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**The health, support needs, access to
healthcare services and social exclusion
of adults with intellectual disabilities
living in rural areas: a rural-urban
comparison**

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Submitted in fulfilment of the requirements for the Degree of Doctor of Medicine

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Abstract

Background

Almost all intellectual disabilities research is conducted in urban areas, and very little is known about the population of adults with intellectual disabilities living in rural areas. It is important to know whether there are significant rural-urban differences, in order to provide appropriate services and address inequalities. In particular, the general rural population is known to be disadvantaged with respect to access to healthcare and social exclusion. Adults with intellectual disabilities are also disadvantaged in these areas, and therefore adults with intellectual disabilities living in rural areas may have a double disadvantage.

Method

A sample of adults with intellectual disabilities living in a rural area on the West Coast of Scotland participated in a face-to-face semi-structured interview; their medical notes were also accessed. Demographics, healthcare, access to services, daytime opportunities, access to community facilities, recent contact with others, the quality of personal relationships, and area deprivation by postcode were measured. Data were already available for a pre-existing urban sample. Data were analysed using direct comparison and binary logistic regression.

Results

A representative sample of adults with intellectual disabilities from rural (n=39) and urban (n=633) areas were compared. There were no significant rural-urban differences over a wide range of variables including: age, gender, ethnicity, level of intellectual disabilities, mental ill health and common co-morbidities such as mobility, visual impairment, incontinence and epilepsy. Both direct comparison and binary logistic regression showed the rural sample to have had significantly more contact with primary (Odds Ratio = 4.02, 95% CI 1.56 -10.35, $P = 0.004$) and secondary health care (OR = 3.93, 95% CI = 1.81 - 8.55, $P = 0.001$.) Participants from rural areas were significantly more likely to have any regular daytime opportunity (Odds Ratio = 10.8, 95% CI = 2.3 - 51.5) including employment (OR = 22.1, 95% CI = 5.7 - 85.5) and attending resource centres (OR = 6.7, 95% CI = 2.6 - 17.2) than were participants from urban areas. They were

also more likely to have been on holiday (OR = 17.8, 95% CI = 4.9 - 60.1); however, were less likely to use community facilities on a regular basis. Participants from urban and rural areas had a similar number of contacts with other people in a wide range of situations, but the quality of relationships may have been less close in rural areas. Finally, rural participants lived in significantly less deprived areas (Mann Whitney U = 7826, Z = -3.675, $P \leq 0.001$).

Conclusion

There were no significant demographic and health differences between the rural and urban samples. The study was underpowered with respect to some of these findings, and some results may reflect a Type II error. Nevertheless this is an important negative finding. Contrary to original hypothesis, the rural sample was found to have better access to healthcare services, had better opportunities and lived in less deprived areas than adults with intellectual disabilities living in urban areas. However, the results suggest that the rural sample may not have held such positive or close relationships, and this may be important when considering the subjective experience of social exclusion.

Additional qualitative sub-study

A qualitative sub-study investigated the difficulties experienced with recruitment to the original study. 10 semi-structured telephone interviews were held with professionals who had helped with recruitment. These were transcribed verbatim and anonymised, then analyzed using the Framework approach. A number of themes arose, including participant factors (interview anxiety, worry about negative feedback), the importance of the researcher (using a personal approach, meeting potential participants prior to recruitment) and motivators (enjoyment of the research interview (participant), obtaining a medical assessment (carer)). The themes were then used to generate strategies to improve recruitment to intellectual disabilities research: these include the research team applying a more personal approach, and considering motivators for both participants and carers. The findings of this study have implications in terms of both time and money. However, successful recruitment is essential to intellectual disabilities research, and the results can be used by intellectual disabilities researchers to review and improve their recruitment processes.

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Author's Declaration

This thesis is the work of the author unless specifically stated otherwise.

Laura Nicholson, MA, BM BCh, MRCP, MRCPsych

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Publications

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Nicholson, L., Cooper, S-A. (2011) Access to healthcare services by people with intellectual disabilities: a rural urban comparison. *Journal of Intellectual Disabilities*, **15** (2), 115-130. DOI: 10.1177/1744629511412659.

Nicholson, L . (2009) Rural mental health, Online CPD module for the Royal College of Psychiatrists, published December 2009

Nicholson, L. (2008). Rural Mental Healthcare. *Directions in Psychiatry*, **28** (November), 271 - 284

Nicholson, L.A. (2008) Rural Mental Health. *Advances in Psychiatric Treatment*, **14**, 302 - 311

Chapter 1: Introduction and literature review

1.1 Rationale for topic selection for this thesis

There is an increasing body of evidence to suggest that adults with intellectual disabilities are disadvantaged compared with the general population. For example, they are more likely to suffer physical and mental ill-health, and are more likely to experience social deprivation and social exclusion. In addition, adults with intellectual disabilities have poorer access to healthcare and other services, and this further compounds inequalities (Cooper et al. 2004; House of Lords et al. 2008; Mencap 2004; NHS Scotland 2004).

There is also evidence that people living in rural places are disadvantaged compared with the urban population, particularly with respect to access and social exclusion (British Medical Association Board of Science 2005; NHS Scotland 2005; Scottish Executive 2001). However, there may be aspects of rural life such as greater community spirit and informal social support that counterbalance these disadvantages. In addition, mental health is thought to be better in rural areas (New Freedom Commission 2004), and this would be of particular benefit to those at high risk of mental ill health, such as adults with intellectual disabilities.

It was therefore hypothesised that adults with intellectual disabilities living in rural areas may experience a double disadvantage, particularly with respect to access and social exclusion. It was not known whether aspects of rural life including better mental health would ameliorate this double disadvantage. Government policy aspires to social inclusion, fairness, opportunity and quality of life for people with intellectual disabilities in the UK (Department of Health 2001; Scottish Executive 2000b). Any double disadvantage therefore should be identified and inequalities addressed. It was also considered that the topic of adults with intellectual disabilities living in rural areas was an important and relevant area for further research, and the themes of access and social exclusion were used to direct the subsequent literature review.

1.2 Definition and terminology of intellectual disabilities

Intellectual disabilities are defined by three core criteria:

1. Significant global impairment of intellectual functioning, accepted as equivalent to an $IQ \leq 70$. IQ scores are used to divide intellectual disabilities into: mild intellectual disabilities (IQ 50 - 69), moderate intellectual disabilities (IQ 35 - 49), severe intellectual disabilities (IQ 20 - 34) and profound intellectual disabilities (IQ under 20).
2. Significant impairment of social or adaptive functioning such that people with intellectual disabilities are likely to require significant assistance with day-to-day life-skills including self care, maintaining social relationships, communication, employment and home living.
3. Age of onset before the brain has fully developed (usually given as age 18).

The term “intellectual disabilities” is widely used by the international research community and is therefore the term used in this thesis. The term “learning disabilities” is commonly used in the UK where this thesis was written. The term “mental retardation” is currently used in the International Classification of Diseases version 10 (ICD 10) (World Health Organisation 1993) and the Diagnostic and Statistical Manual version IV Revised (DSM-IV-R) (American Psychiatric Association 2000). However, it is slowly becoming less acceptable and in keeping with this, the “American Association on Mental Retardation” voted in 2007 to change its name to the “American Association on Intellectual and Developmental Disabilities”. The USA term “developmental disabilities” is a broader category than that of “intellectual disabilities”, and includes other disabling developmental disorders such as physical impairments and psychological disorders of childhood.

1.3 Defining rural

The concepts of “rural” and “rurality” are central to this thesis, and are therefore worth considering in further detail. Rurality can be broadly divided into the following dimensions: spatial, socioeconomic and sociological (table 1). These form the basis of definitions of rurality.

Spatial	Socioeconomic	Sociological
Total population/settlement size	Availability of healthcare and other services	Self-classification as rural or urban
Distance or journey time needed to travel to nearest metropolitan centre	Relationship to the nearest metropolitan area	Attractiveness or beauty of landscape
Population density	Simple socio-economic variables	Community support and cohesion
Isolation, and distance to nearest neighbour	Transport links	Self-sufficiency and independence
Proportion of “greenspace”	Principle economic activity	Principle economic activity
	Predominant land use	
	Cost of providing services	

Table 1 Dimensions of rurality

1.3.1 Spatial definitions

The simplest definition of “rural” is everything that is not a city or large town. For example, all areas (or populations) outside a settlement of 10,000 or 50,000 or 100,000 may be defined as rural. The majority of international classification systems use population or settlement size as the fundamental basis for classifying rurality. The extent of rurality can be determined by the distance or journey time needed to travel to the nearest large urban centre.

Another common way of defining rurality is by using population density. For example, the Netherlands Central Bureau of Statistics defines rural as the 20% of land with the lowest household density. One difficulty with this simple system is that it does not allow for local context; for example, a large farm close to a big city may have a lower population density than a small town in the Western Isles

off the coast of Scotland. Using household density to used to draw up a “density profile” over increasingly large areas may help to address this difficulty (Bibby & Shepherd 2004).

Isolation, and the distance to nearest neighbour are a spatial means of classification that have considerable face value. However, these are hard to measure and are not widely used. The Scottish Executive previously used the number of miles of road per 1000 population to determine remoteness (Scottish Executive 2000a), but this has been replaced by the Scottish Executive Urban Rural Classification (Scottish Executive 2006a).

Finally, “greenspace” is defined as the proportion of “green” land compared with other types of land cover such as domestic buildings, gardens, non-domestic buildings, road, rail, path and water. The concept and measurement of greenspace is increasingly popular within urban research and town planning, but is not used by the rural research community. The proportion of greenspace is so great in most rural areas, that it is probably not a useful discriminator (Maas et al. 1996; Mitchell & Popham 2007).

1.3.2 Socio-economic definitions

In primary healthcare, rurality is commonly defined by the availability of healthcare and other services. For example, the General Practice Rurality Index of Canada defines rural healthcare using six weighted variables: remoteness from basic and advanced service centres, the number of General Practitioners (GPs) and specialists, total population size and availability of acute care hospitals (Leduc 1997). The British Medical Association define rural primary care by the greater proportion of emergency/minor casual work, difficulties associated with distance and travel, and the wider range of skills needed by rural healthcare professionals (British Medical Association Board of Science 2005). The increased cost of providing rural services may also contribute to the definition of rural.

Simple socio-economic variables such as unemployment levels or income have been used in complex composite definitions of rural (Weich et al. 2003; Weich et al. 2006). Other socio-economic variables such as principle economic activity

(e.g. farming and fishing) or predominant land use (e.g. farming) tie in better with the sociological concept of rurality. Finally, transport links, including transport of people and goods, and also electronic communication links (such as mobile phone or internet coverage) have been used as a proxy measure of access and hence rurality.

1.3.3 Sociological definitions

Sociological definitions incorporate subjective aspects of rurality, and may include the attractiveness or beauty of the natural landscape, support and cohesion within the rural community, and self-sufficiency and independence of the rural residents. A small number of published studies have determined rurality by asking participants to decide for themselves whether they live in a rural area. The Scottish Executive state that unless a system of classification considers the look or feel of a place, people included in the research may disagree about the findings (Scottish Executive et al. 2006). Given that rural research is often designed and implemented at a local level, this is important.

1.3.4 Remoteness

A further distinction can be made between rural and remote (Wakerman 2004). Definitions of remoteness all incorporate the concept of distance; this usually refers to spatial distance, but may also refer to distance in terms of access, service provision, or culture. Another distinguishing feature that is more difficult to define is “isolation”.

A number of rural classification systems incorporate remoteness. For example, in the USA a frontier area (equivalent to remote) is defined as 45 miles and/or 60 min from primary care to the next level of care. In Alaska, around one third of the population lives in places without road access, and places are defined as remote when they can only be reached by boat, airplane or snowmachine (Wilcox et al. 2001). An alternative definition of remoteness is “where there are problems of access which it has not been thought worthwhile to overcome,” (Bloor et al. 1978), cited in (Watt et al. 1994).

1.3.5 Rural diversity

Several authors have noted that rural areas can be very diverse. Even within a single country, the differences between different rural areas may be as great as those between urban and rural areas (British Medical Association Board of Science 2005; Hart et al. 2002; NHS Scotland 2005; Philo et al. 2003). The situation and experiences of a crofter living on a remote Scottish island may bear little relationship to those of a commuter living in Essex, even though they both live in places defined as rural.

1.3.6 Which definition should be used?

There have been calls for a universal or international definition of rural to facilitate comparison of research (Humphreys 1998; Peters & Jackson 2005), but at present there is no single definition of rurality which meets all purposes (Muula 2007; Scottish Executive 2006a). Given the complexity of the concept of rurality, and given the differences in rurality both within and between countries, perhaps it is neither possible nor desirable to identify a single definition of rural. When conducting rural research, it is recommended that the researcher becomes familiar with a number of different definitions and consider the advantages and disadvantages of each before selecting the most appropriate (Hart et al. 2005). A primary consideration is the task for which the definition will be used (Couper 2003; Goodyear-Smith & Janes 2006; Humphreys 1998), but other factors such as the geographic scale of the area over which the definition will be used may be relevant (du Plessis et al. 2002). Further discussion of the definition used in this thesis is found in section 3.6.2.

1.3.7 Geographic mobility

Geographic mobility or internal migration is relevant to rurality. The rural population is constantly changing, and a “rural population” may comprise a mixture of locals who have lived there all of their lives, and of incomers who have moved to the area more recently from an urban area. This needs to be taken into consideration when interpreting research that compares “rural” and “urban” populations.

With respect to healthcare, incomers to rural areas may come to a rural area with different health problems to the local population, and may also have very different health beliefs, behaviours and expectations of healthcare. In addition, health problems may themselves affect geographic mobility. For example, people living in rural areas may move to urban areas to access specialist medical services (Larson et al. 2004). Some people with mental ill health may move to rural areas because rural life is perceived as less stressful (Philo et al. 2002). Migration itself contributes to mental ill health (Bhugra 2004).

It therefore appears important that geographic mobility is measured for the rural participants in this thesis. This will determine whether they are local or whether they are incomers to the rural community, and hence facilitate interpretation of the results.

1.3.8 The importance of rurality

However it is defined, rural culture and rural countryside form a significant part of the society in which we live. In the UK, a large minority of the population live in rural places; around 30% in England and Wales (Buchan & Deaville 2005a; Countryside Agency 2004), and 20% in Scotland (Scottish Executive 2006b). 98% of Scotland's land mass is classified as rural. In the USA approximately 25% of the population and 90% of the landmass is considered to be rural (New Freedom Commission 2004). Rural policy forms an increasingly important part of the way that wealth is distributed and services are run in high-income countries. This thesis therefore plans to investigate an important and relevant topic.

1.4 Rural mental health

Mental ill health is an important cause of illness, and depression is now the third leading contributor to the global burden of disease (Collins et al. 2011). Mental ill health is therefore important when considering the health and healthcare needs of a population. As discussed further below, mental ill health is prevalent in people with intellectual disabilities (Cooper et al. 2007), and is therefore a central consideration in this thesis.

1.4.1 Interpretation of rural mental health literature

A number of factors need to be taken into account when reviewing rural mental health literature.

First, it is important to be aware of the measurement that has been used when interpreting studies looking at mental ill health. The gold standard for diagnosing psychiatric illness requires one or more trained psychiatrists to conduct a full clinical psychiatric interview, supported by relevant diagnostic tools. This is lengthy and expensive, and larger studies (particularly epidemiological studies) often use proxy measures of psychiatric illness. For example, Weich et al. (2003 and 2006) investigate the relative prevalence and incidence of “Common Mental Disorders” in rural areas by comparing depression and anxiety scores on the self-administered 12-item General Health Questionnaire (GHQ) (Goldberg & Williams 1988). Lewis & Booth (1994) use a cut-off of five or more on the 10-item version of the GHQ as indicative of psychiatric morbidity. The GHQ is a well recognised simple screening tool, has been validated against standardised clinical interviews and has been shown to have a sensitivity and specificity of around 80%. Nevertheless, it remains a proxy measure of mental ill health. In addition, urban and rural populations may answer standardised interview schedules or questionnaires in different ways; perhaps because of failure to recognise symptoms of mental illness, or because of rural stoicism.

Second, a large number of variables are associated with mental ill health. These include age, gender, socio-economic status and unemployment, poverty, and substance abuse (Judd et al. 2002). These variables are also associated with

rurality, and therefore act as confounders unless studies specifically adjust for them. The majority of major studies comparing urban and rural mental health adjust for some potential confounders, but comparing results from different studies can be difficult if they have adjusted for different variables. Studies that have not adjusted for any confounders should probably be interpreted with caution. In addition, a few studies (such as Weich et al. 2006) have used socio-economic variables to define rurality. This particular study is difficult to interpret, as it adjusted for some of these same socio-economic variables when analysing the results.

Third, some studies compare the utilization of mental health services in urban and rural areas rather than investigating the true prevalence and incidence of mental ill health. However, service utilization in rural areas may be affected by poor rural access. In addition, the threshold for admission to hospital may be different in rural areas, particularly if the hospital is far from the patient's home. Finally, the recognition of mental ill health and therefore utilization of health services may differ in rural and urban areas. Psychotic illness is probably an exception to this, as it is likely to present to mental health services, and severe psychosis typically requires hospital admission. Utilization of services may therefore be a reasonable proxy for the incidence and prevalence of psychotic illness.

1.4.2 Reviews of rural mental health

The student could identify just 4 complete reviews of rural mental health (table 2). The oldest of these reviewed international literature from 1985 to 1994 (Verheij 1996). It concluded that mental health was probably worse in urban areas, but noted that many reasonable studies showed exceptions to this. The review was written very much from the perspective of "urban" rather than rural mental health, and focuses on problems with urban mental health rather than the benefits of rural mental health. The systematic review by Peters & Jackson (2005) lists a good selection of the available literature, but unfortunately fails to draw any conclusions. Finally, two reviews from the USA (New Freedom Commission 2004) and Australia (Judd et.al 2002) conclude that if there are any differences between the epidemiology of urban and rural mental health they are likely to be small, and suggest that other factors such as socio-economic

differences between urban and rural areas are likely to be more important. They both highlight the importance of the quality and experience of mental health problems in rural areas, suggesting that this may be more significant than a crude estimation of the quantity of mental health in rural areas. Judd et al. (2002b) observe that variables that influence mental health (such as socio-economic factors and physical health) do so in a non-linear fashion, and therefore our current preferred means of statistical analysis (namely regression modelling) may not be appropriate.

The student could not find any true meta-analyses of studies comparing urban and rural mental health. However, whilst not true meta-analyses, a couple of studies attempt to draw together results from a number of individual studies that measure the prevalence of mental ill health. The first study by Kovess-Masfety et al. (2005) analysed the results of household surveys conducted across six different countries. They conclude that the prevalence of a wide range of mental illnesses is higher in urban areas, but their analysis did not in fact support this conclusion. The results were analysed using a number of subgroups, and despite very large numbers, there were few significant or consistent results. The definition of urban that they used (any settlement with a population of over 10,000) was not sufficiently detailed to account for the wide range of rural environments in the six different countries. The second study compared results from six studies around the world (Hwu & Compton 1994). Despite the studies all using similar methodology (using a DIS interview schedule to provide a DSM-III psychiatric diagnosis), they found no consistent relationship between prevalence of mental ill health and rurality.

Paper and country of origin	Notes	Conclusion
Verheij (1996), Netherlands	Literature review between 1985-1994. Focuses on urban mental health and the effects of urbanicity rather than rural mental health. Considers a wide range of confounders, and also geographic mobility (in the form of geographical drift).	Mental health is worse in urban areas but there are many exceptions.
New Freedom Commission on Mental Health (2004), USA	Comprehensive and informative report on the state of rural mental health in the USA. Good understanding of the complexity of rural mental health.	The underlying prevalence of mental ill health is likely to be similar in urban and rural areas. However, rural areas are disadvantaged with respect to mental health for a number of other reasons.
Peters & Jackson (2005), UK	This was a methodologically sound literature review of the international literature and provided a comprehensive list and summary of papers relating to rural mental health.	They were unable to draw any firm conclusions.
Judd et al. (2002b), Australia	Well described and thorough international literature review. The authors make the point that simply measuring crude prevalence or "quantity" of mental health problems is less helpful than considering the "quality" of mental health, and the influence of place on mental health. They discuss in depth the limitations of the currently available research.	The majority of studies fail to show a difference between rural and urban mental health prevalence. A number of socio-demographic factors can be shown to be more important predictors of prevalence of mental health problems than rurality.

Table 2 Reviews comparing rural and urban mental health

1.4.3 The prevalence of rural mental health

Table 3 summarises 17 recent major studies that have compared the prevalence of mental health problems in rural and urban areas. Two of these papers collate the results from a number of separate studies and were discussed further above (Hwu & Compton 1994 and Kovess-Masfety et al. 2005). Of the remaining 15, for each of 2 datasets, 2 papers present different aspects of the same study (Bilj et al. 1998; Van Os et al. 2001) and (Johns et al. 2004; Paykel et al. 2003). 12 of the studies are based in the UK, the USA, Australia, and the Netherlands. All of these countries have well defined and distinguishable rural areas, with the possible exception of the Netherlands which is so small that even “rural” countryside is easily accessible from large cities. Many of the studies were not designed for the purpose of urban-rural comparison, and most have been written from an urban rather than rural perspective. It is worth noting that one of the more impressive and complete British datasets (Johns et.al 2004; Paykel et.al 2003) excluded the Highlands of Scotland on the grounds that they were too inaccessible. The Highlands of Scotland are the most rural part of the UK, and are where the study described in this thesis is set.

These studies were mostly well constructed and conducted, and had high internal validity. They measured the prevalence of mental ill health in the general population, and used either self-assessment measures or more commonly face-to-face or telephone interview techniques. Some studies followed up a preliminary assessment by a trained lay person with a clinician-lead interview. Almost all used recognised and validated scales to identify a wide range of psychiatric symptoms and diagnoses. Participants were adults (aged at least 15 or older) and the number recruited was typically in the thousands. The response rate was usually given, and generally fell between 60% and 80%. Although very different measures of rurality were used in each study, they were appropriate for the populations studied.

In 10 out of the 15 original studies, the prevalence of mental ill health was greater in the urban compared with the rural population. Most of these studies adjusted for potential confounders. In the paper by Eckert et al. (2006) the association between urbanicity and mental ill health was lost when the results were adjusted - this contrasts with the paper by Wang et al. (2004) in which the

results were only significant *after* adjusting, and is difficult to explain. Of the remaining five papers, four showed no difference in the prevalence of mental ill health in rural and urban areas. Just one paper showed that after adjusting for a number of variables, mental health was worse in rural areas in the USA (Probst et al. 2006). This was an impressive paper, and it is hard to explain why the results differ. Nevertheless, taking these 15 papers into consideration, current evidence suggests that the prevalence of mental ill health is higher in urban areas.

There may be exceptions to this trend, and some rural areas have a higher than expected prevalence of mental ill health. For example, there is a high prevalence of mental ill health in specific isolated areas of Norway and Iceland. The highest prevalence of schizophrenia worldwide is in a small rural county in the West of Ireland (Freeman 1994).

Table 3 Studies comparing the prevalence of rural and urban mental health

Paper and country of origin	Notes	Conclusions
Bijl et al. (1998), Netherlands	Household survey, part of the NEMESIS trial. Data also described in paper by Van Os et al. (2001) below. N = 7067, response rate not given. Rural defined as the lowest quintile of population density. The study looked at lifetime diagnosis and the 1 and 12 month prevalence of a number of different psychiatric disorders. A face-to-face interview was held with a trained researcher, and symptoms combined to give a DSM-III-R diagnosis (using CIDI).	Higher prevalence of mood disorders and substance abuse in urban areas. Also, higher overall morbidity and co-morbidity in urban areas. No difference in prevalence of anxiety disorders.
Blazer et al. (1985), USA	Household survey, part of the Epidemiological Catchment Area Program. N = 3921, response rate = 79%. Urban was defined as any county or group of contiguous counties that contain at least one city of $\geq 50,000$. The study looked at the point prevalence of a wide range of psychiatric conditions. A face-to-face interview was held with a trained researcher, and symptoms combined to give a DSM-III diagnosis (using DIS). Adjusted for 5 confounders that included geographic mobility in the previous 5 years.	Unadjusted results showed a higher prevalence of major depressive disorder but lower prevalence of alcohol abuse and cognitive deficits in urban areas. After adjusting for confounders, only the results for major depression remained significant.
Caldwell et al. (2004), Australia	Household survey, N = 10641, response rate = 78%. Rural defined by the RRMA (Rural, remote, and Metropolitan Area index). This is well validated and recognised in Australian research. The study looked at the point prevalence of depression, anxiety and substance misuse. A face-to-face interview was held with a trained researcher, and symptoms combined to give an ICD-10 diagnosis (using a modified CIDI). There was no measurement or adjustment for confounders.	Fewer men in "other rural/remote" areas reported substance misuse or "any mental disorder" but there were no other significant rural-urban differences for either men or women.
Eckert et al. (2004), Australia	Cross-sectional telephone survey that asked about symptoms of mental health (using the Kessler-10 and SF 12), and whether the participant's doctor had diagnosed depression in previous year. This was used to ascertain psychological distress, mental wellbeing, clinical depression and self reported mental health problems. N = 2545, response rate = 64%. Rural defined by ARIA, a well validated and recognised measure in Australian research.	No difference between rural and urban areas.

Eckert et al. (2006), Australia	This paper presents more data from the study above; this time they report whether the participant had been given a diagnosis or was being treated for a diagnosis of mental disorder by their GP. They included the diagnoses of depression, anxiety, a stress-related problem, or any other mental health problem. The other difference to the above study is that the authors adjust for a large number of potential confounders.	Higher prevalence in urban areas, but not once adjusted for stressful life events, perceived control over life events, socio-demographic characteristics and lifestyle behaviours.
Hwu & Compton (1994), from six countries around the world	This paper presented an analysis of the results of six studies, all set in different countries and four of which compared mental health in rural and urban areas. All studies involved population/household surveys with face-to-face interviews, using self reported symptoms to give DSM III diagnoses (using DIS). Studies were all conducted in the 1980s. No definition of rural. Only "cultural background" and gender were adjusted for. Number of participants and response rates not given. It was difficult for the authors to compare the studies as they were so heterogeneous.	There was no consistent relationship between rurality and mental ill health across the countries.
Johns et al. (2004), Great Britain	Household survey, N = 8580, response rate = 67%. Data was taken from the larger Office for National Statistics National Psychiatric Morbidity Survey, and is also presented in the paper by Paykel et al. (2003) and Wiles et al. (2006). No definition of rural. A trained interviewer asked about self-reported psychotic symptoms, and this was followed up by assessment by a trained clinician if symptoms were present. Participants were excluded if they were found to have definite or probable psychosis. A large number of potential confounders were measured.	Unadjusted results showed higher prevalence in urban areas, but this was no longer significant after adjusting for multiple confounders.
Kessler et al. (1994), USA	Household survey, N = 8098, response rate = 82.6%. A standard and accepted USA definition was used to distinguish metropolitan, urban and rural counties. Self reported symptoms were used to give a 12 month and lifetime prevalence of a wide range of disorders using DSM-III-R (using CIDI). There was weighting by area, but no adjustment for individual confounders.	The 12 month prevalence of co-morbid (but not individual) disorders was higher in metropolitan areas. No other findings were significant.
Kovess-Masfety et al. (2005), various countries in the EU.	Household survey, N = "21,000 plus", response rate = 62.1%; but there was no attempt to amalgamate the results from different countries. A face-to-face interview was conducted using self reported symptoms to give DSM-IV and ICD-10 diagnoses (using CIDI). The SF12 was also used to measure psychological distress. The study investigated "any disorder", mood disorders, anxiety and alcohol abuse. Urban was defined simply as living in any settlement $\geq 10,000$.	Prevalence higher in urban areas; but quite a confusing analysis, and their conclusion was not really justified by their results.
Lewis & Booth (1994), England, Scotland and Wales	Household survey used a face-to-face interview to assess general physical health, and then left a 30-item version of the GHQ with participants to assess mental health. A score of ≥ 5 points was considered indicative of psychiatric morbidity. N = 6457, response rate = 52.7%. Rurality was determined by the interviewer's judgement. A number of potential confounders were measured.	Psychiatric morbidity was found to be more prevalent in urban areas, even after adjustment for age, sex, social class, marital status and chronic illness.

Parikh et al. (1996), Canada	Household survey, N = 9951, response rate = 76.5%. Face-to-face interview used self reported symptoms to determine DSM-III-R diagnoses of major depression, mania and dysthymia (using CIDI plus supplementary questions). Variables were measured but not adjusted for. Rurality was defined using a population density based nationally recognised classification. Despite differential sampling, the numbers from rural areas were quite small and there was no power calculation.	There was a consistent but non-significant trend for a lower prevalence of mental health problems in rural areas.
Paykel et al. (2003), Great Britain	Household survey reported as part of the National Psychiatric Morbidity Survey of Great Britain. (See also Johns et al. (2004) and Wiles et al. (2006).) N = 9777, response rate = 76.8%. Rurality was determined by interviewer judgement. Face-to-face interviews used the CIS-R to determine alcohol and drug-dependence, with “neurotic disorder” defined as a score of ≥ 12 .	Unadjusted prevalence was higher in urban>semirural>rural areas. This remained significant for “neurotic disorders” but not substance abuse after adjusting for confounders.
Probst et al. (2006), USA	Household survey, N = 30.801, response rate not given. Face-to-face interview used self reported symptoms to give a DSM-III-R diagnosis of depression (using CIDI). Rural areas were defined as those counties outside the Metropolitan Statistical Area; an accepted and widespread system of classification in the USA. A number of variables were adjusted for.	Prevalence of depression higher in rural areas using unadjusted data. No significant difference once variables were adjusted for.
Romans-Clarkson et al. (1990), New Zealand	Following a postal survey with the GHQ (N = 1516, response rate = 75.5%), a stratified sample of participants were interviewed by a trained researcher (N = 314, response rate = 90.0%). The Present State Examination psychiatric interview was used to give a range of clinical diagnoses. The authors gave a good description of the rural and urban areas in this study, but rural not defined.	The prevalence was the same in rural and urban areas.
Van Os et al. (2001), Netherlands	Household survey, part of the NEMESIS trial as described above (Bilj et al., 1998). N = 7076, response rate = 69.7%. The methodology of the paper was the same, but this paper reported the prevalence of psychotic disorders and psychotic symptoms. Unlike the paper above, the results were adjusted for a range of potential confounders (although this made little difference to results.)	The lifetime prevalence of psychotic disorders and psychotic symptoms was higher in urban areas, with a dose-response relationship.

Wang (2004), Canada	Household survey conducted by telephone interviews, and using a short form of the CIDI to determine the 12 month prevalence of depression. N = 17244, response rate not given. A definition of urban was taken from Statistics Canada (national database), but was very broad, and included many small rural towns. A number of potential confounders were measured and adjusted for.	The results showed a higher prevalence of depression in urban areas, but only after multiple regression adjusted for variables.
Weich et al. (2003), Great Britain	First wave of the 1991 British Panel Household survey, which used a self administered GHQ-12 questionnaire. Scores from this were used to define “common mental disorders” (anxiety and depression). N = 8978, response rate = 94.3%. The authors use a very complex definition of rurality that uses several variables that were subsequently adjusted for in the analysis of mental health. This makes it hard to interpret the results with any certainty. The paper below by Weich et al. (2006) used the same dataset.	Unadjusted data showed a higher prevalence of common mental disorders in the urban population (although the statistics supporting this assertion were not convincing). Adjusted data only showed an association for participants who were “economically inactive”.

Table 3 Studies comparing the prevalence of rural and urban mental health

Abbreviations

CIDI	Composite International Diagnostic Interview
DIS	Diagnostic Interview Schedule
GHQ	General Health Questionnaire
NEMESIS	Netherlands Mental Health Survey and Incidence Survey

1.4.4 The incidence of rural mental health

There are just three major studies that compare the incidence of mental ill health in urban and rural areas (table 4).

One of these is helpful in demonstrating the complexity of interpreting rural-urban research. The study was set in the Netherlands and compared the number of new presentations of patients with eating disorders to urban and rural primary care (Van Son et al. 2006). The dataset was likely to be complete, and the analysis was robust. There was no relationship between anorexia and rurality, but there was a strong dose-response gradient between rurality and bulimia; bulimia was most likely to present to urban practices, followed by semi-rural and lastly rural practices. There are two possible interpretations. First, bulimia and anorexia are unrelated eating disorders, and there is an association between rurality and bulimia but not anorexia. Second, bulimia is only recognised as a condition requiring medical attention in urban areas, and this is why there is an apparent negative association with rurality. This could be because of different cultural attitudes towards and awareness of eating disorders in urban areas; affecting both patients and doctors working in urban practices. Bulimia is a disorder that may go unrecognised and hidden from medical attention for many years, and many people with bulimia will never be diagnosed. This contrasts with anorexia, which is likely to come to medical attention once weight loss is sufficiently marked. Presentation of anorexia is therefore less likely to be influenced by cultural attitudes and awareness.

Given that there are only three noteworthy studies, overall there is insufficient evidence to draw any conclusions.

Paper and country of origin	Notes	Conclusions
Van Son et al. (2006), Netherlands	This study used GP registers to identify female cases of anorexia (N = 113) and bulimia (N = 110) using DSM-IV criteria. The 63 GP registers that were used in the study covered approximately 1% of the total representative population. Rurality was classified into three categories using the Dutch National Institute of Statistics definition. Although a small study, the results were significantly significant.	For bulimia there was a dose-response relationship, with the incidence highest in cities. There was no association between rurality and the incidence of anorexia.
Weich et al. (2006), Great Britain	12 month follow-up from the paper by Weich et al. (2003) described in table 3 above. N = 7659, and 80.0% of respondents completed both the initial study and this follow up study. As above, the authors use an extremely complex definition of rurality that is derived from some of the variables that are subsequently adjusted for in the analysis.	There was a small but statistically significant higher maintenance of common mental disorders in the urban population over the year. However, the incidence was not significantly different.
Wiles et al. (2006), Great Britain	18 month follow up study from the paper on psychotic symptoms by Johns et al. (2004) described above. The methodology is described above. After a number of exclusions, only 50.8% of those who participated in the initial interview participated in this follow up study; N = 1795.	There was a greater incidence of psychotic symptoms in the rural population after adjusting for a number of variables.

Table 4 Studies comparing the incidence of rural and urban mental health

1.4.5 Utilisation of rural mental health services

Table 5 describes four papers that all link population or conscript data with subsequent contact with psychiatric services. All four use complete and massive datasets drawn from national datasets, and all four found a significant and strong dose-response association between psychosis and urbanicity. One of the studies also investigated hospital admission for depression (Sundquist et al. 2004). Although there was still a relationship with urbanicity, this was not as strong as the relationship between psychosis and urbanicity.

Paper and country of origin	Notes	Conclusions
Lewis et al. (1992), Sweden	National database (N = 50,456, and response rate over 95%) from all male Swedish conscripts (aged 18 to 19 years) linked to data about subsequent hospital admission. All hospital admissions in Sweden are recorded and coded at discharge and this study investigated a clinical diagnosis of schizophrenia using ICD-8. Rurality was determined by asking where the conscripts mostly lived when they were growing up, and was divided into settlements $\geq 50,000$, settlements $< 50,000$ or “in the country”. The strength of this study is the size and completeness of their data.	There was a strong dose-response relationship between a diagnosis of schizophrenia and urbanicity. This relationship remained after adjusting for a number of potential confounders (including cannabis use).
Sundquist et al. (2004), Sweden	National database of ICD-9 and ICD-10 hospital discharge codes of either depression or psychosis, for first hospital admissions for the total population of Sweden (4.4 million) over a three year period. This was linked with rurality as determined by the population density by quintile of each patient. Data on a number of potential confounders were also available. There are some limitations of this study (for example, not all people with depression will have been admitted to hospital), but as above, the strength of this study is the size and completeness of data.	There was a strong dose-response relationship between a diagnosis of depression or psychosis and urbanicity, with a higher number of hospital admissions in people living in urban areas.
Pederson & Mortensen (2001), Denmark	Danish Civil Registration of all births in Denmark from 1950 to 1993 data linked with all hospital admission and outpatient contacts with an ICD-8 or ICD-10 clinical diagnosis of schizophrenia. The definition of rurality used data from “Statistics Denmark” to define 5 categories and 12 subcategories ranging from urban to rural. Data on a number of potential confounders were also available. Most people in Denmark live within 25 km of a city $\geq 30,000$, and the study is therefore probably more representative of urbanicity rather than rurality. But it was a very large and complete dataset.	There was a strong dose-response relationship between the urbanicity of place of birth and subsequent hospital admission with a diagnosis of schizophrenia. This relationship remained after adjusting for a number of potential confounders.
Mark et al. (2007), Israel	Data from male 16 to 17 year old Israeli conscripts linked with subsequent hospital admission with a clinical ICD-10 diagnosis of schizophrenia. Rurality was determined by population density by quintiles at the time of conscription. Data on a number of potential confounders was also available. Once again, this was a large (N = 371,603) and complete dataset, and had very thorough methodology.	There was a strong dose-response relationship between urbanicity and schizophrenia. This relationship remained after adjusting for a number of potential confounders.

Table 5 Studies comparing the utilisation of mental health services

1.4.6 The experience of mental health in rural areas

Much of the research in this area comes from a body of work investigating the experience of rural mental health in remote and rural Scotland (Philo et.al 2002). This study entailed conducting 107 in-depth semi-structured interviews with psychiatric service users, and a further 61 interviews with formal and informal service providers. In addition, up to 2 months was spent in each rural location where interviews were held, and interview findings were supported with ethnographic research. This source has been quoted throughout this thesis, and provides valuable insight into the experience of mental health in rural Scotland.

However, to the author's knowledge there is no research that makes a direct rural-urban comparison of the experience of mental health. In addition, current research has not explored whether there is a fundamental difference in the phenomenological expression of mental illness itself in rural and urban areas. Finally, there is a lack of research considering whether the severity of mental ill health is different in rural and urban areas. It would be helpful to know all of these things from an epidemiological, individual and service-provider perspective.

1.5 Rural physical health

The following should be considered when interpreting rural-urban comparisons of physical health. First, access may be poorer in rural areas, and so service utilisation may not necessarily represent population need. Second, stigma associated with illnesses such as sexually transmitted diseases may prevent people from seeking help in small rural communities. The true prevalence may therefore be underestimated. Finally, potential confounders including age, obesity, mental ill health, social deprivation and health related behaviours such as smoking and exercise may differ between rural and urban areas. Studies that do not adjust for these variables should be interpreted with caution.

1.5.1 Reviews of rural physical health

Tables 6 and 7 summarise reviews and commentaries that have been written about rural physical health. There is an agreement that physical health is probably better in rural areas in the UK. However, there may be exceptions to this. In addition, although the average population health status may be better in rural areas, there may be pockets of relative ill health which are hidden because of small population numbers.

In contrast, physical health is probably poorer in rural areas outside the UK. This is best studied in the USA and Australia, but is probably also the case in other places around the world.

Countryside Agency (2004)	This review describes better health in rural England, over a range of measures including self-reported health status. However, they note the need to distinguish between the different rural areas in England, citing considerable variation between them. They also recognise a need to identify the high amount of unreported ill health in rural England.
Godden (2005)	This editorial contrasts the tendency towards better rural health in Scotland with a worldwide trend towards poorer rural health, for example in Australia and North America. It is suggested that this may be because healthcare in Scotland is publicly funded.
Godden et al. (2007)	This commentary quotes findings from the Scottish Household Survey 2001, a large representative national survey of self-reported attitudes, behaviours, lifestyle factors and health. It found that people living in rural areas were less likely to report being disabled or to suffer from a long-term limiting illness, and were also less likely to smoke. It concludes that physical health was probably better in rural areas.
Scottish Household Survey (reported in Scottish Executive, 2003a)	As with the 2001 survey, this showed that people in rural areas reported better overall health, and were less likely to report disability or long-term limiting illness. 28% of the urban population or working age had a general health problem that had lasted for more than one year compared with 20% of the rural population.
Scottish Executive (2001)	This large consultation document concluded physical health was similar in urban and rural areas. This was despite significant deprivation and exclusion in some rural areas.
Watt et al. (1994)	This literature review of UK rural and urban health has the advantage that it has used reports from charities and government documents in addition to academic literature. It concluded that health was probably worse in urban areas, but identified a number of contradictions in the literature, perhaps because of the unequal distribution of disadvantage in rural areas. The authors identified a need for further research in this area.

Table 6 Reviews comparing rural and urban physical health within the UK

Dixon & Welch (2000), Australia	This review article uses Australian databases to show that mortality and morbidity for some diseases is worse in rural areas. Although admission to hospital is higher in rural areas, this was felt to relate to difficulties in the provision of rural community services rather than superior access to services (or poorer rural health). Australian health-related data is often skewed by the poorer socioeconomic and health status of the indigenous population; however, many studies specifically account for this.
Humphreys (1999), Australia	This review article also uses national Australian databases to conclude that rural health is worse on a number of indicators. These include higher adjusted mortality and lower life expectancy. Mortality is also higher for a number of specific pathologies including diabetes and coronary heart disease.
Peters & Jackson (2005), UK	This article comprises a systematic review of international literature. The authors conclude that there is probably no real difference between urban and rural physical health, but that the evidence base is poor.
Verheij (1996), Netherlands	Comprehensive review of predominantly European literature published between 1985 and 1994. Verheij concluded there was a tendency towards better perceived general physical health in rural areas, but suggested that this disappeared when factors such as socioeconomic status and age were controlled for. It was quite difficult to see how this conclusion was reached from the studies that were described.

Table 7 Reviews comparing rural and urban physical health outwith the UK

Two articles are described in more detail. The first is a large systematic review of both physical and mental rural health by Peters & Jackson (2005). This was a thorough and well described review, and although the authors may have missed some papers (by using a search strategy that did not include the term “rural”), they included 192 relevant studies. They make a number of general observations regarding the available evidence base. For example, they note that the majority of evidence comes from the USA. The range of physical health conditions covered in the literature is not evenly distributed between the different medical specialities, and there is no research at all into some conditions. Most research considers health in adults or the elderly, with very little in infants or children.

The authors recognise that because so many different outcome measures are used, it is hard to synthesize the data in a meaningful way. They therefore summated the results by making a judgement as to whether the outcome in individual studies was more or less favourable in rural areas, then counting up the number of studies for a number of different medical conditions. Using this technique they determined that on an international level, a majority of studies showed a less favourable outcome in rural areas. The reverse was true in the UK. Because the studies were so heterogeneous, the authors did not attempt to attribute statistical significance to this finding. The authors conclude that there is probably no real difference between urban and rural physical health, but that the evidence base is poor.

The second article used UK census data to look at the relationship between health and deprivation (Haynes & Gale 2000). Overall it described better physical health in rural wards. In general there was a strong association between poor health and deprivation, but this relationship was found to be less strong in rural areas. The authors make a strong case that this is because the actual number of deprived people with associated poor health in rural areas is relatively small. The association between deprivation and poor health is therefore masked because of the more affluent and healthy average for people living in rural areas.

1.5.2 Specific diseases and areas of healthcare

The majority of reviews in tables 6 and 7 compare general measures of ill health, such as “long-term limiting illness”. The following list summarises findings for specific diseases and other areas of ill health.

- Agriculture is the predominant industry in most rural areas, and this accounts for the higher incidence of certain illnesses including farm-related accidents, agricultural-based chemical injuries and zoonoses (British Medical Association Board of Science 2005; Godden et al. 2007). Strong et al. (1998) use national databases to demonstrate a higher rate of injuries in rural Australia.
- There is no strong evidence to suggest that the incidence of cancer is different in rural areas, but diagnosis, treatment and outcome may relate to

rurality. High quality research from rural Scotland showed that the further away from a cancer treatment centre that a person lives, the less likely it is that a diagnosis of cancer will have been made prior to death (British Medical Association Board of Science 2005; Campbell et al. 2000). In addition, the more likely they are to have metastases at diagnosis (British Medical Association Board of Science 2005; Campbell et al. 2001). Remoteness is associated with poorer survival from a number of different types of cancer (British Medical Association Board of Science 2005; Campbell et al. 2000; Jong et al. 2004). Patients living in rural areas may be less likely to receive radiotherapy for cancer, as this usually requires prolonged treatment in an urban treatment centre (Campbell et al. 2002; Nattinger et al. 2001).

- Birth weight and perinatal mortality are good general measures of the health status of a population. They are highly dependent on socioeconomic status, and this should be adjusted for when interpreting results. As with other measures of health, they are probably better in rural areas in the UK (Countryside Agency 2004; Scottish Executive 2003b), and worse in other areas of the world (Hulme & Blegen 1999; Strong et al. 1998).
- Asthma (but not necessarily other respiratory illnesses such as Chronic Obstructive Pulmonary Disease) may be lower in rural communities in the UK (Iversen et al. 2005). Mortality from asthma may rise in relationship to the time taken to travel to the nearest hospital, but numbers in these studies were small and only reached significance after a number of variables had been controlled for (Jones et al. 1999; Jones & Bentham 1995).
- There are probably more deaths from road traffic accidents in rural areas, but this is more likely to relate to the type of high speed accident that occurs on rural roads rather than emergency treatment (Scottish Executive 2003b; Strong et al. 1998). There is no convincing evidence that there is an association between emergency response time and outcome for life threatening conditions (McGuffie et al. 2005; Nicholl et al. 2007).

1.6 Rural access

A number of reviews and consultation documents have highlighted the importance of rural access. Without exception, they conclude that people living in rural areas do not experience equal access to healthcare. Healthcare is considered a fundamental human right (World Health Organisation 2006) and equity of access to healthcare is now considered a priority by many governments. (Table 8)

British Medical Association Board of Science (2005), UK	Important British consultation document reviewing the state of rural healthcare. It describes access and transport as two of the major problems facing rural healthcare in the UK.
Buchan & Deaville (2005a), Wales	Literature review prepared for the Welsh Assembly government. It establishes that the present evidence base is inconclusive, but describes an emerging theme in which increasing distance from healthcare services is associated with poorer access.
New Freedom Commission (2004), USA	Comprehensive consultation document and review on the current status of rural mental health in the USA, with a long section on access, availability and acceptability of mental health services in rural areas. Access is identified as a problem in rural areas.
Scottish Executive (2001), Scotland	Consultation document looking at social exclusion and poverty in Scotland. It describes lack of access as a major cause of social exclusion. Transport was identified by those in rural areas as the overriding problem limiting access.
Scottish Executive et al. (2006), Scotland	Report based on a review of the literature, consultation documents and qualitative focus group research in Scotland. There was a consensus that a main priority area was to improve access to public transport, and support with the increasing costs of private transport. Other priority areas included access to a range of services including healthcare.
Strong et al. (1998), Australia	Report prepared by the Australian Institute of Health and Welfare. It uses a wide range of national data sources to compare the health of people living in remote and rural versus metropolitan places in Australia. It describes poorer access in remote and rural areas.
Slifkin (2002), USA	Review article and discussion from the USA looking at how rural health care researchers can better utilise the available research into rural access to improve current healthcare. It includes an insightful discussion about the complexities of defining and measuring access.
NHS Scotland (2005), Scotland	Large consultation document that discusses and identifies access as a problem in remote and rural Scotland.
Wood (2004), England	English review article that discusses rural healthcare and the issue of poorer access in rural areas.

Table 8 Reviews on rural access

1.6.1 Research measuring and comparing rural-urban access

Because access is such a complex concept, there is no simple or universal way of measuring it. Studies comparing rural-urban access can be divided as follows:

- Studies that consider the utilisation of services.
- Studies that look at the availability of services in rural and urban areas.
- Studies that consider barriers to physically accessing services.
- Studies investigating other barriers to accessing services.

1.6.1.1 *Studies that measure access using service utilisation*

The most common way of comparing urban and rural access is by measuring utilisation of services. If people living in urban areas use more healthcare services, it is assumed that access in urban areas must be easier. It is relatively easy and inexpensive to measure service utilisation, but it is an inaccurate measure of access unless service need is also taken into account (Slifkin 2002).

(Note that some studies make precisely the *opposite* assumption when interpreting their research. For example, as described above, Sundquist et al. (2004) use hospital admission rates to compare the incidence of psychosis and depression in urban and rural Sweden.)

The evidence base comparing rural-urban service utilisation is limited. Because of the heterogeneity of the studies, the findings have been summarised rather than attempting a direct comparison (table 9). Overall these studies suggest that utilisation of services is less in rural areas, and this has generally been interpreted to indicate that access is worse in rural areas. A number of the studies used distance from services rather than rurality; which is reasonable given that most spatial definitions of rurality incorporate distance from urban centres and hence services. A single exception found that inpatient hospital use was actually *higher* in people coming from remote and rural areas of Australia (Strong et.al 1998). This was attributed to the combination of higher morbidity and the need to stay overnight as an inpatient having travelled to access outpatient services.

Table 9 Studies that measure rural access by comparing utilization of services

Arcury et al. (2005), USA	This study surveyed over a thousand adults in twelve rural counties in the USA, and showed that geographic distance from health services was related to using services less for “regular checkups” and “chronic healthcare”, but that there was no relationship with “acute care”. This was a carefully designed and analysed study, and the results are likely to be valid.
Casey et al. (2001), USA	This study linked data from two national datasets to conclude that people in rural areas were less likely to use a number of preventative healthcare services including cervical smear, Faecal Occult Blood, proctosigmoidoscopy for colon cancer and mammography. The only service that was not utilized less in rural areas was influenza and pneumonia vaccinations. This was a large study (n = 130,452), used a sensible definition of rurality, and adjusted for a number of relevant variables including age, gender, income and education.
Cheh & Phillips (1993), USA	Information was drawn from Medicare databases to compare the amount of hospital post-discharge care claimed for in urban and rural counties in the USA. People in urban areas received more home visits from physical therapy services and skilled nurses. However, the duration of the visits was not recorded, and people in rural areas may have received longer visits, and hence an equal amount of overall care. Some of the statistics were questionable (for example, $P < 0.3$ was reported as statistically significant). Overall, this paper is included for completeness and because it is often quoted, but had several limitations.
Haynes & Bentham (1982), England	This study related self-reported service use to home address (n = 1603). It did not use an accepted definition of rurality, but divided participants into those living in the county town of Norwich, villages close to Norwich, and villages relatively far from Norwich. The study also considered whether the villages had a GP surgery. Rates of GP consultation, outpatient contact and inpatient stays all decreased in association with greater distance and poorer accessibility. This study predates multiple regression analysis, but subgroup analysis was consistent with this finding.
Haynes (1991), UK	British General Household Survey data (1982) was used to investigate self-reported health status and self-reported recent health service use. There was a non-significant trend towards lower service use by people (with low self-reported health status and without a car) living in rural areas, but otherwise there were no consistent findings across urban and rural areas.
Haynes et al. (1999), UK	This study considered all hospital inpatient episodes over a two year period in three counties in South East England (n = 470,659). They looked at the electoral ward from which each patient had been admitted, and using a range of publically available census indicators, assigned a value of healthcare “need”, “provision” and “distance” (from the ward to the nearest GP surgery and nearest hospital) to each admission. All three were found to be associated with admission rates, with those living furthest from hospitals least likely to be admitted.
Kenney (1993), USA	Medicare and Medicaid data sets in the USA were used to compare the use of home health care services in urban and rural areas. The authors describe a higher rate of service use in urban areas, and note that services cost more in rural areas. They did not adjust for the income of health care recipients. This was a brief report with few details, but otherwise seemed to have reached reasonable conclusions.
Lindsay et al. (2006), Scotland	Men in the Highlands of Scotland were invited to a screening programme for abdominal aortic aneurysms. Uptake was high (n = 8,292), and was found to depend on income, employment, education and health rather than rurality. Because a mobile screening unit was used, problems with cost and access were minimised even in remote areas. This was a good study for demonstrating the feasibility and success of improving access in rural areas, but less useful in showing an association between rurality and the lower uptake of screening services.

Nemet & Bailey (2000), USA	This study (n = 390) used a mail survey to establish that elderly residents in the USA who lived further from their primary healthcare provider made fewer visits. The authors relate the finding to the individual's spatial relationship with their community and personal activity space rather than simply distance. This ties in well with the concept that access is about much more than distance, but is associated with the barriers that an individual has to overcome to use a service.
O'Neill & Godden (2003), Scotland	This study was set in the Highlands of Scotland and looked at the outcome following a first stroke. There was generally a low uptake of rehabilitation and support services, but this did not seem to be affected by rurality. The study power was limited by small numbers, and there was also potential for selection bias and reporting bias (as the participants were not blinded to the study design.)
Stampfer et al. (1984), Scotland	The authors used old data (collected from the late 1970's) to show that a number of factors (such as the high rural rates of alcohol abuse and conditions of local services) were associated with psychiatric hospital admission to the main city of Perth, rather than distance. The authors suggest that the results contrast with previous findings in the rural literature because the distances involved in this study are so much greater. The authors clearly have an extensive knowledge of the local healthcare services and rural environment, and use this sensibly in their interpretation and discussion of the results.
Stark et al. (1997), Scotland	In this Scottish study, attendance at a mammography screening programme was related to distance. Although a mobile screening unit was used, because of the geography of the two remote island communities studied, attendance still entailed significant travel for many participants. The authors conclude that "non-participants" lived significantly further from the screening site – but because of the design of the study, it was remarkably difficult to work out who the actual "participants" and "non-participants" consisted of. Probably a more robust finding was that attendance was worst in the afternoons when there was less public transport.
Stearns et al. (2000), USA	The authors analysed longitudinal data from a nationally representative sample of elderly and disabled Medicare beneficiaries in the USA in a large and well constructed study. People living in rural counties that were not adjacent to a big city were significantly less likely to have had outpatient care, even after adjusting for income. Other indicators of healthcare utilisation (such as inpatient events) did not differ between urban and rural areas.
Strong et al. (1998), Australia	This report was by the Australian Institute of Health and Welfare. It uses a wide range of national data sources to compare the health of people living in remote and rural versus metropolitan places in Australia. Medicare is the main Australian private medical insurance system, and is considered superior to state provided services. People in remote and rural areas, and especially those of aboriginal origin were more likely to use state provided services. They visited (Medicare) GPs and used (Medicare) specialist care less often. Screening for breast cancer and cervical cancer was similar in rural and urban areas. Interestingly, people living in rural areas had <i>higher</i> hospital use. The authors attribute this to the combination of higher morbidity and the need to stay overnight as an inpatient having travelled to access outpatient services. (This report is also included in tables 8 and 10.)
Wijkkel (1986), Netherlands	This study used a national healthcare insurance database that covered around 70% of the population of the Netherlands. They found that the further the distance by road between a GP practice and a hospital, the fewer referrals were made. They also found an association between hospital referral and both the distance that an individual lived from a hospital, and the degree of urbanization of the area that they lived in. The only caveat is that because the Netherlands are such a densely populated country, most people live within half an hour to a hospital, and it is hard to know how the findings might translate to other rural environments.

