONS tested the electronic questionnaire platform with a wide range of users to ensure it was as accessible as possible, a summary of this work can be found by accessing the following link;
https://www.ons.gov.uk/census/censustransformationprogramme/questiondevelopment/summaryoftestingforcensus2021

Several leading learning disability charities were contacted in advance of the 2019 Census rehearsal to provide feedback and advice on the assistance available. While a response was only received from one of these organisations, a range of work was conducted by the Census office with collaborations with this charity and other partners to ensure that any individual with learning disabilities would be able to complete the Census questionnaire and that they could receive the appropriate guidance when doing so. While this work was primarily conducted for the 2019 rehearsal, the work will continue up until the Census in 2021. Some of the work conducted included;

- An easy to read guidance was developed that can be requested for any individual with learning disabilities to assist them in completing the Census questionnaire. This guidance has been attached to this email as it was available for the Census rehearsal in 2019. This documentation was shared with a learning disability charity and meetings were held with the organisation and some of its members to gain their input. The feedback received was positive and the charity agreed to share the easy read document where necessary.
- The Census office put on a range of assisted digital sessions to provide assistance for anyone wishing to complete the questionnaire online at the time of the rehearsal and aims to continue this work during the full Census in 2021.
- Some charities have agreed to highlighted the rehearsal census and also highlighted the list of libraries that were available for individuals to receive support completing the Census. These will also be advertised by the Census social media and the information can be provided by the helpline or online support. This work will hopefully continue at the time of the Census in 2021
- Work was undertaken in advance to identify all supported accommodation providers and communal establishments to ensure that assistance could be provided where necessary.
- The Census team conducted work with the charity and other organisations to try and identify a parent/carer and also an adult with a learning disability to go through the online survey and make comment. Once agreed with the Census office the charities offered to work with a stakeholder group of adults with a learning disability (or dual diagnoses) and also parents/carers to give feedback.
- Online assistance and a helpline will be made available to anyone seeking assistance when completing the 2021 questionnaire

It has also been made clear that if an individual is unable to make a return themselves that the manager of their care facility can do so on their behalf. Likewise within a household, the main house holder can make the return on their behalf.