Table 9 Studies that measure rural access by comparing utilization of services

1.6.1.2 Studies that measure access using service availability

Another way of comparing rural-urban access is to determine whether or not services are actually available. The most comprehensive study is probably by Strong et al. (1998), who found that in rural and remote Australia there were fewer GPs, pharmacist, specialists, nursing homes and hostels per capita compared with urban areas. Kenney (1993) used Medicare and Medicaid datasets in the USA to show that there were fewer services such as physical therapy, medical social services and occupational therapy in rural areas. (Table 10)

Kenney (1993), USA	Medicare and Medicaid data sets in the USA were used to compare the use of home health care services in urban and rural areas. This brief report included a table drawn from 1987 stating the availability of services (such as physical therapy, medical social service and occupational therapy) available through Medicaid/Medicare certified home care agencies. There was a clear lack of services in rural areas. (This study is also described in table 9.)
Philo et al. (2002), Scotland	The authors used a questionnaire to explore GP's experiences of treating people with mental health problems in the Highlands of Scotland. It seemed that GPs were highly aware of problems with access, and several commented on the lack of local specialist services. Travel to the nearest city was not always affordable or feasible, and as a consequence for some people, services were simply not available.
Scottish Executive (2002), Scotland	This consultation document reports on a study investigating the availability of services in rural Scotland. The study calculated the drive time from households to a number of key services, including GP services. 95% of people living in urban areas or small towns lived within 5 minutes drive of a GP surgery, whereas only 55% living in rural areas did. This was taken to indicate that rural GP surgeries are less available in rural areas. Although an interesting finding, 5 minutes drive time is not necessarily a useful indicator of access. If a person did not have access to a car, and no public transport services were available, they would not be able to access services however close.
Strong et al. (1998), Australia	This report was prepared by the Australian Institute of Health and Welfare. It uses a wide range of national data sources to compare the health of people living in remote and rural versus metropolitan places in Australia. It found that in rural and remote Australia there were: fewer GPs, fewer pharmacists, fewer specialists (although this figure did not allow for rotating outclinics or the use of telemedicine), fewer nursing homes and fewer hostels per capita. There were more nurses, and more nurse-managed care in rural areas, perhaps to balance the lack of GP care.

Table 10 Studies that measure rural access by considering service availability

1.6.1.3 Barriers to physically accessing services, and rural transport

Several studies, reviews and consultation documents have shown that people living in rural areas have to travel further than their urban counterparts in order to access healthcare. Because of larger distances, walking is rarely an option in rural areas, and some form of transport must be used. Transport is therefore a crucial factor in accessing healthcare in rural areas (British Medical Association Board of Science 2005; Gesler et al. 2000), and in some cases this may be the overriding factor that limits access (Scottish Executive 2001).

Public transport is often limited in rural areas. On average, people living in rural areas in the UK live much further from their nearest bus stop, and when bus services are available, they run less frequently than in cities. It is not commercially viable to provide transport services for very small numbers and many services have to be supported by government grants or voluntary agencies. Even if taxi services are available, large distances make taxi journeys prohibitively expensive. Car ownership may therefore be a necessity in some places, and some people living in rural areas would be housebound without access to private cars. Consistent with this, car ownership is higher in rural areas throughout the UK, and people in rural areas are more likely to use their cars on a daily basis for a number of different types of journey. Improving rural transport is seen as a priority both by governments and by people living in rural areas (Farmer et al. 2005; James & Gimson 2007; Scottish Executive et.al 2006).

People with the highest healthcare needs are the least likely to own a car. This is partly due to the association between poor health status and poverty. Owning a car costs more in rural areas, people in rural areas spend more on fuel per week and people in rural areas spend a greater proportion of their income on transport (Countryside Agency 2004; Scottish Executive 2003a; Scottish Executive 2001; Wood 2004). In addition, ill health, physical and intellectual disabilities may directly impact on the ability to drive. People with mental ill health may experience particular difficulties, as they may be automatically prohibited from driving because of a diagnosis of active mental illness. Psychotropic medication may give rise to side effects that make driving unsafe.

1.6.1.4 Other barriers to accessing services

Transport and travel factors are not the only barrier to accessing services. In rural areas, accessing services may incur far greater burden in terms of cost, time, lost employment, and in some cases the emotional burden of leaving one's community. McGrath et al. (2006) investigated the experience of aboriginal people in rural Australia accessing palliative care. Hospice respite services were available in the nearest city, but terminally ill people were extremely reluctant to leave their family and community, and worried that they would not be able to change their minds and return home. This would not have been as much of a problem in urban areas where family could have kept in contact.

Even if services are readily available, whether or not an individual decides to access a healthcare service depends on medical knowledge, beliefs, help-seeking behaviours, expectations of healthcare and personal attitudes towards illness and health. These may differ in rural and urban areas. If the perceived need for care is too low, then even minimal barriers will not be overcome (New Freedom Commission 2004). Healthcare providers also play a rôle in determining access to services, and different treatments or advice may be offered in rural-urban areas. In addition, if a healthcare provider has different standards of care, this is likely to be reflected in the attitudes and expectations of their patients (Goddard & Smith 2001).

1.7 Social exclusion and related concepts

1.7.1 Social exclusion

1.7.1.1 Defining social exclusion

There is no single agreed definition of social exclusion, but most definitions relate to a person's ability to participate fully in key aspects of society. These may include participation in:

- Purchasing goods and services.
- Participating in economically or socially valuable activities.
- Influencing the future by engaging in local or national decision-making.
- Engaging in social interaction with family, friends and community.

(From Burchardt et al. 2002)

Social exclusion may be determined by many factors. For example, a person may be excluded because of their gender, their educational background or because they have a disability (Hills et al. 2002). However, social exclusion describes the relationship that individuals (or groups or people) hold with the rest of society rather than describing the characteristics of the individual themselves.

Social exclusion is closely related to a number of overlapping sociological concepts, namely: deprivation, social inclusion, social isolation, community, social networks and social support. These are discussed in further detail below.

1.7.1.2 Measuring social exclusion

There are no standard or accepted ways of measuring social exclusion, and this makes it difficult to conduct and evaluate research in this field. Objective measures such as different dimensions or indicators of poverty are often used as a measure of exclusion (for example, unemployment, income and educational status), but there is no agreement as to which and how many of these variables are relevant, or how they should be combined into a single measure of exclusion. They are often a better indicator of deprivation than exclusion, and lack any social element. Objective measures have the advantage of being

relatively easy to collect from census data and other available datasets, but may therefore be chosen because the measures are available rather than for any theoretical reason. Subjective measures (such as whether a person *feels* excluded) are used in qualitative research, and may have more face value than objective indicators. However, subjective measures are harder to standardize and use in comparative studies.

1.7.1.3 Rural social exclusion

Social exclusion has been identified as a problem in rural areas. There are no studies that directly compare rural-urban social exclusion, but the Welsh Assembly conducted a large review of the UK literature on rural health and social exclusion (Buchan & Deaville 2005b). The authors identified a number of consistent themes that highlighted the problems of social exclusion faced by the rural community. They drew attention to a number of particularly vulnerable groups, such as people with intellectual disabilities, people on low incomes, and the unemployed. People with mental ill health living in rural areas are also at risk of social exclusion (MIND 2004; Parr et al. 2004; Philo et al. 2002).

It has been argued that the factors associated with social exclusion differ in rural and urban areas (Farmer et al. 2001). In particular, the lack of social housing and the lack of car-ownership combined with poor public transport can have a greater effect on social exclusion in the rural environment. Transport was also identified as a major contributor to rural social exclusion by the Scottish Executive (Scottish Executive 2001).

1.7.2 Deprivation

1.7.2.1 Defining and measuring deprivation

Poverty and deprivation directly affect the ability to participate in society, and are therefore closely related to social exclusion. The Scottish Executive (2001) concluded that it was not possible to separate poverty and social exclusion. Like social exclusion, there are no standard or accepted ways of measuring deprivation. Recognised indicators of poverty, deprivation and disadvantage are listed below (table 11). These measures are all objective, and subjective measures that capture the experience of living in a state of deprivation are

rarely used. No single measure provides a comprehensive description of deprivation, and most researchers combine the measures in complex ways. Established composite measures include the Carstairs' index (Carstairs & Morris 1989) and the Scottish Index of Multiple Deprivation (The Scottish Government 2010).

Measure	Examples
Employment	Employment status, unemployment rates, quality of employment (for example working long hours for poor pay), access to employment, self employment (and consequent poor remuneration).
Income	Total income (mean, median, percentage below a certain centile), disposable income.
Access	Access to a range of services.
Health	Health indicators such as morbidity, mortality, disability and perinatal health outcomes. Proportion on sick pay, incapacity benefits, disability or other health related benefits. It is important to know whether health status has been used to define deprivation when interpreting studies that look at the relationship between deprivation and health.
Educational status	Qualifications achieved, age at which formal education ceased, other skills and training.
Housing	Number of rooms in the household per occupant, type of housing, quality of housing, housing need, housing affordability (for example the ratio of income to the cost of leasing or purchasing housing), the proportion of people in temporary housing or homeless, the frequency of change of address.
Transport	Car ownership or access to private transport.
Benefit uptake	Proportion of people on benefits or tax credits, free school meal entitlement.
Social indicators	Teenage pregnancy rate, child dental health.
Direct financial measures	Proportion holding a bank account, debt rates, amount of savings, proportion describing themselves as being in financial difficulties.
Composition of population	Proportion of single parents, migrants and ethnic minorities
Household composition	Proportion of elderly people, single occupants, children under the age of 5 per household.

Table 11 Measures of deprivation

(From Bishop et al. 2004; Carstairs & Morris 1989a; Haynes & Gale 2000; Scottish Executive 2003b; The Scottish Government 2010; Thornicroft 1991; Wood 2004)

There is an increasing awareness of the close relationship between deprivation and physical and mental ill health. The WHO has set up a commission to look at the socioeconomic determinants of health, and to establish ways of reducing current inequalities (Maryon-Davis 2007). This is also reflected in recent UK policy.

1.7.2.2 Rural deprivation

In the USA, rural deprivation has been demonstrated using a wide range of indicators (Housing Assistance Council 2006). Low income countries may have several areas of extreme poverty in rural places, compared with small pockets of relative affluence within larger cities. Conversely, rural areas in the UK have been shown to be more affluent than urban areas using a range of different indicators (Countryside Agency 2004; Haynes & Gale 2000; Scottish Executive 2003b). However, a number of factors should be taken into account when interpreting this data.

First, current measures of deprivation have typically been developed for use within urban communities and may therefore not reflect rural deprivation. (Countryside Agency 2004; Farmer et al. 2001; Haynes & Gale 2000; NHS Scotland 2005; Watt et al. 1993; Wood 2004). For example, car ownership is a commonly used indicator of wealth, but this may be a necessity rather than a luxury in rural areas. Housing is usually larger and cheaper to buy in rural areas, and is therefore a poorer indicator of wealth. Unemployment is less common in rural areas in the UK, but wages are lower, and there is a higher proportion of part-time and seasonal work. The rate of benefit uptake may be lower in rural areas because of poor access to advice and financial services (including social welfare service points and banks). In addition, because of rural stoicism and independence, people may be more reluctant to admit to indicators of poverty or take advantage of state support such as benefits (Farmer et.al 2001; Scottish Executive 2001; Shucksmith et al. 1996). Census data is typically limited so that indicators that might be more appropriate for rural areas (such as poor access, the high cost of living, low disposable income and the lack of local opportunities) are not routinely measured.

Second, there is now substantial evidence showing that the cost of living is higher in rural areas. The price of essential services and goods is higher across the full range of services, including food and other commodities and rented accommodation. Transport is also more expensive. This is rarely accounted for when comparing rural and urban deprivation.

Third, rural populations are widely dispersed and measures are usually aggregated over wide geographical areas. Overall measures of prosperity may therefore mask isolated patches of deprivation in close proximity to relative wealth (British Medical Association Board of Science 2005; Haynes & Gale 2000; NHS Scotland 2005). This theory is supported by research that demonstrates that the distribution of income is greater in rural compared with urban areas (Farmer et.al 2001). This phenomenon is increasingly recognised as contributing to social exclusion in the most deprived sectors of the rural community.

Acknowledging the existence of rural deprivation does not deny the problems that some inner-city areas experience with extreme poverty.

1.7.3 Social inclusion and social isolation

Social inclusion and social isolation are also closely related to social exclusion. Social inclusion is defined by the UK-based Centre of Economic and Social Inclusion as;

“the process by which efforts are made to ensure that everyone, regardless of their experiences and circumstances, can achieve their potential in life. To achieve inclusion, income and employment are necessary but not sufficient. An inclusive society is also characterised by a striving for reduced inequality, a balance between individuals’ rights and duties and increased social cohesion” (page 14, Britton & Casebourne 2002)

Social inclusion can be seen as the opposite of social exclusion in that people are considered to be socially included if they are not socially excluded. Many of the difficulties relating to the definition and measurement of social exclusion apply equally to social inclusion.

Social isolation relates to the frequency and quality of interpersonal interactions and relationships that an individual holds. It is therefore related to feelings of integration and belonging to society. In rural Scotland, social isolation was found to particularly affects the elderly and young, and was often associated with people being confined to their houses because of disability or lack of access (Shucksmith et.al 1996).

1.7.4 Community

Crow & Allan (1994) define community as the social arrangements that we engage in beyond the private sphere of home and family, but more personal than the wider institutions of society. Communities can take many different forms and structures, but all communities need some type of common or shared experience to develop a sense of belonging and function as a community. “Community” can be measured either by asking people to rate their community, or to pass judgement on the community spirit. Alternatively, community participation can be measured by asking how many community or shared activities each member of the community participates in. (For further discussion of “community” and how it can be measured, see McMillan & Chavis (1986).)

In general, the literature describes a stronger sense of community and stronger community spirit in rural areas. A survey looking at attitudes of people living in England described a “good community spirit” in rural areas (Countryside Agency 2004). The Scottish Household Survey found that people were more likely to feel involved in their local community in more rural and remote areas of the country (Scottish Executive 2003a). A strong sense of community is highly valued by rural dwellers (Scottish Executive 2001). Participants in a qualitative study in Scotland held the belief that people were more supportive of one another in rural areas (Philo et.al 2002). However, in a different study, some participants moving to live from cities to rural areas described being surprised at the lack of rural community, and suggested that the community was stronger where they came from (Shucksmith et.al 1996). Other participants in this study described the rural sense of community as declining. Finally, a single study described further below found that people living in rural areas rated their community more poorly than those in urban areas (Greiner et al. 2004).

There is little research comparing rural-urban community participation. The Scottish Executive used volunteering as an indicator of community participation and found that the proportion of people who participated in voluntary work increased as the area became more rural and remote (Scottish Executive 2003a). People in large urban areas were the least likely to volunteer. This finding was mirrored in a large well designed telephone survey in the USA by Greiner et al. (2004). This study was designed to examine the associations between community participation, rating of the community by participants (as excellent, very good, good/fair and poor) and self reported health indicators. As a secondary outcome, individuals from rural areas were found to have the highest community involvement. A particular strength of this study is that it adjusted for a number of variables including age, gender, ethnicity, education and having a medical doctor. Adjusting for confounders may explain why the rural population in this study rated their community less well.

Belonging to a community is generally considered to be good for social, emotional and physical health. However, a strong rural community may be beneficial to those within it, but this may be at the expense of those who have been excluded. Once a person is enmeshed in a community, they are expected to conform to its values and expectations, and any aberration from this can lead to disapproval and exclusion. People living in the rural Highlands of Scotland have described the closeness of the community as a “double edged sword” (Philo et.al 2002). From an individual perspective, the rural community may not therefore necessarily confer advantage.

1.7.5 Social networks and social support

Social networks are built up from the large number of formal and informal social links between the different members of a group. Social networks can vary according to the number, strength and importance of links between the group members. They differ from communities in that the focus is on the links and connections between group members rather than the group as a whole; however there is a degree of conceptual overlap.

The term social support is used here to refer to the informal support that people receive from members of the community as opposed to from state agencies such

as social and health services. Receiving informal social support may depend both on having a healthy and active personal social network, and on belonging to a strong local community.

Social networks are measured by considering the number and frequency of, the perceived quality of and attitudes towards social contacts. Social support is measured by considering practical and psychological help. However, there is no single validated and accepted measure for either. Social networks may depend on a number of variables such as socioeconomic status, gender, age, education, income and marital status. Unless studies have controlled for these variables, any comparison between rural and urban groups may not be valid (Priebe 2007).

Within the healthcare literature, there is only limited evidence that rural communities have stronger social networks. The strongest evidence comes from a study based in Italy (Magliano et al. 2006). This compared the social networks of 709 relatives of people with schizophrenia, 646 relatives of people with physical diseases and a control sample ($n = 714$). It adjusted for a number of variables (sex, age, educational level, marital status and occupation) and used a validated scale to measure social networks. Although not a primary outcome, it identified that social networks were significantly stronger for those who lived in more rural areas. The main criticism of this study is that rurality was defined simply by identifying areas of the country with a smaller total population. Other evidence is not sufficiently robust to draw firm conclusions.

The evidence comparing rural and urban social support is more convincing. Clark (1992) conducted a large cross-sectional study looking at the care received by disabled adults living in the community in the USA. The study used Medicare data, the sample should have been complete and representative, and the results were adjusted for a number of appropriate variables including age, sex, level of disabilities and socio-economic status. It was found that people living in rural areas were more likely to receive informal assistance, and also that people in rural areas received more total time of informal assistance per week.

A much smaller study in Canada involved interviewing 37 carers of elderly adults with cognitive impairment (Bedard et al. 2004). Most rural caregivers reported support from informal sources, compared with around a third of urban caregivers

reporting this. Although the sample was small, this finding was highly significant ($P = 0.002$), and the definition of rurality was appropriate. There was potential for selection bias, as participants were identified by local knowledge and networking, but the results were probably still valid.

The Scottish Household Survey showed high levels of social support in both urban and rural areas, with around 90% of people stating that they could turn to friends or relatives in their neighbourhoods for help and support (Scottish Executive 2003a). The figures were slightly higher in more rural and remote places. A formal statistical comparison was not given, but as 95% confidence intervals did not overlap, the difference is likely to be significant.

Qualitative research on the experience of mental health in the Highlands of Scotland describe the general feeling that there was more neighbourly support in rural compared with urban areas (Philo et.al 2002).

Finally, a study in Scotland looked at urban and rural attitudes towards informal and formal support (West et al. 1984). Participants were given a number of fictional vignettes in which a person had substantial physical or mental health needs. In each case, participants were asked how support should be divided between informal supports (family and friends) and state support. Their primary conclusion was that there were far more similarities than differences between the urban and rural groups.

Formal support may not always be available or easy to access in rural areas. This may explain the dependence on informal support, and also the expectation that support would have to be provided by family and friends in rural areas. In other words, social support may be greater in rural areas through necessity rather than because of cultural differences between rural and urban populations.

As with communities, although strong social networks and good social support are generally considered to be beneficial, there may be some disadvantages. If a person is enmeshed in a closed social network, they may find it difficult to reach out and develop friendships and opportunities elsewhere. Those on the outside of social networks may experience social exclusion; particularly in rural areas where the population is so small that the number of social networks is limited.

1.8 Other aspects of rural life

There are a number of other aspects of rural life that may affect the rural population. These include the perceived advantage of rural life, quality of life, anonymity and stigma.

1.8.1 The perceived advantage of rural life

Overall, there remains a widely held view that rural life is healthy and wholesome (Countryside Agency 2004), and in the UK, people living in rural areas are more satisfied with where they live. The Scottish Executive publish an annual Scottish Household Survey which takes its data from a continuous cross-sectional survey that samples approximately 31,000 households over a 2 year period. The 2005 data showed that relative to the rest of Scotland, a higher percentage of people in rural Scotland rate their neighbourhood as very good or fairly good (Scottish Executive 2006b). This was most apparent in remote rural areas, where a large majority (77%) of people rated their neighbourhood as a very good place to live. This compared with 65% in accessible rural areas and 48% in the rest of Scotland. The survey also found that both urban and rural residents would rather live in a less urban environment.

Consistent with this, work by Shucksmith et al. (1996) suggests that people living in rural areas consider rural life to be advantageous. They studied 4 different rural areas in Scotland, chosen to represent a range of environments, based on remoteness, population density, and the strength of the local labour market. Quantitative data were collected from a random sample of 125 households in each area. 25 - 30 households from this sample in three of the four areas, and in addition, all households on the Isle of Harris in the Outer Hebrides participated in a subsequent qualitative component. Publically available information about housing, transport, access and availability supplemented the study findings. Shucksmith et al. concluded that there was objective disadvantage in rural areas. Despite this, the participants considered rural life to be advantageous. A similar conclusion was reached by a large consultation paper drawn up by the Scottish Executive, in which the positive features of rural life were felt to counterbalance disadvantage (Scottish Executive 2001).

Table 12 has been drawn from a number of different sources; overall there was good consistency between the sources.

Perceived advantages of rural life	Perceived disadvantages of urban life
Pleasant surroundings, space and the beauty of the natural landscape. Openness and views. Being able to enjoy nature. Freedom Safety, especially for children. Relatively crime free Peace and quiet Less stressful Friendly More forgiving More supportive High moral standards Strong communities Self sufficiency and self reliance. Independence Willingness to share Distance from neighbours and privacy	Unsafe Noisy More stressful Unfriendly Chaotic Pollution Fast pace of life Selfishness Vandalism Materialism

Table 12 Perceived advantages and disadvantages of rural life

(From DEFRA 2000; Denham & Shaddock 2004; James & Gimson 2007; Philo et al. 2002; Scottish Executive 2003b; Scottish Executive 2006b; Shucksmith et al. 1996.)

1.8.2 Rural quality of life

Perceived advantages of rural life could contribute to quality of life, and some of the papers above comment on rural quality of life. However, the student could find just three studies that directly compare quality of life in rural and urban areas.

The first study collected data from a cross-sectional postal survey that was sent to a selection of patients from rural and urban GP practices around Scotland (n = 4,560, response rate = 60%) (Iversen et.al 2005). Patients from rural practices with either Chronic Obstructive Pulmonary Disease or emphysema, or who reported symptoms of cough or phlegm, reported a better respiratory-specific

quality of life than patients from urban practices, despite reporting similar symptom levels. The second study investigated 202 patients with either rheumatoid arthritis or osteoarthritis, living in urban and rural areas (Cornelissen et al. 1988). It showed that despite the same level of illness and functional disability (as measured by a rheumatologist), rural patients were statistically more mobile and more likely to report being “contented” despite their symptoms. The study also showed that people in rural areas without arthritis are also significantly more contented with life. Finally, 56 adults living in the community at least 6 months after traumatic brain injury were interviewed (Farmer et al. 2003). After adjusting for a range of variables including demographic details, objective community participation, the severity of head injury, and willingness to accept social support, rural participants gave a higher rating score for their overall quality of life over the past month.

These studies suggest that people living in rural areas report better quality of life, despite no objective evidence of this. This is similar to the finding by Shucksmith et al. (1996) that people living in rural areas describe rural life as advantageous despite objective evidence to the contrary.

1.8.3 Anonymity and confidentiality

In rural areas, people may live some distance from each other in relatively isolated locations. But because the population is so small, and because there may be so little happening on isolated roads and streets, any movement or sound may be readily visible. Rural society has been described as “physically distant” but “socially proximate” (Parr & Philo 2003). If a family has been in a community for a long time, the family history, relationships and personal life-stories may be common knowledge. Even newcomers are not immune to local interest in their affairs. It has been suggested that most people living in rural communities are known to each other (Judd et al. 2002a), and several authors have identified lack of anonymity and confidentiality as an issue that disproportionately affects rural areas (British Medical Association Board of Science 2005; Gale & Lambert 2006).

Mental ill health may be particularly subject to the problems associated with the lack of anonymity in rural areas (Philo et al. 2002b). Parr & Philo (2003) suggest

that people with mental ill health have to accept that being under constant observation is a fairly unanimous rural experience. A consultation paper by the Scottish Executive describes visibility as a “major issue” for those with mental ill health (Scottish Executive 2001). In rural Australia, three female adolescents described the “rural gossip network” that they experienced when dealing with their mental ill health (Aisbett et al. 2007). They all felt that social visibility had made it more difficult for them to access treatment.

However, there is little evidence that anonymity and confidentiality are worse in rural compared with urban communities. A single direct comparison comes from a study that investigated barriers to accessing general health services, in young people living in Australia (Quine et al. 2003). Eighty-one focus groups were held in schools selected to represent a range of rural and urban settings. A lack of confidentiality was raised as a “barrier to seeking help for health problems” in both the urban and rural groups, but was only described as a major concern in rural areas. This finding was described in the abstract of the paper, but was not in the main body of the text. Additionally, research in younger people may not generalise to the adult population.

While a lack of anonymity is generally considered disadvantageous, there may be some benefits. Caring and supportive communities depend on knowledge about their members, and some gossip may be considered inclusionary if it acknowledges concern about the person being referred to. In addition, a gossip network can act as an informal safety net. For example, a concerned neighbour may notice a change of routine, surmise that a person is not well, and appropriately alert services (Parr & Philo 2003). Local knowledge may also help determine whether a person is likely to need hospitalisation for a mental ill health, or whether they could be cared for in the community (Bachrach 1983).

1.8.4 Stigma

Stigma arises when a person is judged unfavourably by society. It therefore depends upon, and can be measured by considering either the experience of the person experiencing stigma, or the attitudes and expectations of society upon that person (Crawford & Brown 2002). Several authors have described how the lack of anonymity in rural communities contributes to and compounds the

experience of stigma, and a number of reviews consider stigma and anonymity together as a barrier to inclusion.

Most of the research investigating stigma in rural areas has been qualitative in nature. For example, a study in rural Western Australia investigated barriers to using mental health services (Sweeney & Kisely 2003). The authors carried out qualitative analysis of semi-structured interviews with 38 purposefully-selected mental health and community workers. The majority of participants agreed that despite recent community education programmes, stigma remained a major barrier to accessing care. This was particularly pronounced in the elderly and in male farm workers, and was felt to relate to remoteness and a culture of self reliance. Bradley (1996) describes the problems and stigma that were faced when trying to establish a respite service for HIV/AIDS in a Welsh rural community. Outside the field of healthcare, the Scottish Executive describe the perceived stigma of receiving “charity” such as benefits or school meals, both of which are more visible in a small rural community (Scottish Executive 2001).

The only study that makes a direct rural-urban comparison of stigma is a telephone survey of 1487 adults, set in the rural Midwest of the USA (Hoyt et al. 1997). Stigma was measured by asking how embarrassed participants would be if people found out that they were getting help for mental ill health, in combination with how likely they think that it would be that people would actually find out. Persons living in the most rural environments were more likely to hold stigmatised attitudes towards mental ill health (which in turn related to an unwillingness to seek help). Stigma was not affected by other variables, including income, education and health status. This was a well described and thorough study, but it is hard to draw conclusions from a single study.

Finally, there is some evidence that rural communities may tolerate unusual or eccentric behaviours. Qualitative research in “remote and/or rural” Australia asked 22 users and providers of mental health services about the identification and response to mental ill health. Every single person interviewed recognised the stigma associated with mental ill health, but nevertheless, there was also a feeling that many of the communities tolerated a degree of eccentricity that would not be tolerated in other settings (Fuller et al. 2000).

1.9 Rural research and intellectual disabilities

So far, this literature review has only considered the general adult population living in rural areas. This following section is concerned with intellectual disabilities research. Very little literature specifically investigates rural intellectual disabilities, and available studies will be described in detail.

1.9.1 The prevalence and demography of rural intellectual disabilities

1.9.1.1 The prevalence of intellectual disabilities in rural areas

Table 13 outlines all identified studies that measure and compare the prevalence of intellectual disabilities in rural and urban areas. The studies have used different methodologies, are set in very different urban-rural environments, and it is hard draw any firm conclusions. However, on balance the prevalence of intellectual disabilities is probably higher in rural areas. This conclusion is largely based on the impressive study from Western Australia by Wellesley et al. (1992), in conjunction with the dated but consistent findings from Sweden (Akesson 1974). McQueen et al. (1987) found a lower prevalence of intellectual disabilities in rural areas in Canada; this was a robust paper, and it is hard to explain this discrepancy.

Table 13 Studies comparing the prevalence of intellectual disabilities in rural and urban areas

Studies in which prevalence is shown to be higher in rural areas	
Wellesley et al. (1992), Australia	This was a large and thorough study, and probably provides the most compelling evidence for a higher prevalence of intellectual disabilities in rural areas. The study was set in Western Australia, and identified a total of 1602 children aged between 6 and 16 with intellectual disabilities using multiple and well described sources of ascertainment. Intellectual disabilities was measured using the Stanford Binet or WISC-R IQ test for most children, and was defined as an IQ of less than 70. They found an overall prevalence of 7.6 children per 1000, which is comparable to figures from other sources. The prevalence was higher in rural live births (9.9 per 1000 vs. 6.5 per 1000) and this was highly significant (males $P < 0.001$ and females $P < 0.05$). There are a number of limitations to the paper, and urban and rural were not defined. In particular, the authors did not adjust for whether or not the children were of aboriginal origin. Given that there was a high proportion of aboriginal children in this sample (7%), and that aboriginal children are known both to live in rural areas and have poorer health status, this may have affected the results. However, the results seem to be valid – even if only for Western Australia.
Akesson (1974), Sweden	This paper describes 4 studies that were carried out in Sweden in 1916, 1963, 1967, and 1974. They are interesting from a historical perspective, but are also worthy of consideration in their own right, due to the well documented and careful methodology which is well ahead of its time. The first study from 1916 estimated the prevalence of intellectual disabilities in rural areas in Southern Sweden. Intellectual disabilities was defined as $IQ < 67$, and case ascertainment was probably fairly complete (using official records followed by interviewing locals). Despite being conducted over 50 years later, a repeat study of the prevalence of severe intellectual disabilities ($IQ < 52$) on two predominantly rural islands in the West of Sweden in 1967 showed a remarkably similar prevalence. A methodologically identical study in 1974 was conducted in a town with a population of 33,400; this was considered urban. The urban prevalence was found to be approximately half the rural prevalence. Finally, the 1963 study looked at the origins of people admitted to a central institution for people with severe intellectual disabilities ($IQ < 52$). A total of 1,014 people were admitted between 1940 and 1960. It was established that more patients came from urban (rather than rural) communities in just 3 out of the 24 Swedish counties that patients had been admitted from. Assuming that everybody at that time in Sweden with severe intellectual disabilities was institutionalised, he then used general population data to calculate an approximate prevalence for each of the communities that patients had come from, and determined that the prevalence in rural areas was almost twice that of urban areas. The main criticism of this paper is that the data is now so old that it is hard to know whether the results bear any relationship to the present age.
Diaz-Fernandez & Gestal-Otero (1987), Spain	The authors looked through 18 years worth of archived records from Galician Diagnosis and Therapeutic Guidance centres, and the list of registered handicapped people in North West Spain held by the Spanish Department of Social Security. These were used to identify individuals with “severe mental deficiency” ($IQ < 50$ – although it is not clear how this was measured), individuals who were “officially handicapped” (not defined), and people requiring special health and social care. Ascertainment is unlikely to have been complete, and is likely to have identified those in receipt of care and known to the services rather than all individuals with intellectual disabilities. This may have differed according to rurality. Therefore, although the point prevalence of intellectual disabilities was significantly higher in rural areas, it is hard to know how to interpret this finding.

Dupont (1989), Denmark	This paper has been included in the table largely because it is quoted remarkably widely in the literature. It comprises of a review of prevalence studies of intellectual disabilities in “Denmark and other countries”. Many of the studies that it reviews were quite dated (for example from the 19 th Century), and it is not clear whether they are still relevant. At the end, the review concludes that the prevalence of intellectual disabilities is higher in rural areas, but this is not substantiated by their selection of evidence. Neither rurality nor intellectual disabilities is defined.
Hagberg & Kyllerman (1983), Sweden	This study compares the results of 5 different studies, all set in Sweden in the 70s and early 80s – two of which were set in cities, and three of which were set in “mixed urban and rural” areas. It is quoted as showing that the prevalence of intellectual disabilities is higher in rural areas, but because of methodological limitations, the results should be interpreted with caution.
Magina et al. (2003), Slovenia	This research looked for associations with literacy in people with a “self-reported learning disability”. A representative population sample of 2972 replied to an information booklet (response rate = 70%). The number of recruits with “self-reported learning disability” was significantly higher in rural compared with urban areas, but it is hard to know how this relates to the underlying prevalence of intellectual disabilities.
Studies in which prevalence is shown to be equal in rural and urban areas	
Reschley & Jipson (1976), USA	This study administered the WISC-R to a randomised but carefully stratified sample of children receiving special educational services in Pima county, Arizona. They concluded that there was no difference in IQ between rural and urban children in this area. This was before multiple regression, and because of the way in which the data was analysed, some of the actual numbers were extremely small. A power calculation was not given at the start of the paper. In addition, many of the children were of “Mexican-american” race, English was unlikely to have been their first language, and they performed considerably worse on the verbal compared with the performance components of the IQ test. All in all, the results were not convincing.
Stein et al. (1976), Netherlands	<p>This study measured the prevalence of severe mental retardation in the 19-year-old survivors of the male birth cohort of the whole population of the Netherlands from the years 1944-1947. In the 70's, all Dutch males were required to present for military service at the age of 19. They then underwent physical and psychological examination, including aptitude testing. Over the 4 year period studies, there was no consistent relationship between the prevalence of severe mental retardation and rural/urban place of birth.</p> <p>This study had an impressively complete dataset, and the results seem likely to hold true for this specific male population. However, the years between 1944 and 1947 in the Netherlands covered the period at the end of and immediately following the second world war. This is known to have been a period of extreme hardship and famine, and has been associated for example with the later development of schizophrenia in people born during this period. It is likely to have been associated with an increased prevalence of intellectual disabilities, although this has not been shown. It is hard to know how rurality may have affected famine and deprivation, but it is possible that people living in the countryside had relatively better access to food – which may explain why the prevalence of intellectual disabilities was not found to be higher as was the case in the studies above.</p>

Studies in which prevalence is shown to be lower in rural areas	
Deb & Prasad (1994), Scotland	This study was designed to compare the prevalence of autism in urban and rural areas, but the methodology additionally included identifying all children with intellectual disabilities attending 16 “special schools” in the Grampian region of Scotland. These were categorised as either within the “Aberdeen city area” (urban), or in the “counties” (rural). The authors then calculated the proportion of children attending special schools in those areas using all school aged children as a denominator. They found that the proportion of children attending special schools in rural areas was 0.63% (95% CI 0.57%-0.69%) compared with 0.96% (CI 0.86% to 1.06%) in the city. The paper did not explicitly state if this was statistically significantly different, but the confidence intervals do not overlap.
McQueen et al. (1987), Canada	This paper describes the results of a cross-section study of all 7-10 year olds with intellectual disabilities, born and still living in the 3 Canadian Maritime provinces in 1980. Case ascertainment from multiple sources was considered to be virtually complete. Intellectual disabilities was clearly defined as an IQ \leq 55 (although it is not clear if all children had actually been subject to testing). Counties were defined as urban or rural depending on the proportion of the population living in communities of 1,000 or more, and children were then classified according to the rurality of their county of birth. Given the paucity of urban areas in the Maritime provinces, this was a reasonable way in which to distinguish rural from urban. They showed that the prevalence of (moderate to profound) intellectual disabilities was significantly higher in urban compared with rural areas.

Table 13 Studies comparing rural-urban prevalence of intellectual disabilities

1.9.1.2 Rural-urban demographic differences in intellectual disabilities

Very little literature compares demographic characteristics of people with intellectual disabilities living in rural and urban areas. From the same dataset as described above in table 13 (Wellesley et al. 1992), Wellesley et al. (1991) found that some aetiologies of intellectual disabilities were more common in rural areas in Western Australia - namely postnatal cerebral infection, “culturofamilial” (undefined) and “unknown”. The authors speculate that this relates to less adequate peri-natal care, delayed treatment of infections and smaller inbred communities in rural areas. The study showed that children of aboriginal origin were particularly more likely to have experienced postnatal infection, but did not adjust for this finding in their rural-urban comparison. Although this was generally a robust and well conducted study, with large numbers (n = 1602) and thorough case ascertainment, it is hard to extrapolate these findings to the international rural community with intellectual disabilities. A second study by Hagberg & Kyllerman (1983) collated the findings from 5 different epidemiological studies covering 1.2 million of the Swedish population. The studies were set in a variety of urban and mixed urban/rural settings, and only 4 of the studies were described as “similar” in methodology; making rural-urban comparison difficult. Case ascertainment is unlikely to have been complete, and was not described at all for 2 of the studies. The authors suggest that there was a higher prevalence of Foetal Alcohol Syndrome and post-natal causes of intellectual disabilities (such as accidents, severe infections and “suspected battered child syndrome”) in people with intellectual disabilities living in urban compared with rural Sweden. There was no statistical analysis, and overall it was not a convincing paper.

There is no literature directly comparing other demographic characteristics such as age and gender. The research conducted in this thesis will therefore be an original and novel contribution to the literature in this field.

1.9.2 Mental health and intellectual disabilities

People with intellectual disabilities have a high prevalence of mental ill health. A study by Cooper et al. (2007c) screened 1023 adults with intellectual

disabilities for psychiatric illness. This was followed by a full clinical psychiatric assessment for those who scored positive using a purposefully low cut-off point on a specially developed screening tool. The point prevalence of clinical mental ill health was found to be 40.9%. This included problem behaviours and autistic spectrum disorders. Once these were excluded, there remained a point prevalence of 22.4% mental ill health according to clinical criteria, and around 14% using either ICD-10 or DSM-IV criteria. (ICD-10 and DSM-IV are recognised to underestimate the prevalence of mental ill health in people with intellectual disabilities.) This high figure is consistent with previous literature as reviewed in the Health Needs Assessment (NHS Scotland 2004) and Smiley (2005). The incidence of mental ill health is also high, as confirmed by a follow-study to the prevalence study above Smiley et al. (2007). Note that this follow up study provides the urban sample that is used in this thesis for comparison with a rural sample.

There are a number of reasons why the prevalence of mental ill health is likely to be high in people with intellectual disabilities. These include psychological factors (such as difficulties forming relationships, a higher incidence of abuse, bullying and low self-esteem), social factors (such as deprivation and unemployment, poor social networks and few daytime opportunities) and biological factors (such as the underlying cause of disabilities and associated physical health problems). There is probably a relationship between the severity of intellectual disabilities and mental ill health, with those with more severe intellectual impairment at higher risk of mental illness (Cooper et al. 2007b; Smiley et al. 2007 - although note that there are exceptions, Hemmings 2006). This would argue in favour of there being a direct relationship between intellectual disabilities and mental ill health.

The prevalence of mental ill health in people with intellectual disabilities is probably higher than in the general population, but it is hard to make a direct comparison. The study by Cooper et al. (2007c) screened an entire population of people with intellectual disabilities and carried out a full psychiatric assessment by a trained clinician with approximately half of them. This has never been done in the general population. The majority of epidemiological research in the general population relies either on self assessment or by using validated questionnaires to give proxy measures of psychiatric illness. This is likely to

overestimate the true prevalence of mental ill health (Narrow et al. 2002). Nevertheless, a large epidemiological study by The Office of National Statistics (2000) found that 16.4% of adults had a neurotic disorder in the week preceding a structured interview. A number of other studies give results of similar or even greater magnitude (Bilj et.al 1998; Blazer et al. 1985; Kessler et al. 1994; Narrow et.al 2002; Singleton & Lewis 2003). Prescribing information from 2006/2007 shows that in Scotland an estimated 8.8% of the population aged 15 and over take antidepressant drugs on a daily basis. These figures are not dissimilar to the prevalence of mental ill health in the study by Cooper et al. (2007c).

Whether or not the prevalence of “total” mental ill health is higher in people with intellectual disabilities, it remains high and is a significant cause of morbidity in this population. There is stronger evidence for an increased prevalence of psychotic illness in people with intellectual disabilities (Cooper et al. 2007a). This may be more relevant, given the high cost of psychosis to the individual and to society.

In general, mental health is better in rural areas and therefore living in a rural area may be of benefit to people with intellectual disabilities. There is no research investigating rural-urban differences in mental ill health in adults with intellectual disabilities, and this study will therefore be an original and novel contribution to the field.

1.9.3 Physical health and intellectual disabilities

People with intellectual disabilities have worse physical health than the general population. The Health Needs Assessment (HNA, a comprehensive report and literature review commissioned by the Scottish government) concluded that people with intellectual disabilities have more physical health problems than the general population, and also have more unmet health needs (NHS Scotland 2004). They measured health using a number of indicators including mortality and morbidity from a wide range of diseases and conditions and also established that people with intellectual disabilities have more complex and different pattern of health needs than the general population. The HNA suggested that this inequality was due to a number of reasons. First, some causes of intellectual

disabilities are also associated with other specific physical health problems, such as the high incidence of hypothyroidism in people with Down's syndrome. Second, people with intellectual disabilities experience significant barriers when accessing healthcare. Finally, people with intellectual disabilities tend not to benefit from government policies targeting health promotion and healthy lifestyle choices.

Two years later, a further report was compiled up by the Disability Rights Commission (2006). They investigated and reviewed physical health inequalities experienced both by people with intellectual disabilities and also people with mental ill health. They found that despite having worse physical health over a number of indicators, people with disabilities made less use of primary care. Finally, Turner & Moss (1997) came to the same conclusion when they reviewed the physical health and health needs of people with intellectual disabilities in conjunction with the Health of the Nation Strategy.

There are theoretical reasons for supposing that the physical health of people with intellectual disabilities may be different in urban and rural areas. In the UK general population, physical health is probably better in rural areas. However, there are a number of underlying reasons for this (such as rural-urban drift and demographic considerations) that may not apply to people with intellectual disabilities. In addition, access to health services is worse in rural areas, and this may differentially discriminate against people with intellectual disabilities. It is therefore hard to hypothesis how the physical health of people with intellectual disabilities living in rural areas might be affected. There is no previous literature comparing rural-urban physical health in people with intellectual disabilities.

1.9.4 Access and intellectual disabilities

In the UK there is now widespread evidence that people with intellectual disabilities have poorer access to a wide range of services including healthcare (table 14). Despite extensive legislation to try and address inequalities, there is little evidence of improvement over recent years (House of Lords et.al 2008).

Mencap “Treat me right” report (Mencap 2004), UK	Part of this report drew from a survey of almost 1000 people with intellectual disabilities. It uses a selection of cases drawn from the survey to illustrate some of the problems that people with intellectual disabilities have in accessing healthcare. It showed that people with intellectual disabilities have problems accessing both primary and secondary healthcare, and identified some of the reasons for this.
Mencap “Death by indifference” (Mencap 2007), England	This report uses six cases to describe the unequal treatment received by people with intellectual disabilities in hospitals in England. Mencap identify a number of faults, and describe some of the failings as institutional discrimination. They believe in each of the six cases, systematic difficulties contributed to the unnecessary death of the person involved. They highlight how even when access has superficially been achieved, knowledge, attitudes and the unwitting discriminatory behaviour of individuals denies people with intellectual disabilities an equal service.
Disability Rights Commission (2006), UK	This comprises an investigation and review of physical health inequalities experienced by people with intellectual disabilities and/or mental ill health. It found that despite worse physical health over a number of indicators including mortality, people with intellectual disabilities had poorer access to primary health services. In general, primary care was not found to making the “reasonable adjustments” to their service that would allow equal access to people with disabilities.
House of Lords et al. (2008), UK	This large report looks at the lives of people with intellectual disabilities in the UK (primarily England) with particular reference to respect of their human rights and adherence to UK anti-discriminatory legislation (the Disability Discrimination Act 1995). The report comments at length how people with intellectual disabilities have poorer access to a range of opportunities. The authors expressed their concern that despite the laudable vision of government policy (with particular reference to the White Paper, Valuing People), the framework had made very little practical difference to the lives of people with intellectual disabilities.
Health Needs Assessment report (NHS Scotland 2004), Scotland	This is a review of the health needs of people with intellectual disabilities living in Scotland. In addition to recognising the complex healthcare needs of many people with intellectual disabilities, the report identified a number of barriers to people with intellectual disabilities accessing appropriate services and support.
Alborz et al. (2005), UK	Comprehensive and well described literature review looking at access to (primarily) primary healthcare services for people with intellectual disabilities. Overall, the level of evidence was not felt to be high, but a number of issues and barriers to access were identified.

Table 14 Access to services for people with intellectual disabilities

Based on this literature, the student has identified a number of barriers which contribute to inequalities in accessing services (table 15).

Discrimination	Assumptions may be made about a person's quality of life, and they may not be offered the same treatment as a person without intellectual disabilities. In some instances, discrimination has led to indifference about the person's wellbeing.
Reliance on carers	Most people with intellectual disabilities rely on family and carers to support them with healthcare needs. The carer must not only recognise medical symptoms, but must also decide that the symptoms are worthy of medical attention, and arrange appropriate healthcare at a time that suits both the people with intellectual disabilities and themselves. Carers may be required to support the person with intellectual disabilities to carry out an agreed treatment plan.
Recognition of symptoms	People with intellectual disabilities may have a high pain threshold. Even people who know them well may not recognise that they are in pain or unwell.
Complex health needs	People with intellectual disabilities are more likely to have multiple and complex health needs. Some health needs may be specific to people with intellectual disabilities, and appropriate treatment may require specialist care.
Communication	People with intellectual disabilities may not be able to communicate complex medical symptoms. Professionals may not be prepared to question or listen to families or carers, even though families may have years of experience with the person with intellectual disabilities and their individual health needs.
Expectations	People with intellectual disabilities typically have lower expectations of healthcare services. The people who support them may also have low expectations, perhaps based on previous experience.
Inflexibility within the system	People with intellectual disabilities may not manage inflexible appointment times. It may take a couple of hours to support a person with complex needs to get washed, dressed and eat breakfast; early appointments may be impossible to attend. It often takes longer to take a full medical history and perform a physical examination. Some people with intellectual disabilities may not be able to tolerate waiting in a waiting room for prolonged periods of time.
Diagnostic overshadowing	The assumption that a person is displaying a behaviour or symptom because of their underlying intellectual disabilities, rather than searching for an independent and potentially treatable medical problem.
Lack of clarity over carers roles	There may be an assumption that families or carers will provide basic care in inpatient settings for people with intellectual disabilities. Under usual circumstances these would be provided for by trained staff.
Professional ignorance	Poor training and awareness amongst professionals regarding the special healthcare needs of people with intellectual disabilities.
Transport and practical considerations	People with intellectual disabilities are less likely to be able to access public transport on their own, and very few are able to drive. It can therefore be difficult to get to healthcare appointments. Not all healthcare buildings are fully accessible to people with complex physical disabilities, and many fail to accommodate for common comorbid disabilities such as visual or hearing impairments.
Problems carrying out routine procedures	If a person with intellectual disabilities does not understand what is happening, they may be reluctant to comply with physical examination or medical procedures such as having blood taken.

Table 15 Barriers to accessing healthcare services

People living in rural areas have poorer access to a wide range of services and this may differentially affect people with intellectual disabilities. First, people with intellectual disabilities have greater healthcare needs than the general population. They already have difficulties in accessing healthcare services, and this may be exacerbated by problems associated with living in a rural area. Second, people with intellectual disabilities may need specialised healthcare services. Because of small rural populations, it is unlikely that specialised services can be provided locally and most specialised services will be provided from a centralised urban location. This means that the people with intellectual disabilities (and probably a carer) will have to travel to access services. Third, people with intellectual disabilities are disproportionately affected by difficulties associated with travel and transport. They are less likely to be able to access public transport on their own, and very few are able to drive (Emerson et al. 2005). Stopping for comfort breaks can be tricky (Iezzoni et al. 2006).

There is a small amount of research investigating or commenting on access for people with intellectual disabilities living in rural areas. A consultation document for the Scottish Executive suggested that access was a paramount issue for people with disabilities living in rural areas (Scottish Executive 2001). They felt that the lack of services and support staff in rural areas could limit the ability of people with disabilities to live in their own homes. This finding was a minor part of a large consultation process, and did not specifically refer to people with intellectual disabilities, but included people with physical and mental health disabilities. Next, a report from the British Medical Association speculated that the difficulties that the general population experience in accessing healthcare in rural areas were likely to be compounded for people with disabilities (British Medical Association Board of Science 2005). However, this was not well substantiated, and the report suggested that more research was needed. Ridley & Hunter (2005) used a range of quantitative and qualitative methods to collect data for a consultation document for the Scottish Executive. They established that most employment support and opportunities for people with intellectual disabilities were only available in urban or urban/rural mixed areas rather than rural areas. Following the widespread closure of institutionalised care, Forsyth & Winterbottom (2002) compared the expenditure on services for adults with intellectual disabilities by health authorities in

England. This was compared with the total number of people with intellectual disabilities cared for by each health authority. The calculations that they made were described in depth, and although it is possible that some people with intellectual disabilities may have been missed, it seemed a logical cost analysis. They concluded that there was a relative under-spending on intellectual disabilities services in rural health authorities compared with urban ones.

Probably the best study to make a direct rural-urban comparison of access comes from Australia (Iacono et al. 2003). This comprised a large questionnaire-type survey sent to 1105 GPs and 3439 support workers. Although there was a low response rate (22% and 27%), the method of sampling was reasonable, and the results were probably representative. GPs in rural areas were more likely to report that a wide range of specialist services for people with intellectual disabilities were located more than half an hour travel distance away. These services included specialist intellectual disabilities psychiatric, medical and counselling services. Rural GPs were also more likely to describe experiencing greater problems in obtaining a history, completing a physical examination and diagnosing medical problems in people with intellectual disabilities. It was suggested that this was because of the lack of specialist support. Support workers in rural areas were also more likely to report problems with access, and described having to travel further to access services.

Finally, two further studies make a direct rural-urban comparison of service use in people with intellectual disabilities. The first study recruited 60 adults with developmental disabilities living in 8 community residential facilities in the USA (Slater & Black 1986). The facilities were randomly selected, with 4 from an urban and 4 from a rural county. The researchers completed a fairly comprehensive survey to measure demographic details, level of disabilities and use of services, and concluded that people with intellectual disabilities living in urban areas received significantly more “training”, counselling and recreation, and used more transport. Unfortunately the study was limited by poor methodology and statistical analysis. Although comprehensive, the survey was not necessarily accurate, and a lot of missing data was not accounted for. This included a number of variables, such as the level of intellectual disabilities; although the authors stated that this was adjusted for in the subsequent analysis, it is not entirely clear how this was statistically possible. In addition,

because just 4 residential facilities were chosen from two urban and rural counties there was considerable potential for sampling bias and clustering of results. Finally, although the 4 rural residential facilities were based in a predominantly rural county, they may have been located in a town within that county, and therefore may not have been rural by most definitions.

A second study compared the life circumstances, service use and disabilities of 50 adults over the age of 50 with either a mild or moderate level of intellectual disabilities and living in either urban or rural areas (Ashman et al. 1990). They found a number of rural-urban differences. For example, participants living in rural areas were more likely to live with their family or on their own, and appeared to live a more “normalized” life than participants coming from urban areas. This judgement was based upon greater access to and participation in community activities. Unfortunately this study was also limited by the methodology and statistical analysis. In particular, there was an extremely biased selection procedure. 19 out of the total of 20 people known to the intellectual disabilities services in the rural area participated in the study. This compares with 31 urban participants who were purposefully selected from a possible 196 candidates to give a good range of residential settings. There was no adjustment for level of intellectual disabilities; 2 of the rural participants were able to drive, which would also make one question whether they did in fact have intellectual disabilities.

In conclusion, people with intellectual disabilities living in rural areas probably have poorer access to health services, but the evidence supporting this is limited.

1.9.5 Social exclusion and intellectual disabilities

Social exclusion relates to a person's ability to participate fully in key aspects of society. It is easy to understand why people with intellectual disabilities are therefore likely to be socially excluded. For example, a person with severe or profound intellectual impairment is extremely unlikely to be in full-time paid employment, and is unlikely to have much choice when they purchase goods or services. They will probably have limited opportunities to participate in socially valuable activities, and are less likely to enjoy full participation in family and community life. Despite increasing awareness of inequalities, the social exclusion of people with intellectual disabilities remains a major concern (Abbott & McConkey 2006; Department of Health 2001; Emerson et.al 2005; Hall 2005; House of Lords et.al 2008; Myers et al. 1998).

1.9.5.1 Deprivation

People with intellectual disabilities live in more deprived neighbourhoods compared with the general population (Cooper et al. 2010; Emerson et.al 2005; Emerson 2007; Morgan et al. 2000; NHS Scotland 2004). This finding is consistent across the lifespan, and suggests that not only are people with intellectual disabilities more likely to be placed in deprived areas, but also that younger people living with their families originate from deprived areas (Morgan et.al 2000). People with intellectual disabilities rarely have much choice where they live, and house ownership is rare. Adults with intellectual disabilities are much less likely to be in paid employment, and this is probably one of the most important reasons for financial deprivation and its consequences. It is likely that people with intellectual disabilities fare badly on other markers of deprivation such as educational status, car ownership, benefit uptake, and housing, but this has not been formally measured in this population in the context of deprivation.

There is no research investigating either social exclusion or deprivation in people with intellectual disabilities living in rural areas.

1.9.5.2 Community

People with intellectual disabilities are less well integrated into the community than the general population (Baker 2000; Cummins & Lau 2003; Hall & Hewson

2006; Robertson et al. 2005; Scottish Executive 2000b). This is more likely to affect those with more severe intellectual impairments (Felce & Emerson 2001). Cummins & Lau (2003) note that the majority of research in this area focuses on “physical” integration; that is, geographic placement within the community and use of community facilities rather than social integration into the community. They argue that social integration has a greater influence on well-being and quality of life, and suggest that policy makers should not necessarily assume that physical integration will automatically improve well-being. For people with intellectual disabilities, social integration may be more achievable within the intellectually disabled community itself.

In the general population, evidence suggests that rural areas have a stronger community spirit. This would be to the advantage of people with intellectual disabilities living in rural areas. On the other hand, because of small numbers, the community with intellectual disabilities is likely to be much smaller than in urban areas. If people with intellectual disabilities rely on the community with intellectual disabilities for social integration, living in rural areas might lead to greater social isolation. In addition, belonging to a community has disadvantages as well as advantages, and this might be even more so for people with intellectual disabilities. For example, once enmeshed into a tight supporting network, it may be even more difficult for people with intellectual disabilities to break out and gain independence. If a person with intellectual disabilities has established a rôle within the community, it may be hard to change this. Once a person with intellectual disabilities has been excluded from a small rural community, they may never have the opportunity either to re-enter the community, or to establish an alternative source of community integration.

There is very limited research in this area. In a consultation document describing a population with intellectual disabilities in rural Australia, Gething (1997) states that there is a “strong sense of community” but does not give evidence to support this. Krishnan et al. (1993) compare the backgrounds of urban and rural patients with intellectual disabilities admitted to a single psychiatric hospital in the UK. They established that patients from urban areas were younger, had less severe intellectual impairment and levels of dependency, and exhibited more behavioural problems. Patients from rural areas were more socially impaired, had less contact with relatives and had more medical problems. The main reason

for admission in the urban group was behavioural problems whilst for the rural group it was social reasons. They hypothesise that people with intellectual disabilities are generally better integrated in rural areas, that the rural environment is less demanding and that behaviour is generally tolerated better in rural areas. This was felt to explain why only those with more severe intellectual impairment and social breakdown were admitted to hospital, whereas people with less severe intellectual impairment and challenging behaviour were managed in the community. The logic of this is not entirely consistent. In addition, the rigour of the statistics was limited in places, and the rural environment was described only as a “predominantly rural catchment area”.

1.9.5.3 Social networks and social support

There is increasing evidence that people with intellectual disabilities have poorer social networks than the general population, and that this is a major challenge to overcoming social exclusion (Cummins & Lau 2003; Department of Health 2001). Emerson et al. (2005) interviewed almost 3000 adults with intellectual disabilities living in a range of care settings in England. They report a number of findings that relate to social networks. For example, people with intellectual disabilities were less likely to have contact with family and friends than the general population, and just 25% of participants had a friend who did not have intellectual disabilities. 5% had no contact with either friends or family. 92% of people with intellectual disabilities were single and had never had a partner, only 7% had their own children, and only half of these people actually cared for their children themselves. A number of criticisms have been made of this study, including the suggestion that the sample was not representative of the general population of adults with intellectual disabilities. Nevertheless, it is a revealing study.

A UK study investigated the social integration and social networks of 213 people with intellectual disabilities 12 years after resettlement into the community (Forester-Jones et al. 2006). The introduction to the study provides a comprehensive review of the difficulties experienced by people with intellectual disabilities. They describe how even in the most inclusive community settings, people with intellectual disabilities have smaller social networks than the

general population. A particular issue is not so much the lack of regular contact with other people, but the nature and quality of the relationships, and especially the lack of friendship (and contact) outwith relationships with support workers and carers. They hypothesize a number of reasons for this, including: contact tends to be focussed around supporting people with intellectual disabilities rather than a true reciprocal relationship or friendship; communication, behavioural and mental ill health in people with intellectual disabilities; exclusion from participation in usual community opportunities; and a lack of usual lifespan progression from childhood friends and family support to new social opportunities through further study, employment and adult relationships. The results of the study itself supported these hypotheses. For example, the main social interaction and support for people with intellectual disabilities came from staff, followed by other people with intellectual disabilities. Although the relationship of the people with intellectual disabilities with staff could be close, it was less likely to be reciprocal compared with relationships with family or friends. The main limitation of the study is that all participants had previously lived in institutional care, and now predominantly lived in group homes rather than individually. In addition, the majority of participants had mild or moderate learning disabilities, and people who were not able to communicate well enough to participate were excluded. The results may therefore not generalise to all adults with intellectual disabilities.

In order to achieve their full potential and enjoy a reasonable quality of life, people with intellectual disabilities will need help and support from the community. Although there are no studies that directly compare the support needs of people with intellectual disabilities compared with the general population, it is reasonable to assume that people with intellectual disabilities require and receive more support than the general population.

It is possible that people with intellectual disabilities benefit from the stronger social networks and support that probably exists in rural areas. However, research in this area is limited. Two studies from the USA describe the amount of support that parents received to help care for their children with special healthcare needs. (This includes not only children with intellectual disabilities, but also children with behavioural problems and children who receive counselling.) One study found that parents in rural areas spent more time

providing care for their children (Skinner & Slifkin 2007), whereas the other found that parents from urban and rural areas reported similar unmet needs for support and that urban parents reported receiving less support from their families (Sharon et al. 2004). Both of these studies investigated social support in children, and it is difficult to interpret these results with respect to the social support and networks of the population of adults with intellectual disabilities.

1.9.6 Other aspects of rural life and intellectual disabilities

1.9.6.1 Rural Quality of life, advantages and disadvantages

Quality of life is thought to be poorer for people with intellectual disabilities. Schalock (2004) describes how quality of life relates to a number of “domains” including interpersonal relations and family, internal factors (such as confidence and self-esteem), participation and inclusion in society, and physical, emotional and material wellbeing. Schalock discusses how all of these may be impaired for people with intellectual disabilities.

A single study was identified that investigated quality of life (or life-satisfaction) in people with intellectual disabilities living in rural areas. This showed that life-satisfaction scores were similar in 61 urban and rural students with intellectual disabilities in Australia (Bramston et al. 2002). The rural group described feeling significantly safer on one of the subscales. This used a thorough and well described battery of tests including the Quality of Student Life Questionnaire, but used a different method of student selection for participants from urban and rural areas, and also describes life-satisfaction in adolescents rather than adults.

There is no previous literature that investigates the perceived advantages and disadvantages of rural life for adults with intellectual disabilities.

1.9.6.2 Anonymity and stigma

People with intellectual disabilities are likely to experience stigma because of their disability, and in turn this may lead to discrimination and poor self-esteem. Jahoda & Markova (2004) held semi-structured interviews with 28 purposefully selected people with intellectual disabilities at a time of significant transition to

more independent living. Most of the participants were well aware of their need to use specialised services, and also of the associated stigma and discrimination. They were keen to re-identify from either a “patient” in a long-stay institution or dependent on family, to an independent “normal” (pp 725) member of the community. Lack of social acceptance was a common theme, and stigma was something that they had to deal with as part of their everyday lives. Craig et al. (2002) also describe how people with intellectual disabilities are usually aware of the negative social connotations associated with that label. In their study, people with intellectual disabilities tended to either portray themselves as belonging to the non-disabled population, or distanced themselves by comparing themselves favourably to other service users within their peer group. They noted that there was discomfort and awkwardness when the subject of intellectual disabilities was discussed in a focus group setting, and that the subject was often rapidly changed.

Because of the lack of anonymity and increased social visibility in rural areas, most people with intellectual disabilities will be well known and labelled as having a disability by the local community. Intellectual disabilities is a lifelong condition, and a person may never escape this label. This may lead to stigmatisation and discrimination. On the other hand, there may be advantages of being well known within the community. For example, people who are recognised as having intellectual disabilities may be supported and protected. Similarly, difficult or unusual behaviour may be better understood and tolerated because the person is understood to have intellectual disabilities.

There is very little research in this area. A large consultation exercise held with people with disabilities, disability groups, service providers, families and carers in Western Australia found that many participants raised the issues of privacy and confidentiality; but this was not explored further with respect to stigma (Gething 1997). Iacono et al. (2004) asked 101 key stakeholders about their experience of accessing healthcare services for people with intellectual disabilities in rural Australia. Through a series of focus groups, participants described the negative attitudes that many healthcare professionals were felt to hold towards people with intellectual disabilities. This was thought to stem from a lack of knowledge and inaccurate expectations rather than actual stigma. Although an interesting finding, it is possible that healthcare professionals in

urban areas hold equally negative attitudes. Feine & Taylor (1991) describe the case management of a terminally ill and severely handicapped 6 month old baby who was taken home to die by her parents. Her family were well known to the close rural community in the USA, and were considered to be a “do-nothing” family not worthy of support. Significant input from the key manager (social worker) helped to address the stigma and challenges faced by the family. The study does not consider stigma towards intellectual disabilities, but does illustrate how the stigma arising from living in a small rural community can affect informal support given to people with intellectual disabilities and their carers. Of course, it is also possible that equal levels of stigma and discrimination exist in tight knit urban communities. The body of work by Philo et al. (2002) primarily investigated the experience of mental health, but a few of the participants made comments about people with intellectual disabilities in their community. One person described how “local notable characters” with intellectual disabilities were accepted as they wander around the town, as they were seen as part of the local community. A second person said that people with intellectual disabilities could be made to feel quite uncomfortable. Finally, Sinson & Stainton (1990) directly compared attitudes towards intellectual disabilities between attendees at 50 urban and 50 matched rural surgeries. They concluded that there were no differences in attitudes between urban and rural areas. However, there were a number of design faults in the study; for example, there was considerable potential for selection bias amongst recruits, some of whom were handpicked by the author. In addition, although people from urban and rural areas answered a number of set questions in a similar way, it is hard to know how the answers actually relate to attitudes, stigma and discrimination towards people with intellectual disabilities. (For example, there was similar awareness of the existence of the UK based charity MENCAP, there were similar attitudes towards termination of pregnancy following unfavourable amniocentesis, and there were similar attitudes towards the integration of mainstream education for people with intellectual disabilities.)

Chapter 2: Aims and hypotheses

2.1 Aims

Informed by a thorough review of the relevant literature, the aims of this study are:

1. To compare a range of demographic and health variables in a rural and an urban sample of adults with intellectual disabilities.
2. To compare access to healthcare services in a rural and an urban sample of adults with intellectual disabilities.
3. To compare a range of markers of social exclusion in a rural and an urban sample of adults with intellectual disabilities.
4. To make a preliminary exploration of how adults with intellectual disabilities experience rural life, and how they are affected by perceived advantages and disadvantages of rural life.

2.2 Hypotheses

1. It is hypothesised that there are no significant demographic differences between adults with intellectual disabilities living in rural and urban areas.
2. It is hypothesised that adults with intellectual disabilities living in rural areas have better mental health than adults with intellectual disabilities living in urban areas.
3. It is hypothesized that adults with intellectual disabilities living in rural areas have poorer access to healthcare services.
4. It is hypothesized that markers of social exclusion differ between adults with intellectual disabilities living in rural and urban areas. It is difficult to predict whether social exclusion is greater in rural or urban areas as a number of aspects of rural life could potentially influence this.

Chapter 3: Methods

3.1 Samples

3.1.1 Rural sample

The rural sample comprised adults with intellectual disabilities recruited between 2007 and 2009 from very remote rural areas and very remote small towns in the county of Argyll and Bute on the West Coast of Scotland.

3.1.1.1 Inclusion criteria

All adults aged 16 or over with intellectual disabilities living in the area under study.

3.1.1.2 Exclusion criteria

Adults unable to consent themselves and for whom a proxy as defined by the Adults With Incapacity (2000) Scotland Act could not be found to provide consent on their behalf.

3.1.2 Urban sample

This study is an additional extension to a study that recruited participants from a predominantly urban setting. An initial study looked at the prevalence of mental ill health, and recruited adults with intellectual disabilities who were living in Greater Glasgow and Clyde (Cooper et al. 2007b). Two years later during 2004 - 2006, following on from this original study, all participants were invited to participate in a further study investigating the incidence of mental ill health (Smiley et al. 2007). The 651 participants of this second study were used as the basis of the urban sample.

Greater Glasgow and Clyde comprises the city of Glasgow (approximate population 600,000) and immediate surrounding areas (approximate population of a further 600,000). Although the immediate surrounding areas are close to the city, and are likely to have similar characteristics to the city of Glasgow itself, some residencies within the surrounding areas are categorised as rural. The

Scottish Government Urban Rural Classification 8-fold version (2005-2006) (The Scottish Government 2006) was therefore used to identify by postcode and remove the 18 (2.8%) participants from the initial sample who lived in accessible small towns, accessible rural areas and also the 2 participants who had moved from the area since the initial study. This left a final sample of 633 participants, all of whom lived in either large urban areas or other urban areas.

3.2 Recruitment

3.2.1 Rural recruitment

It had been agreed through the relevant ethics committee (MREC (Scotland) - A) that because the student did not currently work for the health board that participants were recruited from, she was not permitted access to existing databases or lists of people in the area known to have intellectual disabilities. In addition, the study was not permitted to approach potential participants directly. Instead, all recruitment had to go through intermediaries.

Participants were therefore recruited via intermediaries over a 16 month recruitment campaign between December 2007 and April 2009. They were recruited from a wide range of settings including local resource centres, service user groups, support agencies and word of mouth (table 16). Every effort was made to try and reach as wide a range of potential participants as possible, and not simply to approach people known to services, as this would have introduced selection bias. The student contacted intermediaries by telephone and email to set up face-to-face meetings to discuss the research project, and also to provide further written information about the research. If the intermediaries were interested in facilitating the research, they were given “information packs” to hand out and discuss with potential participants. Information packs contained a short leaflet about the study, a full information sheet, and a reply slip expressing possible interest and giving permission for the student to contact the potential participant directly (appendix 2). Approximately 250 information packs were distributed during the course of the recruitment campaign. Some participants would not have been able to express interest in the research because of their level of intellectual disabilities; in this case the intermediary or carer was for advice on how best to proceed (if appropriate).

In addition to direct recruitment through intermediaries, the student also spent time meeting potential participants in a range of group settings. Formal meetings were arranged, where the student might give a short presentation about the research followed by an opportunity to ask questions. At other times, the student would take the opportunity to chat informally with people (for example, going into a resource centre during the lunch hour). The student asked for advice from local intellectual disabilities services, and also got feedback from intermediaries so that the recruitment campaign was constantly being revised and modified in a process of cyclical and emergent design (Nierse & Abma 2011).

Because people with intellectual disabilities are less likely to have literacy skills, it was not felt that recruitment via posters and information leaflets in public places was likely to be a successful strategy.

Although the student was not granted ethical permission to access a full database of people with intellectual disabilities living in the area, primary care sources (the Quality and Outcomes Framework learning disability register) (ISD Scotland 2010) were used to ascertain that there were 135 adults with intellectual disabilities living in the area. The student was also able to access the gender and date of birth of these adults, and this information was used to compare participants with non-participants.

Resource centres
Service user groups
Support agencies
Local specialist intellectual disabilities team including learning disabilities psychiatry
Primary care
Supported employment agencies
Local schools (to recruit pupils aged 18 and over who might not yet be accessing adult services)
Informal support networks for people with intellectual disabilities
Local respite care
Local area coordinators
Social services
Charities
Carers centre and a local carer support group

Table 16 Services approached when recruiting to the study

3.2.2 Urban recruitment

In order to recruit to the original urban study, a thorough process of case ascertainment was carried out within Greater Glasgow and Clyde over 2002-2004. This process aimed to include all adults with intellectual disabilities age 16 and over living in the area under study. A register was compiled by accessing records of all people with intellectual disabilities known to intellectual disabilities social services; all people with intellectual disabilities receiving local authority funding; all people with intellectual disabilities accessing specialist intellectual disabilities services; Greater Glasgow and Clyde Health Board records; and the Scottish Executive Statistical Department. In addition, all 631 GPs working in primary care in the area were paid to identify people with intellectual disabilities registered with their practice. The original register was over inclusive, and included a number of people with an IQ of over 70. However, work was undertaken to assess each individual so that only people with intellectual disabilities were included on the final register.

All people on the register were approached and asked if they wished to receive a free comprehensive health check, including a review of any physical or mental symptoms, blood pressure check, testing of vision and hearing and any relevant blood tests. In addition to the intellectual disabilities specialist nurses who carried out the initial screening, six GPs were employed to oversee the health checks. As part of the health check, participants were asked if they agreed for data collected to be used for research purposes. Participants were also asked if they were willing to be contacted regarding future research projects.

Two years later, all participants who had agreed to further contact were approached directly regarding a second study looking at the incidence of mental ill health (Smiley et.al 2007). The urban sample comprised adults with intellectual disabilities who participated in this subsequent incidence study.

The urban sample was therefore recruited in a very different way from the rural sample.

3.3 Ethical approval, consent and clinical governance

Ethical approval was obtained from the Multi-Centred Research Ethics Committee (MREC) - Scotland A (reference 07/MRE00/92) (appendix 3). The student was based in and employed by NHS Greater Glasgow and Clyde, and the urban sample had been recruited from this area. The Research and Development (R&D) Directorate of NHS Greater Glasgow and Clyde Community and Mental Health Partnership therefore acted as the research sponsor, and approval was obtained from Greater Glasgow and Clyde Local Research Ethics Committee. Rural participants were recruited from NHS Highland health board. This site was given a favourable opinion by MREC-Scotland A at the time of the original application. In addition, R&D approval was granted by NHS Highland, and a contract was issued from NHS Highland to employ the student as Honorary Research Fellow.

Wherever possible, consent to participate was directly obtained from the participants themselves. Because of the vulnerability of the participant group, an independent witness also signed the consent form to validate that they considered that the participant understood the process and purpose of the research, and was willing to participate. The student is a qualified intellectual disabilities psychiatrist with experience in assessing capacity, and holds Approved Medical Practitioner (AMP) status.

In keeping with the Adults With Incapacity (Scotland) Act (2000), if participants were not able to give consent themselves, consent was sought from their Welfare Guardian. If the participant did not have a Welfare Guardian, permission was sought from their defined next-of-kin. Potential participants with more severe intellectual impairment and without a welfare guardian or next-of-kin were therefore unable to participate.

Whether or not the participant was able to give formal consent, they had to indicate by their speech or behaviour that they were happy to participate in the study for the research to go ahead. If a participant appeared unwilling (or distressed) by the research interview, the interview was terminated and rescheduled only if deemed appropriate.

As sponsor, NHS Greater Glasgow and Clyde R&D Directorate were responsible for overall clinical governance of the study. In addition, an independent research governance group has been established in Glasgow to ensure that governance and ethical issues are fully complied with. The conditions specified by MREC-Scotland A were adhered to. The research was carried out in accordance with the requirements of the research governance framework, the research sponsor, the Data Protection Act and the Adults With Incapacity (Scotland) Act. All data remains confidential to the research team (and to the research sponsor should access become required), and is kept securely.

3.4 Funding and pilot study

3.4.1 Funding

The student's NHS contract included a research component, and this covered all staffing costs. A successful application was made to the Baily Thomas Charitable Fund for a one-off grant of £3,749.00 to cover additional expenses including mileage, postage and photocopying. The grant was managed through the University of Glasgow. The urban sample had been studied with funding from the Chief Scientist Office.

3.4.2 Pilot study

Because this was an additional extension study, most of the methodology and measures had already been developed and had been successfully used in previous research. A separate rural pilot study was therefore not undertaken.

3.5 Research process

A semi-structured interview was held with each participant in a setting of their choice. This was often in the participant's home, but interviews were also held in other venues such as resource centres. For the urban sample, if screening indicated that the participant may have mental ill health (and with the permission of the participant), a second interview was set up with a trained psychiatrist. For the rural sample, all screening was carried out by a trained psychiatrist, and it was not always necessary to arrange a second separate interview. Most participants were supported by their family or a paid carer during the interview. A few more able participants did not wish for family or a carer to be present. This was particularly the case if a second interview was required, as by then the participant might feel more confident about the research.

Following the interview(s), a semi-structured format was used to gather data from the participant's primary care health records. If urban participants had a clinical diagnosis of mental ill health, psychiatric case notes were also reviewed.

Finally, using participant postcodes, some data (such as urban-rural status) were ascertained from publically available databases.

3.6 Measures

A wide range of measures were recorded. The full interview schedule is given in appendix 4.

3.6.1 Demographic details

These included gender, age, marital status, and ethnicity. The participant's first language was recorded for the rural sample only. The type of accommodation that the participant lived in was also recorded.

3.6.2 The Scottish Executive Urban Rural Classification

This thesis uses the Scottish Executive Urban Rural Classification to define study participants as rural or urban. This defines rural as any settlement or land which has a population of 3,000 or less. The classification system also considers whether settlements and land are within access of larger settlements of over 10,000 people.

The 6-fold and 8-fold classifications are as follows:

1. **Large Urban Areas:** Settlements of over 125,000 people.
2. **Other Urban Areas:** Settlements of between 10,000 and 125,000 people.
3. **Accessible Small Towns:** Settlements of between 3,000 and 10,000 people and within 30 minutes drive of a settlement of 10,000 or more.
4. **Remote Small Towns:** Settlements of between 3,000 and 10,000 people and with a drive time of over 30 minutes to a settlement of 10,000 or more.
5. **Accessible Rural:** Settlements of less than 3,000 people and within 30 minutes drive of a settlement of 10,000 or more.
6. **Remote Rural:** Settlements of less than 3,000 people and with a drive time of over 30 minutes to a settlement of 10,000 or more.

A further 2 categories can be added, to allow for the distinction between remote and very remote areas:

7. **Very Remote Small Towns:** Settlements of between 3,000 and 10,000 people and with a drive time of over 60 minutes to a settlement of 10,000 or more.
8. **Very Remote Rural:** Settlements of less than 3,000 people and with a drive time of over 60 minutes to a settlement of 10,000 or more.

The Scottish Executive has calculated both the 6 and 8-fold classification status of all residencies in Scotland by postcode. This information is available publically and is updated every 2 years. Drive time has been calculated by considering road size, and additional time is allowed for ferry crossings so that the classification can also be applied to islands.

The Scottish Executive Urban Rural Classification was drawn up specifically with the Scottish rural environment in mind, and was developed to facilitate Scottish rural research, rural policy and funding (including healthcare policy). The Scottish Executive considers that the classification is widely used within Scotland, and it is used by the majority of recent research published by the Scottish Executive. It is recommended by the Scottish Executive for research purposes (Bishop et al. 2004) and is also quoted as having become accepted as a pragmatic tool in rural health services research (Godden et.al 2007).

The Scottish Executive Urban Rural Classification has the advantage that it is clear, simple and readily understood. Because postcode data is publically available, it is easy for independent researchers to use. However, there are some disadvantages. First, a large part of the Scottish landmass, including almost all of the Scottish Highlands, is defined as very remote. The classification system does not allow distinction between areas within remote rural Scotland that differ greatly in terms of access. In addition, it does not truly reflect the specific difficulties that island communities face. Second, from an international perspective it could be argued that settlement numbers (i.e. 3,000 and 10,000) are relatively small with respect to defining rural and urban; however, the numbers were chosen to reflect the distribution of population and rural

environment in Scotland, and are probably appropriate for Scottish research. Finally, relatively small changes in the population can mean that the rural statuses of large areas are redefined. In particular, Fort William is a town in the central Highlands of Scotland with a population of just under 10,000 in the winter season. Small population changes in Fort William could mean that large areas of central Scotland would no longer be defined as remote.

Rurality in this study was calculated for each participant by postcode using the Scottish Government Urban Rural Classification (8-fold version). The 2007-2008 version was used for the rural sample (The Scottish Government 2008), and 2005-2006 version for the urban sample (The Scottish Government 2006) as this correlated best with when the data were collected.

3.6.3 Deprivation score

The Scottish Index of Multiple Deprivation (SIMD) (The Scottish Government 2010) was used to determine a deprivation score by postcode for all participants. The SIMD was developed by the Scottish Government in order to support social research and policy in Scotland, with particular consideration to rural-urban comparison. It divides the country into 6,505 data zones. These lie within local authority boundaries, and comprise between 500 and 1000 householders per data zone. The data zones are designed to contain households with similar social characteristics.

Each data zone is ranked according to deprivation. The ranking ranges from the most deprived (rank 1) to the least deprived (rank 6,505). The individual ranking is calculated by combining a number of indicators across the following domains: income, employment, health, education, skills and training, housing, geographic access and crime. In this study, both the actual rank and the ranked deciles were used to compare the rural and urban samples.

3.6.4 Geographic mobility

Rural participants were asked where they were born, and whether they considered this to be rural or urban. They were then asked to provide a brief overview of where they had lived throughout their lives. The purpose of this was

to establish whether the rural sample had lived in predominantly rural areas throughout their lives, or whether they had been born and brought up in an urban environment and only recently become “rural”. In the latter case, it would be more difficult to argue that they were a true rural sample.

3.6.5 Level and cause of intellectual disabilities

The Vineland Adaptive Behaviour Scale (survey form, version 1) (Sparrow et al. 1984) was used to determine the level of intellectual disabilities for all participants. The Vineland is a semi-structured interview delivered by trained interviewees to the main carer of the person with intellectual disabilities being assessed. The carer is asked whether or not the person with intellectual disabilities normally carries out a wide range of skills in the areas of communication, daily living and social and personal skills. They are given scores in each area, and these can be averaged to give an idea of the age equivalent at which the person functions from day-to-day and the corresponding level of intellectual disabilities.

The main advantage of the Vineland is that it is relatively quick and simple to use and to score, and so is well suited for large population studies. However, it has a few disadvantages. First, the Vineland is an assessment of function rather than cognitive ability. There is some correlation with cognitive ability, but a person’s function depends on many additional variables such as physical disability and mental ill health. Also, a person’s usual day-to-day functioning will depend on the opportunities that they have been given to learn skills, and the opportunities that they are given on a daily basis to maintain those skills. Second, the Vineland is based on data from the USA, and some of the questions are not appropriate for adults living in the UK. Third, the Vineland is now over 20 years old, and some of the questions and skills that it asks about are no longer relevant. (For example, the ability to use a pay phone rather than a mobile phone.) There is now a second version of the Vineland, but this was not available at the time of this study. Nevertheless, the Vineland provides a useful indication of a person’s abilities that can be interpreted within a clinical and environmental context to give a reasonable estimate of the level of disabilities. All of the researchers collecting data from the urban sample had specific

training in using the Vineland and the student also had experience and training in this tool prior to the study.

If an IQ score had been carried out previously, and was available in the participant's psychiatric case notes or primary care records, this was also taken into account.

The cause of intellectual disabilities was taken from direct questioning at interview, or from primary care notes. If the cause of intellectual disabilities was not known, this was also recorded.

3.6.6 Current physical health problems

The C21st Health Check (Glasgow U.C.E.D.D. 2001) was used to assess for physical health problems. This is a semi-structured interview that was designed for the purpose of assessing common co-morbidities in intellectual disabilities such as poor mobility, incontinence, epilepsy and visual and hearing impairment. It also screens for common symptoms within each physiological system (for example, asking about common cardiovascular symptoms, or common gastro-intestinal symptoms) with the intention of identifying undiagnosed pathology. The interviews were all reviewed by qualified doctors so that symptoms could be accounted for and assessed further as appropriate. The face-to-face interview was supplemented by a semi-structured review of the participant's primary care notes. In this way, a complete picture of the participant's current physical health could be recorded.

Participants were asked what medication they were currently taking, and this was confirmed using primary care records.

3.6.7 Current mental ill health

In the urban sample, the initial research interview was conducted by either trained research assistants, or intellectual disabilities nurses with additional training with respect to the research project. They did not necessarily have additional training in mental health. All participants were therefore screened using the PAS-ADD Checklist (Moss et al. 1998). This is a screening instrument

that was purpose designed to help carers recognise potential mental ill health in the people with intellectual disabilities that they support. The instrument's properties including validity in relation to clinical opinion by a consultant psychiatrist have been demonstrated using a clinical sample (Moss et.al 1998). However, using the original threshold scores, the PAS-ADD was found only to have a sensitivity of 66% in a sample of people with intellectual disabilities referred to specialist mental health services (Sturmey et al. 2005). This was not deemed sufficiently sensitive for this study. Using Receiver Operating Characteristic analyses, Simpson (1999) determined that when the person's main carer completed the Checklist, if a score of just two positive items on the Checklist was used, the PAS-ADD had a 100% sensitivity to detect participants meeting the criteria for an ICD-10 diagnosis of mental ill health. Using this cut-off point, there was a false positive rate of 58%. Higher thresholds had lower rates of false positives, but also had reduced sensitivity. Because the aim of this study was to identify all cases of mental ill health, a cut off score of two was therefore chosen.

In addition, based on the original work by Moss et al. (1998), Simpson (1999) and a pilot study by the authors of Cooper et al. (2007c), it was not felt that the original PAS-ADD was reliably able to identify all cases of mania or psychosis. Furthermore, there were some symptoms that were deemed of sufficient concern that they required further specialist assessment even if the threshold score of two was not reached (for example if the participant talked about suicide). Therefore an adapted version of the PAS-ADD was used in this study. It include a number of additional questions aimed at detecting mania and psychosis, and also added in a number of "high risk" symptoms that automatically necessitated referral for further psychiatric assessment.

All participants who were found by the adapted PAS-ADD to be at risk of mental ill health underwent comprehensive psychiatric assessment by a psychiatrist trained in the specialty of intellectual disabilities. In addition to clinical assessment including a full psychiatric history, the assessment included the Present Psychiatric State for Adults with Learning Disabilities (PPS-LD) (Cooper 1997). This is a semi-structured schedule that measures a range of psychopathology required for diagnoses using ICD-10-DCR, DSM-IV-TR, DC-LD (Diagnostic criteria for psychiatric disorders for use with adults with learning

disabilities/mental retardation) (Royal College of Psychiatrists 2001) and clinical criteria. Three further purpose designed questionnaires were used to identify ICD-10-DCR, DSM-IV-TR, DC-LD and clinical symptoms of autistic spectrum disorders (PDD questionnaire) (Glasgow U.C.E.D.D. 2002b), problem behaviours (Problem Behaviour Questionnaire) (Glasgow U.C.E.D.D. 2002c), and hyperkinetic disorders including ADHD (ADHD checklist) (Glasgow U.C.E.D.D. 2002a).

The assessment comprised face-to-face interview with the participant and a carer, and further information was also sought from other carers or family if this was required to complete the assessment. If psychiatric notes were available, these were reviewed. Following individual assessment, each participant was discussed at a team meeting so that a consultant psychiatrist consensus diagnosis could be reached.

There were a few minor differences with respect to the rural participants. First, all of the interviews were conducted by an intellectual disabilities psychiatrist rather than a research assistant or trained nurse. If a more detailed psychiatric assessment was required, it tended to follow on as part of the interview rather than as a separate assessment. Second, ethical permission was not sought to review participant's psychiatric case notes and so this did not take place. In practice, if a participant was known to the local psychiatric services, there was a record of this in the participant's primary care notes, and these were reviewed as part of the research process.

3.6.8 Lifestyle factors and health prevention

Participants were asked about smoking habits, how much alcohol they drank in an average week, and whether or not they were currently using illegal substances. Eligible participants were asked when they had last been screened for cervical and/or breast cancer, and this was confirmed using primary care records.

3.6.9 Contact with primary and secondary healthcare services

Participants and their carers were asked to estimate how many times they had had contact with primary or secondary care in the 2 year time period prior to the interview. This included contact with General Practitioners (GPs), practice nurses and “other doctors” (in which case they were asked to specify the specialty). In addition, data were collected from primary care records on the number of contacts that each participant had had with their GP and Practice Nurse in the last 12 months; the number of contacts with secondary or tertiary care in the last 2 years; the number of contacts with emergency services (including out-of-hours GP services and NHS 24 direct telephone advisory service) in the last 12 months; the number of attendances to Accident and Emergency departments; and the number of hospital admissions in the last 12 months.

3.6.10 Contact with other services

Participants and their carers were asked to estimate how many times they had had contact with a range of other services in the 2 year time period prior to the interview. These services included: dietetics, speech and language therapy, podiatry, psychology, specialist intellectual disabilities nursing, occupational therapy, physiotherapy, epilepsy specialist nursing, advocacy, social services, care managers, optician services and dental services.

(A care manager is the individual designated to coordinate and arrange funding for the services and support that people with intellectual disabilities receive.)

3.6.11 Daytime opportunities including employment

Participants and carers were asked about the daytime opportunities that they usually engaged in. Using a purpose designed semi-structured questionnaire, they were asked to estimate the average number of hours that were spent each week in a range of opportunities including employment (paid, supported and voluntary), college attendance, and resource centre attendance. They were then asked how many days in the 2 years prior to the interview the participant had

spent on holiday (with and without family), and also how many days of respite care they had received.

(In the UK, respite care typically consists of supported group accommodation that people with intellectual disabilities can access for one or two weeks at a time and that provides respite for their regular carers.)

3.6.12 Use of community facilities

Participants were asked about frequency of use of a number of community facilities (shops, cafés and cinemas).

Questions were taken from the British Institute of Learning Disabilities (BILD) Life Experiences Checklist (Ager 1998). The BILD Life Experiences Checklist was developed “as a means of gauging for any individual the extent to which they enjoy experiences common to many other members of the population” (page 9, Ager 1998). The full questionnaire includes questions relating to the home environment, leisure and physical access to the environment, the quality of personal relationships, choice and freedom, and other opportunities within and outside the home. The author suggests that it is used as a tool to help assess the quality of intellectual disabilities services, to help plan daytime activities for people with intellectual disabilities and to help staff training and increase their understanding of normalisation.

The tool has been criticized on a number of grounds, both methodological and theoretical (Goble 2000). In particular, the BILD Life Experiences Checklist assumes that because a person with intellectual disabilities has the opportunity to participate in activities available to the general population, this must be positive. It is assumed that the greater the number of activities and experiences, the better. In reality, an individual with intellectual disabilities may be obliged to participate in a busy programme of activities whether or not they actually enjoy it; and it is hard to know how this objective checklist actually relates to the person’s experience and quality of life. Nevertheless, the full checklist provides interesting and useful information about the lives of people with intellectual disabilities, and it is not dissimilar to other research instruments in this area (for example the survey by Emerson et al. 2005).

3.6.13 Contact with others

Questions relating to contact with others were taken from the Interview Measure of Social Relationships (IMSR). The IMSR was first described and evaluated by Brugha et al. (1987). In this original study, it was used to assess the size and density of the primary social network (built up from the core group of relationships held by an individual), contacts with acquaintances and other less important relationships, the quality of the relationships held, and how the individual accesses support in times of need, in a sample of people with mental ill health. The IMSR has subsequently been used in a fairly small number of studies looking at mental ill health, but has not been studied either in the general population or the population with intellectual disabilities and there is therefore no reference range of what “normal” network density, number of contacts with others or quality of relationships might be. In addition, the original methodology and way of calculating network density as described by Brugha et al. was extremely complex, and it is hard to know how data relates to social networks and social support. However, there are a number of advantages of using the IMSR. First, it was specifically developed as a brief interview schedule with large scale epidemiological and social studies in mind. Second, Brugha et al. established that it has good acceptability to participants from a wide range of backgrounds. Third, it aims to collect clear cut data about well defined behaviours and relationships over discrete time periods. Because it collects concrete and unambiguous data about social relationships, it is well suited to studies that rely on information from participants with intellectual disabilities, who are less likely to have the ability to describe complex cognitions and social experiences. For participants with severe intellectual impairment, data can be collected from informants.

In this study, in order to keep the interview as brief as possible, the IMSR was modified so that only the questions about social contact and the quality of relationships were used. Using this modified IMSR, participants and their carers were asked if they had had any contact with people in a range of different situations in the 7 days prior to the interview. The different situations were as follows: at home (excluding support services), with relatives that they did not live with, at work (or in a resource centre/at college), with friends, in a faith gathering and with other local acquaintances.

3.6.14 Quality of relationships

A total of 9 questions from the IMSR were asked about the quality of the relationships that participants held. The questions asked whether the participant had close and meaningful relationships, whether they experienced conflict within their relationships, and whether the participant shared meaningful experiences within their social relationships.

3.6.15 The experience of living in a rural area

A purpose designed questionnaire was developed to look at the experience of people with intellectual disabilities living in rural areas. A range of questions were asked to ascertain whether participants were able to benefit from commonly perceived advantages and disadvantages of rural life. This part of the interview schedule was only used with rural participants.

At the end of the interview, there was an open discussion with rural participants and the person supporting them at interview about the perceived advantages and disadvantages of rural life. Notes were taken and salient quotations transcribed verbatim. These were then transferred into an Excel spreadsheet and the student looked through to identify themes and ideas to guide a preliminary exploration of the experience of people with intellectual disabilities living in rural areas.

3.7 Statistical analysis and power calculation

3.7.1 Statistical analysis

All data were analysed using the Statistical Package for the Social Sciences version 15 for Windows. The data were analysed in two ways: first by direct comparison, and second using binary logistic regression.

Direct comparison between participants and non-participants, and between rural and urban participants was made using Pearson Chi-square (X^2), Fisher's exact, independent t-test and Mann-Whitney U tests. All outliers were removed prior to statistical analysis, and all relevant tests were 2-tailed. Because of the large difference between the rural and urban sample sizes, particular care was taken to ensure that parametric tests were only used when this was appropriate (i.e. the data from both samples were normally distributed, and the variances did not differ significantly using Levene's Test for Equality of Variances).

3.7.2 Regression modelling

For most measures, the data were then analysed by setting up a series of backward conditional binary logistic regression models. For each measure (the dependent variable), the model was set up using a number of independent variables including rurality.

An example is used to illustrate this further, using the dependent variable of clinical mental ill health. This is a dependent variable with a binary outcome; mental ill health is either present or absent. Whether or not each participant has mental ill health depends on many factors, and may be influenced by independent variables such as gender, level of intellectual disabilities, and co-morbid physical illness such as epilepsy. This study hypothesised that mental ill health was also influenced by rurality.

A binary logistic regression model was therefore set up by SPSS for the binary dependent outcome of mental ill health. All of the factors that were thought to influence mental ill health (including rurality) were entered as independent variables. In this study a backwards stepwise model was used; likelihood ratio

tests were used to determine statistical significance for removal of each factor. This was set at $P = 0.05$. In other words, at each step of analysis, the independent variable that was found to be the least correlated (using the partial correlation) with mental ill health was removed if the correlation was less significant than $P = 0.05$. The process was repeated until all of the remaining independent variables had a significant association with mental ill health.

In this study, a number of independent variables were selected prior to data analysis. With a few modifications as described in accompanying text, these were used as independent variables for all regression models. The variables were selected based on previous knowledge of research in the fields of mental health, intellectual disabilities, (rural) access and social exclusion. In addition, resource centre attendance was included as a variable because preliminary analysis showed that this was a source of sample bias in the rural sample.

The categorical variables were as follows:

- Age (by decade)
- Gender (male/female)
- Level of disabilities (mild/moderate/severe/profound)
- Rurality (urban/rural)
- Resource centre attendance
- Deprivation index (SIMD) (by deciles)
- Mental ill health (presence/absence of any clinical diagnosis)
- Type of accommodation (With family carer/independent of support/with paid carer/congregate care setting)
- Epilepsy
- Down's syndrome
- Urinary continence
- Visual impairment
- Hearing impairment
- Mobility (fully mobile/not fully mobile)

There are a number of advantages of using logistic regression models to analyse the data. First, because regression is such a powerful statistical test, and because it is able to use so much of the data available, it is able to provide

powerful results with relatively small numbers. Second, using logistic regression allows adjustment between heterogeneous samples. The rural and urban samples might have differed with respect to a number of variables, and including these into regression models has the effect of adjusting for potential confounders.

Adjustment for multiple comparisons was not considered appropriate; although several variables were entered into the regression models, only rurality was interpreted and discussed. (For further discussion of the Bonferroni adjustment see Perneger (1998).)

Finally, SPSS version 15 takes sample size into consideration, and so was able to automatically compensate for the unequal sample sizes of the rural and urban samples in the regression models.

3.7.3 Pre-study power calculation

Using primary care sources, it was determined that there were 135 adults living in the rural area under study (ISD Scotland 2010). However, there is no previous research involving adults with intellectual disabilities living in rural areas, and so there was no data to inform potential recruitment rates and hence the number of adults that might participate in the study. In addition, there is no previous research that might suggest expected differences between the rural and urban samples. A pre-study power calculation showed that if the rural and urban samples were compared using the Pearson Chi-square test, with a rural sample of 50 and if $\alpha=0.05$, the study would have a power of at least 80% to detect a minimum difference of 20%. The Pearson Chi-squared is the least powerful statistical test that was used to compare the rural urban samples. Other tests, in particular binary logistic regression, are much more powerful. In discussion with the Robertson Department of Statistics at the University of Glasgow, it would be very difficult to conduct a pre-study power calculation for binary logistic regression, but a sample of 50 would easily provide adequate power, and smaller samples would still have sufficient power to permit comparison. Therefore the student set out with the prospect of recruiting around 50 participants to the rural sample. But given the lack of strong evidence to inform this number, and as this was an exploratory study, the aim was in fact to recruit as many eligible participants as possible.

Chapter 4: Results

4.1 Details of rural and urban samples

4.1.1 Description of samples

The number of participants in the rural sample was 39. A further 2 potential participants were interviewed, but one did not meet the study criteria (as they did not have intellectual disabilities) and for the other, consent to participate from the next-of-kin was withdrawn.

The number of participants in the original urban sample was 651; as described previously, the 18 participants who lived in accessible small towns or accessible rural areas were removed. Hence the urban sample used for this study comprised 633 participants.

The total number of participants (urban and rural samples) was 672.

4.1.2 Response rate

Using the Quality and Outcomes Framework (ISD Scotland 2010), primary care medical practices from the rural area provided a list of the gender and date of birth of all adults with intellectual disabilities in their practice; except for 2 small practices who did not provide the gender and date of birth, but indicated that there were just 2 people on the register for each practice. Including the 4 people for whom more detailed data were not available, the registers included a total of 135 people, 39 of whom participated in the study. This gives a response rate of 28.9%.

The urban response rate was 69.9%. Details of how this figure was calculated are described in the discussion section.

4.1.3 Representativeness of samples

4.1.3.1 Rural sample

Gender

The proportion of participating and non-participating males and females was compared using a Pearson Chi-square test. There was no difference in the gender ratio between participants and non-participants ($X^2 = 2.518$, $df = 1$, no cells < 5 , $P = 0.113$). (Table 17)

Gender	Participants N = 39	Non-participants N = 92
Male (n = 60)	22 (56.4%)	38 (41.3%)
Female (n = 71)	17 (43.6%)	54 (58.7%)

Table 17 Gender of rural participants and non-participants

Age

The age distribution of participants and non-participants is given in table 18. Age was calculated from the date that medical practices provided information rather than the date of participation. The age of participants and non-participants was not significantly different. (Independent t-test, $P = 0.918$, 95% CI = -5.3 to 5.8.).

Variable	Participants N = 39	Non-participants N = 92
Mean age	44 years, 3 months	44 y, 0 m
Standard deviation of age	12.21	15.67
Median age	42 y, 3 m	42 y, 3 m
Age range	24 y, 4 m to 70 y, 4 m	19 y, 6 m to 83 y, 11 m

Table 18 Age of rural participants and non-participants

Area of residency

The rural sample was drawn from in and around 3 small towns on the West Coast of Scotland. The total population in each of the three towns and surrounding area was ascertained from the 2001 Census (Office for National Statistics 2001). It can be seen that the balance of participants between the three different areas is representative of the total population in each area. In addition, information from primary care registers was used to calculate the proportion of adults with intellectual disabilities who participated from practices in each of the three areas. The proportion of participants was similar in each area. (Tables 19 and 20)

Area of residency	Number of participants (%) N = 39 (100%)	Total population in area under study (%) N = 33,394 (100%)
Oban area	20 (51.3%)	15,409 (46.1%)
Lochgilphead area	11 (28.2%)	10,273 (30.8%)
Campbeltown area	8 (20.5%)	7,712 (23.1%)

Table 19 Area of residency of rural participants (a)

Area of residency	Number of participants/total number of people on primary care registers (%)
Oban area	20/69 (29.0%)
Lochgilphead area	9/30 (30.0%)
Campbeltown area	10/36 (27.8%)

Table 20 Area of residency of rural participants (b)

Method of recruitment

Participants were recruited from a number of sources, and this could have lead to systemic bias. In keeping with ethical requirements, people helping in the recruitment process were not supposed to know which of the people they were supported had agreed to participate in the study. In practical terms, this requirement was impossible to maintain, primarily because the same people involved in the recruitment process were also involved in supporting participants at interview. In addition, because of difficulties with recruitment, the student sought frequent feedback as to which recruitment methods were most effective. It was therefore possible to determine the probable source of recruitment for all but 3 of the rural participants (table 21).

Probable source of recruitment	Number of participants (%) N = 39 (100%)
Support agency	8 (20.5%)
Resource centre	11 (28.2%)
Word of mouth	10 (25.6%)
Service user support group	4 (10.3%)
General Practitioner (GP)	2 (5.1%)
Supporting Employment Agency	1 (2.6%)
Unknown	3 (7.7%)

Table 21 Probable source of recruitment for rural participants

As the largest source of recruitment, resource centre numbers were analysed as a potential source of bias. In total, there were 77 resource centre places in 3 resource centres available to the 135 adults with intellectual disabilities in the area under study. All three resource centres were approached several times as part of the recruitment campaign. All 77 resource centre attendees should therefore have been offered the opportunity to participate in the study.

However, only 11 participants were ultimately recruited via resource centres. This works out as just 11/77 (14.3%) of the potential participants. Therefore, although the largest source of recruitment in the study, it does not appear to have been a particularly effective source of recruitment.

Although a relatively small number of participants were recruited through resource centres, a large number of participants attended resource centres. (30/39 (76.9%) of rural participants attended a resource centre, compared with 47/96 (49.0%) of rural non-participants. This is significantly higher; $X^2 = 7.75$, $df = 1$, no cells < 5 , $P < 0.001$.) The significance of this will be discussed further later in the thesis. Data analysis has adjusted for this bias by including resource centre attendance in regression models.

4.1.3.2 Urban sample

There was no statistically significant difference between the age, gender, level of intellectual disabilities, type of accommodation/support and prevalence of mental ill health of participants and non-participants (Smiley et.al 2007).

4.2 Demographics and details of intellectual disabilities

4.2.1 Age

The mean age of the rural sample was 43 years and 1 month. This is not significantly different from the age of the urban sample. (Mean urban age = 46 years and 2 months. Independent t-test, $P = 0.19$, 95% CI of the difference = -1.5 to 7.6. The urban distribution showed a degree of kurtosis (kurtosis = -0.710, SE kurtosis = 0.194), but the variances of the rural and urban samples were not significantly different. (Table 22)

	Rural N = 39	Urban N = 633
Mean age	43 y, 1 m	46 y, 2 m
Standard deviation of age	12.1	14.0
Median age	40 y	46 y, 4 m
Age range	23 y, 5 m to 69 y, 7 m	18 y, 2 m to 80 y, 9 m

Table 22 Age distribution of rural and urban participants

The mean age of the total sample was 45 years and 11 months, with an age range from 18 years and 2 months to 80 years and 9 months.

4.2.2 Gender

More males than females participated in both the urban and rural samples. The male:female ratio of the rural sample was 1.29:1. This compares with an urban ratio of 1.20:1. This is not significantly different ($X^2 = 0.054$, $df = 1$, no cells < 5, $P = 0.816$). (Table 23)

	Rural N = 39	Urban N = 633
Number of male participants	22	345
Number of female participants	17	288
Ratio of male to female participants	1.29:1	1.20:1

Table 23 Gender of rural and urban participants

Of the total sample, 367 (54.6%) participants were male, and 305 (45.4%) were female.

4.2.3 Measurement of rurality

Table 24 shows rurality for the two samples.

Urban Rural Classification	Rural N = 39	Urban N = 633
Large urban areas	0 (0%)	588 (92.9%)
Other urban areas	0 (0%)	45 (7.1%)
Accessible small towns	0 (0%)	0 (0%)
Accessible rural areas	0 (0%)	0 (0%)
Remote small towns	0 (0%)	0 (0%)
Remote rural areas	0 (0%)	0 (0%)
Very remote small towns	18 (46.2%)	0 (0%)
Very remote rural areas	21 (53.8%)	0 (0%)

Table 24 Rurality by postcode of rural and urban participants

4.2.4 Marital status

Each participant was identified as *either* married/having a live-in partner *or* single/divorced/separated/widowed. Just 3 (7.7%) of the rural participants were either married or had a live-in-partner. This was significantly higher than in the urban sample (N = 9 (1.5%), Fisher's exact test, $P = 0.028$).

4.2.5 Ethnicity

All of the participants in the rural sample were Caucasian. Only 15 (2.4%) of participants in the urban sample were non-Caucasian. This is not significantly different.

4.2.6 First language

All of the rural participants named English as their first language. This information was not available for the urban sample.

4.2.7 Level of intellectual disabilities

The rural and urban samples did not significantly differ with respect to the level of intellectual disabilities ($\chi^2 = 1.925$, $df = 3$, no cells < 5 , $P = 0.588$). (Table 25) When the total sample was considered, the levels of intellectual disabilities were: mild = 267 (37.9%), moderate = 147 (21.9%), severe = 126 (18.8%), and profound = 132 (19.6%).

Level of intellectual disabilities	Rural N =39	Urban N = 633
Mild	19 (48.7%)	248 (39.2%)
Moderate	7 (17.9%)	140 (22.1%)
Severe	5 (12.8%)	121 (19.1%)
Profound	8 (20.5%)	124 (19.6%)

Table 25 Level of intellectual disabilities

4.2.8 Cause of intellectual disabilities

Data was aggregated: this is partly because of small numbers in the rural sample, but also because of the need to maintain anonymity. (Table 26)

Cause of intellectual disabilities	Rural N = 39	Urban N = 633
Unknown	12 (30.8%)	318 (50.2%)
Down's Syndrome	9 (23.1%)	127 (20.1%)
Birth Injury	7 (17.9%)	64 (10.1%)
Other	11 (28.2%)	124 (19.6%)

Table 26 Cause of intellectual disabilities

If all 4 categories of cause of intellectual disabilities are considered together, there is no significant difference in the cause of intellectual disabilities between the rural and urban samples ($\chi^2 = 6.494$, $df = 3$, 1 cell (12.5% of total) had an expected count of 4.12, $P = 0.090$). However, more participants in the rural sample had a known cause for their intellectual disabilities than the urban sample ($\chi^2 = 5.571$, $df = 1$, no cells < 5 , $P = 0.018$).

4.2.9 Deprivation index

Both the national rank and deciles were used to analyse and compare deprivation in the rural and urban samples. The urban samples showed that the majority of participants lived in more deprived areas, with a median deciles of 3 (i.e. in the third most deprived deciles of the population by postcode). The distribution was not normal, but heavily skewed (and with a marked kurtosis) towards the most deprived deciles. This compares with the rural sample, in which the median deciles was 5. The distribution in the rural sample was normal, but none of the participants lived in either the most or the least deprived deciles. Using Mann Whitney U to compare the actual ranking for each participants, the urban sample lived in significantly more deprived areas than

the rural sample. (Mann Whitney $U = 7826$, $Z = -3.675$, $P \leq 0.001$.) (Tables 27 and 28)

	Rural N = 39	Urban N = 633
SIMD median	5	3
Range	2 to 8	1 to 10
Inter-quartile range	4 to 7	1 to 6

Table 27 Scottish Index of Multiple Deprivation (a)

Scottish Index of Multiple Deprivation deciles	Rural N = 39	Urban N = 618*
1 st (i.e. most deprived)	0 (0%)	172 (27.8%)
2 nd	6 (15.4%)	98 (15.9%)
3 rd	1 (2.6%)	83 (13.4%)
4 th	5 (12.8%)	79 (12.8%)
5 th	10 (25.6%)	20 (3.2%)
6 th	6 (15.4%)	44 (7.1%)
7 th	9 (23.1%)	27 (4.4%)
8 th	2 (5.1%)	24 (3.9%)
9 th	0 (0%)	42 (6.8%)
10 th	0 (0%)	29 (4.7%)

Table 28 Scottish Index of Multiple Deprivation (b)

*missing data = 15 (postcode data missing from lookup table)

4.2.10 Type of accommodation

Participants in the rural sample lived in a range of types of accommodation comprising; the parental home, other family carer home, independent (with or without spouse or partner), supported group living, supported individual living and residential care. Participants in the urban samples lived the same range of accommodation types. Additionally, a small number of urban participants lived in a nursing home ($n = 4$, 0.6%), in NHS accommodation ($n = 5$, 0.8%) or in a family placement ($n = 1$, 0.1%).

Because of small numbers in the rural sample, data were aggregated into the following categories: family home, independent living, supported group living (including NHS accommodation or residential care) and individual supported living. Placement with a family home, and nursing home were classified as missing data, as it is not clear under which category they would lie. The number of participants in each category type is shown in table 29.

Type of accommodation	Rural N = 39	Urban N = 628
Family home	9 (23.1%)	235 (37.1%)
Independent	12 (30.8%)	46 (7.3%)
Group living	9 (23.1%)	258 (41.1%)
Individual supported	9 (23.1%)	89 (14.2%)

Table 29 Type of accommodation

The rural and urban samples are significantly different with respect to accommodation type ($\chi^2 = 30.231$, $df = 3$, 1 cell (12.5% of total) had an expected count of 3.39, $P \leq 0.001$.) An alternative way of analysing the data is to compare family accommodation vs. independent/individual supported vs. group

accommodation. The difference remains significant ($\chi^2 = 21.707$, $df = 2$, no cells < 5 , $P \leq 0.001$).

4.2.11 Geographic mobility

Rural participants were asked where they were born and to judge whether this was rural or urban. The majority were born in a rural area, and over half were born in Argyll and Bute. (Tables 30 and 31)

Place of birth	Number of participants (%) N = 39
Argyll and Bute	24 (61.5%)
Glasgow (Greater Glasgow and Clyde)	3 (7.7%)
Other Scotland	4 (10.3%)
Other UK	4 (10.3%)
Other	3 (7.7%)
Unknown	1 (2.6%)

Table 30 Place of birth of rural participants

Place of birth	Number of participants (%) N = 39
Rural	28 (71.8%)
Urban	8 (20.5%)
Not sure	3 (7.7%)

Table 31 Place of birth of rural participants; rural vs. urban

34 (87.2%) rural participants had left their family home, and all 34 had started independent adult life in a rural area in Argyll and Bute.