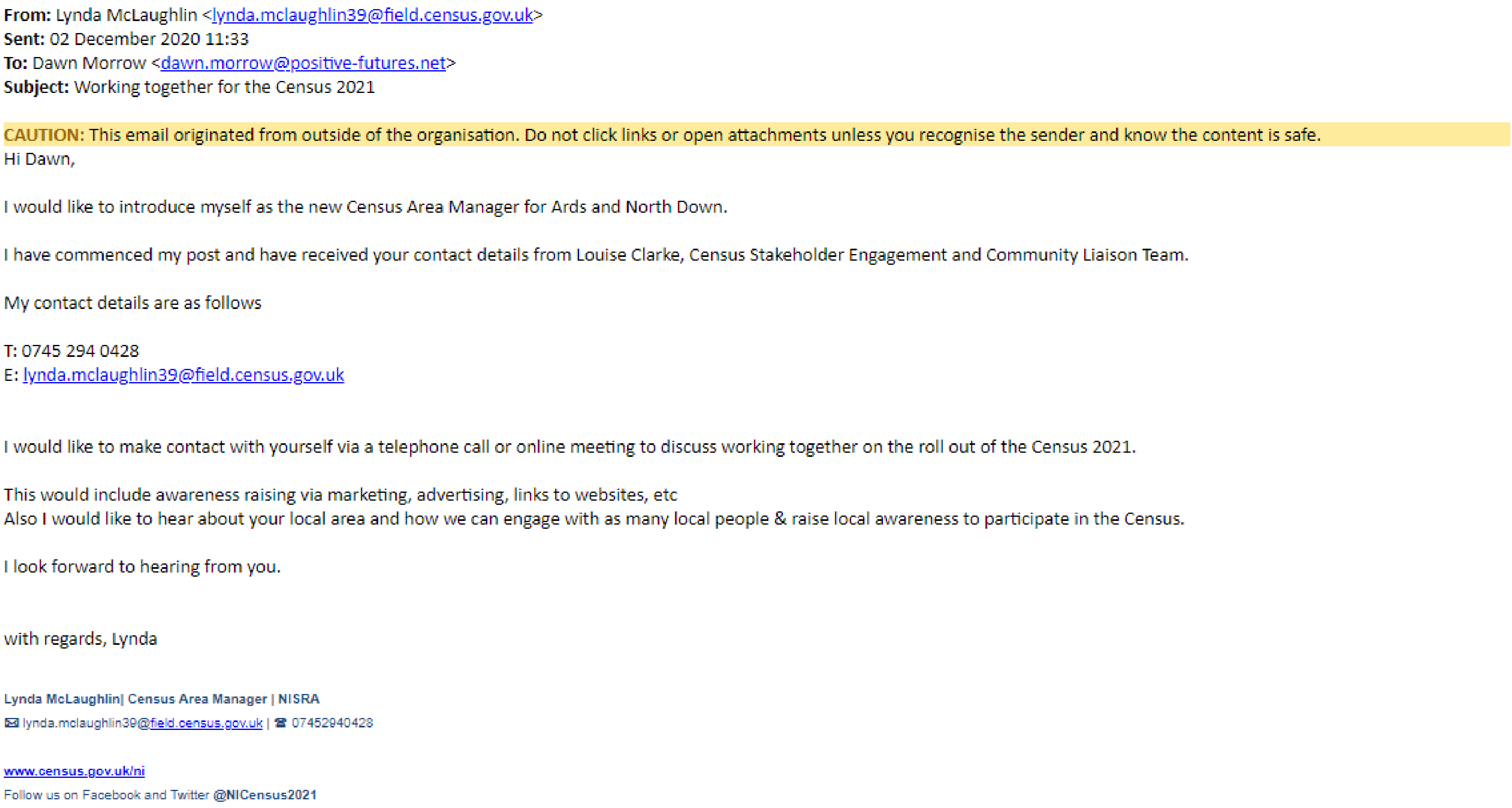
Query 4: *What considerations have been given to supporting individuals with LD to manage the changes in mode of administration of the Census?*
You state that (i) 'Extensive testing of the systems in place has also been completed within the Census office on both the paper and electronic questionnaires' and (ii) 'Work also is currently underway to test the response rates and data received from the Census rehearsal conducted in 2019 to ensure that there are no barriers to any individual within Northern Ireland as they attempt to complete the Census questionnaire'. Our Consortium wish to know how and in what way the specific needs of individuals with a **learning/intellectual disability** in NI, and their carers, have been assessed/considered in relation to both completed and ongoing testing of 'the [Census 2021] systems'. Specifically, our Consortium wish to know if any pilots were conducted or are planned to test the adequacy of the proposed arrangements for people with special needs such as **intellectual/learning disability**.

See answer to query 3
Hope this answers your questions
Best regards
Census office

Thank you once again for engaging with us. We look forward to receiving your response.

Kind regards, Jamie Murphy

Appendix 8



From: Lynda McLaughlin <lynda.mclaughlin39@field.census.gov.uk>
Sent: 02 December 2020 11:33
To: Dawn Morrow <dawn.morrow@positive-futures.net>
Subject: Working together for the Census 2021

CAUTION: This email originated from outside of the organisation. Do not click links or open attachments unless you recognise the sender and know the content is safe.

Hi Dawn,

I would like to introduce myself as the new Census Area Manager for Ards and North Down.

I have commenced my post and have received your contact details from Louise Clarke, Census Stakeholder Engagement and Community Liaison Team.

My contact details are as follows

T: 0745 294 0428
E: lynda.mclaughlin39@field.census.gov.uk

I would like to make contact with yourself via a telephone call or online meeting to discuss working together on the roll out of the Census 2021.

This would include awareness raising via marketing, advertising, links to websites, etc
Also I would like to hear about your local area and how we can engage with as many local people & raise local awareness to participate in the Census.

I look forward to hearing from you.

with regards, Lynda

Lynda McLaughlin| Census Area Manager | NISRA
✉ lynda.mclaughlin39@field.census.gov.uk | ☎ 07452940428

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