Given these findings, it is reasonable to describe the rural sample as “rural” rather than predominantly made up of incomers to the rural countryside.

4.2.11 Summary of demographics

In summary, the demographics and level and cause of intellectual disabilities in the rural and urban samples are not significantly different, and in most cases are extremely similar.

4.3 Mental ill health

4.3.1 Clinical diagnoses

4.3.1.1 *Clinical diagnoses; direct comparison*

The total number of clinical psychiatric diagnoses given to each participant is given in table 32. Comparing whether the participant had ANY clinical diagnosis or not, there was no difference between the rural and the urban samples ($X^2 = 2.245$, $df = 1$, no cells < 5 , $P = 0.134$) However, if the participant had been identified as having one or more clinical diagnoses, they were more likely to have been given multiple diagnoses in the urban samples (Mann-Whitney $U = 1838$, $Z = -2.245$, $P = 0.025$).

Total number of clinical psychiatric diagnoses	Rural N = 39	Urban N = 633
None	19 (48.7%)	385 (60.8%)
One	17 (43.6%)	152 (24%)
Two	3 (7.7%)	60 (9.5%)
More than two	0 (0%)	36 (5.7%)

Table 32 Mental ill health; total number of clinical diagnoses

Because of small numbers in the rural sample (and also to maintain anonymity) the clinical diagnoses were grouped into the following categories:

- Neurotic disorders (i.e. ICD-10 categories 30-48)
- Problem behaviours
- Pervasive developmental disorders (including autism)
- Other disorders

There were no significant differences between the proportion of people in the rural and urban samples for any of the types of disorder, and the numbers are remarkably similar. (Table 33)

Type of disorder	Rural N = 39	Urban N = 633
(One or more) neurotic disorder	7 (17.9%)	89 (14.1%)
(One or more) problem behaviour	6 (15.3%)	90 (14.2%)
Pervasive developmental disorder	2 (5.1%)	48 (7.6%)

Table 33 Mental ill health; type of clinical diagnoses

4.3.1.2 Clinical diagnoses; multiple regression

Binary logistic regression was used to identify explanatory variables associated with a clinical diagnosis of mental ill health. The use of logistic regression is discussed further in the methods chapter. Variables entered into the model were:

- Age
- Gender
- Level of disabilities
- Urban/rural
- Resource centre attendance
- Deprivation index (SIMD)
- Type of accommodation
- Epilepsy
- Down's syndrome
- Urinary continence
- Visual impairment
- Hearing impairment
- Mobility

Factors retained within the model as independently associated with a diagnosis of mental ill health are given in table 34. All other variables, including rurality were not significantly associated with mental ill health.

Independent variables		Odds ratio	95% Confidence Interval	β	Significance (p)
Level of intellectual disabilities	Mild	Reference			≤ 0.001
	Moderate	1.97	1.25 – 3.11	0.68	0.003
	Severe	1.85	1.13 – 3.02	0.61	0.015
	Profound	3.16	1.87 - 5.33	1.15	≤ 0.001
Type of accommodation	With family carer	Reference			≤ 0.001
	Independent of support	2.60	1.35 – 5.03	0.96	0.004
	With paid carer	2.95	1.77 – 4.93	1.08	≤ 0.001
	Congregate care setting	2.48	1.67 - 3.68	0.91	≤ 0.001
Lack of full mobility	(Full mobility as reference)	0.37	0.24 – 0.58	-0.99	≤ 0.001
Down's syndrome	(Not Down's syndrome as reference)	0.57	0.37 – 0.90	-0.56	0.015

Table 34 Associations with clinical mental ill health; regression model

4.3.2 DC-LD diagnoses

The number of participants with one or more DC-LD diagnoses at each level is given in table 35. There were no significant differences between the rural and urban samples for any of the categories, and the proportions are remarkably similar.

Level of DC-LD diagnoses	Rural sample N = 39	Urban N = 633
Level A (Developmental disorders)	1 (2.6%)	43 (6.8%)
Level B (Psychiatric illness)	9 (23.1%)	147 (23.2%)
Level C (Personality disorder)	1 (2.6%)	7 (1.1%)
Level D (Problem behaviours)	5 (12.8%)	82 (13.0%)
Level E (Other disorders)	0 (0%)	15 (2.4%)
ANY DC-LD disorder	16 (41.0%)	235 (37.1%)

Table 35 Mental ill health; DC-LD diagnoses

4.3.3 ICD-10 diagnoses

16 (41.0%) of rural participants had one or more ICD-10 diagnoses compared with 219 (34.6%) of urban participants. This is not significantly different ($X^2 = 0.668$, $df = 1$, no cells < 5 , $P = 0.414$).

4.3.4 DSM-IV diagnoses

12 (30.8%) of rural participants had a DSM-IV diagnosis. This compares with 164 (25.9%) of urban participants and is not significantly different ($X^2 = 0.449$, $df = 1$, no cells < 5 , $P = 0.503$).

4.3.5 Psychiatric contact

In the rural sample, 31 (79.5%) had not been in contact with psychiatric services in the 2 year period preceding the interview. 8 (20.5%) had at least one contact. This compares with the urban sample, in which 505 (79.8%) had not been in contact with psychiatric services and 128 (20.2%) had had at least one contact. This is not significantly different.

In the urban sample, 146 (23.1%) were referred to psychiatric services as a consequence of the interview. This is higher than the 4 people (10.3%) that were referred from the rural sample, but this difference does not reach significance ($\chi^2 = 3.476$, $df = 1$, no cells < 5 , $P = 0.062$).

4.3.6 Summary of mental health

The prevalence of mental illness was not significantly different between the rural and urban samples. This held whether the diagnosis was made clinically, or using the classification systems ICD-10, DSM-IV and DC-LD. Psychiatric contact was also the same in the two samples.

4.4 Physical health, physical co-morbidities, lifestyle factors and health prevention

4.4.1 Physical (medical) conditions

Participants in the rural and urban samples had a current history of a wide range of physical complaints affecting all parts of the body. The four most common conditions in the rural sample were: epilepsy, hypertension, hypercholesterolaemia and cataract. The prevalence of these four conditions was compared with that in urban sample. (Table 36)

Medical condition	Rural N = 39	Urban N = 633	Statistical significance
Epilepsy	11 (28.2%)	207 (32.7%)	$\chi^2 = 0.445$, $df = 1$, no cells < 5 , $P = 0.505$
Hypertension	7 (17.9%)	52 (8.2%)	Fisher's exact test, $P = 0.071$
Hypercholesterolaemia	5 (12.8%)	31 (4.9%)	Fisher's exact test, $P = 0.050$
Cataract	5 (12.8%)	38 (6.0%)	Fisher's exact test, $P = 0.095$

Table 36 Prevalence of the four most common physical ill health conditions

It was noticed that a high proportion of participants in both the rural and urban samples had a history of fracture (using the full sample of 690, $n = 128$ (18.6%)). The proportion of participants with a history of one or more fractures in the rural and urban sample did not differ significantly ($\chi^2 = 2.430$, $df = 1$, no cells < 5 , $P = 0.119$).

4.4.2 Medication

4.4.2.1 Number of drugs

Participants in the rural and urban samples were on a similar total number of prescribed medications. (Comparing the total number of drugs that each participant was currently taking, Mann-Whitney $U = 11060$, $Z = -1.108$, $P = 0.268$.) A similar proportion in the rural and urban samples were not using any prescribed medication ($X^2 = 3.324$, $df = 1$, no cells < 5 , $P = 0.068$). (Table 37)

Current prescribed medication	Rural N = 39	Urban N = 633
Mean number of drugs	3.0	2.54
Median number of drugs	2.0	2.0
Range	0 to 11	0 to 11
Proportion of sample not taking any prescribed medication	6 (15.4%)	183 (28.9%)

Table 37 Number of prescribed medications

4.4.2.2 Type of medication

Using codes from the British National Formulary (BNF), medication was divided into the following categories according to the primary function of the drug.

- GI
- Cardiac
- Respiratory
- CNS
- Analgesic or anti-inflammatory
- Anti-epileptic drugs
- Antibiotics
- Other drugs

The number of drugs in each category that each participant was taking was then compared between the rural and urban samples. The number of drugs in each category was similar in the rural and urban samples, with the exception of the following:

Participants in the rural sample took an average of 0.59 cardiac drugs each, compared with 0.21 in the urban sample. This is significantly different (Mann-Whitney $U = 10244.5$, $Z = -3.122$, $P = 0.002$). In line with this, participants in the rural sample were significantly more likely to be taking any cardiac medication. (11 (28.2%) rural participants, compared with 72 (11.4%) urban participants. Fisher's exact test, $P = 0.005$.)

Participants in the rural sample were also taking a greater mean number of analgesic or anti-inflammatory drugs than the urban sample. (Mann-Whitney $U = 10663$, $Z = -2.257$, $P = 0.024$.) In line with this, participants in the rural sample were significantly more likely to be taking any analgesic or anti-inflammatory drugs. (11 (28.2%) of the rural sample were on analgesic or anti-inflammatory drugs compared with 95 (15.0%) of the urban sample. $X^2 = 4.816$, $df = 1$, no cells < 5 , $P = 0.028$.)

4.4.3 Physical co-morbidities and disabilities

4.4.3.1 Visual impairment

Rates of visual impairment were high in both the rural (30.8%, $n = 12$) and urban sample (46.1%, $n = 292$). However, these were not significantly different ($X^2 = 3.499$, $df = 1$, no cells < 5 , $P = 0.061$).

In the rural sample, only 1 person had never had their vision tested. 5 people (12.8%) were deemed to be overdue a sight test and were advised accordingly. (This information was not available for the urban sample.)

4.4.3.2 Hearing impairment

In the rural sample, only 5 people (12.8%) had a known hearing impairment. This compares with 189 (29.9%) in the urban sample. This is significantly lower ($\chi^2 = 5.193$, $df = 1$, no cells < 5 , $P = 0.023$).

A large proportion of the rural participants did not think that they had ever had their hearing tested. (Table 38) All urban participants had been offered a hearing test two years previously as part of the original urban study design.

When did the participant recall last having their hearing tested?	Number (%)
In the last year	5 (12.8%)
In the last 5 years	2 (5.1%)
At school	9 (23.1%)
Never	22 (56.4%)
Unsure	1 (2.6%)

Table 38 Recency of last hearing test in rural participants

4.4.3.3 Continence

26 (66.7%) of the rural sample were fully continent of urine and 35 (89.7%) had full bowel continence. This was not significantly different from the urban sample. (Full urinary continence, $n = 425$ (67.1%), full bowel continence, $n = 488$ (77.1%), $\chi^2 = 0.003$, $df = 1$, no cells < 5 , $P = 0.958$.)

4.4.3.4 Mobility

Mobility was considered impaired if the participant had any difficulty at all with independent mobilisation. Using this definition, 11 (28.2%) of the rural sample had impaired mobility. This is not significantly different from the urban sample ($n = 137$ (21.6%)). A similar proportion of the rural and urban sample required special footwear or orthosis (rural, $n = 4$ (10.3%); urban, $n = 112$ (18.5%)).

6 (15.4%) of the rural sample had a severe physical disability (as defined by either disabled in all 4 of their limbs, spastic quadriplegia, or requiring a moulded seat). This is significantly different from the urban sample ($n = 30$ (4.7%), Fisher's exact test, $P = 0.014$).

4.4.4 Lifestyle factors and health prevention

4.4.4.1 Smoking

3 (7.7%) of the rural sample smoked, compared with 83 (13.1%) of the urban sample. This was not significantly different ($\chi^2 = 0.952$, $df = 1$, no cells < 0 , $P = 0.329$).

4.4.4.2 Alcohol

Urban participants were significantly more likely to report drinking alcohol each week than rural participants. (169 (26.7%) urban compared with 3 (7.7%) rural participants; $\chi^2 = 7.015$, $df = 1$, no cells < 5 , $P = 0.008$.)

The three rural participants who drank alcohol all drank well within government guidelines (14 or fewer units of alcohol per week for females, and 21 or fewer units of alcohol per week for males.) Only 3 (0.46%) urban participants drank more than the recommended government guidelines. The vast majority of the urban participants who drank anything, took 4 or fewer units per week ($n = 139/169$ (82.2%)).

4.4.4.3 Recreational drugs

A single urban participant reported using recreational drugs (cannabis).

4.4.4.4 Screening

Cervical smears

All 3 (7.7%) people in the rural sample who were eligible for a cervical smear test were up to date with this.

In the rural sample, people were not considered to be eligible if they were not sexually active. However, the urban data simply categorised participants as “eligible” if they were female and within the age range of 25-64. The results were recorded as “in date” if a smear had been performed in the last 3 years, and “out of date” if a smear had not been performed in the last 3 years - whether or not the participant had actually required a smear. If the rural data is analysed in the same way, and assuming similar levels of sexual activity in the 2 groups, this is not significantly different (Fisher’s exact test, $P = 0.455$). (Table 39)

	Rural N = 15	Urban N = 224
In-date	3 (20%)	31 (13.8%)
Out of date	12 (80%)	193 (86.2%)

Table 39 Cervical smear testing in eligible participants

Mammograms

Only 7 (17.9%) of rural participants met eligibility criteria for having a mammogram. Of these, 5 (71.4%) were up to date, and 2 (28.6%) were not. In the urban sample, 36 (38.3%) of eligible participants were in date and 58 (51.7%) were out of date. This difference did not reach statistical significance (Fisher’s exact test, $P = 0.117$.)

4.4.5 Summary of physical health findings

In summary, the rural and urban samples were found to have very similar physical health, physical co-morbidities and lifestyle factors. Exceptions to this are that rural participants were more likely to have a diagnosis of hypertension and hypercholesterolemia, although this finding was not statistically significant with respect to hypercholesterolaemia.

In keeping with this, rural participants were more likely to be taking cardiac medication. They were also more likely to be taking analgesic or anti-inflammatory medication.

Rural participants were less likely to have a diagnosis of hearing impairment, and this may be because it has not been recognised.

Rural participants were less likely to drink *any* alcohol each week, but the proportion of participants in the rural and urban samples who drank within safe limits each week was not significantly different.

4.5 Access to services and daytime opportunities

In this study, access to healthcare and related services was measured by determining the number of contacts with each service over a given time period.

4.5.1 Contact with healthcare services

4.5.1.1 Contact with health services; direct comparison

This is summarised in table 40.

Contact with healthcare services	Rural N = 39	Urban N = 633	Statistical comparison
Number of contacts with General Practitioner in previous 12 months	Median = 4.5 Range = 0 to 13 IQR = 2 to 8.25	Median = 3 Range = 0 to 24 IQR range = 1 to 7	Mann Whitney U = 10017, Z = -1.60, P = 0.109
Number of contacts with practice nurse in previous 12 months	Median = 1 Range = 0 to 4 IQR range = 0.25 to 2	Median = 0 Range = 0 to 4 IQR range = 0 to 4	Mann Whitney U = 4741.5, Z = -4.079, P ≤ 0.001
Total number of contacts with primary care in previous 12 months	Median = 8 Range = 0 to 26 IQR range = 4 to 10.75	Median = 4 Range = 0 to 24 IQR range = 2 to 8	Mann-Whitney U = 7089.5, Z = -3.398, P = 0.001
Proportion of participants with at least one contact with secondary or tertiary care in previous 2 years	17 (43.6%)	137 (21.6%)	$\chi^2 = 10.017$, df = 1, no cells < 5, P = 0.002
Proportion of participants with one or more hospital admissions in previous 12 months	4(10.3%)	74 (11.7%)	Fisher's exact test, P = 1.000
Proportion of participants with one or more contacts with an emergency (out-of-hours) General Practitioner in previous 12 months	4 (10.3%)	128/609 (21.1%)	$\chi^2 = 2.424$, df = 1, no cells < 5, P = 0.119
Proportion of participants with one or more contacts with an Accident and Emergency department (A&E) in previous 12 months	8 (20.5%)	113/610 (18.5%)	$\chi^2 = 0.151$, df = 1, no cells < 5, P = 0.698

Table 40 Contact with healthcare services; direct comparison

Primary care

Rural participants had consulted their GP a median of 4.5 times in the previous 12 months (mean = 5.42, range = 0 to 13, IQR = 2 to 8.25). Urban participants had consulted their GP a median of 3 times in the previous 12 months (mean = 4.66, range = 0 to 24, IQR = 1 to 7). This is not significantly different (Mann-Whitney U = 10017, $Z = -1.600$, $P = 0.109$).

Rural participants had attended their practice nurse a median of 1 time in the previous 12 months (mean = 1.53, range = 0 to 4, IQR = 0.25 to 2). Urban participants had attended a median of 0 times (mean = 0.66, range = 0 to 4, IQR = 0 to 1). This is significantly higher (Mann-Whitney U = 4741.5, $Z = -4.079$, $P \leq 0.001$).

Adding the two together gives the total number of contacts with primary care: rural participants had had contact with primary care a median of 8 times in the previous 12 months (mean = 8.25, range = 0 to 26, IQR = 4 to 10.75). Urban participants had had contact a median of 4 times (mean = 5.4, range = 0 to 24, IQR = 2 to 8). This is significantly different (Mann-Whitney U = 7089.5, $Z = -3.398$, $P = 0.001$).

Secondary and tertiary care

Rural participants were significantly more likely to have had contact with secondary or tertiary care in the two years prior to the interview. (17 (43.6%) of rural participants reported contact with secondary care compared with 137 (21.6%) of urban participants. $X^2 = 10.017$, $df = 1$, no cells < 5 , $P = 0.002$. This data does not include contact with psychiatric services.)

The number of hospital admissions was not significantly different. (4 (10.3%) of rural participants had had one or more admissions in the previous year compared with 74 (11.7%) urban participants. Comparing the total number of admissions, Mann-Whitney U = 12167.0, $Z = -0.270$, $P = 0.787$.)

Emergency services

There was no significant difference in the number of contacts with an emergency (out-of-hours) GP between the rural and urban participants. (4/38 (10.3%) of rural participants and 128/609 (21.1%) of urban participants in the previous 12 months, $X^2 = 2.424$, $df = 1$, no cells < 5 , $P = 0.119$.)

There was no significant difference in the number of participants who had one or more contacts with A&E between the rural and urban participants. (8/38 (20.5%) of rural participants and 113/610 (18.5%) of urban participants) in the previous 12 months, $X^2 = 0.151$, $df = 1$, no cells < 5 , $P = 0.698$.)

4.5.1.2 Contact with health services: multiple regression

Binary logistic regression was used to identify explanatory variables associated with access to healthcare services. (Table 41)

As almost all participants had had contact with primary care in the previous year, “contact” was taken as 4 or more contacts with primary care in the previous year; 4 being the median number of contacts.

Rural participants remained significantly more likely to have had contact with primary care, secondary and tertiary care. There remained no association between rurality and use of emergency GP services and hospital admission. However, following binary logistic regression, rural participants were now found to be more likely to have attended A&E in the previous 12 months.

Table 41 Binary logistic regression model; associations with contact with healthcare services

Dependent variables	Independent variables	Odds ratio	95% Confidence Interval	β	P value
Contact with primary care	Rurality	4.03	1.60 – 10.17	1.39	0.003
	Severity of disability	Reference			0.001
	Mild				
	Moderate	0.63	0.39 – 1.02	-0.46	0.061
	Severe	0.53	0.32 – 0.88	-0.64	0.015
	Profound	0.30	0.17 – 0.54	-1.21	≤ 0.001
	Incontinence	2.83	1.81 – 4.41	1.04	≤ 0.001
	Mental ill health	1.83	1.26 – 2.66	0.61	0.001
	Epilepsy	1.53	1.04 – 2.25	0.42	0.033
	Accommodation type	Reference			0.001
Contact with secondary or tertiary care	With family carer				
	Independent of support	1.33	0.65 – 2.71	0.29	0.431
	With paid carer	1.79	1.03 – 3.09	0.58	0.038
	Congregate care setting	2.23	1.49 – 3.33	0.80	≤ 0.001
Contact with secondary or tertiary care	Rurality	2.75	1.40 – 5.39	1.01	0.003
	Incontinence	1.56	1.05 – 2.32	0.44	0.028
	Down's Syndrome	2.07	1.33 – 3.20	0.73	0.001

Contact with out-of-hours GP	Incontinence	1.76	1.16 – 2.67	0.56	0.008
	Epilepsy	1.77	1.17 – 2.67	0.57	0.007
Contact with A&E	Rurality	2.89	1.11 – 7.53	1.06	0.029
	Scottish Index of Multiple Deprivation*	*	*	*	*
	Hearing impairment	0.55	0.34 – 0.86	-0.61	0.010
	Epilepsy	1.61	1.04 – 2.48	0.47	0.034
	Down's Syndrome	0.50	0.27 – 0.95	-0.69	0.033
One or more hospital admission	Hearing impairment	0.54	0.33 – 0.90	-0.61	0.018
	Down's Syndrome	0.46	0.22 – 0.95	-0.78	0.037

Table 41 Contact with healthcare services; regression model

* For the Scottish Index of Multiple Deprivation, there were 10 categories (deciles). Of these, only the second and sixth deciles were significantly related to contact with A&E, with both being less likely to have contact.

4.5.2 Contact with allied health professionals and other services

4.5.2.1 Contact with allied health professionals; direct comparison

On direct comparison, there were no significant differences in the self-reported contact with allied health professionals in the previous 12 months. (Table 42)

Allied Health Professional	Contact with Allied Health Professional in previous 12 months		Statistical significance
	Rural N = 39	Urban N = 633	
Dietician	5 (12.8%)	148 (23.4%)	$\chi^2 = 2.330$, df = 1, no cells < 5, $P = 0.127$
Speech and language therapist	7 (17.9%)	60 (9.5%)	Fisher's exact test, $P = 0.097$
Psychologist	4 (10.3%)	54 (8.5%)	Fisher's exact test, $P = 0.766$
Occupational therapist	2 (5.1%)	80 (12.6%)	Fisher's exact test, $P = 0.211$
Podiatrist	23 (59.0%)	456 (72.0%)	$\chi^2 = 3.06$, df = 1, no cells < 5, $P = 0.08$
Physiotherapist	9 (23.1%)	100 (15.8%)	$\chi^2 = 1.432$, df = 1, no cells < 5, $P = 0.231$
Learning Disabilities Nurse	9 (23.1%)	130 (20.5%)	$\chi^2 = 0.144$, df = 1, no cells < 5, $P = 0.704$
Epilepsy Specialist Nurse	1 (2.6%)	35 (5.5%)	Fisher's exact test, $P = 0.715$

Table 42 Contact with allied health professionals; direct comparison

4.5.2.2 Contact with other services; direct comparison

Contact with other services relevant to people with intellectual disabilities is presented in table 43. Rural participants were significantly more likely to have had contact with an optician or dentist.

Service or professional	Contact with the service or professional in the previous 12 months		Statistical significance
	Rural N = 39	Urban N = 633	
Social services (social worker or care manager)	26 (66.7%)	386 (61.0%)	$\chi^2 = 0.501$, df = 1, no cells < 5, $P = 0.479$
Advocacy	2 (5.1%)	24 (3.8%)	Fisher's exact test, $P = 0.658$
Dentist	33 (84.6%)	438 (69.2%)	$\chi^2 = 4.167$, df = 1, no cells < 5, $P = 0.041$
Optician	29 (74.4%)	345 (54.5%)	$\chi^2 = 5.869$, df = 1, no cells < 5, $P = 0.015$

Table 43 Contact with other services; direct comparison

4.5.2.3 Contact with allied health professionals and other services; multiple regression

Binary logistic regression was used to identify explanatory variables associated with contact with allied health professionals and other services. (Table 44)

Rural participants remained significantly more likely to see a dentist or optician but in the regression model they were significantly less likely to see a podiatrist.

Table 44 Binary logistic regression model: associations with contact with allied health professionals and other services

Dependent variables	Independent variables	Odds ratio	95% Confidence Interval	β	P value
Dietician	Gender (male as reference)	1.53	1.04 – 2.26	0.43	0.033
	Immobility	3.35	2.20 – 5.11	1.21	≤ 0.001
	Accommodation type	Reference			
	With family carer				
	Independent of support	0.90	0.38 – 2.10	-0.11	0.80
	With paid carer	1.67	0.90 – 3.07	0.51	0.10
	Congregate care setting	2.38	1.52 – 3.75	0.87	≤ 0.001
Speech and Language Therapy	Immobility	2.74	1.52 – 4.95	1.01	0.001
	Severity of disability	Reference			≤ 0.001
	Mild				
	Moderate	2.31	0.78 – 6.82	0.84	0.131
	Severe	6.28	2.40 – 16.47	1.84	≤ 0.001
	Profound	8.58	3.33 – 22.12	2.15	≤ 0.001
Psychologist	Mental ill health	4.66	2.52 – 8.64	1.54	≤ 0.001
Occupational therapist	Immobility	2.28	1.32 – 3.96	0.83	0.003
	Severity of disability	Reference			0.021
	Mild				
	Moderate	1.68	0.82 – 3.46	0.52	0.156
	Severe	2.95	1.49 – 5.83	1.08	0.002
	Profound	1.97	0.95 – 4.09	0.68	0.070
Podiatrist	Rurality	0.306	0.12 – 0.73	-1.85	0.012
	Scottish Index of Multiple Deprivation*				

	Age**					
	Immobility	1.75	1.00 – 3.07	0.56	0.048	
	Visual impairment	1.77	1.14 – 2.75	0.57	0.011	
	Down’s Syndrome	2.61	1.49 – 4.60	0.96	0.001	
	Accommodation type	With family carer	Reference		≤0.001	
		Independent of support	1.58	0.75 – 3.31	0.54	0.232
		With paid carer	4.44	2.33 – 8.46	1.49	≤0.001
		Congregate care setting	9.58	5.21 – 17.61	2.26	≤0.001
Physiotherapist	Immobility	9.02	5.66 – 14.37	2.20	≤0.001	
Learning disabilities nurse	Hearing impairment	0.54	0.35 – 0.84	-0.61	0.006	
	Epilepsy	1.59	1.03 – 2.44	0.46	0.035	
	Down’s Syndrome	0.40	0.20 – 0.80	-0.92	0.009	
	Mental ill health	2.92	1.93 – 4.42	1.07	≤0.001	
	Accommodation type	With family carer	Reference		0.021	
		Independent of support	2.54	1.20 – 5.35	0.93	0.015
		With paid carer	2.42	1.27 – 4.61	0.88	0.007
		Congregate care setting	1.91	1.12 – 3.24	0.65	0.017

Epilepsy specialist nurse	Gender	3.24	1.41 – 7.47	1.18	0.006
	Visual impairment	0.39	0.17 – 0.89	-0.94	0.025
	Epilepsy	2E+008		19.30	0.991
	Accommodation type With family carer	Reference			0.966
	Independent of support	0.00	0.00	-18.24	0.997
	With paid carer	0.00	0.00	-17.44	0.996
	Congregate care setting	1.24	0.55 – 2.83	0.217	0.605
Social services	Scottish Index of Multiple Deprivation***				
	Incontinence	1.59	1.11 – 2.29	0.47	0.012
	Mental ill health	1.75	1.23 – 2.46	0.57	0.001
Advocacy	Accommodation type With family carer	Reference			0.101
	Independent of support	4.40	0.86 – 22.39	1.48	0.075
	With paid carer	5.07	1.24 – 20.68	1.62	0.024
	Congregate care setting	4.55	1.29 – 16.04	1.51	0.018
Dentist	Rurality	3.41	1.32 – 8.81	1.23	0.011
	Age****				
	Immobility	0.427	0.28 – 0.65	-0.85	≤0.001
	Accommodation type With family carer	Reference			≤0.001
	Independent of support	0.95	0.8 – 1.89	-0.05	0.882
	With paid carer	1.34	0.77 – 2.34	0.30	0.295
	Congregate care setting	3.26	1.99 – 5.26	1.18	≤0.001

Optician	Rurality	2.59	1.19 – 5.61	0.95	0.016
	Immobility	0.59	0.38 – 0.91	-0.53	0.016
	Visual impairment	1.42	1.01 – 1.98	0.35	0.44
	Severity of disability	Reference			0.009
	Mild				
	Moderate	0.77	0.49 – 1.20	-0.27	0.243
	Severe	0.54	0.33 – 0.87	-0.62	0.011
	Profound	0.45	0.27 – 0.75	-0.81	0.002
	Accommodation type	Reference			≤0.001
	With family carer				
	Independent of support	1.24	0.65 – 2.36	0.22	0.512
	With paid carer	1.92	1.16 – 3.18	0.65	0.012
	Congregate care setting	2.41	1.64 – 3.54	0.88	≤0.001

Table 44 Contact with allied health professionals and other services; regression model

* For the Scottish Index of Multiple Deprivation, there were 10 categories (deciles). Of these, only the first and sixth had significant relationship with contact with a podiatrist.

** For age, there were 8 categories (decades, with the first two decades amalgamated to include all participants under the age of 20.) Only this first category of the first decile (i.e. participants aged 20 or under) showed a significant relationship with contact with a podiatrist. As it was used as the reference category, it is not possible to give an odds ratio.

*** For the Scottish Index of Multiple Deprivation, there were 10 categories (deciles). The first decile was significantly different from the others but as it was used as the reference category, it is not possible to give an odds ratio. The odds ratio was significantly above one for the fourth, sixth and tenth deciles.

**** As participants became older, the odds of them seeing a dentist in the previous 2 years steadily declined. After the age of 50, this reached statistical significance.

4.5.3 Daytime opportunities, holidays and respite care

These are summarised in table 45.

Type of opportunity	Rural N = 39	Urban N = 633	Statistical significance
Paid employment without support	8 (20.5%)	28 (4.4%)	Fisher's exact test, $P = 0.01$
Supported paid employment	1 (2.6%)	11 (1.7%)	Fisher's exact test, $P = 0.515$
Employment with or without support	9 (23.1%)	39 (6.2%)	Fisher's exact test, $P = 0.001$
Voluntary work	6 (15.4%)	39 (6.2%)	Fisher's exact test, $P = 0.039$
Resource centre attendance	30 (76.9%)	311 (49.1%)	$\chi^2 = 11.353$, $df = 1$, no cells < 5 , $P = 0.001$
College attendance	6 (15.4%)	155 (24.5%)	$\chi^2 = 1.671$, $df = 1$, 0 cells < 5 , $P = 0.196$
Any daytime opportunity	37 (94.9%)	490 (77.4%)	$\chi^2 = 6.619$, $df = 1$, no cells < 5 , $P = 0.01$
Holiday with family	20 (51.3%)	196 (31.0%)	$\chi^2 = 6.695$, $df = 1$, no cells < 5 , $P = 0.008$
Holiday with support agency	21 (53.8%)	0 (0%)	Fisher's exact test, $P \leq 0.001$
Any holiday	36 (92.3%)	278 (43.9%)	$\chi^2 = 34.557$, $df = 1$, no cells < 5 , $P \leq 0.001$
Respite care	6 (15.4%)	107 (16.9%)	$\chi^2 = 0.061$, $df = 1$, no cells < 5 , $P = 0.806$

Table 45 Daytime opportunities, holidays and respite care; direct comparison

4.5.3.1 Employment; direct comparison

Participants in the rural sample were significantly more likely to be in employment or doing voluntary work than urban participants. (9 (23.1%) rural participants compared with 39 (6.2%) urban participants were in employment

(Fisher's exact test, $P = 0.001$) and 6 (15.4%) rural participants compared with 39 (6.2%) urban participants did voluntary work (Fisher's exact test, $P = 0.039$).)

4.5.3.2 College and day centre attendance; direct comparison

A similar number of rural and urban participants attended a college course (6 (15.4%) rural participants compared with 155 (24.5%) urban participants, $X^2 = 1.671$, $df = 1$, no cells < 5 , $P = 0.196$).

A significantly greater proportion of rural participants attended some sort of day centre (resource centre) each week. (30 (76.9%) rural participants compared with 311 (49.1%) urban participants. $X^2 = 11.353$, $df = 1$, no cells < 5 , $P = 0.001$.) However, of those who attended a day centre, rural participants spent fewer hours per week at the day centre compared with urban participants. (A median of 12 hours per week for rural participants (range 2 to 26) and a median of 24 hours per week for urban participants (range 1 to 40), Mann-Whitney $U = 2340.5$, $Z = -4.287$, $P \leq 0.001$.)

4.5.3.3 Any daytime opportunity; direct comparison

Just 2 (5.1%) rural participants had no regular day-time opportunity or occupation of any sort. This is significantly fewer than the proportion of urban participants with no opportunities (133 (22.6%) of urban participants, $X^2 = 6.619$, $df = 1$, no cells < 5 , $P = 0.01$). However, if they *did* participate in daytime opportunities, participants in the urban sample spent more hours per week engaging in specific opportunities than rural participants. (The urban sample spent a median of 24 hours per week (range 1 to 60) compared with a median of 18.1 hours (range 2 to 51) in the rural sample, Mann Whitney $U = 6724.5$, $Z = -2.32$, $P = 0.020$.)

4.5.3.4 Holidays and respite care; direct comparison

Only 3 (7.7%) of rural participants had not had any sort of holiday or short break in the previous 2 years. This compares with 353 (56.1%) urban participants. This is significantly different ($X^2 = 34.557$, $df = 1$, no cells < 5 , $P \leq 0.001$). This included holidays with family; 20 (51.3%) of rural participants had been on holiday with their family in the previous 2 years compared with 196 (31.0%) of

urban participants ($X^2 = 6.695$, $df = 1$, no cells < 5 , $P = 0.008$). Many of the rural participants had also been on holiday with their support agencies ($n=21$, 53.8%) compared with none of the urban participants (Fisher's exact test, $P \leq 0.001$).

Rural and urban participants were equally likely to have had respite care in the previous 2 years (6 (15.4%) rural participants, compared with 107 (16.9%) urban participants. $X^2 = 0.061$, $df = 1$, no cells < 5 , $P = 0.806$). The majority of participants who had respite care were living with their families. (5 out of the 6 rural participants (83.3%) who had respite care, and 105 out of the 112 urban participants (93.8%).)

An alternative way of comparing the proportion of rural and urban participants who received respite care is to only consider those participants living with their families. In this case, 5 out of 9 rural participants living with their families received respite care (55.6%). This compares with 105 out of 242 urban participants (43.4%). This is still not significantly different (Fisher's exact test, $P = 0.511$). However, urban participants spent significantly longer in respite care than rural participants. (The urban sample spent a median of 42 days (range 1 to 112) compared with the rural sample median of 14 days (range 8 to 42). Mann-Whitney $U = 154.5$, $Z = -2.134$, $P = 0.033$.) All of the rural participants had used respite care for planned respite breaks for them and their families - rather than following breakdown in their placement. This information was not available for the urban sample, but the range of days suggests that at least some of the respite care was not planned.

4.5.3.5 Daytime opportunities, holidays and respite care; multiple regression

All of the above findings were confirmed using binary logistic regression modelling. (Table 46)

Table 46 Binary logistic regression model; associations with daytime opportunities, holidays and respite care

Dependent variables	Independent variables	Odds ratio	95% Confidence Interval	β	Significance (p)
Paid employment	Rurality	40.25	8.15 – 198.77	3.70	≤ 0.001
	SIMD*				
	Immobility	0.19	0.04 – 0.99	-1.68	0.048
	Severity of disability	Reference			0.238
	Mild				
	Moderate	0.42	0.14 – 1.22	-0.88	0.109
	Severe	0.36	0.10 – 1.34	-1.02	0.128
	Profound	0.00	0.00	-18.69	0.995
Any employment (i.e. paid or supported)	Mental ill health	0.24	0.09 – 0.67	-1.42	0.006
	Resource centre attendance	0.17	0.06 – 0.47	-1.76	0.001
	Rurality	22.12	5.72 – 85.46	3.10	≤ 0.001
	SIMD*				
	Immobility	0.16	0.03 – 0.78	-1.85	0.023
	Severity of disability	Reference			0.044
	Mild				
	Moderate	0.29	0.10 – 0.80	-1.25	0.017
	Severe	0.35	0.11 – 1.06	-1.07	0.063
	Profound	0.00	0.00	-18.83	0.995
	Mental ill health	0.33	0.14 – 0.76	-1.11	0.009
	Resource centre attendance	0.22	0.10 – 0.52	-1.50	≤ 0.001

Voluntary work	SIMD**					
	Incontinence		0.08	0.02 – 0.36	-2.48	0.001
	Mental ill health		0.36	0.16 – 0.81	-1.03	0.013
	Accommodation type	With family carer	Reference			0.001
		Independent of support	4.39	1.65 – 11.67	1.48	0.003
		With paid carer	2.03	0.78 – 5.26	0.71	0.145
		Congregate care	0.40	0.16 – 1.03	-0.92	0.057
Resource centre[†]	Rurality		6.68	2.59 – 17.2	1.90	≤0.001
	SIMD***					
	Age****					
	Gender		1.90	1.32 – 2.74	0.64	0.001
	Down's Syndrome		1.97	1.22 – 3.19	0.68	0.006
	Severity of disability	Mild	Reference			≤0.001
		Moderate	2.56	1.54 – 4.26	0.94	≤0.001
		Severe	2.38	1.39 – 4.07	0.87	0.002
		Profound	2.34	1.36 – 4.00	0.85	0.002
	Accommodation type	With family carer	Reference			≤0.001
		Independent of support	0.23	0.10 – 0.50	-1.49	≤0.001
		With paid carer	0.18	0.10 – 0.34	-1.70	≤0.001
		Congregate care	0.32	0.20 – 0.53	-1.13	≤0.001

College	Age****				
	Immobility	0.44	0.24 – 0.81	-0.82	0.009
	Severity of disability	Reference			0.038
	Mild				
	Moderate	0.95	0.57 – 1.58	-0.06	0.832
	Severe	1.12	0.66 – 1.91	0.115	0.670
	Profound	0.39	0.19 – 0.79	-0.95	0.009
	Mental ill health	0.58	0.38 – 0.88	-0.54	0.011
	Resource centre attendance	0.43	0.28 – 0.65	-0.85	≤0.001
ANY opportunity[†]	Rurality	10.81	2.27 – 51.46	2.38	0.003
	SIMD* ****				
	Gender	1.80	1.16 – 2.80	0.59	0.009
	Incontinence	0.51	0.31 – 0.84	-0.67	0.009
	Severity of disability	Reference			0.053
	Mild				
	Moderate	1.30	0.74 – 2.29	0.26	0.367
	Severe	2.55	1.30 – 5.01	0.93	0.007
	Profound	1.75	0.88 – 3.46	0.56	0.108
	Mental ill health	0.51	0.34 – 0.79	-0.67	0.002
	Accommodation type	Reference			≤0.001
	With family carer				
	Independent of support	0.25	0.12 – 0.53	-1.39	≤0.001
	With paid carer	0.53	0.28 – 1.01	-0.64	0.055
	Congregate care	0.39	0.22 – 0.66	-0.96	0.001

Family holiday	Rurality	2.20	1.10 – 4.40	0.79	0.027
	Age** *****				
	Down's Syndrome	2.35	1.54 – 3.59	0.85	≤0.001
	Severity of disability Mild	Reference			0.003
	Moderate	0.79	0.50 – 1.26	-0.24	0.319
	Severe	0.45	0.27 – 0.76	-0.80	0.002
	Profound	0.48	0.29 – 0.79	-0.74	0.004
Holiday with support or other short break	Rurality	402.12	62.09 – 2604.32	6.00	≤0.001
	SIMD*** *****				
	Age**** *****				
	Severity of disability Mild	Reference			0.047
	Moderate	0.18	0.04 – 0.77	-1.75	0.021
	Severe	0.09	0.01 – 0.77	-2.40	0.028
	Profound	0.46	0.11 – 1.91	-0.77	0.286
	Accommodation type With family carer	Reference			0.045
	Independent of support	0.13	0.02 – 0.90	-2.04	0.039
	With paid carer	1.44	0.34 – 6.13	0.37	0.620
	Congregate care	0.36	0.08 – 1.67	-1.03	0.190

Any holiday	Rurality	17.76	4.91 – 60.10	2.84	≤0.001
	Age****				
	Down's Syndrome	1.83	1.13 – 2.96	0.60	0.014
	Accommodation type	Reference			≤0.001
	With family carer				
	Independent of support	0.40	0.19 – 0.86	-0.92	0.019
	With paid carer	0.47	0.26 – 0.83	-0.76	0.010
Respite	Congregate care	0.27	0.17 – 0.42	-1.33	≤0.001
	Resource centre attendance	2.26	1.53 – 3.34	0.82	≤0.001
	Gender	0.52	0.29 – 0.92	-0.66	0.024
	Immobility	4.75	2.32 – 9.75	1.56	≤0.001
	Visual impairment	0.52	0.29 – 0.91	-0.66	0.023
	Accommodation type	Reference			≤0.001
	With family carer				
	Independent of support	0.04	0.01 – 0.27	-3.36	0.001
	With paid carer	0.02	≤0.01 – 0.13	-4.06	≤0.001
	Congregate care	0.02	0.01 – 0.05	-4.12	≤0.001
	Resource centre attendance	8.75	4.10 – 18.69	2.17	≤0.001

Table 46 Daytime opportunities, holidays and respite care; regression model

* For the Scottish Index of Multiple Deprivation, there were 10 categories (deciles). Of these, only the second decile was significantly associated with paid or paid/voluntary employment

** Of the 10 deciles, only the first and seventh showed a significant association.

*** Of the 10 deciles, only the 3rd and 6th showed a significant association.

****Participants in their 40s and 50s were significantly more likely to attend a resource centre.

***** Nobody in the last category (i.e. aged 80 or above) attended college. Otherwise there was no significant relationships with age.

* ***** Of the 10 deciles, only the 9th showed a significant association.

** ***** Younger participants were more likely to have been on holiday with their families, and by the time that participants were in their 50's or older, this reached statistical significance.

*** *****Participants living in the least deprived decile were significantly more likely to have been on holiday with a support agency. Participants living in the sixth decile were significantly less.

**** ***** Almost all age categories were significantly less likely to have been on holiday with a support agency than the youngest reference category.

***** ***** All participants were less likely to have been on holiday than the reference category, but this was only statistically significant for participants in their 50's and 60's.

† Resource centre attendance was not included as an independent variable in these analyses.

4.5.4 Access to community facilities

These questions relate both to access and social exclusion.

4.5.4.1 Café; direct comparison

Table 47 shows how often participants went to a café. It was not possible to compare the rural and urban samples directly using χ^2 as 4 cells (40%) had an expected count of less than 5. Data were therefore aggregated to whether the participant went to a café on a regular basis (at least monthly) or not (table 48). This showed a significant difference, with urban participants more likely to go to a café on a regular basis (Fisher's exact test, $P = 0.019$).

How often does the participant go to a café?	Rural N = 39	Urban N = 632*
Every day	0 (0%)	5 (0.8%)
At least weekly	25 (64.1%)	481 (76.0%)
At least monthly	6 (15.4%)	93 (14.7%)
At least once a year	7 (17.9%)	34 (5.4%)
Never	1 (2.6%)	19 (3.0%)

Table 47 Frequency of access to community facilities; café (a)

(* missing data = 1 from urban sample)

How often does the participant go to a café?	Rural N = 39	Urban N = 632*
On a regular basis (at least monthly)	31 (79.5%)	579 (91.5%)
Infrequently (less than monthly)	8 (20.5%)	53 (8.4%)

Table 48 Frequency of access to community facilities; café (b)

(* missing data = 1 from urban sample)

4.5.4.2 Cinema; direct comparison

Urban participants were significantly more likely to go to the cinema than rural participants ($\chi^2 = 27.97$, $df = 3$, no cells < 5 , $P \leq 0.001$). (Table 49) This finding remained when the data were analysed in a similar way to above; only 5 (12.8%) rural participants compared with 349 (55.1%) urban participants went to the cinema on a regular basis ($\chi^2 = 26.39$, $df = 1$, no cells < 5 , $P \leq 0.001$). (Table 50)

How often does the participant go to the cinema?	Rural N = 39	Urban N = 633
At least weekly	0 (0%)	150 (23.7%)
At least monthly	5 (12.8%)	199 (31.4%)
At least once a year	20 (51.3%)	182 (28.8%)
Never	14 (35.9%)	102 (16.1%)

Table 49 Frequency of access to community facilities; cinema (a)

How often does the participant go to the cinema?	Rural N = 39	Urban N = 633
On a regular basis (at least monthly)	5 (12.8%)	349 (55.1%)
Infrequently (less than monthly)	34 (87.2%)	284 (44.9%)

Table 50 Frequency of access to community facilities; cinema (b)

4.5.4.3 Shops; direct comparison

It was not possible to analyse this using χ^2 as 3 cells (30%) had an expected count of less than 5. However, if the data is analysed by considering whether participants went to the shops regularly vs. infrequently, the rural and urban samples did not differ significantly (Fisher's exact test, $P = 0.351$). (Tables 51 and 52)

How often does the participant go out to the shops?	Rural N = 39	Urban N = 633
Every day	8 (20.5%)	182 (28.8%)
At least weekly	27 (69.2%)	366 (57.8%)
At least monthly	3 (7.7%)	34 (5.4%)
At least once a year	1 (2.6%)	18 (2.8%)
Never	0 (0%)	33 (5.2%)

Table 51 Frequency of access to community facilities; shops (a)

How often does the participant go out to the shops?	Rural N = 39	Urban N = 633
On a regular basis (at least monthly)	38 (97.4%)	582 (91.9%)
Infrequently (less than monthly)	1 (2.6%)	51 (8.1%)

Table 52 Frequency of access to community facilities; shops (b)

4.5.4.4 Access to community facilities; multiple regression

Independent variables	Dependent variables	Odds ratio	95% Confidence Interval	β	Significance (p)
Regular café	Rurality	0.34	0.13 – 0.93	-1.07	0.035
	Mental ill health	0.43	0.24 – 0.79	-0.83	0.006
	Accommodation type	Reference			0.001
	With family carer				
	Independent of support	0.55	0.24 – 1.27	-0.59	0.163
	With paid carer	2.43	0.96 – 6.15	0.89	0.061
	Congregate care	2.89	1.34 – 6.24	1.06	0.007
	Resource centre attendance	4.27	2.14 – 8.52	1.45	≤ 0.001
Regular cinema	Rurality	0.11	0.04 – 0.32	-2.18	≤ 0.001
	SIMD*				
	Mobility	0.58	0.38 – 0.89	-0.54	0.012
	Hearing impairment	1.48	1.01 – 2.17	0.39	0.043
	Down's Syndrome	1.69	1.06 – 2.67	0.52	0.026
	Mental ill health	0.68	0.48 – 0.98	-0.38	0.036
	Accommodation type	Reference			0.020
	With family carer				
	Independent of support	0.44	0.22 – 0.91	-0.82	0.026
	With paid carer	0.76	0.44 – 1.31	-0.27	0.322
	Congregate care	1.27	0.84 – 1.92	0.24	0.260
	Resource centre attendance	1.60	1.11 – 2.31	0.47	0.013

Regular shops	Hearing impairment	2.00	1.08 – 3.72	0.70	0.027
	Mental ill health	0.48	0.26 – 0.90	-0.74	0.021
	Accommodation type				
	With family carer	Reference			0.073
	Independent of support	3.14	0.71 – 13.99	1.15	0.133
	With paid carer	5.76	1.31 – 25.42	1.75	0.021
	Congregate care	1.34	0.69 – 2.58	0.29	0.398

Table 53 Frequency of access to community facilities; regression model

* For the Scottish Index of Multiple Deprivation, there were 10 categories (deciles). Of these, only the second decile was significantly associated with going to the cinema.

All of the findings using direct comparison were confirmed using binary logistic regression. (Table 53 above)

4.5.5 Summary of access to services and opportunities

Rural participants had significantly more contact with primary care. This is accounted for by greater contact with practice nurses.

Although there were minor differences in contact with allied health professionals between the rural and urban samples on direct comparison, these were not statistically significant, and did not remain when analysed using binary logistic regression. Likewise, contact with social services and advocacy was very similar. The exception to this was contact with podiatry, with urban participants significantly more likely to have had recent contact with a podiatrist.

Rural participants were significantly more likely to have seen a dentist and optician in the previous 12 months.

Rural participants were significantly more likely to be in paid employment or doing voluntary work. They were no more likely to attend a college course, but were significantly more likely to attend a day centre. A far greater proportion of urban participants had no regular daytime opportunities.

Rural participants were significantly more likely to have been on holiday in the previous 2 years - both with family and with support agencies. They were no more likely to have accessed respite care, but there was a suggestion that urban participants were more likely to have used respite care because of breakdown in their care package rather than as planned respite.

Rural participants were equally likely to regularly go to a shop or other local amenities, but were significantly less likely to go regularly to a café or restaurant for a meal or to the cinema.

4.6 Social networks and social support

These were measured by:

1. Analysis of whether or not participants had had any contact with a range of potential social supports in the 7 days previous to the interview.
2. Nine questions that explored the quality of the relationships that participant held with their social network, and whether they had received positive or negative support from their social supports in the previous 7 days.

4.6.1 Contact in the previous 7 days; direct comparison

The only significant finding was that rural participants were more likely to have had contact at work, in a resource centre, or at college. No participant had had *no* contact in any of the categories, which is either reassuring or an indication of selection bias. (Table 54)

Number of participants that have had NO contact in the last 7 days . . .	Rural N = 39	Urban N = 633	Statistical significance
At home (excluding support services)	1 (2.6%)	17 (2.6%, missing data = 3)	None (identical proportions)
With relatives that they do not live with	10 (25.6%)	213 (33.8%, missing data = 2)	$\chi^2 = 0.974$, df = 1, no cells < 5, $P = 0.324$
At work, in a resource centre, or at college	6 (15.4%)	200 (31.7%, missing data = 2)	$\chi^2 = 4.768$, df = 1, no cells < 5, $P = 0.029$
With friends	15 (38.5%)	203 (32.2%, missing data = 2)	$\chi^2 = 0.656$, df = 1, no cells < 5, $P = 0.418$
In a faith gathering	30 (76.9%)	501 (79.4%, missing data = 2)	$\chi^2 = 0.150$, df = 1, no cells < 5, $P = 0.699$
With other local acquaintances	14 (35.9%)	144 (22.9%, missing data = 3)	$\chi^2 = 3.385$, df = 1, no cells < 5, $P = 0.66$

Table 54 Contact with others in the previous 7 days

4.6.2 Contact in the previous 7 days; multiple regression

The finding that rural participants were more likely to have had contact at work, in a resource centre, or at college no longer remained when the data were re-analysed using binary logistic regression. (Table 55)

Independent variables	Dependent variables	Odds ratio	95% Confidence Interval	β	Significance (p)
At home (excluding support services)	Accommodation type With family carer	Reference			≤ 0.001
	Independent of support	0.02	0.00 – 0.14	-4.12	≤ 0.001
	With paid carer	7439039	0.00	15.82	0.997
	Congregate care	0.46	0.04 – 5.34	-0.78	0.532
With relatives that they do not live with	Age*				
	Epilepsy	1.64	1.10 – 2.45	0.50	0.015
	Accommodation type With family carer	Reference			≤ 0.001
	Independent of support	0.76	0.36 – 1.58	-0.28	0.459
	With paid carer	0.32	0.18 – 0.56	-1.15	≤ 0.001
	Congregate care	0.27	0.17 – 0.44	-1.31	≤ 0.001
At work, in a resource centre, or at college	Age*				
	Mental ill health	0.35	0.22 – 0.54	-1.06	≤ 0.001
	Resource centre attendance	24.85	14.06 – 43.95	3.21	≤ 0.001

With friends	Gender		1.55	1.08 – 2.23	0.44	0.019
	Incontinence		0.60	0.41 – 0.88	-0.50	0.009
	Mental ill health		0.39	0.27 – 0.56	-0.95	≤0.001
	Accommodation type	With family carer	Reference			0.014
		Independent of support	1.28	0.64 – 2.55	0.24	0.492
		With paid carer	1.42	0.81 – 2.49	0.35	0.23
		Congregate care	0.66	0.44 – 0.99	-0.41	0.046
In a faith gathering	SIMD**					
	Severity of disability	Mild	Reference			≤0.001
		Moderate	0.64	0.38 – 1.08	-0.45	0.091
		Severe	0.47	0.26 – 0.84	-0.77	0.012
		Profound	0.26	0.13 – 0.50	-1.36	≤0.001
	Accommodation type	With family carer	Reference			0.035
		Independent of support	0.83	0.37 – 1.85	-0.19	0.642
		With paid carer	1.37	0.73 – 2.56	0.32	0.325
		Congregate care	1.92	1.18 – 3.12	0.65	0.009

With other local acquaintances	SIMD***					
	Visual impairment		1.54	1.04 – 2.29	0.43	0.033
	Mental ill health		0.45	0.30 – 0.67	-0.80	≤0.001
	Accommodation type	With family carer	Reference			≤0.001
		Independent of support	0.72	0.33 – 1.58	-0.33	0.412
		With paid carer	1.15	0.57 – 2.33	0.14	0.691
		Congregate care	0.34	0.21 – 0.54	-1.10	≤0.001

Table 55 Contact with others in the previous 7 days; regression model

* For age, there were 8 categories (decades, with the first two decades amalgamated to include all participants under the age of 20.) Only this first category of the first decile (i.e. participants aged 20 or under) showed a significant relationship.

** For the Scottish Index of Multiple Deprivation, there were 10 categories (deciles). Of these, only the first and eighth deciles were significantly associated.

*** For the Scottish Index of Multiple Deprivation, there were 10 categories (deciles). Of these, only the first, sixth and tenth deciles were significantly associated.

4.6.3 Quality of relationships; direct comparison

Rural participants were equally likely to have had a recent enjoyable social interaction, to have had an argument or disagreement, to be on first name term with their neighbours, and go out to meet friends or relatives on a regular basis. However, they were much less likely to have one or more best friends, or to tell secrets to anybody, and were less likely to have a meal with a friend or a relative on a regular basis. They were more likely to have friends or relatives to stay the night, or to stay overnight themselves with friends or relatives. (Table 56)

Question	Rural N = 39	Urban N = 633	Statistical significance
Has the participant had an enjoyable social interaction in the previous 7 days?	37 (94.9%)	578 (91.3%)	Fisher's exact test, $P = 0.764$
Has the participant had an argument or disagreement in the previous 7 days?	17 (43.6%)	186 (29.4%)	$X^2 = 3.516$, $df = 1$, no cells < 5 , $P = 0.061$
Has the participant got one or more best friends?	23 (59.0%)	550 (86.9%)	$X^2 = 22.786$, $df = 1$, no cells < 5 , $P \leq 0.001$
Is the participant on first name terms with their neighbours?	32 (82.1%)	479 (76.3%, missing data = 5)	$X^2 = 0.684$, $df = 1$, no cells < 5 , $P = 0.408$
Does the participant tell secrets to anyone or not?	15 (38.5%)	475 (76.9%, missing data = 15)	$X^2 = 28.533$, $df = 1$, no cells < 5 , $P \leq 0.001$
Does the participant meet friends or relatives for a meal on a regular basis?	15 (38.5%)	373 (58.9%, missing data = 3)	$X^2 = 6.488$, $df = 1$, no cells < 5 , $P = 0.011$
Does the participant go out to meet friends or relatives on a regular basis?	23 (59.0%)	442 (69.8%)	$X^2 = 2.030$, $df = 1$, no cells < 5 , $P = 0.154$.
Does the participant have friends or relatives to stay overnight?	15 (38.5%)	143 (22.6%)	$X^2 = 5.145$, $df = 1$, no cells < 5 , $P = 0.023$.
Does the participant ever stay overnight at a friend or relative's house?	18 (46.2%)	195 (30.8%)	$X^2 = 3.997$, $df = 1$, no cells < 5 , $P = 0.046$.

Table 56 Quality of relationships; direct comparison

4.6.4 Quality of relationships; multiple regression

When the data were reanalysed using binary logistic regression, although rural participants remained equally likely to have had an enjoyable social interaction, to be on first name terms with their neighbours, and to go out with friends or relatives on a regular basis, they were now also no more likely than urban participants to stay overnight with friends or relatives. The finding that rural participants were more likely to have had a recent argument or disagreement now reached statistical significance, and they remained less likely to have one or more best friends or tell secrets to anybody. Finally, although rural participants were more likely to have friends or relatives to stay overnight, they remained less likely to meet friends or relatives for a meal on a regular basis. (Table 57)

Although not the focus of the thesis, it is interesting to note other associations in this population; for example the association of mental ill health with a poor quality of personal relationships.

Table 57 Binary logistic regression model; associations with quality of relationships

Independent variables	Dependent variables	Odds ratio	95% Confidence Interval	β	Significance (p)
Any enjoyable social interaction	Incontinence	0.54	0.30 – 0.96	-0.62	0.037
Any argument or disagreement	Rurality	2.05	1.03 – 4.09	0.72	0.040
	Age*				
	Severity of disability Mild	Reference			0.004
	Moderate	2.16	1.36 – 3.43	0.77	0.001
	Severe	1.74	1.07 – 2.82	0.55	0.026
	Profound	1.10	0.67 – 1.82	0.10	0.705
	Mental ill health	1.79	1.26 – 2.56	0.58	0.001
One or more best friend	Rurality	0.14	0.06 – 0.30	-1.98	≤ 0.001
	Gender	2.13	1.26 – 3.60	0.76	0.005
	Incontinence	0.33	0.20 – 0.55	-1.11	≤ 0.001
	Visual impairment	1.82	1.10 – 3.00	0.60	0.020
	Mental ill health	0.38	0.23 – 0.63	-0.97	≤ 0.001
	Accommodation type With family carer	Reference			0.002
	Independent of support	0.64	0.22 – 1.86	-0.45	0.408
	With paid carer	0.46	0.20 – 1.06	-0.78	0.067
	Congregate care	0.27	0.14 – 0.54	-1.30	≤ 0.001

First name terms with neighbours	SIMD**					
	Incontinence		0.53	0.32 - 0.87	-0.64	0.013
	Hearing impairment		0.58	0.35 – 0.97	-0.55	0.038
	Down's Syndrome		0.48	0.26 – 0.89	-0.73	0.019
	Severity of disability	Mild	Reference			0.002
		Moderate	0.72	0.37 – 1.40	-0.33	0.33
		Severe	0.75	0.37 – 1.52	-0.29	0.42
		Profound	0.28	0.14 – 0.56	-1.28	≤0.001
	Mental ill health		0.63	0.40 – 0.98	-0.47	0.042
	Accommodation type	With family carer	Reference			≤0.001
		Independent of support	0.32	0.12 – 0.84	-1.16	0.021
		With paid carer	0.95	0.37 – 2.40	-0.06	0.905
		Congregate care	0.11	0.06 – 0.21	-2.17	≤0.001
	Resource centre attendance		1.67	1.02 – 2.72	0.51	0.041
Tell secrets to anyone or not	Rurality		0.09	0.04 – 0.22	-2.37	≤0.001
	SIMD***					
	Severity of disability	Mild	Reference			≤0.001
		Moderate	0.42	0.24 – 0.74	-0.87	0.003
		Severe	0.28	0.15 – 0.50	-1.29	≤0.001
		Profound	0.18	0.10 – 0.32	-1.71	≤0.001
	Mental ill health		0.60	0.40 – 0.90	-0.51	0.014

Meet friends or relatives for a meal on a regular basis	Rurality	0.35	0.17 – 0.73	-1.05	0.005
	Immobility	0.45	0.29 – 0.68	-0.81	≤0.001
	Mental ill health	0.67	0.47 – 0.96	-0.40	0.028
	Accommodation type With family carer	Reference			0.015
	Independent of support	0.77	0.39 – 1.53	-0.26	0.457
	With paid carer	0.57	0.33 – 1.00	-0.56	0.049
	Congregate care	0.48	0.31 – 0.77	-0.73	0.002
	Resource centre attendance	1.54	1.06 – 2.22	0.43	0.022
Go out to meet friends or relatives on a regular basis	SIMD****				
	Age*****				
	Severity of disability Mild	Reference			≤0.001
	Moderate	0.94	0.56 – 1.58	-0.06	0.821
	Severe	0.47	0.29 – 0.77	-0.76	0.003
	Profound	0.38	0.23 – 0.62	-0.97	≤0.001
	Mental ill health	0.64	0.45 – 0.93	-0.44	0.017
Have friends or relatives to stay overnight	Rurality	2.38	1.05 – 5.38	0.87	0.037
	Down's Syndrome	1.73	1.05 – 2. 84	0.55	0.032
	Accommodation type With family carer	Reference			≤0.001
	Independent of support	0.50	0.26 – 0.97	-0.69	0.039
	With paid carer	0.14	0.07 – 0.28	-1.95	≤0.001
	Congregate care	0.02	0.01 – 0.05	-3.85	≤0.001

Stay overnight at a friend or relative's house	Age***** *				
	Down's Syndrome	1.92	1.25 – 2.94	0.65	0.003
	Severity of disability	Reference			≤0.001
	Mild				
	Moderate	0.80	0.51 – 1.26	-0.22	0.342
	Severe	0.54	0.33 – 0.88	-0.62	0.014
	Profound	0.31	0.18 – 0.53	-1.17	≤0.001

Table 57 Quality of relationships; regression model

* For age, there were 8 categories (decades, with the first two decades amalgamated to include all participants under the age of 20.) Only this first category of the first decile (i.e. participants aged 20 or under) showed a significant relationship.

** For the Scottish Index of Multiple Deprivation, there were 10 categories (deciles). Of these, only the first and sixth deciles were significantly associated.

*** For the Scottish Index of Multiple Deprivation, there were 10 categories (deciles). Of these, first, second, third and fifth deciles were significantly associated. However, there was no trend across all 10 categories.

**** For the Scottish Index of Multiple Deprivation, there were 10 categories (deciles). Of these, only the first, ninth and tenth deciles were significantly associated. (And the ninth and tenth odds ratios were below and above 1 respectively.

***** For age, there were 8 categories (decades, with the first two decades amalgamated to include all participants under the age of 20.) Only this first category of the first decile (i.e. participants aged 20 or under) showed a significant relationship.

***** * For age, there were 8 categories (decades, with the first two decades amalgamated to include all participants under the age of 20.) Only this first category of the first decile (i.e. participants aged 20 or under) showed a significant relationships.

4.7 The experience of rural life, and perceived advantages and disadvantages of rural life

Participants considered some places to be more rural than others. As the largest town, Oban was thought of as relatively urban with well developed facilities and services. Some participants described how many of the disadvantages associated with rural life could be overcome by moving to Oban. Some participants living in particularly rural locations described problems accessing facilities in Oban, let alone in Glasgow. However, the same common themes about rural life emerged, wherever the participant lived.

The large majority of respondents ($n = 34$ (87.2%)) felt that they were well known compared with the rest of the population, and that this was a positive experience. This was confirmed in the subsequent open-ended questions asking about advantages and disadvantages of rural life.

This was associated with the level of intellectual disabilities, with participants with a mild or mild-moderate level of disabilities *less* likely to feel that they were well known. Only participants with mild intellectual disabilities answered that they were either not well known, or no more well known than anybody else (Fisher's exact test, $P = 0.02$). Likewise, only participants with mild intellectual disabilities answered that people either did not stop and talk to them on a regular basis, or if they did, no more than would happen to anybody else (Fisher's exact test, $P = 0.001$).

The large majority of participants were happy to be living in a rural rather than an urban area. (Table 58)

Question	Answer	Number (%)
Is the participant well known?	Most people know them Reasonably well known, but no more than anybody else Not well known	34 (87.2%) 1 (2.6%) 4 (10.3%)
If the participant is well known, is this a positive thing?	Yes Not sure	34 (97.1%) 1 (2.9%)
If the participant goes into town, will people stop and talk to them or ask them how they are on a regular basis?	Yes, more than average Yes, but not more than anybody else No	31 (79.5%) 5 (12.8%) 3 (7.7%)
If people stop and talk to the participant more than average, is this a positive thing?	Yes No Not sure	30 (90.9%) 2 (6.1%) 1 (3.0%)
Would the participant prefer to live in a place where nobody recognised them?	No Not sure Yes It would not make any difference to them	35 (89.7%) 1 (2.6%) 1 (2.6%) 2 (5.1%)
Would the participant rather live in a rural area?	Yes No Not sure It would not make any difference to them	35 (89.7%) 4 (10.3%) 0 (0%) 0 (0%)
On balance, would the participant be better off if they moved to the city?	Yes No Not sure It would not make any difference to them	4 (10.3%) 34 (87.2%) 1 (2.6%) 0 (0%)

Table 58 The experience of living in a rural area (a)

The large majority of participants were able to appreciate or benefit from some of the same perceived advantages of rural living as the general population. People with severe or profound intellectual disabilities were *less* likely to be able to appreciate living in a beautiful place (Fisher's exact test, $P = 0.014$); but the carers of 9 participants with severe or profound intellectual disabilities thought that the person that they supported was able to appreciate the beauty at some level. (Table 59)

There was no relationship between the level of intellectual disabilities and appreciation of the quietness or safety of where the participant lived.

Question	Answer	Number (%)
Does the participant (or carer) think that they live in a beautiful part of Scotland?	Yes	35 (89.7%)
	No	3 (7.7%)
	Not sure	1 (2.6%)
If yes, is the participant able to appreciate it?	Yes	31 (79.5%)
	No	4 (10.3%)
	Not sure	1 (2.6%)
Does the participant (or carer) think that they live in a quiet part of Scotland?	Yes	35 (89.7%)
	No	4 (10.3%)
	Not sure	0 (0%)
If yes, is the participant able to appreciate or benefit from this?	Yes	32 (82.1%)
	No	2 (5.1%)
	Not sure	2 (5.1%)
	Missing	3 (7%)
Does the participant (or carer) think that they live in a safe part of Scotland?	Yes	35 (89.7%)
	No	1 (2.6%)
	Not sure	3 (7.7%)
If yes, is the participant able to appreciate or benefit from this?	Yes	31 (79.5%)
	No	4 (10.3%)
	Not sure	2 (5.1%)
	Missing	2 (5.1%)

Table 59 The experience of living in a rural area (b)

The findings from the open-ended discussion at the end of the semi-structured interview have been summarised in tables 60 and 61, and then explored in greater detail in the following pages.

Perceived advantages of rural life	Perceived disadvantages of rural life
<p>Being known in the community. This was felt to confer a degree of safety and also greater independence. People were more likely to be acknowledged as an individual and there was greater potential to be properly integrated into the community.</p> <p>Generally quieter, less busy and consequently safer. It was acknowledged that there were exceptions to this even in rural areas.</p> <p>Being able to enjoy specific “rural” activities such as cycling (on quiet rural tracks), fishing, travelling on the ferry, canoeing, gardening, horse-riding and going for walks in the countryside.</p> <p>It is easier for people to get to know a small rural area with a limited turnover of population.</p> <p>Primary care was seen as more personalised and accessible.</p>	<p>There is not as much to do and some activities don’t exist in rural areas (for example ten-pin bowling, shops, ice-skating, cinema, parks, music and shows.)</p> <p>Fewer services and less individual choice of services for people with intellectual disabilities.</p> <p>Difficulties in having to travel to access many services, and the problems that this posed for some people with intellectual disabilities.</p> <p>Poor access to some local services for people with severe physical disabilities.</p> <p>Problems typically identified as urban problems – such as alcohol, drugs, traffic and noise.</p> <p>Bullying within a small community.</p>

Table 60 Perceived advantages and disadvantages of rural life

Perceived advantages of urban life	Perceived disadvantages of urban life
<p>Easy access to a wide range of activities and facilities (such as shops, shopping centres, cafés and restaurants, ten-pin bowling, concerts, shows and pantomimes, the cinema, and clubs and pubs.)</p> <p>Better access to services for people with intellectual disabilities and specialised health services.</p>	<p>Cities are too busy, too noisy and too crowded and there is too much traffic.</p> <p>Higher risk of crime, and generally less safe.</p> <p>There is less community spirit and people were thought to be less friendly.</p> <p>Things cost more.</p>

Table 61 Perceived advantages and disadvantages of urban life

4.7.1 Perceived advantages of rural life

One of the strongest themes to emerge was the benefit of being “known” in a small rural setting. Many participants described being known within the community as being a welcome and important part of rural life. This was also the case for the few participants who would have preferred to live in a city.

In general, it was felt that being known conferred a degree of safety, and several people described people “keeping an eye out” for them. One participant described how;

“Everybody knows your and looks out for you. If you collapsed in the street in a city, people would drive past. In [name of town] they would say “that’s [name of participant]” and call an ambulance.”

There was also the feeling that because people were generally known within the community, they were able to achieve a far greater degree of independence than they might have otherwise managed, especially for people with more severe disabilities. For example, it was safe for participants to go to the shops on their own, as if they got lost, somebody would recognise and help them.

A final perceived advantage of being well known was it was associated with feeling integrated in the community. For example, a number of participants described how much they enjoyed people stopping to talk to them. One of the participants described a “really good community spirit” and said that it was “amazing that everybody knows him” and stopped to talk to him. A number of carers described how because the participants were known within the community, they tended to be judged and included as individuals rather than excluded because of their disabilities. On the whole, people were perceived as being more friendly in rural compared with urban areas.

A second theme to emerge was that rural life was thought generally to be quieter, less busy and generally safer than urban life. Nevertheless, some participants were aware that rural areas were not universally safe;

“There are safe places in Glasgow and dangerous places in [name of town].”

As a third theme, a number of participants (and their carers) identified specific activities that they enjoyed and associated with living in a rural area. These included cycling, fishing, travelling on the ferry, canoeing, gardening, horse-riding and going for walks in the countryside. For some participants, these activities constituted an important part of their daily schedule.

A final couple of themes were identified by carers rather than participants. First, because rural areas tend to be small, participants could easily get to know both the geographical area and the small population of friends and carers that lived and worked there. This was felt to be a particular advantage for less able participants. Second, a couple of carers talked about the importance of primary healthcare for the people that they supported. They felt that care was more personalised and accessible than it would have been in a larger place.

4.7.2 Perceived disadvantages of rural life

One of the most striking findings was the number of participants and carers who were genuinely unable to think of any disadvantages of living in a rural area ($n = 12$, 30.8%).

The most important theme to emerge was that there are a number of specific activities and facilities that simply do not exist in rural areas. These included ten-pin bowling, shops, ice-skating, cinema, parks, music and shows. There was a sense that there is generally not as much to do in rural areas. In keeping with this, a number of people described where they lived as “too small” and “too quiet”.

A number of carers expressed concern about the lack of specialist healthcare services for people with intellectual disabilities living in rural areas. In addition, a number of carers felt that local intellectual disabilities services were simply too small to provide a wide range of activities and services to cater for individual needs. A couple of carers felt that the lack of individualised care was exacerbated by rural attitudes within services. One carer described the problems that she experienced in trying to get respite care at short notice; primarily because the available pool of carers was so small. Another carer described her struggle to find enough local support workers to provide an

appropriate package of care for her son. Both carers felt that it would have been easier to find support in urban areas.

Access was another key theme identified by both participants and carers. In general, participants felt that they had to travel to access facilities and services. Not all people with intellectual disabilities found it easy to make long journeys, especially if they also had physical disabilities. In some cases, participants would simply miss opportunities because they felt that it wasn't worth the effort of travelling. One person highlighted the difficulties that arise when there is a serious road accident and roads are closed for several hours. The cost of travel was a problem for many. Although people with intellectual disabilities are entitled to free public transport, it could be expensive to pay for an accompanying carer. Although the cost can often be re-claimed, carers described having to pay large amounts of money up front. Because of the distances involved, "transport" costs sometimes included the cost of overnight accommodation for the participant and carer. In general, most of the discussion around access was in relation to Glasgow. However, participants living in more remote areas also described the difficulties that they experienced in travelling to the small towns of Oban, Lochgilphead and Campbeltown. The poor rural transport network was identified as a contributing factor. Finally, a number of participants and carers commented on the poor access (and facilities) for people with severe physical disabilities, in particular people who required wheelchair access. (This was noted not only by the participants in wheelchairs, but also other participants who noticed that there were certain activities that their friends were unable to enjoy.)

When asked to describe disadvantages of living in rural areas, many participants highlighted difficulties that are typically thought of as urban problems. For example, one participant said that even in [name of town], there were "still some alcohol and drugs". Another participant complained that there were "lots of Neds, especially on a Saturday night". Other participants described disadvantages such as "fights in the town centre", "young people getting drunk", "children asking for cigarettes", "vandals", and "people sitting around and loitering in doorways". One participant said that where they lived was too "noisy" at times, and another felt that the traffic had got worse.

Finally, even though in general people liked to be well known in the area, a couple of participants identified problems with this. One participant described being teased, and another said that they would like to live somewhere larger (such as Oban) where nobody would know who they were, so that they didn't get bullied. One participant commented that a disadvantage of everybody knowing each other was that they could "find out stuff about other people".

4.7.3 Perceived advantages of urban life

A number of participants (and their carers) were unable to think of any advantages of living in an urban area ($n = 11$, 28.2%). When prompted further, a few participants explained that although there were things that they liked about cities (such as the activities and facilities described below), they were more than happy to live in a rural area and access cities when required. A number of carers felt that the people that they supported would not have been able to benefit from urban facilities (for example, because they were frightened by large crowds and busy places).

Following this, the main theme that emerged was the benefits of the numerous activities and facilities available in urban areas. In particular, shops and shopping centres were highlighted. Other activities and facilities identified included: cafés and restaurants, ten-pin bowling, concerts, shows and pantomimes, the cinema, and clubs and pubs. It is possible that this theme has emerged so strongly simply because this is what people with learning disabilities actually do in urban areas. As one carer explained, the people that they supported associated Glasgow almost entirely with day-trips, holidays and shopping excursions.

A lesser theme that tended to come from carers rather than participants, was that urban areas had better intellectual disabilities resources. Access to health services was also thought to be much easier. For some participants with multiple health problems, this was seen as a large advantage.

One participant thought that it would be easier for them to get a job in an urban area, and a couple of participants had friends and family that they enjoyed visiting in Glasgow.

It is interesting that although many participants and their carers were able to identify a number of specific advantages of urban life, nobody suggested that urban places might simply be nicer places to live.

4.7.4 Perceived disadvantages of urban life

Only 2 people (5.1%) felt that there were no disadvantages of urban life.

The main theme to emerge was the feeling that cities were too busy, too noisy and too crowded. This was a particular issue for the many participants who felt anxious in noisy and crowded environments. Traffic was also seen as a major disadvantage. There were felt to be too many cars, and crossing the road was seen to be a problem; especially for people with poor mobility or using wheelchairs. As one participant described, you “might get hit by traffic or a bus”. Because of the difficulties involved in travelling around the city, there was a sense that many people would lose the independence that they enjoyed in the countryside. They might also get lost, simply because the city is so large. One participant was concerned that she would find it hard to use public transport in a city, and worried that she wouldn’t be able to get the right bus.

A second theme to emerge was that urban life was seen as being inherently less safe. The risk of crime was felt to be greater, and Glasgow was described as being “dangerous”. One person explained that “you have to keep an eye out for your property because of pickpockets” and another described how “there is a risk of your handbag being stolen”. There was also thought to be a greater risk of more violent crime, and one participant said that there was a higher chance of being “mugged, stabbed or shot.” Many of the participants felt very strongly about these issues.

In conjunction with this, a number of participants and carers felt that there were more “bad” people in cities. One carer described how “people are rude - and push and shove compared with [name of town]”. A participant complained that in Glasgow “nobody speaks to you”. There were also felt to be more dangerous and undesirable people in cities - these included drug addicts, drunken people, buskers and beggars. One participant was concerned that it was hard to protect children from drug abusers in cities. Overall, there was not felt

to be the same degree of community spirit as in rural areas - and because participants would not be as well known in bigger places, this made them more “vulnerable” to all of the bad things that were going on.

Only one participant mentioned active stigma because of his disability; he complained that people, especially children, looked at him more in Glasgow because of his disability.

Finally, one carer noted that even though there were more activities in cities, things tend to cost more.

Following analysis of the results, all participants, nominated family and carers, and people who had helped with the recruitment process were sent information about the results of the study (appendix 5).

Chapter 5: Recruitment to intellectual disabilities research; a qualitative sub-study

5.1 Literature review

Based on perceived local interest and experience with the urban sample, it was assumed that there would be few difficulties with recruitment to the original study. In fact, this was not the case at all. Therefore, on completion of the original study a further qualitative sub-study was undertaken to investigate the difficulties in recruitment to intellectual disabilities research.

The previous evidence base investigating recruitment to intellectual disabilities research is limited. Table 62 gives an overview of 12 papers that were found by performing a literature search and reviewing references of identified papers. Of the 12 papers, seven are best described as descriptive papers, three as review or opinion articles, one as a survey and one as exploratory analytical research. None of the papers uses rigorous methodology in coming to their conclusions with respect to recruitment difficulties, and a number of the papers have other limitations as described in the table. Some papers have primarily been included in the table because they have been frequently cited by other authors. However, taken as a whole, the papers suggest that recruitment difficulties in intellectual disabilities research are widespread. There appear to be a number of barriers to recruitment that differentially affect the population with intellectual disabilities. These difficulties and barriers were described repeatedly throughout the limited literature base. The papers have therefore been analysed as a whole, with the original findings, opinions and reflections of the authors; the latter not necessarily based on original research findings.

A number of ideas and concepts have also been taken from the standard sociology text book “Doing research on sensitive topics” (Lee 1993).

There is no previous literature that looks at recruitment to intellectual disabilities research in rural areas.

Table 62 Papers investigating (or commenting on) recruitment to intellectual disabilities research

Paper	Type of study, and aim or purpose of study	Methodology of the paper	Details of the study that was being recruited to	Main findings	Comments on paper
Becker et al. (2004)	Descriptive study: to describe the challenges of conducting a survey with people with disabilities and to suggest strategies to overcome these challenges.	Personal reflection based upon the experience of recruitment to a study with people with disabilities.	Over a period of 2 years, researchers held interviews with adults with disabilities to ascertain their perceptions of their needs and strengths. No reference was given for "Project ACTION", and it was not clear if the study was published.	They identified a number of issues including: suspicion of the research process, the need to recruit through intermediaries, the need for researchers to build up trust with the potential participants, and the benefit of using financial incentives.	The methodology was not described. The study that was being recruited to included people with physical disabilities (both congenital and acquired), and developmental disabilities. Only people with mild or moderate intellectual disabilities were included. The reflections were of interest and had face validity.
Cleaver et al. (2010)	Descriptive study: to analyse the factors associated with high participation in intellectual disabilities research.	The authors identified a well defined sample of original research studies. They calculated study participation using three methods, and compared participation rates with study design factors.	Not applicable.	Participation was higher where potential participants were approached directly, the study was relatively non-invasive, and consent was required only from substitute-decision makers.	There were only 9 studies eligible for inclusion in their study. The authors make a series of descriptive observations, but there was no statistical analysis to support their conclusions.
Evenhuis et al. (2004)	Descriptive study: to describe the difficulties encountered when recruiting to a specific study.	The authors retrospectively reviewed their research reports and notes looking for factors associated with participation and look for reasons for non-participation.	The aim of the original study was to assess visual and hearing impairment in a sample with intellectual disabilities using day and residential services (Evenhuis et al. 2001).	Participation was lower from community based organisations. Barriers to participation included problems of coordination within care organisation, and also practical considerations.	This was a very detailed exploration of what went wrong in their study. A lot of this is specific to this study, and does not generalise. The paper managed to convey the complexity of recruitment well.

Iacono (2003)	Review article: to review the difficulties experienced when recruiting people with intellectual disabilities to research.	Review of literature, contemporary ethics guidelines and contemporary Australian (State of Victoria) legislation. Description of the difficulties that the author had encountered in recruiting to a particular study.	Researchers wished to establish whether “pica” (the ingestion of inedible objects such as cigarette ends and stones) was associated with mineral deficiencies including iron and zinc. They planned to take a blood sample from people with intellectual disabilities who had pica. It is not clear if the research was ever published, or if the proposed study actually took place.	It is difficult to involve vulnerable people with severe intellectual impairment and who are unable to give informed consent in research. Legislation, government bodies and researchers all have a role in balancing the protection of vulnerable people against the benefits to those people of participating in research.	The author gives a detailed description of many of the difficulties encountered by different researchers in obtaining informed consent, and in obtaining permission to proceed with research with people with intellectual disabilities. This is considered from a theoretical as well as a practical perspective. Some of the paper is specific to the locality where the author is based (the state of Victoria in Australia), but this is still an informed overview of the ethics and practicalities of informed consent.
Iacono (2006)	Review article/opinion article: to review and discuss how ethics committees apply guidelines when considering research with people with intellectual disabilities.	Review of literature and other materials such as relevant legislature.	Not applicable	There are a number of ethical issues when recruiting to intellectual disabilities research. These pose challenges for researchers, ethics committees and potential participants.	An informed overview of the ethics and practicalities of obtaining ethical permission for intellectual disabilities research.

Lennox et al. (2005)	Descriptive study: to describe the barriers encountered when recruiting to intellectual disabilities research.	Personal reflection based on the authors' experience of recruitment to a particular study, supported by careful records of their recruitment campaign and by questioning participants about the difficulties they encountered when considering participation.	An RCT compared an advocacy and educational intervention programme with treatment as usual with adults with intellectual disabilities, to establish if this improved health outcomes. From the Advocacy and Health project in Queensland, Australia (no reference).	Recruitment to their study was much lower than anticipated (only 265 of a potential 1000 eligible people were finally recruited). The authors describe a number of significant barriers to recruitment.	The authors describe a number of difficulties and barriers in good detail, but have not described their methodology well. In particular, they do not give any details about the feedback that they got from participants in the study and how this was analysed.
Oliver-Africano et al. (2010)	Descriptive study: to describe the difficulties encountered in recruitment to a specific study and to propose reasons for this.	"Structured interviews" were held with 15 of the 34 clinicians who had originally expressed an interest in recruiting to the trial. Factors associated with eventual clinician participation were also considered.	A randomized controlled trial (RCT) was carried out to compare the effectiveness, side effects and costs of two antipsychotic drugs used to treat challenging behaviour in people with intellectual disabilities (Tyrer et al. 2008).	The authors conclude that the poor recruitment in their study was because people did not believe that the trial intervention was effective, there were problems within multidisciplinary teams and because of ethical concerns about using medication for challenging behaviour.	The majority of the paper focussed on details of the original RCT study. There was little information and no detail about how the authors came to their conclusions with respect to difficulties in recruitment. In particular there were no details about either the "structured interviews" or the subsequent analysis of the data.
Oliver et al. (2002)	Descriptive study: to describe and stimulate discussion about the difficulties in recruiting people with intellectual disabilities to RCTs.	Personal reflection based upon the authors' experience; in particular following discussion and debate with care providers and commissioners involved in an attempt to set up an RCT.	The proposal (not realised) was to set up an RCT to compare assertive outreach with standard care for 30 people with intellectual disabilities with mental health problems or challenging behaviour.	The authors describe ethical, methodological and service capacity issues that made recruitment to this RCT more difficult.	The methodology was not described. The authors give a good description of the difficulties that arise when recruiting people with intellectual disabilities to a RCT. They also discuss why the lack of robust research is a problem for intellectual disabilities services.

Patrick et al. (1998)	Exploratory analytical research: to investigate the cost of different methods of recruitment such as going through agencies, support groups or the media. The study also looked at the success of each of these methods in recruiting a racially representative sample.	The authors described their recruitment campaign in detail. In addition, they asked all participants how they had heard about the study. They then made a detailed analysis of how effective each method of recruitment had been by ascertaining response/participation rates.	838 older mothers of offspring with either schizophrenia or developmental disabilities were interviewed to see how the perceptions and burdens associated with caregiving related to their own mental health (Pruchno et al. 1996).	Different methods of recruitment have different costs and some methods are more successful in recruiting than others. Some methods are more successful than others in recruiting from ethnic minority groups.	This paper looks at the recruitment of carers rather than people with intellectual disabilities. However, the authors were recruiting a very select and low prevalence group within the general population, and they utilised some of the same strategies as with people with intellectual disabilities (e.g. recruiting through support groups and agencies). In addition, for people with more severe intellectual disabilities, recruitment is often through parents and main carers, so there is some relevance to intellectual disabilities research.
Siegel & Ellis (1985)	Survey: to describe the difficulties experienced by intellectual disabilities researchers in recruiting to their research.	A questionnaire was mailed to 48 representative and carefully defined intellectual disabilities researchers in the USA. The answers to the questionnaires were described.	Not applicable.	Only 31 of the 42 returned questionnaires were from researchers who had done research in the previous 2 years. Of these, only 11 stated that they had experienced problems with recruitment. A number of difficulties are described; particularly delay in obtaining parental consent.	The paper is based on just 11 returned surveys, and it is hard to see how the author's conclusions are substantiated. Because the paper was written in 1985, there are likely to have been substantial changes to ethical and legislative procedures since the paper was published. In addition, at that time a lot of recruitment is likely to have taken place through institutions that have now ceased to exist.

Swaine et al. (2011)	Descriptive study: to describe the recruitment process in an intellectual disabilities study that was felt to be unusually successful in recruiting from the community.	The authors describe in detail the process for recruitment and consent to a community based randomised controlled trial. They received some anecdotal and informal feedback from people involved in the recruitment process as to why potential participants did or did not choose to participate.	A multi-site RCT determined whether a specially designed educational programme (Women Be Healthy) would increase the uptake of breast and cervical screening in women with intellectual disabilities. (The results of the study are not referenced.)	The response rate of 75% was attributed to the detail of their successful recruitment campaign. Potential participants with legal guardians were less likely to take part because of lower rates of guardian consent.	Participation rates were expressed as the proportion of people who finally participated from a sample who were carefully selected to attend recruitment/information sessions. This may account for the high response rate. The methodology was not described. In particular, there were no details about the anecdotal and informal feedback and how this was analysed.
Tuffrey-Wijne et al. (2011)	Opinion article: to explore and describe issues around involving people with intellectual disabilities in palliative research.	Personal reflection and opinion, based on the authors' experience of intellectual disabilities research in palliative care and cancer.	Not applicable.	The authors describe a number of issues including difficulties identifying the participant sample, having to work through intermediaries, gaining informed consent, and the researcher-participant relationship.	Opinion article based on personal experience – but well researched and balanced paper, with many interesting issues discussed.

Table 62 Papers investigating recruitment to intellectual disabilities research

In summary, the literature suggests that the difficulties in recruitment to intellectual disabilities research can be described under the following headings:

- Accessing the target population
- Ethics regulations and legislation
- Intermediaries
- Consent and assent
- The complexity of the recruitment process
- Previous experience of research
- Motivators
- Sensitive research

5.1.1 Accessing the target population

Intellectual disabilities has a low prevalence in the community, and therefore it is necessary to pull from a large population base in order to recruit sufficient numbers into a study. However, with a few notable exceptions (of which the urban sample used in this study is one) there are very few high quality data sets or registers of people with intellectual disabilities available to researchers. This means that details of the population under study are essentially not known. There is also little previous research to guide power calculations of sample size, and this makes it even more difficult to set up a robust study design (Oliver et al. 2002).

In addition, ethical legislation and regulations mean that even if people with intellectual disabilities are known (for example to services), researchers are rarely able to approach potential participants directly. This is because of fears that the researcher would coerce, or unduly influence this vulnerable population into participation. Although this safeguard protects people with intellectual disabilities, it arguably denies them the right to participate in research, and to benefit from evidence based practise and policy. A number of authors believe that this makes recruitment much more difficult, as all contact with potential participants has to go through intermediaries (Becker et al. 2004; Iacono 2006; Lennox et al. 2005). A small study by Cleaver et al. (2010) found that studies in

intellectual disabilities that were able to approach participants directly had much higher response rates; this would be in keeping with experiences described in the literature. However, this paper only sampled 9 studies, and no statistical calculations were made to support their assertion.

The concept of “gatekeepers” was first described in 1993 by Lee (1993). He used the term to refer to intermediaries who were effectively able to control the activities of researchers. Even if they permit access, they may limit or control access to both the participant and other potential sources of information. Gatekeepers may have preconceptions about the way that the research can be carried out, and can impose conditions on the research. Although Lee does not use the term specifically with respect to intellectual disabilities research, the concept fits well with some of the practices described in the literature.

5.1.2 Ethics regulations and legislation

People who are unable to give informed consent to participation in research are vulnerable to exploitation. This includes many people with intellectual disabilities. The Nuremberg Code of 1949 and the Declaration of Helsinki of 1964 form the basis of modern day ethical research using humans as participants. These were drawn up following discovery of the experimentation on World War II prisoners in concentration camps, and they hold informed consent as a fundamental underlying principle. In the USA, legislation regulating research with people with intellectual disabilities arose following a number of infamous cases including the Willowbrook study. In this study, children with intellectual disabilities were injected with viral hepatitis so that the natural course of the disease could be studied. Many other countries also have specific legislation and procedures that must be followed to gain permission prior to undertaking research with people with intellectual disabilities.

A number of researchers describe this as a specific barrier to recruitment. For example, Siegal and Ellis (1985) conducted a representative survey of intellectual disabilities researchers in the USA. They report delay in gaining approval for their study as contributing to the difficulties in recruitment. Iacono (2003) describes in some detail the measures that her group of researchers were required to take to satisfy the board approving their study. Initial demands by

the board (for a psychologist to carry out a full assessment of every participant to see if they could consent) were deemed unfeasible and prohibitively expensive and would have prevented the research from proceeding. 3 years later, Iacono (2006) describes the difficulties posed by ethics committees with large numbers in Australia. Only one member of the committee need veto a proposal to prevent research from proceeding. Given the range of attitudes towards research in intellectual disabilities, the odds of a single veto is high. McDonald et al. (2008) take this further in their description of scientific gatekeepers. They suggest that intellectual disabilities researchers and their funders determine the focus and direction of intellectual disabilities research, and ethics committees then determine who is permitted to participate in the research. Together they form scientific gatekeepers and influence what we know about intellectual disabilities, and even how we perceive people with intellectual disabilities.

5.1.3 Intermediaries

If potential participants cannot be approached directly, then the researchers must find an intermediary. This poses further difficulties to recruitment.

Becker et al. (2004) describe having to go through “gatekeepers” in their study. The researchers approached administrators to gain access to potential participants; but then administrators would often delegate the actual recruitment to the workers in the organisation. Workers might be too busy to help with recruitment, and also may not have any interest in the research. Becker et al. found that intermediaries tended to be more successful in recruiting participants if they were already known to the participants, and they suggest that building local relationships should be seen as an important part of the recruitment plan. Lennox et al. (2005) describe similar problems. Particularly in small organisations, they found that intermediaries could be overwhelmed by their regular duties and were unable to spend any time helping to recruit. In addition, unless their intermediary was an insider to the organisation, they tended to have little success. Lennox et al. (2005) and Siegal & Ellis (1985) describe some intermediaries as being suspicious towards the research, and this cannot have facilitated recruitment.

Lee (2003) uses the term “sponsor” to describe three rôles that intermediaries can take in the recruitment process. These rôles consist of acting as a bridge, a guide and a patron. A sponsor often holds a combination of all three rôles.

1. A bridge provides the researcher with some sort of link or connection to the participant’s surroundings and culture.
2. A guide helps by explaining confusing and unfamiliar aspects of the participant’s environment, and may advise on what constitutes appropriate and inappropriate behaviour.
3. A patron associates themselves with the researcher, and by doing so increases trust in and acceptance of the researcher.

Lee uses examples of research from the criminal world, such as research into drug trafficking. However, the rôle of the sponsor as intermediary can also be applied to intellectual disabilities research. The term has not been used in the literature, but reading the descriptions of some of the parts played by intermediaries they fit the rôles of the sponsor as described by Lee (Becker et al. 2004; Lennox et al. 2005; Swaine et al. 2011).

5.1.4 Consent and assent

Oliver-Africano et al. (2010) give a good description of the distinction between consent and assent. They conducted a large multicentre randomized-controlled-trial investigating the use of medication in people with intellectual disabilities. There was very poor recruitment to the study, and the authors explore the reasons for this. They observed that two requirements had to be fulfilled before a participant could be recruited. First, informed consent had to be obtained. This was sometimes from the participant but more often from a carer or family member. Second, even if consent had been granted, both the participant and carer/family member had to agree to participation. They called this “assent”. Either participant or family could veto participation at this stage. Oliver-Africano et al. describe how in some cases the family would be willing, but the participant would refuse to cooperate with the research. In other instances, the

participant was keen to take part but the family refused because of the perceived potential risk to the participant.

Other authors also describe the need for assent and approval from family and carers. Oliver et al. (2002) considered that their influence can be critical in decisions regarding participation. Lennox et al. (2005) explained how some of the carers in their research were willing to support the research in theory, but in practice they were so worn out by the day to day challenges of caring for people with intellectual disabilities that they had no time or energy left to support participation. Iacono (2003) suggests that some carers may refuse to give consent because they do not believe that the participant would have given consent if they had been able. Another reason for refusing consent was because research was not felt to be in the best interests of the participant. This is difficult, as research is often *not* in the immediate best interests of the participant (although it may potentially benefit a future population with intellectual disabilities.)

The process of obtaining consent may be difficult in intellectual disabilities research. Lennox et al. (2005) described how it could be difficult to identify the person most appropriate to give proxy consent, and found that this lengthened the recruitment process. Siegel and Ellis (1985) also describe how delay and effort in gaining parental consent added to difficulties in recruitment.

Finally, Lennox et al. (2005) note that some family and carers may themselves have literacy problems or trouble in understanding the research. This adds further to the difficulties in recruitment.

5.1.5 The complexity of the recruitment process

A number of authors describe their complex recruitment campaigns in some detail. For example, an initial recruitment campaign was unsuccessful in the study by Lennox et al. (2005). They therefore extended the recruitment period and included additional elements to the campaign. This included paying an intermediary known to the participants to contact them directly by telephone. They also arranged a number of public information sessions to which carers and participants were invited. Lennox et al. also describe how the combination of

complex intellectual disabilities organisations and the need to work through intermediaries could sometimes make the recruitment process unworkable. For example, in one case they counted 17 levels of management between the nominated intermediary and the potential participant. This organisation was not successful in recruiting any participants to their study. Swaine et al. (2011) and Tuffrey Wijne et al. (2011) note that it is important to communicate with participants using appropriately pitched easy-read and multi-media formats that they can understand. This requires more time and effort. A number of authors advise that enough time, effort and resources should be allocated to recruitment when planning intellectual disabilities research.

5.1.6 Previous experience of research

People with intellectual disabilities and the people supporting them may have less experience of research. This may make them less willing to participate. Iacono (2006) also notes that if people with intellectual disabilities had taken part in research, it was important that they received feedback of the results, as otherwise they may be unwilling to participate in future studies. Even though it may be a requirement of the original ethical permission, they found that feedback was often overlooked.

5.1.7 Motivators

Most of the literature above centres on barriers to recruitment, and reasons why people are unwilling to participate in intellectual disabilities research. However, it is also helpful to consider motivators. Participation in some research can confer immediate benefit to participants, and this can act as an incentive. For example, participants in the study by Lennox et al. (2005) said that they hoped to learn more about advocacy through the study. The intervention offered in the study by Swaine et al. (2011) was an educational programme to improve awareness of breast and cervical cancer. The intervention was purposely promoted as “fun”, and also the authors thought that women wanted to participate as they were interested in their own health. Becker et al. (2004) thought that participants enjoyed their actual research process; i.e. sitting and chatting about themselves .

Offering money to participants can be seen as coercive, particularly if participants are viewed as vulnerable. In addition, it may bias the sample towards more deprived people. Nevertheless, Swaine et al. (2011) and Becker et al. (2004) both offered a small payment for participation in their studies. Becker et al. stress that the amount was agreed through the appropriate ethics committee and was not deemed to be coercive. The payment was found to be a big incentive for participants. It was paid in recognition of and as compensation for the participant's time, and this was much appreciated. In addition, people with intellectual disabilities often have limited funds, and money may be allocated within a strict budget. Payment for participation was extra money that the participants could do whatever they liked with, and this was particularly welcomed. Swaine et al. also describe how much their small payment was appreciated by participants.

There is often no direct benefit to research participants, and in the general population, participation can be seen as an altruistic act. Just one study thought that participants took part through a wish to help other people with intellectual disabilities (Lennox et al. 2005).

Motivators also apply to gatekeepers and intermediaries. Tuffrey-Wijne et al. (2011) found that gatekeepers were more likely to agree to facilitate recruitment if they could see a direct benefit for the person that they were supporting. Tuffrey-Wijne et al. were writing about research that explored palliative care and dying in people with intellectual disabilities. In their experience, gatekeepers were motivated because they thought that the participant would enjoy talking to the research interviewer. In addition, because of the medical nature of the research, they hoped to get an independent medical review from the researcher.

Lee (1993) also describes how gatekeepers may request something in return for access to the participant. For example, this could be a report written following the research interview. He notes that researchers are in a relatively weak position with respect to bargaining, and also that from a researcher perspective, the deal is not unreasonable.

5.1.8 Sensitive research

Perhaps because of the historical background and the vulnerability of the participants, research in intellectual disabilities can be considered “sensitive” research. All the authors quoted here implied that research in intellectual disabilities was somehow different from research with the general population. This was even more pertinent when researching a “sensitive” topic with this population (such as palliative care and dying, Tuffrey-Wijne et al. 2011).

5.1.9 Is intellectual disabilities research necessary?

As described above, there are a number of difficulties in recruiting to studies involving people with intellectual disabilities. This is likely to impact on the quantity and quality of available intellectual disabilities research. Yet because this population have higher health needs, they have potentially more to gain from rigorous research. If clinicians and policy makers have to rely on poor (or absent) evidence bases, people with intellectual disabilities will experience inferior treatment to the general population (Lennox et.al 2005). In addition, quality of practice is now judged through the process of clinical governance, and this prioritises evidence based practice; preferably evidence gathered through randomised-controlled-trials. If intellectual disabilities research and services do not adhere to this, they may not receive support (including financial support) from healthcare managers (Oliver et.al 2002).

5.2 Aims

The aims of the qualitative sub-study were:

1. To identify difficulties in recruitment to intellectual disabilities research.
2. To use these findings to generate strategies to improve recruitment to future intellectual disabilities research.

5.3 Methods

5.3.1 Sample

People who had acted as intermediaries and helped to recruit to the original study were asked to participate in this qualitative sub-study. Intermediaries had a number of different rôles and relationships with potential participants, and purposeful sampling was used to recruit from as wide a range of backgrounds as possible. Potential participants to the original study and immediate carers and relatives were not invited to participate.

5.3.2 Ethical approval and consent

A substantial amendment to the original application was granted by MREC-A Scotland ethics committee so that this additional qualitative study could be undertaken (appendix 2). All interviews were preceded by a recorded script that explained the research procedure and obtained verbal consent.

5.3.3 Study design

A number of telephone interviews were carried out and audio-recorded by the student between September 2009 and May 2010.

5.3.4 Measures

A topic guide was designed, and a series of questions was used to conduct semi-structured interviews (appendix 6). Difficulties in recruitment were experienced from an early stage in the study, and hence feedback and guidance had been sought at the time of recruitment. This both modified the subsequent recruitment strategy and helped to draw up the guided questions used in the semi-structured interviews.

Interviewees were encouraged to talk generally about their experience of recruitment, and their perceptions of successful and unsuccessful strategies. They were asked to illustrate their experience with specific examples. Many of the interviewees had close relationships with potential participants, and had clearly discussed the research in some detail with them. Hence, although

participants were not approached directly, it was possible to build up a picture of the participants' views, as well as those of families, carers and other intermediaries.

5.3.5 Analysis

The interviews were transcribed verbatim, and then anonymised. Next, the anonymised transcripts were returned to the interviewees for comment, to ensure that they were an accurate reflection of the interviewees' views. The interviewees were also invited to comment further on the recruitment process if they wished. No further comments were added at this point.

The data were analysed using the Framework approach (Ritchie & Spencer 1994). This is an analytic means of interpreting qualitative data, and developed from a background of applied qualitative research. It is well suited to a functional approach, and can be used to generate specific outcomes or answers. In addition, the Framework approach uses an explicit research methodology that can be easily viewed and scrutinised by other researchers.

The data were analysed by the student and also by Dr Mathew Colyer, Trainee Intellectual Disabilities Psychiatrist. Dr Colyer had previous experience of qualitative research and also intellectual disabilities research. The final analysis was reviewed and discussed with the student's supervisor.

Both analysers independently familiarised themselves with the interview transcripts. They then independently drew up a thematic framework (index) that identified the main themes within the transcripts. This comprised a list of main themes with subheadings and ideas under each theme. To facilitate analysis, the themes and subheadings were numbered. They then compared their indexes. There was considerable overlap between the two versions; any discrepancies were examined in some detail. After discussion, the student and Dr Colyer agreed on a final index (appendix 7).

The student and Dr Colyer then went back to the original transcripts, and independently applied the index by coding the relevant text in the transcripts as appropriate.

This is illustrated using the following excerpts:

“You weren’t a complete stranger. I think actually, you know, and also you’re a medical person which is, you know, people put a high value on that.” (7, 114-115)

3b (Researcher known to participants)

3a (Researcher as doctor)

“Uhu, yeah, so but, that’s maybe more reason beyond that but I don’t know. I think for some people their son/daughter had been assessed to the nth degree, you know, and it might be something about that. Or a bit about something along the line if somebody had said something negative about the person, was there going to be anything negative about the person, you know, what else is going to come up?” (8, 71-75)

6c (Over-assessment)

6d (Negative consequences)

Quotations have been referenced by giving the interview number followed by the sentence numbers in the anonymised transcript. I.e. (1, 24-26) refers to interview number 1, lines 24 to 26.

Once all of the interviews had been coded separately, the student and Dr Colyer met to discuss each interview in detail until they had agreed on the exact coding of each of the transcripts. As they started to develop new ideas and increase their understanding of the original transcripts, the original thematic framework and index was modified and adapted to reflect this.

Next, the student used the modified index to chart the transcripts. This entailed creating a separate chart for each of the main themes identified. The columns of each chart comprised the sub-themes within each theme. Each row of the chart was used to pull out ideas and appropriate quotations from each of the ten transcripts. For example, one of the main themes identified was named “Participant factors”. A separate page on an Excel spreadsheet was therefore entitled “Participant factors”. Subthemes within this main theme included

“Interview anxiety”, “The concept of research” and “Choice and consent”. A column was set up for each of these subthemes. A row was then created for each of the coded interview transcripts. The student then read through each of the interview transcripts carefully. Every time that “Interview anxiety”, “The concept of research” and “Choice and consent” was coded in the transcript, this was documented in the chart with explanatory notes and quotations if appropriate. So for example, column “Interview anxiety”, row (transcript) 1 had the following text:

“Potential participants may find the process of being asked threatening. They may need to be reassured before getting as far as the actual interview. Potential participants might worry what the researcher is going to ask. “Is this going to be hard?” “Will I be able to answer some of these questions?” (line 185) Participants need to feel safe and secure during the interview, or they will not take part.”

Finally, the student and Dr Colyer reviewed these charts. There was some overlap between the different subthemes, and in some cases, the subthemes were merged to make a more comprehensive single subtheme. In other cases, further discussion helped clarify the underlying concepts that the student and Dr Colyer were trying to establish, and the subthemes were modified and refined. A final version of a chart was agreed upon, and this was used to write up the results.

5.4 Results

12 people were asked if they would be interviewed, of whom 10 people agreed. These comprised 2 members of the local intellectual disabilities team, 2 doctors (neither of whom was directly involved in the research), 2 support workers, 2 team leaders/managers of support services, a manager of a resource centre and a manager of a service user support group. They had all been approached by the student between 1 and 2 years previously and had helped her recruit to the original study.

The following themes were identified as affecting recruitment:

- Participant factors
- The research process
- The importance of the researcher
- The impact of previous experience
- Families and carers
- “Active recruitment”
- Motivators

Although the themes are described separately, there was often overlap and interaction between the different themes.

The terms participant and potential participant have been retained to mean adults with intellectual disabilities who were approached about taking part in the study. The term interviewee has been used to describe the people who were interviewed for this qualitative sub-study.

5.4.1 Participant factors

5.4.1.1 *Interview anxiety*

A number of interviewees reported that potential participants were worried about taking part in the research. For some, the anxiety was not specified, with the research simply being described as “scary” (4, 109). One participant was described as being so shy that she found it difficult to talk to anybody that she

was not familiar with. Other potential participants had specific concerns such as the research interview being too difficult and being unable to answer questions.

“... it would have been maybe just too much for her and she would have thought “oh wow, I can’t do that”. She’d have just took herself out of it and said “no, I can’t do things like that.”” (10, 383-385)

One interviewee said that some potential participants had had experiences in the past that they didn’t want to talk about. She had to reassure them that the student was not a psychologist, and that the research was not about previous bad experiences. One interviewee felt that potential participants might worry that if they gave feedback on local services, this might have negative consequences for them. In contrast, two interviewees were confident that participants were not worried about the interview; one of these was involved in recruiting participants who were relatively able, and this may have affected her experience.

5.4.1.2 The concept of research

Every effort was made to explain the research process and the rôle of the participant prior to taking part in the study. This was always carried out by the student, but in addition was also often carried out at an earlier stage of recruitment by the interviewees.

This posed difficulties for a number of the potential participants. Because of cognitive impairment, many of the potential participants had difficulty in fully understanding the concept of research. A number of interviewees described having to go over the research process a number of times. Even then, some of the participants were unable to grasp the necessary information. One interviewee thought that the concept of research was quite abstract and altruistic, and felt that people with intellectual disabilities may be reluctant to take part in something if they could not see a direct outcome. Another interviewee described it being hard for potential participants to understand the concept of participating to benefit people in the future.

"Initially I found it very hard to get people to connect with wanting to broaden themselves in a survey which is for not themselves today but for perhaps when they're older or for the next generation." (9, 52-54)

If potential participants were not able to understand what the research and research process was all about, they were less willing to agree to take part.

5.4.1.3 Interest in participation

A number of interviewees noted that many people with intellectual disabilities have busy schedules, and that it could be difficult to fit a research interview around this. In some cases, the potential participants were worried how the interview would tie in with their usual routine, and were concerned that they would miss an enjoyed activity. This fear could be allayed by explaining that the student would find a time to suit the participant. Even so, potential participants could be reluctant to reschedule what they perceived to be a more interesting activity. Leisure and social activities held a higher priority than research, and as one interviewee put it, potential participants had better things to do with their time.

"Trying to think back, I think there was some people that just really actually to be quite blunt, couldn't be bothered. They had better things to do, thank you very much. I don't think there was anybody that had cited the reasons being that it felt something that would be worrying or cause anxiety or anything like that. I think it was more that it was just something that didn't really interest them. I would say that was the main reason." (6, 69-74)

In addition, one interviewee wondered if there might be a degree of apathy;

"If I don't bother, if I sit back for long enough, somebody else will come in and do this for me." (8, 205-206)

She thought that this related to the potential participant having intellectual disabilities. Likewise, one interviewee described some people with intellectual disabilities as being "quite self-centred and self-focussed" (9, 59) in a way that

might be developmentally appropriate - but that did not favour participation in research.

5.4.2 The recruitment process

5.4.2.1 *Practicalities*

There was a lot of discussion in the interviews about the practicalities and difficulties surrounding the actual recruitment process. The interviewees confirmed and clarified the importance of different aspects of the recruitment campaign. For example, a number of interviewees highlighted the value of the student having met potential participants in person. This was often through informal meetings or events, during which the potential participant may not even have spoken to the student. Having become more familiar and comfortable with the student, the participant would then have the confidence to ask for their details to be passed on. They were more likely to trust the motives behind the research. One interviewee gave an explanatory example of when the community police in a small town wanted to work with the local resource centre;

“... One of my friends is a policewoman and she used to come in either in, you know, semi-clothed or in police clothes and we used to get really bothered about her coming round in her police clothes. And then when we started introducing her and she would sit and she would have a coffee and everything, and then trying to introduce that the police aren’t scary. We had a walk round the police station and did all the things that they, you know, that they tell you about. It made so much difference for them just having them coming in and sitting down and having coffee and having a chat and a laugh with them.” (10, 297-304).

An informal and relaxed approach was much less threatening for potential participants, and therefore was more successful in encouraging them to participate in the research.

For many potential participants, they needed to have met the student on multiple and separate occasions, and this added greatly to the recruitment campaign - a fact that was appreciated by the interviewees. Informal meetings would sometimes be followed by formal meetings, often with the interviewee present at a joint visit, and this would entail further time and organisation.

“Oh certainly if you hadn’t been introduced to somebody and it was a sort of cold call situation I think the processes in some of the folks minds would be; What does she want to know? Is this going to be hard? ... you know ... Will I be able to answer some of these questions?” (1, 183-186)

“I think, without a doubt, the strongest thing was you, your personal time to be available to meet groups and meet people. And that in itself was going to be a limiting factor. But it can’t be, I would really like to emphasise that’s your strongest get.” (1,279-282)

One interviewee described how the potential participants wanted to know detailed and concrete information about the student before they would participate. They were reassured that the interviewee had met the student and could describe her in person. Another interviewee described giving photos of the student to potential participants so that they could become familiar with her if they saw her around the resource centre.

One interviewee described the immense effort that she put into recruiting a single participant. She had a number of reasons for wanting to recruit this particular participant, and was certain that the participant would benefit from the research. She therefore approached the participant on a number of separate occasions. The participant was not initially keen, and in fact refused to participate at first. After subsequent discussion, she agreed to consider participating; however, the interviewee knew that the participant could not cope with the stress of a pre-arranged appointment. In the end, the interview was arranged at very short notice because of a cancellation and was held at the participant’s own home. The participant was very happy to have participated and continues to talk in a positive way about the experience. But this précis illustrates the efforts that were sometimes required to recruit a single participant.

This particular study was conducted in a rural area, and hence recruitment and research interviews sometimes entailed travelling long distances. This added further to the complexity of the recruitment process. One interviewee also wondered if the long distances may have impacted on recruitment as people helping to recruit could be working over a wide catchment area. It might be a long time before a recruiter met a potential participant again to follow up any initial approach. However, another interviewee noted that it can also take a lot of time and effort to travel across a city, even though distances are less.

Because of the work that was perceived to be necessary to successfully recruit to the study, a number of interviewees commented that a lot of time, effort and money needed to be invested in the process. Some interviewees also observed that with a single researcher on a low budget, it was perhaps not surprising that the final response rate was lower than hoped for. This was very different from the urban component of the study:

“Well that was completely different. I don’t think that you can make a comparison with that. They had whole teams of people purposely doing things and, you know, phoning them back and it, you know, that people went out and recruited.” (7, 203-205)

However, other interviewees felt that the recruitment campaign had been a success; and had ultimately managed to approach all potential participants, and to recruit all of the people who had wanted to participate in the research.

5.4.2.2 Supplementary information

People assisting in the recruitment process were given “information packs” to hand out to participants and carers. These comprised a single page booklet with a list of key facts, a reply slip and a longer information leaflet with four A4 pages of questions and answers about the study. After review by the ethics committee, neither the booklet nor the information sheets were permitted to have any pictures. The font was size 14 or more to improve readability, and the language was purposefully kept simple. The information packs were designed and written by the student.

Most interviewees felt that the information sheets were long, but that all of the information therein was necessary. Carers may have dismissed the research project if their questions about the research had not been satisfactorily answered at this stage. Some of the potential participants may have been able to identify with the information sheets, but the general feeling was that the information sheets were more aimed at people involved in the recruitment process and carers rather than the potential participants themselves. The carers could then sit down and take the time to explain the information to potential participants at an appropriate level.

“I think the information would [be] good for the carer ... but too much for their clients. So I think it’s probably here been pretty guided by the carer.” (3, 196 and 200-201)

One interviewee thought that potential participants would have been put off by the information pack if they had seen it.

Given that the information packs were perceived as being aimed primarily at recruiters and carers, a number of interviewees commented that it would have been useful to have produced something aimed at potential participants. Potential participants may not have good literacy skills, and an easy-read format and pictures may have been less threatening. In addition, a number of interviewees suggested that making a DVD (or even a PowerPoint presentation with a voice recording) would have been a good way of communicating with potential participants.

Finally, whilst acknowledging budgetary restrictions, one interviewee suggested that the student should have used professional support to produce the information packs. For example, a graphic designer should have been used and the information packs printed professionally. All in all, the interviewee thought that the recruitment would have benefited from a glossier image.

5.4.2.3 Timing

A number of the interviewees talked about how recruitment had been affected by the timing of the research project. Because of economic circumstances, a

number of cuts had recently been made to local intellectual disabilities services, and further cuts were planned. There had also been a number of recent studies and consultation processes that were aimed at increasing the efficiency of local services. This made potential recruiters suspicious of the motives behind the research.

“Yeah, and it’s, you know, almost as it could be another agenda going on, you know, is this ... I think we’re at the age at the moment when people are suspicious about X [unclear from tape recording] , you know, trying to find ways of cutting services, you know. And most studies at the moment seems to me that the agenda seems to be more around, you know, how to cut things, you know, how to make things more efficient and so that just, I think the initial feeling I got ... but I tried to explain it a bit more and then, and then people seemed a lot more easy to go along with it, I think.” (4, 57-63)

There was also one particular consultation exercise where the local authorities took the decision to make changes even before the consultation period was over. This made both recruiters and potential participants even more reluctant to participate in further “research”.

A couple of interviewees noted that at the time of the study, there were fewer structures and support in place to facilitate recruitment. After the recruitment campaign had finished, a number of locality forums and service user groups were set up. These would have been ideal forums to engage with potential participants. In addition, one of the support agencies underwent a number of changes that made it into a much more effective and motivated organisation. The interviewee was confident that they would be much more successful in recruiting participants if the study were repeated.

5.4.3 The importance of the researcher

As described above, the student was an integral part of the research process. However, the attributes of the student were perceived to be one of the most important factors in recruitment, and they have therefore been described under an additional separate heading.

In this study, the researcher (i.e. the student) was both a doctor and a psychiatrist. These rôles were sometimes important for both recruiters and potential participants when deciding whether or not to participate in the study. In general, doctors were seen as having “kudos” (8,169) and were valued.

“...you’re a medical person which is, you know, people put a high value on that.” (7, 114-115)

In addition, doctors were thought of as having specialist medical knowledge which was of potential interest to both participants and carers. This study was primarily about health, and one interviewee thought that people may have been reluctant to take part if the student did not come from a health background. On the other hand, coming from a medical background may have made some participants less willing to take part. Some potential participants felt anxious about doctors, and a couple of interviewees commented that perhaps because of the local culture, doctors were sometimes seen as knowing everything and always being right. This meant that potential participants would be less likely to believe that they were participating as an equal in the research interview, and might feel that their opinions were unimportant. One participant elevated the doctor image even further;

“[the participant] has quite a naive way of looking at things. Doctors and, they’re God, sort of thing.” (10, 116-117)

There is a psychiatric hospital in the centre of the area under study. Although now much smaller and modernised with a good local reputation, the hospital was previously a large institution and major employer in the area. Psychiatry and psychiatrists were therefore relatively familiar concepts both to recruiters and potential participants. Several of the interviewees did not feel that using the title psychiatrist influenced recruitment in any way. One interviewee suggested that the term psychiatrist endowed a degree of familiarity to potential participants, as they would be likely to either know somebody working at the hospital, or at least know a relative of somebody working at the hospital. On the other hand, because of its previous identity as an institution, one interviewee described the hospital as being used as a threat;

“I mean there has been times parents have turned round and said “oh if you don’t behave then we’ll get the police to take you away”. And I’m sure that things like “if you don’t behave yourselves we’ll take you up the [local psychiatric hospital]” has been said as well when they’ve maybe been growing up things like.” (10, 307-310).

A couple of the interviewees commented that they thought that potential participant’s relatives and carers might be concerned by the student being a psychiatrist.

“Yes, I think that probably made, yes families and everybody else may get more, because of wrong connotations of it, may become worried about why are you interested in my son, daughter or this person.” (1, 214-216).

Different interviewees therefore introduced the student in different ways; sometimes even in different ways to different people. One interviewee introduced the student as a doctor to parents and staff, but used the student’s first name when describing her to potential participants. One interviewee tried to avoid any titles such as doctor or psychiatrist (and even “researcher”) as they might be associated with authority. (The student was described to potential participants in this case as an “individual” (1, 23).) One interviewee described the student as “a very nice doctor” (6, 86), presumably as a compromise.

Only one interviewee thought that the gender of the student was important. One particular participant found it very difficult to speak with males, and would have been unlikely to participate if the student had not been female.

Perhaps more significant than the rôle of the student, it was important that the student was known to the potential participants. This is discussed in more detail above. In addition, some interviewees felt that it helped that the student was local to the area. One of the interviewees lived nearby the student; the fact that the interviewee knew the student personally helped to reassure his staff. The study involved a rural-urban comparison, and because the student lived in a rural area, this also helped to convince people that her motives were genuine. This may have been particularly important given that the student did not have much time to build up relationships within the area.

Finally, and perhaps most important of all was the personal approach of the student. A number of interviewees made comments about how the student worked with recruiters and potential participants. For example, the student was described as being a “nice person with people” (1,60). The same interviewee described how “the way you [the student] personally are with people's been very positive and they like that.” (1, 116). Another interviewee commented that the student had “a lovely gentle approach” (9, 251) and was “very personable” (9, 255). One interviewee described;

“Having somebody that's approachable, that doesn't turn up, you know, in a suit in a tie or high heels or whatever, yeah, it is a barrier. And I think the fact that people saw you as, yes, an ordinary person, was really important.” (6, 92-94)

Potential participants and participants would discuss the student among themselves, and the overall impression that the student had made on them was crucial. Word about the student's personal qualities also spread around recruiters, and affected how enthusiastic they were to engage in active recruitment.

5.4.4 The impact of previous experience

Previous experience of research and consultation processes may have affected recruitment in a couple of ways. First, one interviewee suggested that studies were set in an area where research has not previously taken place, the whole concept and experience of research may be so far removed from people's experience, that it simply does not register in their consciousness. They were therefore less likely become actively involved in recruitment. Another interviewee did not feel that people in the area under study were even used to being asked their opinions on local services, let alone participating in research;

“Yeah, I'm really talking, you know, as a whole cultural thing, people being asked, they aren't used to being asked. The approaches to that, so consequently we've got a generation of people who haven't grown up expecting that. And then getting the understanding that what they feedback has value and it doesn't come back on them with any negative or anything like that, you

know, they're just not experiencing that: a) there's the surprise when people ask their views; b) probably what you said there is I'll just say something nice because the person that's speaking to me, I don't want to offend them. A huge culture of that in the West Coast of Scotland ..." (1, 87-94)

This may contrast with places where there are universities and other academic departments, where the local population may be accustomed to the idea of participating in research. On the other hand, another interviewee thought that if the population had already been exposed to research and consultation, they would be less willing to participate in further studies.

Second, people's personal experience of previous research and consultation was thought to affect the likelihood that they would participate again. It did not appear to be so much the actual research experience as the outcome of research. For example, one interviewee felt that based on previous experience, local people expected negative outcomes when they gave feedback on services. In addition, three of the interviewees commented that previous local surveys had not provided any results or feedback to participants, and that this had put them off from participating in further research.

The study was held in a rural area, but it was hard to know whether this influenced people's experience and expectations of research. Although the area is not directly associated with an academic centre, there had been plenty of recent local consultation processes; and most of the interviewees did not distinguish between surveys, consultation and academic research during the interview. In addition, although some interviewees thought that there was a cultural element to the expectation that research would not have a positive outcome, it was not clear whether this was a rural-urban distinction.

5.4.5 Families and carers

Whether or not the families and carers of potential participants were required to give consent, they were usually included in the recruitment process. In addition, family members or carers were often present during the research interview. As a consequence, the attitudes of the families and carers of potential participants were central to successful recruitment.

Some families and carers were reluctant to engage in research, even when the actual potential participant was keen. Some interviewees described a general suspicion and mistrust of the whole process;

"I think that people are, I just think naturally reticent to this kind of thing and even suspicious" (4, 52)

" . . .almost as it could be another agenda going on" (4, 57).

"I don't know if I did, I think I asked another one lady that ... she ... or did I? 'Cause it would have meant going through her mum and her sister and everything and it was just going to be ... they have got a really weird idea of what psychiatrists do. A really old way of looking at it and we just felt it wasn't maybe the best thing to for her, for her in it would have involved the family ... I think I had sent the stuff home, my memory's not so good. I think had sent, the leaflets had gone home with everybody but they were a bit, oh what's the psychiatrist? What's she doing? They look at things seriously as if we're trying to do someone off, you know what I mean? So it was just going to cause too much hassle..." (10, 242-246 and 255-259)

One interviewee described a close knit family that was difficult to "pierce through, disrupt if you like" (2, 241). She thought that the family saw the research as challenging the status quo rather than a quest for information. Another interviewee described how;

"I think quite often the people and the families that I'm working with at the moment down this end are content with their lot, you know ..." (8, 224-226)

"...they're not really looking at it and they're scared of change." (8, 230)

A consequence of the families being "content with their lot" was that they were less likely to envisage any direct benefit from the research. One interviewee suggested that this may be different in other areas where people are less satisfied with health and other services.

One interviewee said that some families were fed up of their relatives being assessed further, as "their son/daughter had been assessed to the nth degree"

already (8, 72). In addition, she thought that some families may have been scared that the research would find out something negative about their relative, and this would have been hard for them to accept.

All in all, this is likely to have affected the success of recruitment to the study. One interviewee didn't even ask a potential participant if she wished to participate, as this would have meant involving her family.

Many of the attitudes and beliefs described above are related to the culture of the area, but it is hard to know whether there is a rural-urban cultural difference. One interviewee suggested that being "content with your lot" was a rural attitude, but other interviewees described the general suspicion and mistrust of research as also applicable to urban areas.

5.4.6 "Active recruitment"

Because the student was not allowed to approach potential participants directly, all recruitment had to go through others. This was usually support staff, or staff working with local services, but sometimes included families and other close carers. This gave rise to at least one intermediary between the student and potential participant, and sometimes there could be a number of intermediaries. As described above, the attitudes of the intermediaries towards the research were crucial in determining whether or not potential participants subsequently took part in the research. In addition, there needed to be "active recruitment" in order for the process to be successful.

The term "active recruitment" has been adopted because time and time again, the interviewees implied that somehow *more* had been needed. It wasn't enough just to ask a person to hand out some leaflets on the student's behalf. Instead, the student, and all the intermediaries involved in recruitment needed to actively approach people, take the time that was needed to explain the research, and finally (and perhaps most important) to follow the process through until they were satisfied that they had completed their part in recruitment.

For example, one interviewee described how information packs were distributed at a meeting so that staff could go out and recruit participants on the student's behalf. She reported that the time, everybody was very keen; describing a kind

of buzz, with everybody talking about the research. But then nobody actually took the leaflets and distributed them. The interviewee didn't think that this was because they weren't in favour of the research; perhaps they hadn't grasped that this is what they had been asked to do? But more likely, she thought that they didn't see the research as important or interesting enough to go one step further and actively recruit people.

The same interviewee described why her own attempts to recruit may have failed. Although she handed out a number of information packs and spoke to potential participants, she didn't think that a single talk was enough. She thought that she needed to get the message across to the carers and families as well as potential participants. She would have needed to keep on reminding them about the research, and this would not have been possible within her regular professional duties. The interviewee suggested that when she was initially asked to help with recruitment, this hadn't been spelt out to her. It might have been useful if she had been given specific advice on how to recruit.

Other interviewees described similar problems;

"People might go away with the form and then if the care providers weren't interested in doing then it wouldn't get done, you know, so they, I think that's possibly why it kind of fell down. There was no kind of follow- up which I suppose if we had been involved there might have been." (8, 92 - 95)

"And for it not to feel like it's a token thing, that you've asked people and they've said no and you've gone away. That you could have invested that time in explaining it and making sure people were understanding what you were talking about and all that kind of thing so, yeah, I would say that's a relevant, a relevant factor." (6, 294 - 298)

A couple of the interviewees who the student had initially asked to help with recruitment explained why they had *not* engaged in active recruitment. One interviewee did not want to approach potential participants in person, as she felt that this might introduce bias. She thought that she might have asked people who were "interesting" (7, 65), or only people who were in contact with local services. She therefore took a more passive rôle by simply encouraging

other recruiters and potential participants to take part if the research project was being discussed. A second interviewee approached carers and gave them the information packs to discuss with potential participants. She did not feel that it was appropriate to follow this initial approach up as she thought that this was the remit and rôle of the student. In addition, she didn't want to put any pressure on the carers who she knew professionally.

"I guess that I really had no, once I actually approached people I really have to say I didn't have much feedback after that, and I didn't ask cause I felt it was inappropriate because they had moved into your domain and I didn't ... I personally didn't want to put any pressure on them at all so I didn't follow it up." (3, 205-207 and 211)

5.4.7 Consent and choice

All interviewees believed that potential participants should be given a free choice as to whether or not they participated in the research, and some interviewees expressed concerns about this. One interviewee didn't directly approach any potential participants at all because she was so worried that because of her rôle and professional relationship with them, potential participants might have felt obliged to participate. Another interviewee described how she could have made people take part in the study;

"... because, yes, it would be very easy ... I could have easily told everyone to do it [i.e. participate] and they would have 'cause I asked them rather whether they really wanted to or not." (7, 66-67)

This knowledge made her wary of directly asking potential participants about taking part in the study.

5.4.8 Motivators

5.4.8.1 Participant motivators

A number of interviewees thought that the main motivator for many potential participants was simply that people with intellectual disabilities enjoy

participating in research interviews. They like sitting down on a one-to-one basis with somebody who is interested in them, and talking about themselves.

“...it’s a sort of human nature that people are pleased to talk about themselves so long as, you know, they feel safe, they feel secure and like they’re not having to think I’m missing out on my favourite television programme while I’m sitting here, you know...” (1, 310-312)

In addition, people with intellectual disabilities are rarely asked for their opinions and given a chance to get their voices heard. Potential participants were flattered to be asked to take part in the study.

“That particular part was really interesting because it gave the people that we work with, and the client group, an opportunity to get their voice across which was great. And to a huge degree, [name of student], they’ve not been asked or given the entitlement to do that before. So that was, that gave them their piece on the map, you know, their mark on the map and I think that was, that was quite a compliment to the people.” (9, 204-208)

One interviewee thought that potential participants were probably not motivated by the desire to help other people, but another interviewee referred to one particular participant who had really appreciated being able to do something for other people.

One interviewee talked at length about the importance of giving participants something in return for their input into the study. This could be something material (like giving them a t-shirt), or alternatively arranging a social event that they would enjoy. He talked about his experience of asking people with intellectual disabilities to participate in consultation exercises;

“... could you organise, offer, do something that is a straight out front deal? You know, if you will be good enough to give me your time ... I feel strongly when we have over the years recruited teams of people to go and do consultations and all of that, it’s not so much form filling, it’s get groups to a hotel and we do things and look at that, I’ve still said we’re asking people, unemployed or

not, for their time and I used to always make sure , and the old one is, good food being put on, going to a nice setting ...” (1, 393-399)

The same interviewee thought the lack of perceived direct benefit to the participants may have affected the enthusiasm of some of the people helping recruit;

“That’s an interesting one here, isn’t it, yeah and so what was, what was the benefit? ... Why should a person, individual cancel something to spend time with you if they couldn’t see an outcome ...” (1, 360-363)

5.4.8.2 Recruiter motivators

Because the student was a doctor and intellectual disabilities psychiatrist, she was seen as having specialist knowledge that could be of use to the participants and their support team. This was a motivator for many of the people helping to recruit to the study.

“And I suppose I obviously had an ulterior motive as well that with your expertise we were getting possibly more information on some folk from a diagnostic point of view.” (8, 54-46)

Four of the interviewees talked at length about specific participants who they were very keen to engage in the research project. The first interviewee had identified a potential participant who was not previously known to have intellectual disabilities, and wanted an assessment of this. Two of the interviewees felt that one of the people that they supported had much greater needs than had previously been identified. A fourth interviewee wanted to increase a potential participant’s confidence and to overcome her fear of doctors. In all four cases the outcome of the research interview was deemed successful, and the interviewees went on to recruit more participants to the study. In at least one of the cases, this was in direct gratitude to the student. One of the other interviewees described the initial interview as giving her;

“ ... a huge amount of confidence and verve for wanting to get other people involved in the whole process.” (9, 115 - 116)

In addition, people recruiting to the study were motivated because they thought the research would provide a thorough description of the local services for people with intellectual disabilities. There were a number of potential benefits of this. First, gaps in the services could be identified, and hence services could be improved. Second, strengths in the services could be highlighted, and therefore used as examples of good practice. Finally, a number of changes and cuts to local services were anticipated in the near future. If the research project were repeated, it could be used to monitor the effect of any changes.

5.4.9 Using the results to generate strategies

Based on the themes above, and also drawing directly on comments made by individual interviewees, a number of strategies were generated. (Figure 1)

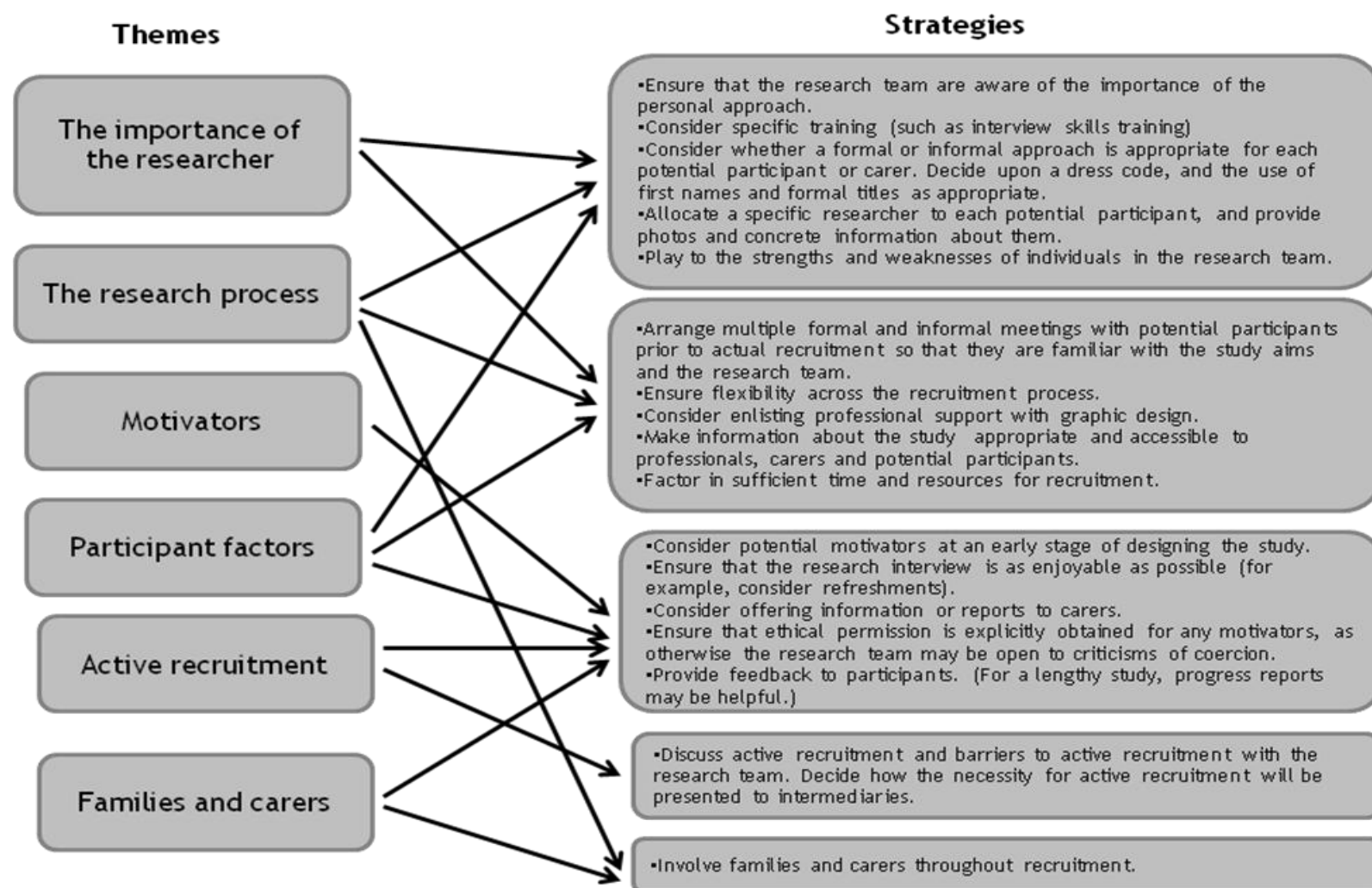


Figure 1 Recruitment strategies generated from the qualitative themes

These strategies broadly fall into three categories:

5.4.9.1 The research team

The research team is essential to the success of recruitment and it is important that everybody involved in active recruitment is aware of the difference that they can make as an individual. Researchers all have different skills and weakness, and the recruitment process should play to personal strengths within the team. If weaknesses are identified, then support and advice should be given. Specific training such as interview skills training could be considered.

When introducing research to potential participants and carers, a personal approach is probably most effective. A decision needs to be taken with respect to dress code, the use of titles and first names, and the degree of formality with which the research is presented. This might be different for different participants and carers. It is useful to allocate a specific researcher to each potential participant (or groups of participants) and then provide appropriate but specific information about the researcher. It is also helpful to provide photos so that potential participants recognise the researcher.

5.4.9.2 The recruitment process

A complex and multi-layered recruitment strategy is required for successful recruitment to intellectual disabilities research. Sufficient time and resources must be identified as part of the original research protocol. Multiple meetings may be needed with potential participants and carers prior to approaching them directly about the research. This gives them an opportunity to address any concerns, and also allays anxieties by allowing them to become familiar with the research team. Families and carers are as important to the recruitment as the potential participants, as without their assent, recruitment is unlikely to be successful.

Information about the study needs to be accessible to potential participants as well as professionals and carers. Professional support with graphic design may enhance recruitment.

Finally, all researchers involved in recruitment need to be aware of the need for active recruitment, and should be prepared to discuss this directly with intermediaries. They should also offer intermediaries the opportunity to discuss any concerns or unwillingness relating to recruitment.

5.4.9.3 Motivators

Motivators as well as barriers to recruitment need to be considered as part of the study design. If appropriate, motivators should be included in the application for ethical approval, as this should reduce the risk that the research team will be criticised for coercion. Potential participants, carers and families are motivated by different factors, all of which contribute to the success of recruitment.

One of the main motivators for participants may be that they enjoy the research interview itself. The research team should therefore aim to make this as enjoyable as possible, ensure it is held in a pleasant environment and consider providing refreshments.

Professionals and carers may hope to gain information or an assessment of the person that they support following the research interview. This needs to be explicitly discussed as part of the research protocol, and issues such as participant consent taken into consideration. Intermediaries and participants value feedback about the research, and this should be timely, appropriate and accessible.

Chapter 6: Discussion

6.1 Interpretation of the results of the original study

6.1.1 Demographics and details of intellectual disabilities

6.1.1.1 The similarity of the rural and urban samples

One of the main findings of this thesis is that the rural and urban samples did not differ significantly across a wide range of demographic and health variables. Although some of these results may have reflected a Type II error as discussed further in section 6.3.2, the rural and urban samples were similar over such a wide range of variables, it was felt that overall the samples were unlikely to represent different populations.

This negative finding is very important for people with intellectual disabilities living in rural areas and for rural intellectual disabilities research. First, almost all the available literature involving people with intellectual disabilities is urban. Unless people with intellectual disabilities living in rural areas are sufficiently similar to people with intellectual disabilities living in urban areas, it may not be appropriate to apply previous research findings to this population. This would mean that support and care for people with intellectual disabilities in rural areas would not be evidence based, and would not therefore be the most appropriate. Second, current services for people with intellectual disabilities are designed and funded according to estimated need. If the health and support needs of people with intellectual disabilities living in rural areas were significantly different, then services and funding may not have been appropriate. The results are therefore important and reassuring.

Despite small numbers in the rural sample, the sample was representative and the rural-urban comparison is therefore valid. This is discussed at further length in section 6.2.7.

6.1.1.2 Marital status and ethnicity

Rural participants were more likely to be married or have a live-in partner. This result was statistically significant, but was based on just 3 rural participants.

Two of these were married to each other, and had agreed to participate as a couple. Because of this bias, it is wise to interpret the finding with caution.

All of the participants in the rural sample were Caucasian; this was not significantly different from the urban sample, and probably reflects the fact that the number of people from minority ethnic populations living in rural Scotland is very low. In Scotland, just 2% of the total population described themselves as belonging to a minority ethnic population in 2001 (The Scottish Government 2004). Over 70% of people from minority ethnic backgrounds in Scotland live in large urban areas, and only 0.5% of the population in remote rural areas comes from a minority ethnic background (Scottish Executive 2003a). As the prevalence of intellectual disabilities is already low, it follows that the total number of people with intellectual disabilities from an ethnic minority group is likely to be extremely low in rural areas. Specialist intellectual disabilities and other healthcare services in rural areas are therefore unlikely to have the experience, knowledge and skills to support the cultural needs of people with intellectual disabilities from ethnic minorities. It would be helpful if services were aware of this, and were able to access professional support as necessary.

6.1.1.3 Level of intellectual disabilities

The level of intellectual disabilities in the combined rural and urban samples were: mild = 267 (37.9%), moderate = 147 (21.9%), severe = 126 (18.8%), and profound = 132 (19.6%). Because of the difficulty with case ascertainment for people living in the community with mild intellectual disabilities, it is hard to know whether these figures are representative of the population with intellectual disabilities as a whole. Logistic regression was used to analyse much of the data in this study, with the level of disabilities included as a variable. Therefore even if the sample were biased with respect to disabilities, this will have been accounted for when making a rural-urban comparison.

It is pleasing that such a high proportion of adults with severe and profound intellectual disabilities were able to participate in this research. Many studies exclude people with more severe disabilities if they are unable to consent to the research or if they are unable to participate fully. This study gave people with

more severe disabilities the opportunity to participate in and hence benefit from intellectual disabilities research.

6.1.1.4 Cause of intellectual disabilities

The cause of intellectual disabilities was grouped into the following categories: Down's syndrome, birth injury, unknown and other. Although there was no significant difference between the rural and urban samples when compared across all four categories, the rural sample were significantly more likely to know the cause of intellectual disabilities.

It is unclear why this might be the case. The proportion of participants with Down's syndrome was almost identical in the samples. Down's syndrome is usually easily identified at birth from its characteristic phenotype, and it is unlikely that cases are missed. This suggests that the underlying aetiology of intellectual disabilities in the two samples was similar, and that the only difference was whether or not the participant and health services actually knew the underlying diagnosis.

One possibility is that participants in rural areas were more likely to have had the appropriate investigations to exclude a known cause for intellectual disabilities. This would be consistent with the finding from this study that people with intellectual disabilities in rural areas have better access to healthcare services. Another possibility is that people living in rural areas are more likely to attribute the cause of intellectual disabilities to birth injury. Although this didn't reach statistical significance, a cause of birth injury was attributed to a higher proportion of the rural sample. It is often difficult to prove that birth injury has caused intellectual disabilities, and it is possible that participants and their carers living in rural areas were more likely to attribute intellectual disabilities to a difficult birth or prolonged labour rather than accepting an alternative explanation, or that a cause could not be found.

6.1.1.5 Type of accommodation

The rural and urban samples differed significantly with respect to the type of accommodation that they lived in; rural participants were more likely to live independently or in individual supported packages, and urban participants were

more likely to live with their families or in group-living settings. Given that demographic and health variables were very similar in the rural and urban samples, it is unlikely that this reflects different support needs. This finding may therefore reflect the availability of services and accommodation, and also expectations and attitudes of both intellectual disabilities services and the general population in rural and urban areas.

Independent living is generally promoted within intellectual disabilities services in the UK, as it is assumed that this provides more opportunities and choice for the individual with intellectual disabilities. If this is the case, then the rural sample are advantaged compared with the urban sample. However, physical inclusion into the community does not necessarily equate with true social inclusion, and people with intellectual disabilities may form the majority of their meaningful relationships with carers and other people with intellectual disabilities (Cummins & Lau 2003). If this is the case, then living with family or in settings with other people with intellectual disabilities may actually decrease social exclusion. Without knowing the details of each individual care package (including the wishes of each participant and their families) it is not possible to comment further in this study.

6.1.2 Geographic mobility

The majority of rural participants in this study were born in a rural area, and all of the rural participants who had left their family homes had started out life in a rural area. This is important, as it helps to identify the rural sample as “rural” rather than recent urban incomers to the area.

Rurality was defined and measured in this instance by asking the participant and their carers whether or not they would judge the area to be predominantly rural or urban. This was supported by identifying locations as within or without Argyll and Bute, as this is an almost entirely rural county. Although not an ideal way of measuring rurality, self-assessment of rurality has some advantages, and has been used previously in mental health literature (for example Wiles et al. 2006). Very few participants were able to give any detail about where they had lived in the past. The original intention had been to ascertain postcodes and use the Scottish Government Urban Rural Classification for participants living within

Scotland. This plan had to be reviewed when it became apparent that none of the participants or their carers knew the postcode of their place of birth.

It would have been interesting to compare the geographic mobility of rural participants with the general population. Unfortunately data from the general population is not available; the most recent census of the British population only measures country of birth and change of address in the previous year (Office for National Statistics 2001).

6.1.3 Mental ill health

The prevalence of clinically diagnosed mental ill health in the rural and urban samples was not significantly different; both using direct comparison and also when binary logistic regression models were set up to adjust for heterogeneity between the rural and urban samples. The prevalence of mental ill health seems very high (39.9%) over the combined rural and urban samples, but this includes problem behaviours and pervasive developmental disorders (autistic spectrum disorders) and is in keeping with general literature in this field.

Although the overall prevalence of mental ill health was the same, urban participants were significantly more likely to have attracted more than one psychiatric diagnosis at interview. This is very hard to explain. A possible reason is that all of the psychiatric interviews with rural participants were carried out by a single psychiatrist whereas the urban participants were interviewed by a number of different psychiatrists, some of whom may have been more likely to give multiple diagnoses. However, all the psychiatric diagnoses were discussed with consultant colleagues so that a consensus diagnosis was reached, and this should have reduced interviewer bias.

Using a clinical diagnosis had a higher sensitivity for identifying mental ill health than using the classification systems of ICD-10, DSM-IV and DC-LD. However, this difference was only significant for DSM-IV. This can probably be accounted for by the fact that DSM-IV does not allow for the coding of problem behaviour; this was therefore not included as a DSM-IV diagnoses, and hence the prevalence of mental ill health diagnosed using DSM-IV was significantly lower. (Problem behaviour is incorporated in Level D of DC-LD. ICD-10 permits the qualifier “with

significant impairment of behaviour requiring attention or treatment” when the level of intellectual disabilities is coded. ICD-10 does not provide an operationalized diagnosis, and it is unclear from ICD-10 classification whether or not the impairment of behaviour is adaptive or maladaptive. However, using ICD-10 did permit coding of problem behaviour within this study.)

The methodology used in determining mental ill health was generally robust, and this study assessed a far wider range of diagnoses than most other population studies. In addition, this study used a screening tool with a very high sensitivity and around half of the participants received full psychiatric assessment by a trained psychiatrist. However, it is still open to some of the criticisms of other rural-urban comparative studies of mental ill health. For example, there was no specific assessment for some diagnoses such as personality disorders, and some cases are likely to have been missed. In addition, the only assessment of substance abuse was made by asking participants about intake. There was no attempt to categorise the severity of mental ill health for the majority of participants, and there was no assessment of the experience of mental ill health to see if this differed between rural and urban areas. Like most other literature in this area, the urban study was not initially designed as a rural-urban comparative study.

6.1.4 Physical health, physical co-morbidities, health prevention and lifestyle factors

6.1.4.1 Physical health

It was not possible to identify a single measure of physical health in this study. Numbers were too small to use general indicators of population health such as mortality rates and the urban study was not set up in a way that might have allowed for the identification of “long term limiting illness” or other recognised indicators of ill health. Because the rural sample was so small, only a few participants or sometimes just a single participant suffered from individual medical conditions. The medical diagnoses were therefore analysed by directly comparing the four conditions that were most prevalent in the rural sample (epilepsy, hypertension, hypercholesterolemia and cataracts); essentially because these were the only four conditions for which it was possible to make a

statistical comparison with the urban sample. It is not meaningful to combine these conditions in any way to try and derive a general indication of physical health. However, in combination with the other findings looking at medical co-morbidities, the results do have some value.

Epilepsy is very prevalent in people with intellectual disabilities and is an important cause of morbidity (NHS Scotland 2004). The advantage of using epilepsy as marker of physical health is that if a person has had a witnessed seizure, they are likely to have received medical help and attracted a diagnosis of epilepsy. The diagnosis of epilepsy is therefore relatively independent of rural factors such as stoicism or access to services. The prevalence of epilepsy in the rural and urban samples was very similar in this study, and this is consistent with the proposal that physical health is similar in adults with intellectual disabilities living in rural and urban areas.

Conversely, hypertension and hypercholesterolaemia are unlikely to present with medical symptoms, and a diagnosis often depends on the success of primary care in screening for these conditions. The prevalence of hypertension was found to be significantly higher in the rural sample, and hypercholesterolemia non-significantly higher. The most likely explanation for this is that people with intellectual disabilities living in rural areas are more likely to receive appropriate primary health prevention than people with intellectual disabilities living in urban areas. This is in keeping with the study finding that the rural sample had more overall contact with primary care than the urban sample. Participants in the rural sample were significantly more likely to be taking prescribed cardiovascular medication, and this is also consistent with this explanation. Alternatively, people with intellectual disabilities living in rural areas may have a higher prevalence of cardiovascular disease; this seems less likely. Cardiovascular disease is a common cause of morbidity and ill health in the general population, but the causes of ill health are different in people with intellectual disabilities, in part because they are exposed to different risk factors for disease (NHS Scotland 2004). In addition, there were no rural-urban differences in the cardiovascular risk factors that were measured in this study; namely age, gender and smoking status.

The other significant finding with regards to prescribed medication was that participants from the rural sample were significantly more likely to be using analgesic or anti-inflammatory medication. It is possible that the rural sample had a higher prevalence of painful or inflammatory conditions, but on reviewing specific medical conditions in the rural and urban samples, there was no evidence to suggest this. The most likely explanation is therefore that rural participants found it easier to access primary care and receive appropriate treatment for their symptoms than urban participants.

6.1.4.2 Physical co-morbidities

This study investigated the prevalence of a range of conditions that are a common cause of co-morbidity for people with intellectual disabilities. The majority of these showed no significant difference between the rural and urban samples. The exceptions are discussed further below.

The prevalence of hearing impairment was significantly higher in the urban sample. However, this is probably accounted for by a methodological difference in the rural and urban research protocols. All urban participants in the original study had been offered a hearing test at the time of interview. Therefore, just 2 years later, the prevalence of hearing impairment in the urban sample in this study was likely to be reasonably accurate. In contrast, the majority of the rural participants did not recall ever having their hearing tested, and only a small proportion had had a recent test. A hearing test was not offered to rural participants as part of the study and rural participants may therefore have had undiagnosed hearing impairment. By using the urban data as a base-line, it was calculated that the expected number of rural participants with a hearing impairment was 11.2. This suggests that around 6 (15.4%) out of the 39 rural participants had an unrecognised hearing impairment, and this is a significant unmet health need.

Despite a similar proportion of rural and urban participants having impaired mobility or requiring special footwear or orthosis, significantly more rural participants were described as having a severe physical disability. This was unambiguously defined on the semi-structured interview assessment tool as being either disabled in all 4 of limbs, having spastic quadriplegia, or requiring a

moulded seat. Despite small numbers in the rural sample, this finding was highly significant, and is hard to explain.

6.1.4.3 Health prevention and lifestyle factors

This study suggests that the uptake of preventative screening (cervical smear testing and mammography) is the same in rural and urban areas. However, the numbers eligible for screening were very small, and it is possible that a Type II error has occurred. Likewise, the number of smokers in both the rural and urban samples was very small, and only a single participant in the urban sample reported using cannabis. It is therefore hard to draw any firm conclusions from this data.

Urban participants were significantly more likely to report drinking alcohol each week than rural participants. Only three participants drank more than recommended guidelines, and the majority drank 4 or fewer units per week consistent with occasional social drinking rather than problem drinking or harmful use of alcohol. Given that the rural and urban samples were so similar over a large range of demographic variables, and that alcohol was equally available in the rural and urban areas under study, it is most likely that cultural factors and attitudes towards alcohol account for the difference.

In the general population, harmful alcohol use is probably more common in the urban population (Scottish Executive 2003b). However, there is very little research that compares social drinking in rural and urban areas. One study on alcohol use in a rural and urban community in England suggested that limited social opportunities meant that alcohol was often seen as one of the only social options in rural communities, and drinking in moderation was therefore accepted, even in the young (Valentine et al. 2007). However, in this study the close knit stable rural community was able to regulate local attitudes towards drinking, and the lack of social anonymity tended to limit excessive drinking. The study also considered the importance of the temperance movement on abstinence and attitudes towards drinking. This was dependent on the local history of the area rather than rurality. A study from the USA suggested that people living in rural areas were more likely to be lifelong abstainers; but although the difference was statistically significant, it was not large in

magnitude (Dawson et al. 1995). All in all, it is difficult to draw any firm conclusions from this limited research; and therefore hard to know why rural participants in this study were less likely to drink.

In addition, it is important to consider not only attitudes towards drinking within the general rural population, but also attitudes towards people with intellectual disabilities drinking alcohol. People with more severe intellectual disabilities are unlikely to be able to access alcohol without the support and approval of the people that support them. It is possible that family and carers in rural areas have a more protective or paternalistic attitude towards people with intellectual disabilities drinking alcohol. However, there is no rural-urban literature in this area to support this.

6.1.5 Access to healthcare services

As discussed further in the introduction, service utilization is a common way of measuring access to services (Slifkin 2002). In this study, demographic and health-related variables were measured and included in the statistical analysis using binary logistic regression. This adjusted for differences in rural-urban health need, and comparing utilization of services was therefore an appropriate measure of access. This study found that rural participants had significantly more contact with both primary and secondary healthcare, and this suggests that people with intellectual disabilities living in rural areas have better access to healthcare services. This is an important and new finding. Previous research had suggested that problems with accessing healthcare in rural areas may differentially discriminate against people with disabilities, who may therefore be at a double disadvantage. This research suggests otherwise.

Based on the data that were collected through the open ended discussions following the interview, there are a number of potential reasons why access to medical services may be better in rural areas. First, a couple of carers talked in some detail about how they believed primary care in rural areas to be of better quality than primary care in urban areas. Because the rural communities were so small, they felt that the GPs (and practice nurses) were able to know individual patients better; both with regard to their health and also at a personal level. GPs were more likely to go out of their way to provide a personalised service in a

way that would not be possible in larger medical practices. Participants would therefore receive more primary care input and would also be more likely to be referred appropriately to secondary care. Second, because rural communities are smaller, everybody in the community is known. Even if a participant did not receive regular formal support, the community would notice if they were becoming unwell and would encourage them to access the medical care that they needed. Finally, it was apparent that participants and their carers were sometimes willing to surmount significant difficulties to access specialist medical services. This suggests that the health of people with intellectual disabilities is given a high priority in rural areas. This may reflect attitudes in general towards health, or may reflect the attitudes towards people with intellectual disabilities. In addition, it suggests that people in rural areas are able to recognise symptoms of illness in people with intellectual disabilities rather than attributing illness related behaviours to challenging behaviour or to the underlying disabilities; this is important as this has been identified as a significant barrier to accessing care in this population.

Although rural participants had more contact with primary care, this was primarily because of increased contact with practice nurses rather than GPs. Given that rural and urban participants probably had very similar health needs, this finding probably reflects the way that medical care is provided in rural areas, in which practice nurses often provide a wide range of medical services.

Utilization of services is only one way of measuring access. Despite clear evidence that rural participants utilised medical services more frequently than urban participants, access was a key theme identified by participants and carers in the open discussion about advantages and disadvantages of rural life held at the end of the research interview. There was a consensus that many medical specialist services were not available locally, and that it was therefore necessary to travel long distances to access secondary care. Long journeys could be problematic for participants and their carers, and this was exacerbated by the difficulties and expense of rural transport. It therefore seems that although participants and their carers are able to access healthcare services, this is because they are sometimes willing to overcome significant barriers to do so.

In contrast to medical services, the results of this study did not suggest that rural participants had better access to allied health professionals, to social services or to advocacy. (Indeed, rural participants had poorer access to podiatry than urban participants; an isolated finding that is hard to explain). Because of geographical distances in the rural group, these services were often quite thinly spread over large areas. There had been longstanding concerns from within intellectual disabilities services that people with intellectual disabilities living in rural areas were disadvantaged compared with their urban counterparts. These findings suggest that this is not the case, and this is reassuring.

Finally, rural participants were significantly more likely to have seen a dentist and optician in the last 12 months compared with urban participants. In the UK dental and optician services are free for people with intellectual disabilities. There are problems with service availability in some specific areas in the UK due to funding arrangements, and access may be a problem for some very remote rural places. However, these are not issues in either the rural or urban area under study. The most likely explanation for the rural-urban discrepancy is therefore that the people supporting adults with intellectual disabilities in rural areas feel that dental care and regular eyesight tests are important, and so are more willing to initiate and facilitate consultations. This is consistent with the earlier suggestion that people in rural areas prioritise and facilitate access to medical care for people with intellectual disabilities.

These hypotheses are not supported by strong evidence, and further research looking at the reasons why access appears to be better in rural areas would be useful. Access to healthcare services is a problem for people with intellectual disabilities, and contributes to inequalities in health. Research that furthered our understanding in this field could help to improve the health of people with intellectual disabilities living in both rural and urban areas.

6.1.6 Social exclusion

As discussed earlier in section 1.7, social exclusion is a complex concept and there are no accepted ways of measuring it. Many of the variables that were measured in this study are related to social exclusion.

6.1.6.1 Participation in daytime opportunities

Rural participants were significantly more likely to participate in daytime opportunities than urban participants. For example, rural participants were more likely to be in employment and attend a day centre, and were much less likely to report having no regular opportunities during the day. In addition, rural participants were significantly more likely to have been on holiday in the previous 2 years, both with family and with support agencies. (This was despite rural participants being less likely to live with their families.) Engaging in daytime and community opportunities is a marker of social inclusion; even if the opportunities are limited to participation with an intellectual disabilities peer group and supporting staff. These results are surprising given that existing research had suggested that opportunities are generally poorer in rural areas.

In contrast to daytime opportunities, the findings were less conclusive with respect to use of community facilities. Rural participants were equally likely to regularly go to a shop or other local amenities, but were significantly less likely to regularly go to a café or to the cinema. This might suggest that the rural sample had poorer access to local facilities. However, a couple of things should be taken into consideration. First, there is a single cinema in the rural area and this is located almost 100 miles away from some of the participants. Cinema attendance is therefore not a particularly useful indicator of the use of community facilities in this group. Second, almost all of the rural participants had regular daytime opportunities during the week, and probably had less time to use community facilities. Urban participants with no structured activities during the day may be more likely to go to a café simply to fill their time. As noted by Goble (2000), the number of different activities that a person with intellectual disabilities attends each week does not necessarily correlate with their quality of life.

Finally, the open discussion at the end of the research interview highlighted that many amenities are simply not available in rural areas. These include a number of activities and facilities that the participants enjoyed such as shopping centres, ten-pin bowling and music shows. Participants therefore had to travel to engage in these activities, and travel was sometimes difficult for participants, particularly those with physical disabilities. This may have contributed to social

exclusion for these individuals. Other participants and carers did not identify the lack of amenities as a problem; but this was probably because these particular participants were able to access urban facilities relatively easily.

6.1.6.2 Deprivation

Paid employment was the only measure of personal deprivation in this study. Rural participants were significantly more likely to be in paid employment and this will have not only reduced personal deprivation, but will also have facilitated social inclusion and contact with others.

Deprivation was also compared by calculating the postcode area level of deprivation (using the Scottish Index of Multiple Deprivation (SIMD)) for all of the participants. This showed that rural participants lived in significantly less deprived areas than the urban participants. In addition, none of the rural participants lived in the most deprived decile, whereas over a quarter of the urban participants lived in the most deprived areas. It is worth noting that both rural and urban participants on balance lived in more deprived areas than the general population, and this is in keeping with previous research (Morgan et.al 2000; NHS Scotland 2004).

Greater Glasgow and Clyde contains some of the most deprived areas in the UK. Deprivation is associated with a number of variables in the general population, including poorer physical and mental health and poorer access to services. Deprivation could therefore have confounded the results in this study. For that reason, the SIMD decile was included in all regression models so that deprivation was adjusted for when comparing the rural and urban samples.

In fact, there was very little association between area deprivation and dependent variables in the regression models. Although the regression models in the results section often show a significant association with SIMD as a whole, this is because there was a significant difference between the reference decile and a single other decile from the remaining nine. If there were a true relationship between deprivation and a dependent variable, there would be a gradient (or other pattern) across the deciles; for example, the more deprived the area, the worse the mental health; or the less deprived the area, the more likely to access

healthcare and other services. This dose-response relationship was not present for any of the dependent variables modelled.

This is not necessarily surprising. In the general population, area based deprivation scores are derived from the composition of the resident population, and therefore generally have a very good association with individual deprivation. Markers of deprivation include personal income, educational achievement, employment, and house and car ownership. These measures are not as useful in the population with intellectual disabilities, and at present there is not an established means of rating individual deprivation in this population. In addition, there is some evidence to suggest that area deprivation scores do not show the same associations as for the general population. For instance, the strong relationship between area deprivation and access to health services in the general population is not found for people with intellectual disabilities (Cooper et.al 2010). This may be because people with intellectual disabilities are dependent on support to access healthcare; and in fact are likely to be dependent on support for many of the factors that contribute to social exclusion. Support (and the expectations of those who support people with intellectual disabilities) may not originate from the area in which the person with an intellectual disabilities lives, and therefore may not relate to that area's measure of deprivation.

Given the uncertain relationship between area deprivation and intellectual disabilities, care should be taken when interpreting the finding that rural participants lived in less deprived areas than urban participants. It is an interesting finding, but is hard to hypothesise how this might affect people with intellectual disabilities.

6.1.6.3 Community, social networks and social support

Rural and urban participants did not report having significantly different patterns of contact with people in a wide range of settings. This suggests that despite sometimes living in quite geographically remote areas, rural participants were not physically isolated. Data were analysed by comparing whether rural and urban participants had had *any* contact with people in a range of settings.

This only gives a limited measure of contact, and more detailed data collection may have identified rural-urban differences not found in this study.

Daytime opportunities, the use of community facilities and contact with others are objective measures of social exclusion. A number of authors criticise this approach to social exclusion. They have argued that the frequency of physical presence in the community and the frequency of contact with others does not equate well with any meaningful definition of true social integration (Cummins & Lau 2003; Goble 2000; Myers et.al 1998). Much of the research in this field has depended on more able participants who have the ability to engage in discussion about the meaning and subjective quality of the relationships that they hold. This research is valuable in highlighting the experience of social exclusion at a personal level. However, it is more difficult to use this research to compare and contrast different groups; for example in rural and urban areas. In addition, it is very difficult to conduct qualitative research with participants with severe and profound intellectual disabilities, who may have limited or no verbal communication skills. Although simple objective measures such as daytime opportunities may not encompass the full experience of social exclusion, it is probably reasonable to suppose that if people with intellectual disabilities have no or very few daytime opportunities, they are unlikely to be fulfilling their potential to participate in society. These measures also have the advantage that they can be used with participants of all abilities.

The final questions in this part of the study looked at the quality of relationships in an attempt to explore the subjective experience of social exclusion. The questions were valuable in that they demanded simple and objective answers that could be answered fairly easily by a carer if necessary. However, it is a little difficult to know how the answers should best be interpreted. On balance, they probably suggest that rural participants did not have as many positive or close relationships as urban participants. For example, rural participants were less likely to have a best friend, were less likely to tell secrets to anyone, and were less likely to have a meal with friends or relatives. In addition, rural participants were more likely to have had a recent confrontation. This is considered positive, on the assumption that a degree of closeness and equality in a relationship is necessary to engage in confrontation. On the other hand, it also suggests that there is a negative element to that relationship. This is of

particular concern given the high rate of bullying and abuse in people with intellectual disabilities (NHS Scotland 2004). Rural participants were more likely to have friends or relatives to stay overnight, which may suggest closer relationships. However, it could simply be because the larger rural geographical distances make overnight stays a necessity. There is no previous literature that helps in the interpretation of these results.

It is difficult to explain why the quality of relationships might be poorer in rural areas. Previous research suggests that rural areas have a stronger community spirit, better social networks and rely more on informal support. This should all be to the benefit of people with intellectual disabilities. However, this does presume that people with intellectual disabilities benefit from the same community, social networks and support systems as the general population. The small amount of research in this area suggests that most social support and relationships for people with intellectual disabilities comes from paid staff and other people with intellectual disabilities. This may be much more limited in rural areas, simply because numbers are so much smaller. Perhaps in urban areas people with intellectual disabilities have more choice and opportunities to develop personal relationships and friendships, as they are able to access a range of different communities of people with intellectual disabilities.

6.1.6.4 The experience of living in a rural community and perceived advantages and disadvantages of rural life

Many of the findings in this section relate to the subjective experience of social exclusion and quality of life.

First, most of the rural participants considered that they were well known in the places in which they lived. This was thought to be one of the benefits of living in a small rural community. Because they were known and recognised in the community, a number of participants felt that this conferred a degree of security as people would keep an eye out for them if they ran into difficulties. This therefore allowed them a far greater degree of independence than they would have had in an urban area. In addition, because the participants were so well known, there was a sense that they were included in the communities as individuals in their own right rather than being judged because of their

disabilities. This will all have lead to greater social inclusion in the rural community.

Second, it was hypothesised in the introduction that because people with intellectual disabilities living in rural areas were likely to be well known, this could lead to problems with anonymity and stigma and hence could contribute to social exclusion. In fact, this does not appear to have been the case in this study. A single participant attributed bullying to the fact that she was well known in the small rural town where she lived. However, her proposed solution was to move to another small rural town in the area. Only one participant mentioned active stigma towards his disability. This stigma was experienced when he visited Glasgow.

Finally, almost all of the rural participants preferred to live in a rural area. A large majority of participants were able to appreciate or to benefit from exactly the same rural attributes as appreciated by the general population; namely beauty, quietness, and safety. This was the case even for some participants with severe or profound intellectual disabilities. Rural participants perceived urban areas as too busy, noisy and crowded, and worried that they might not be able to manage the challenges posed by urban life (particularly traffic).

These are important findings for a number of reasons. First, there is no previous literature in this area, and this is the first opportunity that people with intellectual disabilities have had to tell people about their experience of life in a rural area. Second, although people with an intellectual disabilities living in rural areas may not necessarily experience the same quality of relationships as people with intellectual disabilities living in urban areas, these findings suggest that they feel included and protected by their local community. In addition, there is no evidence that they are experiencing active discrimination in the rural environment that could contribute to social exclusion. Third, these findings suggest that although there may be disadvantages of rural life, on the whole, people with intellectual disabilities living in rural areas are happy with where they live. This is important because people with intellectual disabilities often lack choice as to where they live. It is reassuring to know that even though they may not have had any choice, people with intellectual disabilities living in rural areas are happy to be living there.

6.2 Discussion of the design and methodology of the original study

6.2.1 Defining rurality

A strength of this study is that it used a well defined and established definition of rurality that was specifically developed for the Scottish rural-urban environment. In addition, the West Coast of Scotland satisfies criteria for rurality on a number of other grounds. For example, the landscape is undeniably rural, with sparse population and beautiful coastal and mountainous scenery. The predominant industries include farming, fishing, forestry work, public sector service provision and tourism. The West Coast of Scotland is known to have a strong local rural culture and this is celebrated by local events such as a number of Highland Games and the promotion of the Gaelic language. Healthcare services are considered to be (and funded by the Scottish Government as) rural services.

One difficulty in evaluating rural research is that it is hard to generalise research from one specific rural environment to another. In this study, although rural, the West Coast of Scotland is a very different rural environment for example to the outback of Australia or to Alaska. An argument has even been made that the rural environment on the West Coast of Scotland is not representative of other remote rural areas in Scotland where distances may be much greater and services much harder to access. However, whilst the specific rural environment does need to be taken into account when interpreting the results, because the West Coast of Scotland can be defined as rural by so many criteria, some elements of the rural environment in this study are likely to apply to most other rural environments. The results were therefore felt to represent a valid rural-urban comparison, and it was felt that they were relevant to and should generalise to other rural environments.

The West Coast of Scotland was specifically chosen as the rural area in this study for two reasons. First, Greater Glasgow and Clyde is the closest large urban area to the West Coast of Scotland and this is where the pre-existing urban sample

was based. For geographical and historical reasons, there are strong links between the West Coast of Scotland and Greater Glasgow and Clyde. The county of Argyll is now served by the Health Board of NHS Highland which covers the whole of the Highlands in Scotland. However, until 2006 Argyll was served by the Health Board of Argyll and Clyde. This covered a large population of what is now the Health Board of Greater Glasgow and Clyde. This means that there is still a lot of overlap in the healthcare management, funding and policy between Argyll and Greater Glasgow and Clyde. In addition, simply because it is the nearest large city, Glasgow continues to provide the majority of training (including further professional training) for healthcare professionals in Argyll. It also provides most of the specialist medical services that are unavailable in Argyll. Consequently, there are no major differences in the way that healthcare services are provided between Argyll and Greater Glasgow and Clyde. This means that if differences do exist (for example in access to services for people with intellectual disabilities), they are more likely to reflect rural-urban differences rather than simply because two different services are being compared.

Second, it was important to exclude a commuter population from the rural sample. “Very remote” is defined by the Scottish Executive as a distance of over 60 minutes from a large settlement. However, it could be argued that people living just inside a very remote area (for example 65 minutes drive from Glasgow) could easily commute to an urban area to work or to use urban facilities. This would make it more difficult to make a true rural-urban comparison between the rural and urban populations. In this study, the sample was drawn primarily from three small very remote towns and the surrounding rural areas. The towns are all located between 2 and 3 hours drive from the city of Glasgow, and some of the surrounding rural areas are further still. It was therefore felt to be less likely that the study was targeting a commuter population. People with intellectual disabilities are unlikely to commute themselves. However, their families and other people who support them may commute, and this could have an effect on health-related beliefs and behaviours that in turn could affect the health and support needs of the person with intellectual disabilities.

With regards to the specific areas within the West Coast of Scotland that were covered by the study, it was decided to work within the boundaries of social service catchment areas for the three small towns included in the study. This is because recruitment was initially conducted through services for people with intellectual disabilities, and these are all organised within social services boundaries. The active decision was taken to exclude islands from the study. This was partly because of practical considerations, but mostly because island populations experience different problems compared with mainland Scotland with respect to access to services. Other factors such as health problems, island culture and social exclusion may also differ from the mainland. Finally, the small town of Dunoon and surrounding rural areas are also in the county of Argyll and are defined as very remote by the Scottish Urban Rural Classification. However, the town of Dunoon can be accessed by a short ferry trip from the larger town of Greenock and a large proportion of the working population commute on a regular basis across the water. Although small, Dunoon faces a number of typically urban problems such as high substance abuse because of easy access to urban areas. In addition, because of the proximity to larger urban areas, it is likely that the culture in Dunoon is a mixture of rural and urban. Therefore it was not felt to be appropriate to include Dunoon in this study.

Finally, the original urban sample included a small number of participants from accessible small towns ($n = 7$, 1.1%) and accessible rural areas ($n = 9$, 1.4%). (There was also a single participant who had moved away from the area to a remote rural area.) These participants were removed from the final urban sample so that only participants coming from large urban areas ($n = 588$, 92.2%) and other urban areas ($n = 45$, 7.8%) remained. This was because it was felt to be important to distinguish the rural and urban sample as far as possible with respect to rurality.

6.2.2 Recruitment and selection bias

Because of seeking constant feedback, the estimated “probable source of recruitment” for each participant is thought to be accurate. Some “probable sources” were much more successful at recruiting than others. For example, as highlighted earlier, resource centres were not very effective at recruiting participants. However, significantly more participants than expected attended a

resource centre. It is unclear why this was. It is possible that although participants were not recruited through the resource centres, they had met the student during one of her visits to the centres and were therefore more familiar and comfortable with the research. Alternatively, it is possible that the sort of people with intellectual disabilities who attend resource centres are also the sort of people who might enjoy participating in research. Resource centres tend to be quite busy and noisy places and most of the available activities are carried out with small groups. Resource centres are most appropriate for people who enjoy spending social time with others, and hence for people who would enjoy participating in a research interview.

As a potential source of selection bias, resource centre attendance was included as a variable in the regression models. In fact, resource centre attendance was only rarely significantly associated with any of the outcomes; for example, participants who attended resource centres were no more likely to access primary care, secondary health services or associated healthcare services. Participants attending a resource centre *were* less likely to be in paid employment, but this is likely to be a consequence of other factors. (For example, people with intellectual disabilities who are in paid employment are generally less intellectually impaired than people attending resource centres. Also, they are less likely to have time in their weekly schedule to both work and attend a resource centre.) It is therefore unlikely that resource centre attendance constituted a major source of selection bias.

Another potential source of selection bias relates to the use of intermediaries to recruit participants. Intermediaries were initially identified through local intellectual disabilities services, and therefore may not have known people with intellectual disabilities who were relatively isolated from intellectual disabilities and healthcare services and who relied entirely on their family for support. This is a potential source of bias, as these potential participants may have been relatively more able and healthy than people with intellectual disabilities requiring services. However, the rural area comprises a number of small and relatively tight-knit rural communities, and the number of adults with intellectual disabilities not known within the community is likely to be extremely small. Although intermediaries were initially drawn from intellectual disabilities services, as recruitment progressed, the student widened her access to people

with intellectual disabilities not using services. In the end, just over a quarter of participants had been recruited primarily through word of mouth. By the end of the recruitment period, it was estimated that almost all adults with intellectual disabilities living in the rural area had heard of the study, and had been offered an opportunity to participate. The student is therefore confident that by the end of the recruitment campaign, any potential selection biases related to recruitment had evened out.

6.2.3 Response rate

The response rate for the rural sample was 28.9%. This was calculated from the proportion of the total population of adults with intellectual disabilities living in the area under study. Adults with intellectual disabilities who would not in fact be eligible for the study were included in the denominator. (For example, adults with intellectual disabilities were not eligible if they were unable to consent and did not have a next of kin to consent on their behalf.) The response rate was not high, but difficulties to recruitment in intellectual disabilities research are common. It difficult to compare the figure of 28.9% with the response rate quoted in other intellectual disabilities studies, as response rates are generally calculated as the proportion of participants approached about the research rather than as a proportion of the total population (Cleaver et al. 2010). Using this method gives a much higher figure, especially if only participants who are eligible to participate have been approached.

The response rate in the urban sample is quoted as 69.6%; this was calculated as follows. The urban sample was taken from the follow-up cohort in an incidence study. The original prevalence study was conducted 2 years previously. The response rate in this study was 70.6%; the recruitment for this study was very different from the rural study. Recruitment began after considerable effort was made to draw up a complete register of all adults with intellectual disabilities living in the urban area of study. The register was then used to approach potential participants and offer them a comprehensive health check, run by NHS staff and involving assessment by specialist intellectual disabilities nurses and GPs. If the participant agreed to a health check they were subsequently asked for permission for the data gathered in the health check to be used for research purposes. They were also asked if they agreed to be approached at a later date

about future research projects. 1202 agreed to this, 1023 of whom lived in a geographically discrete area within Greater Glasgow health board and who were therefore the focus of the urban prevalence study. Two years later, by the time of the incidence study, the potential eligible cohort had reduced to 936. This was partly due to participant mortality ($n = 54$), but mainly because of new Scottish legislation that only permitted intellectual disabilities research either if the participant could give consent themselves, or if they had a next-of-kin or welfare guardian who could give consent on their behalf. This excluded a further 184 potential participants. The figure of 936 was used to calculate the response rate of 69.6%.

Because of the different ways that the rural and urban response rates were calculated, it is not possible to directly compare the two rates.

6.2.4 Representativeness of samples

The rural response rate was probably in keeping with other intellectual disabilities research, but nevertheless the final sample of participants represented a relatively low proportion of the total population of adults living in the area. It is therefore important to consider whether the participants were representative of the rest of the intellectual disabilities population living in the area. The gender and age was available for participants and non-participants from the general practices in the area. These were not found to be significantly different. Another potential source of bias was geographical; more participants could have been recruited from one small town (and the surrounding areas) than another within the rural area under study. This would have led to clustering of results. However, it was possible to calculate geographic representativeness in two ways, and both of these showed that participants were distributed evenly throughout the area. Finally, it is possible that selection bias gave rise to an unrepresentative sample. However, as discussed above, no major sources of selection bias were identified. Overall, it is therefore likely that rural participants were representative of the rest of the intellectual disabilities population living in the area.

It is worth considering that because recruitment is often mediated through family and carers, recruitment to intellectual disabilities research may be more

determined by carer characteristics than participant characteristics. This mitigates against some of the potential sample bias in research with participants with intellectual disabilities.

6.2.5 Similarities between the rural and urban methodology

This rural study was added on to a pre-existing and much larger urban study. This conferred a number of advantages. First, a lot of work had gone into developing the methodology and tools that were used in the urban study. The rural study was directly able to benefit from this. Second, the semi-structured questionnaires that were used to collect data had been tried and tested at length, essentially providing a huge pilot study for the rural study. Finally, a large quantity of data was available from the urban study, all of which was available for analysis in this thesis. This allowed a much larger, and a more robust study than would have otherwise been possible working as a lone student.

However, because the purpose of this study was primarily a rural-urban comparison, data collection was limited to variables already collected in the urban component of the study. Although a small section investigating the experience of rural life was added to the interview schedule, the equivalent urban data were not available to make any comparisons. The aims of the rural study included investigation of topics of specific relevance to the rural (and intellectual disabilities) population; namely, access and social exclusion. A study that was developed primarily to investigate these issues would probably have included additional measures to those studied. For example, it would have been useful to investigate barriers overcome to access healthcare, and to include some additional objective measures of social exclusion such as disposable income, quality and ownership of housing, and participation in community decisions such as voting. It was important that the research questionnaire was not too long; but perhaps other areas of the questionnaire could have been omitted if rural-urban comparison had been the purpose of the original study.

6.2.6 Differences between the rural and urban methodology

Although the student aimed to make the urban and rural components of the study as similar as possible, some differences were inevitable.

First, approximately two years elapsed between the urban and rural components of the study. Within that time period, it is possible some of the variables measured in the urban sample could have changed. However, it seems unlikely that any changes would have been significant. For example, the physical health of individual urban participants is likely to have deteriorated with ageing; but an urban sample recruited two years later would include some younger participants that would not previously have been eligible, and so the overall health of the urban sample would not differ. Urban and rural areas are constantly changing as buildings are constructed and destroyed; but in fact both the 2005-2006 and 2007-2008 Scottish Government Urban Rural Classification were calculated for all of the urban participants, and there were no changes in rurality for any of the participants. The appropriate year of the Scottish Index of Multiple Deprivation (SIMD) were used for the rural and urban samples so that the SIMD measure was suitable for the point at which the other data were collected. There were no major governmental or health policy changes between the time of the urban and rural studies that might have impacted on access to services or other opportunities.

Second, the urban and rural samples were recruited in different ways.

Recruitment to the urban sample was carried out by directly approaching all adults with intellectual disabilities known to be living in the urban area. This compares with recruitment to the rural sample, which involved approaching potential participants through intermediaries. However, by the end of the rural recruitment campaign it was felt that almost all of the adults with intellectual disabilities living in the area under study had been approached with regard to the study. Therefore it is reasonable to make a comparison between the rural and urban populations approached about the study, even though the process of recruitment was very different.

Third, a single investigator (the author of this thesis, and a trained psychiatrist) collected all of the data from rural participants. Data in the urban study were collected primarily by specialist intellectual disabilities nurses, with additional assessments of mental health by trained psychiatrists only if participants screened positive for symptoms of mental ill health. This may have lead to systematic bias. However, all data were collected using the same instruments, and all researchers (including the student) were trained in their use prior to data collection. Most of the data that were collected were unambiguous and relatively objective. In addition, diagnoses of mental ill health were only made for the rural sample after discussion with the student's research supervisor. This ensured review by a trained consultant psychiatrist, with the added advantage that the supervisor not only lead on the urban research project, but was also personally involved in the coding of all psychiatric diagnoses in the urban sample.

Finally, ethical permission was not sought to review the psychiatric case notes of participants in the rural sample who were found to have mental ill health. In practice this did not make much difference to data collection, as all rural participants with mental ill health had a full psychiatric interview that included a review of their psychiatric history. In addition, if a participant was known to the local psychiatric services, their psychiatric history was usually available in primary care records. These were reviewed as part of the research process.

6.2.7 Comparing the rural and urban samples

Despite the differences between the rural and urban samples, it was felt that it was appropriate to compare the two samples for a number of reasons. Some of these are described above in more detail. However, because the primary purpose of the study was to make a rural-urban comparison, it is worth summarising why the student believes that the comparison was valid.

First, although the rural and urban sample sizes were very different, the statistical programme SPSS automatically compensates for unequal sample size, and so the results are statistically valid. In addition, binary logistic regression adjusted for differences between the rural and urban samples and so compensated for the heterogeneity between the two samples.

Second, although the response rates in the rural and urban samples were different, because of the different ways in which they were calculated, it is not possible to compare them. Both the rural and urban samples were drawn from the total population of adults with intellectual disabilities living in defined geographic areas.

Finally, the rural area was chosen very carefully so that it matched the urban area as closely as possible with respect to a number of factors. For example, for geographic and historical reasons, the structure, management and funding of services for people with intellectual disabilities, social services and health services in the two areas are closely matched. Most professional training in the rural area is provided through the urban area, and a number of rural services are centrally managed from within the urban area. As a consequence, any differences were felt to reflect true rural-urban differences.

6.2.8 Regression modelling

The full regression models have been presented in the results section of this thesis and therefore show all of the independent variables that had a significant association with the dependent variable in question. This was important as it helps to place rurality in the context of the other independent variables. In addition to associations with rurality, several of the models suggest other interesting associations. For example, people with intellectual disabilities with a clinical diagnosis of mental ill health were significantly more likely to have had an argument or disagreement in the last week, were less likely to have one or more best friends, less likely to be on first name terms with their neighbours, less likely to tell secrets to anyone, and less likely to meet friends or relatives for a meal on a regular basis. This might suggest that people with intellectual disabilities and mental ill health are more socially isolated than people with intellectual disabilities without mental ill health. Many of the associations had strong face value, and this gives more weight to the validity of the regression models. For example, the single variable that was associated with contact with a psychologist was a clinical diagnosis of mental ill health. Participants with severe or profound disabilities were more likely to have seen a speech and language therapist. There was a dose-response relationship between the level of intellectual disabilities and the likelihood that the participant was in paid

employment. Likewise, there was a dose-response relationship between the level of intellectual disabilities and mental ill health; the more severe the intellectual disabilities, the more likely that the participant had mental ill health. This is an association that has been previously described in the literature.

However, it is important to remember that the models were primarily set up to look at associations with rurality. Categories (such as the type of accommodation and the presence or absence of “mobility”) were chosen to facilitate comparison between the rural and urban samples rather than to explore the variables in their own right. In addition, some of the variables (such as age and the SIMD) had multiple categories, and because the analysis was not adjusted for multiple comparisons, it is likely that a number of apparent associations have arisen by chance. It is therefore best to view the full regression models as a post-hoc analysis. The associations should be used to direct future research rather than being interpreted as evidence of true associations.

6.2.9 The experience of rural life

From a methodological perspective, the section exploring the experience and advantages and disadvantages of rural life was the weakest section of the thesis. The semi-structured questionnaire that was used had been developed by the student, based on a review of relevant literature. It had not been validated or indeed piloted. The semi-structured questionnaire was followed by an unstructured discussion of the advantages and disadvantages of rural life. This was not transcribed verbatim (although salient quotes were recorded) and it was not analysed according to recognised qualitative methodology.

This section of the thesis was always intended as a preliminary exploration. There is very little previous research investigating people with intellectual disabilities living in rural areas, and no research at all looking at the experience, advantages and disadvantages of rural life for this population. It was felt that there was so little information available as to how to structure and analyse this section of the thesis, that it was best carried out as a pilot study with the intention of collecting baseline data that could be used to inform future

research. Therefore, the findings (for example with respect to social exclusion) have not been included in the abstract or conclusion of the thesis.

Despite these limitations, this section of the thesis has provided a wealth of valuable insight into the lives of people with intellectual disabilities living in rural areas, in subject areas that have not been previously described in the literature. In addition, this section of the thesis is important to understanding the thesis as a whole, and the findings have been successfully used in the discussion chapter to explain some of the other study results.

6.3 Strengths and limitations of the original study

6.3.1 Strengths of the original study

One of the main strengths of the study is that it is innovative, and to the student's knowledge, there is no previous research in this area. There is only a small body of research that considers people with intellectual disabilities living in rural areas, and no previous studies that systematically describe and compare a wide range of demographic, health and support related variables with an urban sample. The thesis has been able to identify a number of key similarities and differences between the rural and urban populations that have not been described before. The research is therefore original and novel.

An advantage of this study is that a clear and appropriate definition of rurality was used to distinguish the rural and urban samples. In addition, the rural area was carefully selected so that the results would generalise to other rural environments, and so that an appropriate comparison with the urban area could be made. This is described in more depth in section 6.2.1, and is a major strength of this work compared with other rural research.

6.3.2 Limitations of the original study

The main limitation of this study is the small rural sample size of just 39 participants. This was despite an extensive recruitment campaign, and is fewer than the 50 participants defined by the pre-study power calculation. The study was therefore underpowered to exclude Type II errors when making a direct comparison of the rural and urban samples using the Pearson Chi-square test.

One of the original hypotheses of the thesis was that there were no significant demographic differences between adults with intellectual disabilities living in rural and urban areas. Almost all direct rural-urban demographic comparisons were made using the Pearson Chi-square test. There were very few significant differences between the samples, but this may have been because the rural sample was too small. However, the samples were very similar over a wide range of variables. There were no consistent trends suggesting a true difference between the samples. It therefore seems unlikely that a Type II error has

masked significant differences between the samples and that they represent truly different populations; but it remains a statistical possibility.

In the original power calculation, if $\alpha=0.05$, and if the rural sample size had been 50, the study would have a power of around 80% to detect a minimum difference of 20% between the rural and urban samples. Whether or not a difference of 20% is actually meaningful is a value judgement and depends on the exact comparison that is being made. For example, in the case of gender (i.e. looking for significant gender differences between the rural and urban samples), the figure of 20% is probably not unreasonable. In terms of funding, planning for services, and generalising urban research to the rural population, it probably makes little difference if there is a small difference in the proportion of males to females. With respect to the prevalence of epilepsy, it might be quite important to identify a 20% difference between the rural and urban samples when planning services. If a retrospective power calculation is performed, with a rural sample size of 39 and if $\alpha=0.05$, the study has a power of around 80% to detect a minimum difference of 22.5% between the rural and urban samples (Dupont & Plummer). This is not very different from the minimum difference in the original power calculation. Taking this all into account, it is suggested that the meaning and importance of each non-significant comparison is considered individually when analysing the results.

It is worth noting that large numbers are required to exclude Type II errors using the Pearson Chi-square test. For example, if all 135 adults with intellectual disabilities living in the area under study had agreed to participate in the study, if $\alpha=0.05$, the study would have a power of around 80% to detect a minimum difference of 13% between the samples. Even if the rural sample could have matched the urban sample in size (i.e. $n = 633$ in both the rural and urban samples) and if $\alpha=0.05$, the study would still only have a power of around 80% to detect a minimum difference of 8% between the samples. Therefore, even with large clinical samples, there is likely to be a risk of Type II errors when using the Pearson Chi-square test.

Both age and mental health were analysed using more powerful statistical tools (independent t-test and binary regression modelling) and therefore the finding that they did not differ is very unlikely to represent a Type II error.

As discussed further in section 3.7.3, using binary logistic regression not only ensured sufficient power to analyse the results, but also compensated for heterogeneity in the small rural sample. As discussed in section 6.2.7, the rural sample was felt to be representative, and it was felt to be appropriate to make a valid comparison with the urban sample. Therefore, although the rural sample was small, statistical analysis using regression models was felt to be valid.

Despite the small rural sample size, the study has come up with a large number of very statistically significant results.

Other potential limitations of the study (such as selection bias, and representativeness of the rural sample) have already been discussed in further detail above.

Because of the small sample size, the student considered extending the original study to include additional rural areas. However, she decided against this for two reasons. First, as discussed further in section 6.2.1, it was felt that one of the main strengths of this study was that the rural area was homogeneous with respect to rurality on a number of grounds. For example, there was similar geography, culture, rural industry and relationship with the nearest large city (Glasgow) across the rural area under study. Because of local geographical considerations, extending the study area would have lost this important advantage. Second, the student had previously worked in the area under study and had a number of pre-existing links with intellectual disabilities services. Even so, she struggled to recruit sufficient numbers. Extending outside this area would have required considerably more time and effort for successful recruitment. It is likely that potential participants would be even more dispersed than in the original area under study and hence travel times would be longer. Recruitment to the study had already taken 16 months, and was at the limit of the original research protocol as agreed by the ethics committee. It was decided that on balance the effort required to recruit each additional participant would not justify the small increase in power that it would confer on the study.

6.4 Interpretation of the results of the qualitative sub-study

6.4.1 Participant factors

A number of ideas were developed from the theme of participant factors. These include the importance of interview anxiety and the problem that participants may have in understanding the concept of research. In addition, the results suggest that some participants are simply not interested in participating. This is a useful (if self-evident) finding. The only other previous study to mention this aspect of non-participation is by Swaine et al. (2011). Their research had a response rate of 75%. The authors tried to follow up non-participants “anecdotally”, to establish why they didn’t wish to participate. They were unable to ask non-participants directly, but “suspect” that some participants simply did not want to take part. It is interesting that this is also the only previous research to point out that although researchers aim for a response rate of 100%, if in fact every single potential participant agreed to participate in research, this would imply a degree of coercion and lack of choice. They were satisfied that their response rate of 75% reflected the true number of participants who had actually wanted to take part in their study.

6.4.2 The recruitment process

The results describe the complexity of the recruitment process; this has already been described in previous literature. However, this study described the process in more detail than previously published. For example, it was able to highlight the large amount of work that was sometimes required by interviewees (as intermediaries) to recruit a single participant. It may be helpful for both researchers, and in turn, intermediaries to be aware of this. In addition, this study is useful in that it has come up with a number of very specific successful strategies that could help with future recruitment campaigns. For example, a number of interviewees comment on how useful it was that the student had met informally with potential participants prior to the study. Photos of the student were helpful in identifying and familiarising the researcher. Another finding was the importance of being flexible when conducting the research. Lennox et al. (2005) mention the need for flexibility, and suggest that researchers must be

prepared to visit participants in their own home and also see them out of normal working hours to suit participants and carers. This study takes this suggestion further, and confirms that the flexibility to see participants at their convenience was not only appreciated, but at times was essential to successful recruitment.

Previous literature has suggested that more time and money in intellectual disabilities research should be spent on recruitment; in addition, perhaps researchers should hold more realistic expectations about recruitment, and incorporate it as an important part of the research process in its own right. On completion of the research it was estimated that the student spent a total of 60 hours on recruitment. This included all driving, time spent on administration, and time spent meeting potential participants and intermediaries. As part of this, 250 information packs were distributed. The student was employed by a separate budget, and not including her wages the total estimated total cost of the recruitment campaign was just £320, or £8.21 per participant. This is relatively low compared with other studies (Lennox et al. 2005; Patrick et al. 1998). One of the interviewees suggested that “budget permitting” the study should have been given a glossier image, and used professional support in recruitment. In fact, the budget could have allowed for professional support, and perhaps this would have led to a more successful campaign.

6.4.3 The importance of the researcher

One theme that came out as particularly important in recruitment was the personal approach and the personal characteristics of the researcher. The only mention of this in previous literature is a comment by Swaine et al. (2011). They attribute their success in part to the fact that all members of the research team had at least 9 years of experience in working with people with intellectual disabilities. This meant that the team was effective at working with and in particular communicating complex concepts to people with intellectual disabilities. However, the study by Swaine et al. did not discuss any other attributes of the researchers that might have helped the recruitment process.

Some attributes that might affect recruitment are fixed; for example, in this study the researcher was a female doctor and psychiatrist. However, researchers can choose to portray their rôle in a different light to different audiences. This is

akin to the interviewee who introduced the student as a doctor to families and carers, but used her first name when talking to potential participants. It also suggests that care should be taken when preparing written or aural information about the study. Attributes such as taking a relaxed and informal approach are more amenable to intervention, and if recruitment is conducted by a group, it may be worth playing to individual strengths within the team. The way that the attributes of the researcher are interpreted will depend on personal experience and cultural expectations. These are relatively inflexible in the context of a research project. However, given that recruitment can be so difficult - and given that it is reasonable to expect considerable effort to be made when recruiting each participant - it may be worth considering these at an individual level.

6.4.4 Active recruitment

Active recruitment was another new theme that arose during analysis. This refers to the necessity of each of the intermediaries in the link between the researcher and participant to follow through all of their recruitment efforts. The student herself was diligent in following through any contact with intermediaries. However, she did not ask any of the intermediaries to take the same active approach to recruitment. And as one interviewee suggested, it may have been helpful to explain about the need for active recruitment when asking intermediaries to help. Otherwise the intermediary might hand over information packs to potential participants, but would have no idea that more effort was needed to actually recruit a participant to the study.

6.4.5 Consent, assent and choice

In addition to formal consent, both the participant and usually the participant's immediate family and carers had to agree to participation in the study. Once consent had been given for the participant to take part, as much as possible was done by the student to make it likely that the participant would agree (or not object) to taking part. For example, the student tried to be as flexible as possible about times of appointments, and the interview was always held in a location of the participant's choice. In addition, the student tried to pace the research interview so that the participant did not find it too difficult or tiring. This often meant spreading the interview over 2 visits, and in one case, she

conducted the interview over 4 separate days. However, it was not possible to demonstrate any flexibility unless the participant agreed to be contacted by the student in the first place.

Even if the potential participant themselves was willing and able to give consent, some families and carers did not give permission for the participant to take part in the study. Although this may sometimes occur with research in the general population, this is likely to be a much greater problem in intellectual disabilities research. Interestingly, gaining *formal* consent was not raised as a difficulty by any of the interviewees, and it was not experienced as a particular problem by the student. Out of the final 39 participants, just one next-of-kin refused to consent for an additional participant who was willing but unable to give consent herself.

An unexpected finding was that a couple of the interviewees were reluctant to approach participants themselves; the interviewees felt that because of their relationship with the participant, the participant would not be able to make a free and fair choice about whether or not to participate. Of course the alternative to this is that the participants were not given any choice at all with respect to participating in the study. It may have been helpful to discuss this explicitly with intermediaries, and talk through ways that they could introduce the research to potential participants while making it quite clear that participation was completely voluntary.

6.4.6 The impact of previous research

The impact of previous research has been described before in the literature, and this study confirms this. In particular, potential participants were put off future participation in research if they had not received any feedback from previous studies. Of all the barriers to participation, this is potentially one of the most amenable.

In the UK, the National Ethics Research Service requires a final report to be submitted for all research involving human subjects. This specifically requires information on arrangements for feedback to participants. The results of all UK intellectual disabilities research should therefore have been fed back to

participants. However, this only covers actual research. Audits and other service evaluations (such as consultation exercises) do not have to go through any form of ethical review and there is therefore no external onus on the researcher to give feedback to participants. In addition, most research is likely to go through academic centres with experience of formal research procedures. Audit and service evaluation is more likely to go through local services with less experience and potentially less expectation of feeding back results to participants. When discussing research in this study it was clear that a number of interviewees made no distinction between academic research and local surveys and consultation exercises. From the participant's perspective they must appear very similar. Therefore one of the reasons why potential participants describe not receiving feedback from previous studies may be that they have confused research with consultation exercises.

Given that consultation exercises and surveys are often run outside the health service, it is difficult for healthcare professionals to change current practice. In the meantime it would be helpful for researchers to advise potential participants exactly how they plan to feed the results back on completion of the study.

6.4.7 Motivators

This study explored research participation as an altruistic act in more depth than previous literature. Interviewees felt that most participants were unable to fully understand how participation could help other people, and therefore for most participants, it was unlikely to work as a motivator. However, one interviewee described a participant who really benefitted by being able to do something for other people. People with intellectual disabilities are often dependent on others, and it can be difficult for them to be able to contribute to society in the same way as the general population. For more able participants, research may provide one of few opportunities to directly help others. Not only are participants able potentially to help other people with intellectual disabilities in the future, but they are also able to give direct assistance to the researcher through their participation. Therefore, for a small number of participants it may be helpful to promote research as a genuine opportunity to help others.

Payment for research participation was not mentioned by any of the interviewees; it is not part of the current research culture of the UK, and payment would not be expected or necessarily acceptable. However, one of the interviewees talked at length about giving some sort of direct exchange from the student in return for participation. Although this would have to go through ethical review, there is no reason why a small (non-coercive) incentive could not be exchanged for participation. Previous literature suggests that rewarding participants was not only successful, but also was really appreciated by participants who felt that their contribution and time were valued.

Finally, the student was surprised how openly some of the interviewees talked about what had motivated them to recruit to the study. In addition to more general reasons (such as the potential to improve services in the area), some interviewees talked at length about how they wanted specific people with intellectual disabilities to participate so that they could be seen and reviewed by a medical doctor and specialist intellectual disabilities psychiatrist. There was an expectation that the student would not only feedback to the interviewees, but would also write reports and refer to appropriate services for any follow up required. This did in fact happen; partly because the student did not feel that it would be ethical to ignore an unmet need, and partly because the student had previously worked with local intellectual disabilities services, and found it relatively easy to make appropriate referrals. This was all drawn up in the research protocol and agreed by the ethics committee. However, it did make the student slightly uncomfortable at times. Although participation was in the participant's interest (and did not proceed if the participant objected), it was not always clear what the participant's own personal motivation to participate was.

6.4.8 Was rurality an important factor?

It was very difficult to know from these interviews whether or not rurality had an impact on recruitment. The local culture could potentially affect recruitment in a number of ways: for example, families and carers may be more suspicious of research because of their culture. Previous experience of research is likely to be influenced by rurality, simply because less academic research is conducted in rural areas. Some of the recruitment process may have been affected by aspects

of rurality such as geographic distance. However, as a number of the interviewees commented, it was hard to know whether the interviewees were identifying rural barriers to research, or simply describing their personal experience of the recruitment process, and this happened to be in a rural area. None of the interviewees had been involved in equivalent urban recruitment, and so none of them were able to make a direct comparison of their experiences. Rural factors either could act as a barrier or could improve recruitment. Overall, the impression of the student was that although rurality was a factor, the other themes specifically identified by the qualitative analysis were far more important to recruitment.

Nevertheless, it is probably worth considering local cultural factors when designing a recruitment campaign. A “guide” (as described by Lee 2003) may help advise the researcher. In this case the student lived in the rural area under study and therefore did not feel the need for a guide. Even so, she did not hesitate to ask for advice from professionals who had lived and worked in the area for longer than her.

6.4.9 The generation of strategies to aid future research

The themes that were identified in this study were used to generate a number of strategies and suggestions for recruitment to future intellectual disabilities research. Some of these have been previously described in the literature. For example, a number of authors have highlighted the need to allow plenty of time for a successful recruitment campaign (Tuffrey-Wijne et al. 2011; Evenhuis et al. 2004; Lennox et al. 2005). Lennox et al. (2005) note the need for flexibility when scheduling research appointments, Becker et al. (2004) identify the need to involve families and carers in the recruitment process and d’Abrera et al. (2011) describe the importance of using a proactive and personal approach to recruitment. However, this study has used original data to explore and describe themes in more depth, and this has allowed the generation of a number of new and specific strategies, as described in more detail in above.

6.5 Strengths and limitations of the qualitative sub-study

6.5.1 Strengths of the qualitative sub-study

One of the main strengths of this qualitative sub-study is that there is very little previous research in this field and hence this is a novel contribution. To the author's knowledge, there is only a single dated previous study with the primary outcome of investigating difficulties recruiting to intellectual disabilities research (Siegel & Ellis 1985). All other research in this area has relied on concurrent or more often retrospective analysis of recruitment to existing studies. Although this study was conducted subsequent to the original rural study, it was designed independently as a prospective and separate study in its own right. The design of the study was carefully considered prior to data collection, and independent ethical permission was granted; this permitted, for example, compilation of verbatim transcripts. This has allowed a more in-depth exploration of the difficulties experienced in recruitment to intellectual disabilities research than previous research in this area

All of the interviews were analysed strictly in keeping with the Framework analytical approach. However, other types of qualitative analysis also influenced the direction and interpretation of the interviews. For example, there are aspects of grounded theory to the analysis. The study was not conducted according to a strict grounded theory design (as described by Bryman & Burgess 1994). But from the start, the recruitment campaign was driven by a process of data collection followed by reflection and generation of ideas or theories. These modified the ongoing recruitment campaign, and subsequently influenced the questions contained in the semi-structured interview. Any ideas or theories brought up in individual interviews were explored further with subsequent interviewees, so that by the final interview it was felt that no new ideas were emerging. There was also an element of social anthropology to the data collection. The student lives in the community where the research was conducted, and was aware of some of the local cultural issues that affected the research. She carried out the recruitment campaign herself, and therefore had personal experience of all of the difficulties that the interviewees described. It would have been difficult to direct the qualitative study without these

experiences. These features of data analysis have helped to give a much broader insight than strict adherence to a Framework analytic approach might have allowed.

6.5.2 Limitations of the qualitative sub-study

Although only 10 people were interviewed for the qualitative sub-study, by the end of the interviews, no new topics were emerging, and it was felt that saturation had been reached. It was not felt that further interviews would have added value to the study. However, it is possible that additional interviews could have identified new ideas and themes, and hence generated further strategies for future recruitment.

Purposeful sampling was used to ensure that interviewees were recruited from a wide range of sources. Almost everybody who was approached about taking part in the study agreed to participate. Interviewees were encouraged to speak not only about their own experiences of recruitment, but also to reflect on the attitudes of other intermediaries and also of potential participants and their families. Taking these factors into account, it was felt that selection bias should have been minimal, and it was hoped that the ideas and themes generated from the interviews did not just represent the views of the interviewees themselves, but of the community as a whole.

The interviewees in this study were professionals associated with intellectual disabilities services, and family and unpaid carers were not invited to participate. Permission had not been sought at the time of the original rural study to approach family and unpaid carers with respect to future research; it was therefore felt that it would have been an ethical breach to approach them about the sub-study. Potential participants were also not invited to participate in this study. As described above, interviewees were encouraged to reflect on the attitudes of potential participants and their families during the interviews. However, potential participants and families may have been able to provide different insights into the recruitment in intellectual disabilities research, and this is acknowledged as a limitation.

Chapter 7: Conclusions

7.1 Were the aims of the original study achieved?

The original aims of the study were as follows:

1. To compare a range of demographic and health variables in a rural and an urban sample of adults with intellectual disabilities.
2. To compare access to healthcare services in a rural and an urban sample of adults with intellectual disabilities.
3. To compare a range of markers of social exclusion in a rural and an urban sample of adults with intellectual disabilities.
4. To make a preliminary exploration of how adults with intellectual disabilities experience rural life, and how they are affected by perceived advantages and disadvantages of rural life.

The study recruited a representative sample of 39 adults with intellectual disabilities living in a rural area, collected extensive data through semi-structured interview and compared this with data from a pre-existing urban sample of 633 adults with intellectual disabilities. Variables measured included demographic details, health-related data, data on access to healthcare services and markers of social exclusion. In addition to direct comparison between the rural and urban samples, a series of binary logistic regression models were set up to see if rurality was associated with a selection of the variables. Using regression models compensated both for the small size of the rural sample, and for any heterogeneity between the rural and urban samples. Finally, semi-structured interview and open discussion with participants and their carers explored how adults with intellectual disabilities experience rural life. The author believes that the design and methodology of the study were appropriate, that the data is accurate and valid, and therefore that the study was successful in achieving the original aims.

7.2 Were the hypotheses of the original study addressed?

A number of hypotheses were drawn up prior to data collection. These were as follows:

1. It was hypothesised that there would be no significant demographic differences between adults with intellectual disabilities living in rural and urban areas.
2. It was hypothesised that adults with intellectual disabilities living in rural areas would have better mental health than adults with intellectual disabilities living in urban areas.
3. It was hypothesized that adults with intellectual disabilities living in rural areas would have poorer access to healthcare services.
4. It was hypothesized that markers of social exclusion would differ between adults with intellectual disabilities living in rural and urban areas. It was difficult to predict whether social exclusion would be greater in rural or urban areas as a number of aspects of rural life could have potentially influenced this.

The first hypothesis was addressed by measuring and comparing a wide range of variables. This study found that there were few demographic differences between the rural and urban samples; for example, they did not significantly differ with respect to age, gender, ethnicity, cause and level of disabilities, and also the prevalence of a number of common co-morbidities including epilepsy, visual impairment, and continence. However, because of poor recruitment and consequent small rural numbers, some of these results may have reflected a Type II error. Overall, the rural and urban samples were similar over such a wide range of variables that it was felt that the rural and urban samples were unlikely to represent different populations, and the hypothesis was felt to be upheld. However, the study was underpowered to address this hypothesis satisfactorily.

Because the prevalence of mental ill health is higher in urban areas in the general population, it was hypothesized that urban participants in this study would also have a higher prevalence of mental ill health. This would be a particularly important finding given the high prevalence of mental ill health in adults with intellectual disabilities. However, this hypothesis was not upheld; the study did not show any difference between the prevalence of mental ill health in the rural and urban samples, both on direct comparison and using a binary logistic regression model with clinical mental ill health as the outcome variable. Because of the statistical power of the regression model, this negative finding is unlikely to represent a Type II error.

Despite previous research strongly suggesting that access to healthcare services is worse in rural areas, this study found that adults with intellectual disabilities living in rural areas had significantly better access to both primary (OR = 4.02, 95% CI 1.56-10.35, $P = 0.004$) and secondary care (OR = 3.93, 95% CI = 1.81 - 8.55, $P = 0.001$). Access to allied health professions did not differ between the rural and urban samples, apart from the significant finding that rural participants were more likely to have had recent contact with a dentist (OR = 3.41, 95% CI 1.32-8.81, $P = 0.011$) and optician (OR = 2.59, 95% CI 1.19 -5.61, $P = 0.016$). The third hypothesis was therefore also not upheld.

Next, as originally hypothesized, a number of markers of social exclusion differed between adults with intellectual disabilities living in rural and urban areas. Rural participants were significantly more likely to have a regular daytime opportunity (OR = 10.8, 95% CI = 2.3 - 51.5, $P = 0.003$) including employment (OR = 22.1, 95% CI = 5.7 - 85.5, $P \leq 0.001$) and resource centre attendance (OR = 6.7, 95% CI = 2.6 - 17.2, $P \leq 0.001$). They were also more likely to have been on holiday (OR = 17.8, 95% CI = 4.9 - 60.1, $P \leq 0.001$). However, rural participants were less likely to use community facilities such as cafés (OR = 0.34, 95% CI = 0.13 - 0.93, $P = 0.035$) and the cinema (OR = 0.11, 95% CI = 0.04 - 0.32, $P \leq 0.001$) on a regular basis. Participants from urban and rural areas had a similar number of contacts with other people in a wide range of situations, but the quality of relationships may have been poorer in rural areas. Finally, participants lived in significantly less deprived areas when in rural compared with urban areas (Mann Whitney U = 7826, $Z = -3.675$, $P \leq 0.001$).

In summary, these results show that adults with intellectual disabilities living in rural areas have better daytime opportunities and live in less deprived areas than adults with intellectual disabilities living in urban areas. These are objective markers of social exclusion. However, adults with intellectual disabilities living in rural areas may not hold such positive or close relationships, and this suggests that for adults with intellectual disabilities, subjective markers of social exclusion may be poorer in rural areas.

7.3 Were the aims of the qualitative sub-study achieved?

The original aims of the qualitative sub-study were as follows:

1. To identify difficulties in recruiting to intellectual disabilities research via intermediaries.
2. To use these findings to generate strategies to improve recruitment to future intellectual disabilities research.

The qualitative sub-study entailed audio-recording 10 semi-structured interviews with people who had been involved as intermediaries in recruitment to the research project. These were transcribed verbatim and independently analysed by the student and a colleague using the Framework approach. A number of themes emerged from the transcripts, including participant factors (interview anxiety, difficulties in understanding the concept of research and worry about negative feedback), the importance of the researcher (using a personal approach, and meeting potential participants prior to recruitment) and motivators (such as enjoyment of the research interview (participant), and obtaining a medical assessment (carer). The themes were therefore successfully used to identify difficulties in recruiting to intellectual disabilities research via intermediaries.

These themes were then used to generate strategies to improve recruitment to intellectual disabilities research: these include the research team applying a more personal approach, designing the recruitment process to allow for flexibility and multiple meetings with potential participants, and considering motivators for both participants and carers. The second aim was therefore also achieved.

7.4 What this thesis adds

To the author's knowledge, there is no previous research that systematically describes and compares adults with intellectual disabilities living in rural areas with adults with intellectual disabilities living in urban areas. The methodology and data analysis in this study are robust, and the study has come up with a number of interesting and significant findings. In particular, the study has shown that there are no significant demographic or health differences for adults with intellectual disabilities living in rural and urban areas, access is better in rural areas, and that objective but not necessarily subjective markers of social exclusion are better in rural areas. Rural participants were able to describe benefitting from a number of advantages of rural life. These are all novel findings. This research is therefore both original and valuable, and contributes new knowledge to the fields of both intellectual disabilities and rural research.

To the author's knowledge, there is no previous research that has investigated recruitment to intellectual disabilities research as a primary outcome. The qualitative sub-study identified a number of themes relating to recruitment, and then used these themes to generate a number of strategies to improve future recruitment to intellectual disabilities research. Some of the themes have been described before in the literature, but using a rigorous method of qualitative analysis has given more strength to the findings, and allowed exploration of the themes in more depth than previously. In addition, a number of the themes have not been described before in the literature. Likewise, strategies generated were described in more detail than previously, and a number of them have not been previously considered. Successful recruitment is essential to intellectual disabilities research, and this research is therefore both novel and a valuable contribution to future intellectual disabilities researchers.

7.5 Directions for future research

The main limitation of the original study was the small sample of rural participants. It would therefore be useful to repeat the study, aiming to recruit a larger rural sample. It would be important to choose the rural area carefully, noting any similarities and differences with the rural area in the original study. If the study were repeated in a rural area elsewhere in Scotland or the UK, it would be important to ensure that there was an appropriate urban comparator sample.

The original study specifically excluded adults with intellectual disabilities living on Islands. It would be interesting to repeat the study again in an Island setting; both to compare with an urban population, and also with the rural population in this study.

Having identified that access to healthcare is better in rural areas, it would be valuable to explore the reasons for this. People with intellectual disabilities are known to have poorer access to healthcare services than the general population, and research in this area could be used to address current inequalities. It would also be interesting to conduct a more in-depth exploration of aspects of social exclusion for people with intellectual disabilities living in rural areas; particularly with respect to the quality of relationships held.

It is possible that the findings in this study are not specific to the population with intellectual disabilities, but are also true for the general population. For example, perhaps access to healthcare services is generally better for people living in rural areas, and not only for people with intellectual disabilities? Although previous research suggests that access is worse in rural areas, to the student's knowledge there are no previous studies that have investigated access in the same way as this study. It would therefore be helpful to repeat the study with the general population in the areas under study and see if the findings were replicated. This would be an important and new finding, and would be valuable in helping shape and improve health services in both rural and urban areas.

The final section of the original study was intended as a preliminary exploration. It would be helpful to repeat this, perhaps as a separate study to allow for more

in-depth analysis, and using the findings of this thesis to draw up a more detailed semi-structured questionnaire. A recognised means of qualitative analysis (such as the Framework Approach) could be used to analyse audio-recorded and transcribed interviews. It would also be interesting to use focus groups as a means of stimulating discussion and generating ideas.

It would be valuable if the qualitative sub-study could be extended to include family, immediate carers and potential participants. This would offer additional useful information about the experiences and perceptions of recruitment to intellectual disabilities research. It would also be of interest to repeat the study as a sub-study to an existing urban project; for example, the urban study on which this research was based. Although the sub-study did not suggest any rural-urban differences, it was not specifically designed to identify these. An urban study could aid rural-urban comparison, and also uncover additional themes and generate additional strategies to help with future recruitment.

References

- Abbott S. & McConkey R. (2006) The barriers to social inclusion as perceived by people with intellectual disabilities. *Journal of Intellectual Disability*, **10**, 275-87.
- Ager, A. (1998) The BILD Life Experiences Checklist, second edition. Kidderminster, Worcestershire, BILD Publications.
- Aisbett D. L., Boyd C. P., Francis K. J. & Newnham K. (2007) Understanding barriers to mental health service utilization for adolescents in rural Australia. *Rural and Remote Health*, **7** (online), 624.
- Akesson H. O. (1974) Geographical differences in the prevalence of mental deficiency. *British Journal of Psychiatry*, **125**, 542-6.
- American Psychiatric Association 2000, *Diagnostic and Statistical Manual of Mental Disorders Text Revision, Fourth Edition* American Psychiatric Association, Washington D.C.
- Ashman A. F., Hulme P. & Suttie J. (1990) The life circumstances of aged people with an intellectual disability. *Australia and New Zealand Journal of Developmental Disabilities*, **16** (4), 335-47.
- Bachrach L. (1983) Psychiatric services in rural areas: a sociological review. *Hospital and Community Psychiatry*, **34** (3), 215-26.
- Baker P. A. (2000) Measurement of community participation and use of leisure by services users with intellectual disabilities: the Guernsey Community Participation and Leisure Assessment (GCPLA). *Journal of Applied Research in Intellectual Disabilities*, **13**, 169-85.
- Becker H., Roberts G., Morrison J. & Silver J. (2004) Recruiting people with disabilities as research participants: challenges and strategies to address them. *Mental Retardation*, **42** (6), 471-5.
- Bedard M., Koivuranta A. & Stuckey A. (2004) Health impact on caregivers of providing informal care to a cognitively impaired older adult: rural versus urban settings. *Canadian Journal of Rural Medicine*, **9** (1), 15-23.
- Bhugra D. (2004) Migration and mental health. *Acta Psychiatrica Scandinavica*, **109**, 243-58.
- Bibby P. & Shepherd J. (2004) Developing a new Classification of Urban and Rural area for policy purposes - the methodology. Office for National Statistics, London, UK.
- Bilj R. V., Ravelli A. & van Zessen G. (1998) Prevalence of psychiatric disorder in the general population: results of The Netherlands Mental Health Survey and Incidence Study (NEMESIS). *Social Psychiatry and Psychiatric Epidemiology*, **33** (12), 587-95.

- Bishop J., Clark D., Harris V., Stockton D. & Sutton M. (2004) Deprivation and urban rural measurements in ISD.
- Blazer D., George L. K., Landerman R., Pennybacker M., Melville M. L., Woodbury M. et.al. (1985) Psychiatric disorders. A rural/urban comparison. *Archives of General Psychiatry*, **42** (7), 651-6.
- Bloor, M., Horobin, G., Taylor, R., & Williams, R. (1978) Island health care: access to primary services in the Western Isles. Occasional Paper No 3. Aberdeen, Institute of Medical Sociology, University of Aberdeen.
- Bramston P., Bruggerman K. & Pretty G. (2002) Community perspectives and subjective quality of life. *International Journal of Disability, Development and Education*, **49** (4), 385-97.
- British Medical Association Board of Science (2005) Healthcare in a rural setting. London, UK. http://www.bma.org.uk/healthcare_policy/healthcarerural.jsp.
- Campbell N. C., Elliot A. M., Sharp L., Ritchie L. D., Cassidy J. & Little J. (2002) Impact of deprivation and rural residence on treatment of colorectal and lung cancer. *British Journal of Cancer*, **87** (6), 585-90.
- Campbell N. C., Elliot A. M., Sharp L., Ritchie L. D., Cassidy J. & Little J. (2001) Rural and urban differences in stage at diagnosis of colorectal and lung cancers. *British Journal of Cancer*, **84** (7), 910-4.
- Campbell N. C., Elliot A. M., Sharp L., Ritchie L. D., Cassidy J. & Little J. (2000) Rural factors and survival from cancer: analysis of Scottish cancer registrations. *British Journal of Cancer*, **82** (11), 1863-6.
- Carstairs V. & Morris R. (1989) Deprivation: explaining the differences in mortality between Scotland and England and Wales. *British Medical Journal*, **299**, 886-9.
- Cleaver S. H., Ouellette-Kuntz H. & Sakar A. (2010) Participation in intellectual disability research: a review of 20 years of studies. *Journal of Intellectual Disabilities Research*, **54** (3), 187-93.
- Collins, P., Patel, V., Joestl, S., March, D., Insel, T., Daar, A. et al. (7-7-2011) Grand challenges in global mental health. *Nature* **475**, 27-30
- Cooper S.-A. (1997) Epidemiology of psychiatric disorders in elderly compared with younger adults with learning disabilities. *British Journal of Psychiatry*, **170**, 375-80.
- Cooper, S.-A., McConnachie, A., Allan, L., Melville, C., Smiley, E., & Morrison, J. (2010) Neighbourhood deprivation, health inequalities, and service use of adults with intellectual disabilities. Cross sectional study. *Journal of Intellectual Disability Research* **55**, 313-323
- Cooper S.-A., Melville C. & Morrison J. (2004) People with intellectual disabilities. *British Medical Journal*, **329**, 414-5.

- Cooper S.-A., Smiley E., Morrison J., Allan L., Williamson A., Finlayson J. et.al. (2007a) Psychosis and adults with intellectual disabilities. Prevalence, incidence and related factors. *Soc Psychiatry Psychiatric Epidemiology*, **42**, 530-6.
- Cooper S.-A., Smiley E., Morrison J., Williamson A. & Allan L. (2007b) Mental ill-health in adults with intellectual disabilities: prevalence and associated factors. *British Journal of Psychiatry*, **190**, 27-35.
- Cornelissen P. G., Rasker J. J. & Valdenburg H. A. (1988) The arthritis sufferer and the community: a comparison of arthritis sufferers in rural and urban areas. *Annals of the Rheumatic Diseases*, **47** (2), 150-6.
- Countryside Agency (2004) A report to the countryside agency. Review of countryside issues in England. Countryside Agency Publications, Wetherby,
- Couper I. D. (2003) Rural hospital focus: defining rural. *Rural and Remote Health*, **3** (online), 205.
- Crawford P. & Brown B. (2002) 'Like a friend going round': reducing the stigma attached to mental healthcare in rural communities. *Health and Social Care in the Community*, **10** (4), 229-38.
- Cummins R. A. & Lau A. L. D. (2003) Community integration or community exposure? A review and discussion in relation to people with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, **16**, 145-57.
- Dawson D. A., Grant B. F., Chou S. P. & Pickering R. P. (1995) Subgroup Variation in U.S. Drinking Patterns: Results of the 1992 National Longitudinal Alcohol Epidemiologic Study. *Journal of Substance Abuse*, **7**, 331-4.
- Department of Health (2001) Valuing People: A New Strategy for Learning Disability for the 21st century. Department of Health, HMSO, London, 5086.
- du Plessis V., Beshiri R., Bollman R. D. & Clemenson H. (2002) Definitions of "Rural", Agricultural and Rural Working Paper. Statistics Canada, Agricultural Division, Ottawa, 061.
- Dupont W.D. & Plummer W.D. (1998) Power and Sample Size Calculations for Studies Involving Linear Regression. *Controlled Clinical Trials*, **19**, 589-601.
- Emerson E. (2007) Poverty and people with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews*, **13**, 107-13.
- Emerson E., Malam S., Davies I. & Spencer K. (2005) Adults with learning difficulties in England 2003/2004. NHS Health and Social Care Information Centre,
- Evenhuis H. M., Theunissen M., Denkers I., Verschuure H. & Kemme H. (2001) Prevalence of visual and hearing impairment in a Dutch institutionalized population with intellectual disability. *Journal of Intellectual Disability Research*, **45**, 457-64.
- Farmer J., Hinds K., Richards H. & Godden D. (2005) Urban versus rural populations' views of health care in Scotland. *Journal of Health Services and Research Policy*, **10** (4), 212-9.

- Farmer J. C., Baird A. G. & Iversen L. (2001) Rural deprivation: reflecting reality. *British Journal of General Practice*, **51** (467), 486-91.
- Farmer J. E., Clark M. J. & Sherman A. K. (2003) Rural versus urban social support seeking as a moderating variable in traumatic brain injury outcome. *Journal of Head Trauma Rehabilitation*, **18** (2), 116-27.
- Felce D. & Emerson E. (2001) Living with support in a home in the community: predictors of behavioural development and household and community activity. *Mental Retardation and Developmental Disabilities Research Reviews*, **7**, 75-83.
- Forester-Jones R., Carpenter J., Coolen-Schrijner P., Cambridge P., Tate A., Beecham A. et.al. (2006) The social networks of people with intellectual disability living in the community 12 years after resettlement from long-stay hospitals. *Journal of Applied Research in Intellectual Disabilities*, **19**, 285-95.
- Freeman H. (1994) Schizophrenia and city residence. *British Journal of Psychiatry*, **23** (Sup), 39-50.
- Fuller J., Edwards J., Procter M. & Moss J. (2000) How definition of mental health problems can influence help seeking in rural and remote communities. *Australian Journal of Rural Health*, **8** (3), 148-53.
- Gale J. A. & Lambert D. (2006) Mental Healthcare in Rural Communities: The Once and Future Role of Primary Care. Commentary. *NC Medical Journal*, **67** (1), 66-70.
- Gesler W., Arcury T. A., Preisser J., Trevor J., Sherman J. E. & Spencer J. (2000) Access to care issues for health professionals in the mountain region of North Carolina. *International Quarterly of Community Health Education*, **20** (1), 83-102.
- Gething L. (1997) Sources of double disadvantage for people with disabilities living in remote and rural areas of New South Wales, Australia. *Disability and Society*, **12** (4), 513-31.
- Glasgow U.C.E.D.D. (2001) C21st Health Check Glasgow. Glasgow, Glasgow U.C.E.D.D.
- Glasgow U.C.E.D.D. (2002a) ADHD Checklist. Glasgow, Glasgow U.C.E.D.D.
- Glasgow U.C.E.D.D. (2002b) Pervasive Development Disorder Questionnaire. Glasgow, Glasgow U.C.E.D.D.
- Glasgow U.C.E.D.D. (2002c) Problem Behaviour Questionnaire. Glasgow, Glasgow U.C.E.D.D.
- Goble C. (2000) The BILD life experiences checklist; Book review. *British Journal of Developmental Disabilities* (90), 73-5.
- Goddard M. & Smith (2001) Equity of access to health care services: theory and evidence from the UK. *Social Science and Medicine*, **53** (9), 1149-62.
- Godden D., Heaney D. & Farmer J. (2007) Contemporary Issues in Scottish Rural Health Care. A briefing paper. *Health and Rurality Digest (HEARD)* (12).

Goldberg, D. & Williams, P. (1988) The User's Guide to the General Health Questionnaire (1st edn). Windsor: NFFR-Nelson.

Goodyear-Smith F. & Janes R. (2006) The 2005 Rural Health Workforce Survey. New Zealand Institute of Rural Health, Ministry of Health, Wellington,

Greiner K. A., Li C., Kawachi I., Hunt D. C. & Ahluwalia J. S. (2004) The relationships of social participation and community ratings to health and health behaviors in areas with high and low population density. *Social Science and Medicine*, **59** (11), 2303-12.

Hall E. (2005) The tangled geographies of social exclusion/inclusion for people with learning disabilities. *Health and Place*, **11**, 107-15.

Hall L. & Hewson S. (2006) The community links of a sample of people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, **19** (204), 207.

Hart L. G., Larson E. H. & Lishner D. M. (2005) Rural definitions for health policy and research. *American Journal of Public Health*, **95** (7), 1149-55.

Hart L. G., Salsberg E., Phillips D. M. & Lishner D. M. (2002) Rural health care providers in the United States. *Journal of Rural Health*, **18** (Suppl), 211-32.

Haynes R. & Gale S. (2000) Deprivation and poor health in rural areas: inequalities hidden by averages. *Health and Place*, **6** (4), 275-85.

Hills, J., Le Grand, J., & Piachaud, D. 2002, *Understanding Social Exclusion* Oxford University Press, Oxford.

House of Lords, House of Commons & Joint Committee on Human Rights (2008) A Life Like Any Other? Human Rights of Adults with Learning Disabilities. The Stationary Office Limited, London, Volume 1, report and formal minutes. HL Paper 40-I HC 73-I.

Housing Assistance Council (2006) Poverty in Rural America. Housing Assistance Council, Washington DC,

Hoyt D. R., Conger R. D., Valde J. G. & Weihs K. (1997) Psychological distress and help seeking in rural America. *American Journal of Community Psychology*, **25** (4), 449-70.

Hulme P. & Blegen M. A. (1999) Residential status and birth outcomes: is the rural/urban distinction adequate? *Public Health Nursing*, **16** (3), 176-81.

Humphreys J. S. (1998) Delimiting 'rural': implications of an agreed 'rurality' index for healthcare planning and resource allocation. *Australian Journal of Rural Health*, **6** (4), 212-6.

Hwu H. G. & Compton W. M. (1994) Comparison of major epidemiological surveys using the diagnostic interview schedule. *International Review of Psychiatry*, **6** (4), 309-27.

- Iacono T. (2006) Ethical challenges and complexities of including people with intellectual disability as participants in research. *Journal of Intellectual and Developmental Disability*, **31** (3), 173-9.
- Iacono T., Davis R., Humphreys J. S. & Chandler N. (2003) General Practice and support people's concerns and priorities for meeting the health care needs of individuals with developmental disabilities: a metropolitan and non-metropolitan comparison. *Journal of Intellectual and Developmental Disability*, **28** (4), 353-68.
- Iezzoni L. I., Killeen M. B. & O'Day B. L. (2006) Rural residents with disabilities confront substantial barriers to obtaining primary care. *Health Services Research*, **41** (4 Part 1), 1258-75.
- ISD Scotland (2010) General Practice - Quality and Outcomes Framework (List of indicators and domains). www.isdscotland.org/isd/3305.html.
- Iversen L., Hannaford P. C., Price D. B. & Godden D. (2005) Is living in a rural area good for your respiratory health? Results from a cross-sectional study in Scotland. *Chest*, **128** (4), 2059-67.
- James C. & Gimson S. (2007) Families and neighbourhoods. Report from Family and Parenting Institute. Family and Parenting Institute, www.familyandparenting.org.
- Johns L. C., Cannon M., Singleton N., Murray R., Farrell M., Brugha T. et.al. (2004) Prevalence and correlates of self-reported psychotic symptoms in the British population. *British Journal of Psychiatry*, **185** (5), 298-305.
- Jones A. P. & Bentham G. (1995) Emergency medical service accessibility and outcome from road traffic accidents. *Public Health*, **109** (3), 169-77.
- Jones A. P., Bentham G. & Horwell C. (1999) Health service accessibility and deaths from asthma. *International Journal of Epidemiology*, **28** (1), 101-5.
- Jong K. E., Smith D. P., Yu X. Q., O'Connell D. L., Goldstein D. & Armstrong B. K. (2004) Remoteness of residence and survival from cancer in New South Wales. *Medical Journal of Australia*, **180** (12), 618-22.
- Judd F., Jackson H., Komiti A., Murray G., Hodgins G. & Fraser C. (2002) High prevalence disorders in urban and rural communities. *Australian and New Zealand Journal of Psychiatry*, **36** (1), 104-13.
- Kessler R. C., McGonagle K. A., Zhao S., Nelson C. B., Hughes M., Eschleman S. et.al. (1994) Lifetime and 12-month prevalence of DSM-III-R psychiatric disorders in the United States: Results from the national comorbidity survey. *Archives of General Psychiatry*, **51** (1), 8-19.
- Larson A., Bell M. & Young A. F. (2004) Clarifying the relationships between health and residential mobility. *Social Science and Medicine*, **59** (10 Spec. Iss.), 2149-60.
- Leduc E. (1997) Defining rurality: a General Practice Rurality Index for Canada. *Canadian Journal of Rural Medicine*, **2** (2), 125.

- Lee, R. M. (1993) *Doing research on sensitive topics*. Sage publications, London.
- Lennox N., Taylor M., Rey-Conde T., Bain C., Purdie D. M. & Boyle F. (2005) Beating the barriers: recruitment of people with intellectual disability to participate in research. *Journal of Intellectual Disabilities Research*, **49** (4), 296-305.
- Maas J., Verheij R. A., Groenewegen P. P., Vries S. & Spersuwenberg P. (1996) Green space, urbanity, and health: how strong is the relation? *Journal of Epidemiology and Community Health*, **60** (7), 587-92.
- Magliano L., Fiorillo A., Malangone C., De Rosa C. & Maj M. (2006) Social network in long-term diseases: a comparative study in relatives of persons with schizophrenia and physical illnesses versus a sample from the general population. *Social Science and Medicine*, **626**, 1392-1402.
- Maryon-Davis A. (2007) Achieving health equity for all. *British Medical Journal*, **335**, 522-3.
- McGuffie A. C., Graham C. A., Beard D., Henry J. M., Fitzpatrick M. O., Wilkie S. C. et.al. (2005) Scottish urban versus rural trauma outcome study. *Journal of Trauma*, **59** (3), 632-8.
- Mencap (2007) Death by indifference. Following up the *Treat me right!* report. Mencap, London.
- Mencap (2004) *Treat me right! Better healthcare for people with a learning disability*. Mencap, London.
- Mitchell R. & Popham F. (2007) Greenspace, urbanity and health: relationships in England. *Journal of Epidemiology and Community Health*, **61** (681), 683.
- Morgan C., Ahmed Z. & Kerr M. P. (2000) Health care provision for people with a learning disability. Record-linkage study of epidemiology and factors contributing to hospital care uptake. *British Journal of Psychiatry*, **176**, 37-41.
- Moss S., Prosser H., Costello H., Simpson N., Patel P., Rowe S. et.al. (1998) Reliability and validity of the PAS-ADD Checklist for detecting psychiatric disorders in adults with intellectual disability. *Journal of Intellectual Disability Research*, **42**, 173-83.
- Muula A. S. (2007) How do we define "rurality" in the teaching on medical demography. *Rural and Remote Health*, **7**, 653.
- Myers F., Ager A., Kerr P. & Myles S. (1998) Outside Looking In? Studies of the Community Integration of People with Learning Disabilities'. *Disability and Society*, **13** (3), 389-413.
- Narrow W. E., Rae D. S., Robins L. N. & Regier D. A. (2002) Revised prevalence estimates of mental disorders in the United States. Using a clinical significance criterion to reconcile 2 surveys' estimates. *Archives of General Psychiatry*, **59**, 115-23.

- Nattinger A. B., Kneusel R. T., Hoffman R. G. & Gilligan M. A. (2001) Relationship of distance from a radiotherapy facility and initial breast cancer treatment. *Journal of the national Cancer Institute*, **93** (17), 1344-6.
- New Freedom Commission (2004) New Freedom Commission on Mental Health, Subcommittee on Rural Issues: Background Paper. Rockville, MD, DHHS Pub. No. SMA-04-3890.
- NHS Scotland (2004) Health Needs Assessment Report, People with learning disabilities in Scotland. Clifton House, Clifton Place, Glasgow.
- NHS Scotland (2005) Kerr Report. Rural Access Action Team. The National Framework for service change in Scotland. Final Report.
- Nicholl J., West J., Goodacre S. & Turner J. (2007) The relationship between distance to hospital and patient mortality in emergencies: an observational study. *Emergency Medicine Journal*, **24**, 665-8.
- Nierse, C. J. & Abma, T. A. (2011) Developing voice and empowerment: the first step towards a broad consultation in research agenda setting. *Journal of Intellectual Disability Research*, **55**, 411-421.
- Office for National Statistics (2001) UK Census 2001. UK Government. <http://www.statistics.gov.uk/census/default.asp>.
- Oliver P. C., Piachaud J., Done J., Regan A., Cooray S. & Tyrer P. (2002) Difficulties in conducting a randomized controlled trial of health service interventions in intellectual disability: implications for evidence-based practice. *Journal of Intellectual Disability Research*, **46** (4), 340-5.
- Parr H. & Philo C. (2003) Rural mental health and social geographies of caring. *Social and Cultural Geography*, **4**, 471-88.
- Paykel E., Abbott R., Jenkins T., Brugha T. S. & Meltzer H. (2003) Urban-rural mental health differences in Great Britain: findings from the National Morbidity Survey. *International Review of Psychiatry*, **15**, 97-107.
- Peters J. & Jackson R. (2005) The impact of rurality on health; a systematic review. Is there a health impact of rural compared with urban residence? What health related interventions work for elderly populations living in rural areas? Rural Evidence Research Centre, Sheffield, UK.
- Philo C., Parr H. & Burns N. (2002) Social Geographies of Rural Mental Health: Findings papers. ESRC Funded Research Project, Award No. R000 238453. Universities of Glasgow and Dundee, Scotland. Originally published online, no longer available.
- Philo C., Parr H. & Burns N. (2003) Rural madness: a geographical reading and critique of the rural mental health literature. *Journal of Rural Studies*, **19**, 259-81.
- Priebe S. (2007) Social outcomes in schizophrenia. *British Journal of Psychiatry*, **191** (Sup 5), s15-s20.

- Probst J. C., Laditka S. B., Moore C. G., Harun N., Powell M. P. & Baxley E. G. (2006) Rural-urban differences in depression prevalence: Implications for family medicine. *Family Medicine*, **38** (9), 653-60.
- Pruchno R. A., Patrick J. H. & Burant J. C. (1996) Mental health of aging mothers with offspring who are chronically disabled: Examination of a two-factor model. *Journal of Gerontology: Social Sciences*, **51** (B), S284-S296.
- Quine S., Bernard D., Booth M., Kang M., Usherwood T., Alperstein G. et.al. (2003) Health and access issues among Australian adolescents: a rural-urban comparison. *Rural and Remote Health*, **3** (online), 245.
- Ritchie, J. & Spencer, L. (1994) "Qualitative data analysis for applied policy research," in *Analyzing Qualitative Data*, A. Bryman & R. G. Burgess, eds., Routledge, London. pp. 172-194.
- Robertson J., Emerson E., Pinkney L., Caesar E., Felce D., Meek A. et.al. (2005) Community based residential supports for people with intellectual disabilities and challenging behaviour: the views of neighbours. *Journal of Applied Research in Intellectual Disabilities*, **18**, 85-92.
- Royal College of Psychiatrists (2001) *DC-LD. Diagnostic criteria for psychiatric disorders for use with adults with learning disabilities/mental retardation. Occasional Paper OP48*. Gaskell, London.
- Scottish Executive (2000a) Fair Shares for All. Final Report. National Review of Resource Allocation. Scottish Executive.
<http://www.scotland.gov.uk/Publications/2005/10/19142752/27522>.
- Scottish Executive (2003a) Living In Scotland: An Urban-Rural Analysis of The Scottish Household Survey - Research Findings. Scottish Executive, Edinburgh.
- Scottish Executive (2006a) Scottish Executive Urban Rural Classification 2005 - 2006. Scottish Executive, St Andrew's House, Edinburgh.
- Scottish Executive (2000b) The same as you? A Review of Services for People With Learning Disabilities. Scottish Executive, The Stationary Office, Edinburgh.
- Scottish Executive (2001) Poverty and social exclusion in rural Scotland. Scottish Executive, Edinburgh.
- Scottish Executive (2003b) Social focus on urban rural Scotland. Edinburgh.
- Scottish Executive (2006b) Rural Scotland Key Facts 2006. Edinburgh.
www.scotland.gov.uk/Publications/2006/11/02103309/2.
- Scottish Executive, Accent Scotland & Mauthner N. (2006) Service priority, accessibility and quality in rural scotland. Scottish Executive, Edinburgh.
- Sharon M., Darling P. & Gallagher A. (2004) Needs of and Supports for African American and European American Caregivers of Young CHildren with Special Needs in Urban and Rural Settings. *Topics in Early Childhood Special Education*, **24** (2), 98-109.

- Shucksmith, M., Chapman, P., & Clark, G. M. (1996) *Rural Scotland Today: the best of both worlds?* Ashgate publishing Ltd, Avebury, Aldershot, UK.
- Singleton N. & Lewis G. (2003) *Better or Worse: A Longitudinal Study of the Mental Health of Adults Living in Private Households in Great Britain*. The Stationary Office, London.
- Skinner A. C. & Slifkin R. T. (2007) Rural/urban differences in barriers to and burden of care for children with special health care needs. *Journal of Rural Health*, **23** (2), 150-7.
- Slater M. A. & Black P. (1986) Urban-rural differences in the delivery of community services: Wisconsin as a case in point. *Mental Retardation*, **24** (3), 153-61.
- Slifkin R. T. (2002) Developing policies responsive to barriers to health care among rural residents: what do we need to know? *Journal of Rural Health*, **18** (Suppl), 233-41.
- Smiley E., Cooper S.-A., Finlayson J., Jackson A., Allan L., Mantry D. et.al. (2007) Incidence and predictors of mental ill-health in adults with intellectual disabilities. Prospective study. *British Journal of Psychiatry*, **191**, 313-9.
- Sparrow, S. S., Balla, D. A., & Cicchetti, D. V. (1984) A revision of the Vineland Social Maturity Scale by E. A. Doll. Minnesota, American Guidance Service.
- Strong K., Trickett P., Titulaer I. & Bhatia K. (1998) Health in rural and remote Australia. The first report of the Australian Institute of Health and Welfare on rural health. Australian Institute of Health and Welfare, Canberra, AIHW Cat. No. PHE 6. <http://www.aihw.gov.au/publications/health/hrra/index.html>.
- Sturmey P., Newton J. T., Cowley A., Bouras N. & Holt G. (2005) The PAS-ADD Checklist: independent replication of its psychometric properties in a community sample. *British Journal of Psychiatry*, **186**, 319-23.
- Sundquist K., Frank G. & Sundquist J. (2004) Urbanisation and incidence of psychosis and depression: follow-up study of 4.4 million women and men in Sweden. *British Journal of Psychiatry*, **84**, 293-8.
- Sweeney P. & Kisely S. (2003) Barriers to managing mental health in Western Australia. *Australian Journal of Rural Health*, **11** (4), 205-10.
- The Scottish Government (2006) Scottish Government Urban Rural Classification 2005 - 2006. The Scottish Government, Edinburgh. <http://www.scotland.gov.uk/Publications/2006/07/31114822/0>.
- The Scottish Government (2008) Scottish Government Urban Rural Classification 2007-2008. The Scottish Government, Edinburgh. www.scotland.gov.uk/Resource/Doc/233802/0063988.pdf.
- The Scottish Government (2004) Analysis of ethnicity in the 2001 Census - summary. <http://www.scotland.gov.uk/Publications/2004/02/18876/32937>.
- The Scottish Government (2010) The Scottish Index of Multiple Deprivation. www.scotland.gov.uk/Topics/Statistics/SIMD.

- Tyrer P., Oliver-Africano P., Ahmed Z., Bouras N., Cooray S. & Deb S. (2008) Risperidone, haloperidol and placebo in the treatment of aggressive challenging behaviour in patients with intellectual disability: a randomised controlled trial. *Lancet*, **371**, 57-63.
- Valentine G., Holloway S. L., Jayne M. & Knell C. (2007) Drinking places: Where people drink and why. Joseph Rowntree Foundation, York, UK. <http://www.jrf.org.uk/sites/files/jrf/2139.pdf>.
- Van Os J., Hanssen M., Bilj R. V. & Vollebergh W. (2001) Prevalence of psychotic disorder and community level of psychotic symptoms: An urban-rural comparison. *Archives of General Psychiatry*, **58** (7), 663-8.
- Van Son G. E., Van Hoeken D., Bartelds A. I. M., Van Furth E. F. & Hoek H. W. (2006) Urbanisation and the incidence of eating disorders. *British Journal of Psychiatry*, **189**, 562-3.
- Verheij R. A. (1996) Explaining urban-rural variations in health: a review of interactions between individual and environment. *Social Science and Medicine*, **42** (6), 923-35.
- Wakeman J. (2004) Defining remote health. *Australian Journal of Rural Health*, **12** (5), 210-4.
- Watt I. S., Franks A. J. & Sheldon T. A. (1994) Health and health care of rural populations in the UK: is it better or worse? *Journal of Epidemiology and Community Health*, **48** (1), 16-21.
- Watt I. S., Franks A. J. & Sheldon T. A. (1993) Rural health and health care. Unjustifiably neglected in Britain. *British Medical Journal*, **306**, 1358-9.
- Weich S., Twigg L., Holt G., Lewis G. & Jones K. (2003) Contextual risk factors for the common mental disorders in Britain: a multilevel investigation of the effects of place. *Journal of Epidemiology and Community Health*, **57** (8), 616-21.
- Weich S., Twigg L. & Lewis G. (2006) Rural/non-rural differences in rates of common mental disorders in Britain: prospective multilevel cohort study. *British Journal of Psychiatry*, **188**, 51-7.
- West P., Illsley R. & Kelman H. (1984) Public preferences for the care of dependency groups. *Social Science and Medicine*, **18** (4), 287-95.
- Wilcox D. A., Dowrick P. W. & Ward K. M. (2001) Effectiveness of a model for training direct service personnel in rural and remote locations. *Journal of Intellectual and Developmental Disability*, **26** (4), 311-23.
- Wood J. (2004) Rural Health and Healthcare: A North West perspective. A Public health information report from the North West Public Health Observatory. Lancaster University, UK.
- World Health Organisation 1993, *The ICD-10 Classification of Mental and Behavioural Disorders. Diagnostic criteria for research*. World Health Organisation, Geneva.

World Health Organisation . (2006) Constitution of the World Health Organisation. Basic Documents, Forty-fifth edition. Supplement, October 2006 , United Nations.

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Appendix 1: Literature search

A literature search into aspects of rural life, rural mental health, rural physical health, and access and social exclusion in rural areas, and also mental health, physical health, access and social exclusion in the general population and in people with intellectual disabilities was carried out prior to designing and conducting the original study. The search was performed through OVID managed electronic databases until the date March 2007 (specific databases included Medline, Cinahl, Embase and Psychlit). In addition, all search terms were also run through the Google and Google Scholar search engine. Key papers were then read for further appropriate references. Following this, the student explored a number of relevant web-sites including those of DEFRA (Department of Environment, Food and Rural Affairs), the WHO, the Scottish Executive, SHOW (Scotland's Health on the Web), the Centre for Rural Health Research and Policy (Scotland), and the UK Royal Colleges of Psychiatry and Medicine.

Search terms included the following: access, autism, asperger, attitude, challenging behaviour, demography, geographic/rural mobility/migration, health (care) services/primary care/secondary care, intellectual disability (also learning disability, mental retardation, mental deficiency, mental disability, mental handicap, mental subnormal, developmental disability, idiocy), mental health (also mental disorders, psychiatry, mental illness), physical health (health status), quality of life, rural, suburban, urban, social (behaviour, isolation, discrimination, integration, participation, support, exclusion, inclusion, contact, network), socioeconomic status, prejudice, and stigma.

Appendix 2: Information sheets/packs

Invitation

to participate in a research study

THE HEALTH AND SUPPORT NEEDS OF ADULTS WITH LEARNING DISABILITIES LIVING IN RURAL AREAS

Dear Sir or Mađam,

- ★ I would like to invite you to join in a research programme
- ★ The information sheet tells you about the study
- ★ The study will find out how to help people get better health and better health services in the future
- ★ It would be good to talk about it with a relative or someone who supports you
- ★ It's your choice if you want to take part
- ★ Have a think about it
- ★ There is a slip for you to fill in, and an envelope to send it back
- ★ Please phone me if you want to ask any questions

Yours sincerely,

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THE HEALTH AND SUPPORT NEEDS OF ADULTS WITH LEARNING DISABILITIES LIVING IN RURAL AREAS

We wish to invite you to take part in a research study. You can choose if you want to be included in the study. Please read this information sheet, and talk with the person who supports you. It tells you about the study, and what it involves. If you are interested in helping with the study, a researcher will talk with you about the study and answer your questions. This information is also available on disc.

What is the purpose of the study?

A few years ago there was a big study in Glasgow that showed that lots of people with a learning disability have problems with their health. We want to find out if people living in the countryside have the same sorts of problems. We also want to find out if living in the countryside makes it more easy or more difficult for people to get help and support when they need it. For example, perhaps living in a small town means that there are fewer services available. Or perhaps living in a small town makes it easier to get help when you need it. At the moment we just don't know.

The information will help everybody decide whether or not people with learning disabilities living in the countryside are getting enough help and support. The information may also help to answer questions in the future about health and support needs for people with a learning disability in general, so the people doing the research wants to keep the information safe for future use.

Why have I been chosen?

Adults with a learning disability who stay around Oban, Lochgilphead and Campbeltown have been invited to take part.

Do I have to take part?

No.

It is your choice if you want to take part or not. If you want to take part in the research, you will be asked to sign a consent form to show that you understand

what the research is all about. You will get a copy of the consent form, and this information sheet to keep.

If you say “no”, you don’t have to say why. Saying “no” won’t change the services and supports you are getting at the moment. If you say “yes” now, but then change your mind, that’s OK. You can stop being in the study whenever you want. It still won’t change any of the services or supports you are getting.

What happens to me if I take part?

A researcher (Laura Nicholson) will arrange to meet up with you and the person who supports you at home. She will ask you questions about your physical and mental health and wellbeing, and the services and supports you have. This will take about one and a half hours. Laura may ask if it is OK to arrange another visit to discuss your mental health and wellbeing in a bit more detail. (You can say “no” to this.) If you are happy to meet up again, Laura will arrange another visit, which will take about another one and a half hours.

Laura will also ask if it is OK to look through your medical notes at your doctor’s surgery, and if she can contact the Information and Statistics Division of NHS Scotland to link your name with the records that they hold on you.

We will keep the information about you very confidential (private) and safe. We will use a computer database to look at the information from everybody who takes part in the research. Only people involved in the study will be able to look at the information on the computer. Nobody else will even know if you have taken part.

Once the study is finished, we will write to you (or send a DVD) to tell you what the research found out.

What are the possible disadvantages or risks of taking part?

There are no risks.

What are the possible benefits of taking part?

If you take part in the study, there are no benefits to you just now. If the study finds out how to improve services and supports for people living in the countryside, there may be benefits in the future.

What if there is a problem?

If you are unhappy with the study, you can complain. All complaints will be treated with respect and properly dealt with. You can complain to Laura Nicholson (01698 855578) or Professor Sally-Ann Cooper (0141 211 0690). If you are still unhappy, you can complain formally to the bosses who check to see that the study is working (Mr Brian Rae, Research Sponsor Manager, 0141 232 9523).

Will the study team keep my details confidential?

Yes.

All information about you is very confidential (private). A secret code (a number) is used on the computer database with the health information about you. Your name is not used on the database. Only the study team know the secret code to find out your name. The study team will never give away your name or personal details in any reports about the research. No-one else will know if you took part in the study. The study team obeys the Data Protection Act, 1998.

In the UK, people doing research and studies have to obey a “code of practice”. This means that there is a list of rules to say what they can and can’t do. The bosses (the research sponsor) can check up on the people who do studies, to make sure we are following the rules and doing our job properly. If that happens in this study, the bosses would have access to the information about you. They would also keep your details very confidential (private). An independent group will check that the information about you is properly protected. The independent group makes sure that the study is done properly and ethically.

Although the study team have to keep the results very private, you can talk to anybody you want to about the study. If you want to talk about it with your friends, carers and family, that is OK.

What will happen to the results of the study?

Reports will be written about what the study finds out. We will send you a copy of the results if you want. We will also send a copy to the people who plan and provide services for people with learning disabilities for Oban and Lochgilphead. The information in the reports will be anonymous. Nobody will be able to tell if you took part in the study.

Who is organising and funding the study?

The study team have asked a charity (the Baily Thomas charitable fund) for money to help pay for the study. NHS Greater Glasgow is the research sponsor. The doctors who are carrying out the study are not paid any money for including you in the study.

Who has reviewed this study?

This study was checked by the Multi-centre Scotland A Research Ethics Committee, who gave permission for the study to go ahead.

Contact details

If you would like more information or have any questions about the study, we are happy to discuss it with you. Please contact Dr Laura Nicholson, SpR Learning Disabilities Psychiatry, Department of Psychiatry, Kirklands Hospital, Fallside road, Bothwell, Glasgow, G71 8BB. Tel. 01698 855578. email lauranicholson@nhs.net.

THANK YOU FOR TAKING THE TIME TO READ THIS INFORMATION, AND THANK YOU FOR CHOOSING IF YOU WANT TO BE INCLUDED IN THE STUDY



THE HEALTH AND SUPPORT NEEDS OF ADULTS WITH LEARNING DISABILITIES LIVING IN RURAL AREAS

Reply slip

Please tick (☒) the box to tell us what you want:

- Yes, I want to be included in the study. Please fix an appointment to visit me

☐

- I'm not sure. Please phone me so we can talk about it

☐

- I'm not sure. Please fix an appointment to visit me so we can talk about it

☐

- I do not want to be included in the study

☐

- I have completed this form myself

☐

My name is.....

My address is.....

.....

My telephone number is.....

THANK YOU FOR FILLING IN THIS FORM

Please put it in the envelope to send it back to Laura Nicholson, SpR Learning Disabilities psychiatry, Department of Psychiatry, Kirklands Hospital, Fallside road, Bothwell, Glasgow, G71 8BB. Tel. 01698 855578. email lauranicholson@nhs.net. If you have completed the form for someone else, please complete the rest of the form. Thank you

I have completed this form on behalf of:



Name.....

Address.....

.....

Telephone number.....

My own name is.....

Our relationship is (e.g. support worker).....

If you are NOT the next-of-kin, we will also need to contact the person's next-of-kin/welfare guardian. Who is the next-of-kin/welfare guardian?

Name of next-of-kin.....

Address of next-of-kin.....

.....

Telephone number of next-of-kin.....

Relationship of next-of-kin (e.g. mother).....

Appendix 3: Ethical approval documents

Scotland A Research Ethics Committee

Secretariat:
Deaconess House
148 Peasance
Edinburgh
EH8 9RS
Telephone 0131 536 9026
Fax 0131 536 9346
www.corec.org.uk



Dr Laura Nicholson
SpR Learning Disabilities Psychiatry
NHS
Department of Learning Disabilities, West
House
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow
G12 0XH

Date: 20 November 2007
Your Ref:
Our Ref: 07/MRE00/92

Enquiries to: Walter Hunter
Extension: 89026
Direct Line: 0131 536 9026
Email: walter.hunter@lhb.scot.nhs.uk

Dear Dr Nicholson

Study title: The health and support needs of adults with intellectual disabilities living in rural areas

REC reference: 07/MRE00/92

Thank you for your letter of 10 November 2007, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair together with Dr A Munro, Mrs M Sweetland and Mrs M Thomson.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical review of research sites

The favourable opinion applies to the research sites listed on the attached form. Confirmation of approval for other sites listed in the application will be issued as soon as local assessors have confirmed that they have no objection.

Chairman Professor Kennedy Lees
Vice-Chairman Dr George Masterton
Vice-Chairman Dr Malcolm Booth



Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Application Form Parts A and B		02 September 2007
Investigator CV: Supervisor		31 July 2007
Investigator CV: CI	1	31 July 2007
Protocol	1	31 July 2007
Covering Letter		03 September 2007
Response to Request for Further Information		10 November 2007
Questionnaire: C21st Health Check		01 January 2005
Questionnaire: Carer Satisfaction Questionnaire	1	31 August 2007
Questionnaire: Supplementary Rural/Geographic Mobility Questions	1	31 August 2007
Letter of invitation to participant: Participant	2	31 October 2007
Letter of invitation to participant: Relatives	1	31 July 2007
GP/Consultant Information Sheets	2	31 October 2007
Participant Information Sheet: Relative	1	06 June 2007
Participant Information Sheet: Nearest Relative	1	06 June 2007
Participant Information Sheet: Participant	2	31 October 2007
Participant Consent Form: Relative	2	31 October 2007
Participant Consent Form: Participant	2	31 October 2007
Participant Reply Slip	2	31 October 2007

R&D approval

All researchers and research collaborators who will be participating in the research at NHS sites should apply for R&D approval from the relevant care organisation, if they have not yet done so. R&D approval is required, whether or not the study is exempt from SSA. You should advise researchers and local collaborators accordingly.



REC reference number: 07/MRE00/92-Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely

Kelly Sturges

Professor Kennedy Lees
Chairman

cc: Mr Brian Rae
R&D Manager
Clinical Research Facility
Tennant's Building
Western Infirmary
Glasgow
G11 6NT

Prof David J Godden, MD, FRCP(Fdin), FRCP(Glasg)
 Research Director
 NHS Highland Research Office
 Unit 18
 The Green House
 Beechwood Business Park
 Inverness, IV2 3BL
 Tel: 01463 667320
 Fax: 01463 667310
 E-mail: david.godden@haht.scot.nhs.uk



30 November 2007

Dr Laura Nicholson
 SpR Learning Disabilities Psychiatry
 NHS Greater Glasgow & Clyde
 West House
 Department of Learning Disabilities
 Gartnavel Royal Hospital
 1055 Great Western Road
 Glasgow
 G12 0XH

Dear Dr Nicholson,

Management Approval for Non-Commercial Research

I am pleased to tell you that you now have Management Approval for the research project entitled: **'Rural Intellectual Disabilities: The health and support needs of adults with intellectual disabilities living in rural areas'**. I acknowledge that:

- The project is funded by the Baily Thomas Charitable Fund.
- The project is sponsored by NHS Greater Glasgow & Clyde.
- Ethics approval for the project has been obtained from the Scotland A Research Ethics Committee (reference number: 07/MRE00/92).

The following conditions apply:

- The responsibility for monitoring and auditing this project lies with the sponsor (NHS Greater Glasgow & Clyde).
- The paperwork concerning all incidents, adverse events and serious adverse events, thought to be attributable to participant's involvement in this project should be copied to the NHS Highland R&D Office.
- All amendments (minor or substantial) to the protocol or to the REC application should be copied to the NHS Highland Research Office together with a copy of the corresponding approval letter.

Working with you to make Highland the healthy place to be

Headquarters:
 NHS Highland, Assynt House, Beechwood Park, Inverness, IV2 3HG

Chairman: Mr Garry Coutts
 Chief Executive: Dr Roger Gibbins BA MBA PhD
Highland NHS Board is the common name of Highland Health Board



Please report adverse and serious adverse events, and any changes in resources used or staff involved in the project, to the NHS Highland Research Manager, Dr Catherine Sinclair (01463 667317, catherine.sinclair@haht.scot.nhs.uk).

Yours sincerely,



Prof David J Godden
NHS Highland Research Director

cc: Dr Catherine Sinclair, Unit 18, The Green House, Beechwood Business Park, Inverness
IV2 3ED.

Acute Services Division

Dr Laura Nicholson,
SPR Learning Disabilities Psychiatry
Department of Learning Disabilities
West House
Gartnavel Royal Hospital,
1055 Great Western Road,
Glasgow G12 0XN

Research & Development Directorate
NHS Greater Glasgow and Clyde
The Tennent Institute
WIG, 38 Church Street
Glasgow
G11 6NT



Date 10 December 2007

Direct Line 0141 232 9524
Fax 0141 232 9516
Email mary.fraser@ggc.scot.nhs.uk

Dear Laura Nicholson,

Project Title: The health and support needs of adults with intellectual disabilities living in rural areas

I am pleased to inform you that R&D management approval has been granted by NHS Greater Glasgow & Clyde Community and Mental Health Partnership, subject to the following requirements:

- You should notify me of any changes to the original submission, including copies of notification to ethics committee(s) and send regular, brief interim reports including recruitment numbers where applicable. You must also notify me of any changes to the original research staff and send CVs of any new researchers
- Researchers covered in this approval are - **yourself; and professor Sally-Ann Cooper**
- Your research must be conducted in accordance with the Scottish Executive Health Department, *Research Governance Framework for Health and Community Care* (Second Edition, 2006) see Chief Scientist Website <http://www.sehd.scot.nhs.uk/cso> Local research governance monitoring requirements are presently being developed. This may involve audit of your research at some time in the future
- You must comply with any requirements regarding data handling (Data Protection Act). Advice may be obtained from the Scottish Executive Confidentiality and Security Advisory Group for Scotland website <http://www.csags.scot.nhs.uk/>
- A final report, with an abstract which can be disseminated widely within the NHS, should be submitted when the project has been completed

Do not hesitate to contact the R&D Office if we can be of any assistance

We wish you every success with your project.

Yours sincerely

Dr Mary Fraser

Delivering better health

www.nhsggc.org.uk

40385

Scotland A Research Ethics
Committee

Deaconess House
148 Pleasance
Edinburgh
EH8 9RS
Tel: 0131 536 9067
Fax: 0131 536 9346
dorothy.garrow@nhslothian.scot.nhs.uk



20 May 2009

Dr Laura Nicholson
Kirklands Hospital
Fallside Road
Bothwell
Lanarkshire
G71 8BB

Dear Dr Nicholson

Study title: The health and support needs of adults with intellectual disabilities living in rural areas
REC reference: 07/MRE00/92
Amendment No: No 1
Amendment date: 06 May 2009

The above amendment was reviewed at the meeting of Scotland A Research Ethics Sub-Committee held on 19th May 2009.

The members of the Committee present gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation. However the committee made a comment that they would like confirmation that the interviewee would have an opportunity to review the transcribed notes.

The documents reviewed and approved at the meeting were:

Document	Version	Date
Consent and Guided Questions	V1	06 May 2009
Notice of Substantial Amendment (non-CTIMPs)		07 May 2009
Covering Letter		07 May 2009

The members of the Committee who were present at the meeting are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Chairman: Professor Kennedy Lees
Vice Chairman: Dr Malcolm Booth

Scotland A Research Ethics
Committee

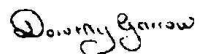
Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

07/MRE00/92:

Please quote this number on all correspondence

Yours sincerely



Mrs Dorothy Garrow
Sub-Committee Co-ordinator

Scotland A Research Ethics
Committee

**Scotland A Research Ethics Committee
Amendments Sub-Committee**

**Meeting Held on 19th May 2009
Members Present**

**Chairman
Dr Malcolm Booth**

**Dr Colin Selby
Canon Matt McManus**

Appendix 4: Interview schedule

THE HEALTH AND SUPPORT NEEDS OF ADULTS WITH LEARNING DISABILITIES LIVING IN RURAL AREAS

Part 1 - demographics

Name of professional completing health check.....

Grade / profession []

LD nurse I = 1; LD nurse H = 2; LD nurse G = 3; Primary care nurse G = 4; Doctor = 6;

Other = 7 & specify.....

Date of interview (date / month / year) [][]/[][][][][]

Name of person supporting the client.....

Relationship of supporting person to client []

Next of kin = 1; Other relative = 2; Principle contact = 3; Other support worker = 4;

Other = 5 & specify.....

How long has the supporting person known the client?.....

PERSONAL DETAILS

Forenames.....

Surname.....

Date of Birth.....

Address1 (flat number, house number, street, district)

Address2 (town, city)

Address3 (post code)

Home telephone number.....

GP initials and surname.....

GP address1 (name of surgery / health centre).....

GP address4 (post code)

Male = 1; Female = 2; Other = 3 & specify.....

Married / live in partner = 1; Separated / divorced = 2; Single = 3; Widow/er = 4

Black African = 7; Black other = 8; Other = 9 & specify.....

First language.....

Part 2 – physical health

1. KNOWN HEALTH PROBLEMS

Ask what health problems the person is known to have, or receives treatment for.

[illegible]

2. CURRENT HEALTH CONCERNS

Ask if the person with learning disabilities or the person supporting her / him is aware of, or concerned about any health problems in particular, or any new symptoms.

.....

.....

.....

3. MEDICATIONS

a. Ask to see all the medications the person is currently taking, and list them. Ask why the person is prescribed each medication, and how long she / he has taken it. Include non-prescription medications such as those bought over the counter e.g. antihistamines, and complementary medications.

Drug name	Dose and frequency	Estimated start date	Reason for prescription

b. Does the person have any **problems taking their medications** e.g. problems swallowing tablets, timing of doses, difficulty remembering to take doses, not wanting to take their medications?

.....

.....

.....

4. ALLERGIES

List any allergies that the person has. Also state if the person has hayfever.

.....

.....

THROUGHOUT SECTIONS 6 – 28

(except where it is indicated otherwise) code each item as:

No = 0; Yes = 1; Unsure = 8; Not applicable = 9

>>>> Provide further information for any item coded 1 (yes), including an indication of severity and / or frequency

>>>> These questions refer to the person's health over the LAST YEAR

6. COMMUNICATION

- a. Is the person able to use **words**? []
- b. Do other people use **objects / gestures / pictures** as a recognised way of communicating with the person if she / he does not use words? []
- c. Does the person use a **high-tech communication aid** e.g. a switch / computer-based aid? []
- d. Has the person had a significant **communication change**? []
- e. Has the person ever requested or wanted to see a **S<** (self-referral)? []
- f. Further information
.....

7. BREATHING

- a. Does the person have a known **breathing problem** e.g. asthma, chronic bronchitis, repeated chest infections? []
- b. If YES,
specify.....
- c. Does the person have a **cough**? []
- d. Does the person cough up **blood**? []
- e. Does the person cough up stuff / **mucous / sputum**? []
- f. Does the person get **short of breath**? []
- g. Does the person **wheeze**? []
- h. Further information.....

8. HEART AND CIRCULATION

- a. Does the person have a known **heart or circulation problem** e.g. raised blood pressure, []
angina, heart failure, a previous heart attack?
- b. If YES, specify.....
.....
- c. Does the person have **chest pain**? []
- d. Does the person's heart "**race**" / **beat quickly**? []
- e. Do the person's **ankles swell**? []
- f. Does the person get **short of breath** while lying in bed? []
- g. Does the person get **blue skin**, e.g. on fingers, lips, toes? []
- h. Further information.....
.....

9. STOMACH, BOWEL AND NUTRITION

- a. Does the person have a known **stomach, bowel or nutritional problem** e.g. peptic ulcer, []
swallowing problem, underweight?
- b. If YES, specify.....
.....
- c. Has the person **lost weight** without trying to? []
- d. Does the person have trouble **swallowing / choking / spluttering**? []
- e. Does the person **regurgitate / vomit**? []
- f. Does the person get "**heart burn**"? []
- g. Does the person have **diarrhoea**? []
- h. Does the person have **black bowel motions**? []
- i. Does the person have **blood in their stool** / bowel motion? []

- j. Does the person get **constipated**? []
- k. Does the person have **abdominal / stomach pain**? []
- l. Are you concerned about the person's **diet**? []
- m. Does the person have a problem drinking **enough fluid** (> 1,600 ml per day = 8 teacups)? []
- n. Does the person have problems with **tongue thrust, poor lip closure, drooling**? []
- o. Does the person require **PEG / tube feeding**? []
- p. Does the person require **dietary supplements**? []
- q. Does the person need **assistance with eating / drinking** e.g. physical help or equipment? []
- r. Does the person seem to experience **discomfort after eating**? []
- s. Further information.....

10. CONTINENCE

- a. How continent is the person with her / his **urine** []
 Fully continent = 1; Occasional accidents / continent with toileting programme = 2;
 Incontinent at night only = 3; Incontinent (wears pads) = 4; Incontinent (catheter) = 5
- b. How continent is the person with her / his **bowels**? []
 Fully continent = 1; Occasional accidents / continent with toileting programme = 2;
 Incontinent (wears pads) = 4

11. URINARY SYSTEM

- a. Does the person have a known problem with their **kidney or bladder** e.g. prostate problem, []
 repeated urine infections?
- b. If YES, specify.....

- c. Does the person have **pain when passing water**? []
- d. Does the person have **blood in the water**? []
- e. Does the person have **hesitancy** when trying to pass water? []
- f. Does the person have to get up more often in the **night** to pass water? []

g. Does the person **dribble** water after completing urination? []

h. Does the person pass water a lot more **frequently** than usual? []

i. Further information.....

.....

12. MUSCLES, JOINTS AND LOCOMOTION

a. Does the person have a known problem with their muscles, joints or mobility e.g. arthritis, osteoporosis, scoliosis? []

b. If YES, specify.....

.....

c. Does the person have **joint pain or back pain**? []

d. Does the person have **muscle pain**? []

e. Does the person have any **contractures or fixed deformities**? []

f. Is the person disabled in all four of their limbs (**spastic quadriplegia**) and / or does she / he use a molded seat? []

g. Does the person have any problems with their **feet, toes or toenails**? []

h. Does the person need **special footwear** or orthoses? []

i. Does the person have a **balance** problem? []

j. Does the person have a **co-ordination** problem? []

k. How **mobile** is the person? []

Fully mobile = 1; Walks with stick/s, frame or some assistance = 2; Requires wheelchair when outside only = 3; Requires wheelchair in and outside = 4; Can weightbear / transfer only = 5; Cannot weightbear / transfer = 6

l. Does the person have a problem with their **wheelchair / special seating**? []

m. Does the person have any limb injuries / soft tissue injuries? []

n. Further information (include details of any mobility aids or requirements for special adaptations).....

.....

13. PAIN

a. Is the person unable to **communicate** when she / he has pain? []

- b. Does the person **complain of pain** or do you suspect she / he may be in pain? []
- c. If YES, specify site and characteristics of pain.....
.....
.

14. VISION

- a. Does the person have a known **visual impairment** or problem in her / his eye/s []
e.g. cataract, registered blind, short sighted?
- b. If YES, specify type and which eye/s affected.....
.....
- c. If NO, do you **suspect the person may have a problem** with her / his vision? []
- d. Has the person ever been prescribed **glasses**? []
- e. Does she / he wear glasses? []
- f. Does the person **follow your movements** around the room when you give them no sound clues / when you move silently? []
- g. Does the person **screw up their eyes** when taken into bright sunlight? []
- h. Does the person **react to your smile** (when you do not make any sounds)? []
- i. Does the person **reach out for objects** held out in front of them? []
- j. Is the person aware of a **spoonful of food** if you move it towards her / his mouth? []
- k. If YES, do you think the person **sees it**? []
- l. If YES, do you think the person **smells it**? []
- m. Is the person aware of themselves in a **mirror** when 6 feet away? []
- n. When was the person's vision **last tested**?.....

15. HEARING

- a. Does the person have a known **hearing impairment** or problem with her / his ear/s []
e.g. repeated ear infections, deaf?
- b. If YES, specify type and affected ear.....
.....
- c. If NO, do you **suspect the person may have a problem** with her / his hearing? []

- d. Has the person ever been prescribed a **hearing aid**? []
- e. Does she / he wear a hearing aid? []
- f. If YES, when was the **hearing aid last reviewed / tested**?.....
- g. When was the person's **hearing last tested**?.....

16. SKIN

- a. Does the person have a known problem with their **skin or nails** e.g. eczema, psoriasis? []
- b. If YES, specify.....
.....
- c. Does the person have any **rashes**? []
- d. Does the person have any **skin infection / eruption**? []
- e. Does the person have **itch**? []
- f. Does the person have **dry skin**? []
- g. Does the person have any **skin breaks / ulcers / pressure sores / bruising**
- h. Does the person have a **scalp problem**? []
- i. Further information.....
.....

17. EPILEPSY

- a. Has the person ever experienced **seizures, epilepsy or fits**? []

[IF NO, SKIP TO SECTION 18]

- b. If the person has not had seizures for two or more years, and still takes anti-epileptic drug/s []
has their possible **discontinuation** been attempted?
No, never suggested = 1; No, because person declined = 2; No, because carer declined on person's behalf = 3; Previous attempt at discontinuation failed = 4; Other = 5 & specify.....
- c. If the person has a known **epilepsy syndrome**, please specify.....

d. Describe the **type/s of seizure/s** that the person experiences (and classify the seizure type/s if possible)

Complex partial = 1; Simple partial = 2; Primary generalised tonic-clonic = 3; Absence = 4; Tonic = 5; Clonic = 6; Atonic = 7; Myoclonic = 8; Atypical = 9; Other = 10 & specify; Not sure = 88

i = [] [] ii = [] [] iii = [] [] iv = [] []

e. Does the person have **secondarily generalised tonic-clonic** seizures? []

h. Does the person's require a **review** of their epilepsy (i.e. not reviewed by a health professional in the last year)? []

i. If NO, already reviewed, specify
details.....
.....

18. NERVOUS SYSTEM (OTHER THAN EPILEPSY)

a. Does the person have a known problem with their **nervous system** e.g. migraine, head injury []

b. If YES, specify.....
.....

c. Does the person **faint**? []

d. Does the person get **unsteady** when walking? []

e. Is the person more **clumsy or unco-ordinated** than usual? []

f. Does the person have a **tremor**? []

g. Have the person's arms or legs become **weaker than usual**? []

h. Does the person have **tingling** or strange feelings in the skin? []

i. Does the person have **sleep disturbance**? []

j. Does the person experience frequent **headaches**? []

k. Further information.....
.....

19. SEXUAL HEALTH

- a. Does the person have a known problem with their **sexual health**? []
- b. If YES, specify.....
.....
- c. Does the person have a **sexual partner/s**?.....
- d. Is the person at risk from HIV infection or other infection (e.g. frequent unprotected sex, intravenous drug use)? []
- e. Further information.....

[FOR MEN, NOW SKIP TO SECTION 21]

20. WOMEN'S HEALTH

- a. Does the person have a known problem related to **women's health** e.g. polycystic ovaries, menopausal symptoms? []
- b. If YES, specify.....
.....
- r. When did the person last have a **smear**?.....
- s. If the person is aged 18 - 60 years, may ever have been sexually active, and has []
NOT had a smear in the last 3 years, indicate why not
Person distressed = 1; Smear planned = 2; Preparation planned = 3; Preparation in progress = 4; Person refused = 6; Carer refused on person's behalf = 7; Other = 5 & specify.....
- t. Does the person have a problem regularly **checking her own breasts**? []
- u. If YES, indicate if the person does not have a GP / nurse to check them []
- v. When did the person last have a **mammogram**?.....
- w. If the person is aged 50 - 65 years (or has a family history of breast cancer in a close relative), and has NOT had a mammogram in the last 3 years, indicate why not []
Person distressed = 1; Mammogram planned = 2; Preparation planned = 3; Preparation in progress = 4; Person refused = 6; Carer refused on person's behalf = 7; Other = 5 & specify.....

[FOR WOMEN, NOW SKIP TO SECTION 25]

21. MEN'S HEALTH

- a. Does the person have a known problem related to men's health e.g. prostate problem? []
- b. If YES, specify.....

25. DEVELOPMENT

- a. What is the **cause** of the person's learning disabilities? []

Unknown = 1; Down's syndrome = 2; Tuberous sclerosis = 3; Eclampsia / ante-partum haemorrhage / complications of pregnancy = 4; "Birth injury" = 5; Meningitis/encephalitis = 6; Fragile X syndrome = 7; Head injury = 8; Brain tumour = 9; Hydrocephalus = 10; Microcephaly = 11; Phenylketonuria (PKU) = 12; Prader-Willi syndrome = 13; Smith-Magenis syndrome = 14; Congenital rubella = 17; Rett syndrome = 15; Unclear if ever assessed = 88; Other = 16 & specify.....

- b. How much support does the person need with **eating and drinking**? []

Totally independent = 1; Minimum assistance = 2; Regular prompting / supervision = 3; 1:1 support required = 4; 1:1 support required and special equipment / positioning or PEG feeding = 5

- c. How much support does the person need with **intimate care** e.g. bathing, dressing? []

Fully independent = 1; Minimum assistance = 2; Regular prompting / supervision = 3; 1:1 support required, but able contribute in a limited way - may require special lifting equipment = 4; 1:1 support required, unable to contribute and totally dependent - requires special lifting equipment = 5

- d. How much support does the person need with **personal safety**? []

Aware of personal safety and acts accordingly = 1; Minimum assistance = 2; Some awareness/ appropriate action, but requires some supervision = 3; Requires constant supervision to ensure safety = 4; Total dependency for personal safety = 5

- e. How much support does the person require with **communication**? []

Communicates clearly and independently = 1; Communicates reasonably clearly, including using signs / aids = 2; Requires staff support with communication = 3; Much time is required to understand and facilitate the person's communication = 4; Communication skills are extremely limited = 5

- f. How much support does the person require with **decision making**? []

Makes own decisions in informed way = 1; Minimum support to make own decisions = 2; Can make some choices / decisions = 3; Support required for even simple decisions = 4; Total dependence on others for decision making / choices = 5

- g. Add up the sum of scores in 25b – 25f

[] []

h. Health professional's opinion: estimation of the person's ability level []

Mild learning disabilities = 1; Moderate learning disab = 2; Severe learning disabilities = 3;
 Profound learning disabilities = 4; Unsure = 8; Person does not have learning disabilities = 9

VINELAND

26. ADDITIONAL INFORMATION

a. Does the person have any other known health problems e.g. hypothyroidism, diabetes? []

b. If YES, specify.....

.....

c. Does the person have any other symptoms or other problems of concern? []

F. PAST MEDICAL HISTORY

Ask if the person has any other past health problems or health information which have not been mentioned. Ask specifically about operations or medical problems e.g. jaundice, rheumatic fever.....

.....

.....

.....

27. HEALTH PROMOTION

a. When did the person last have a **dental check**.....

b. Number of **cigarettes** smoked per day / amount of tobacco smoked per day?.....

c. Number of units of **alcohol** drunk per week?.....

d. Does the person **avoid regular exercise**? []

e. Specify any exercise undertaken

.....

f. Does the person use recreational drugs? []

If YES, specify

.....

g. Health professional's opinion: is the person in a high risk group for ☐ ☐

Gastro-Oesophageal Reflux Disorder (severe or profound learning disabilities or cerebral palsy, together with low / borderline Hb or disturbed sleep pattern; dental erosions; vomiting, regurgitation or other GI symptoms)

h. Health professional's opinion: is the person in a high risk group for **Osteoporosis** ☐ ☐

(post menopause not on HRT; depo-provera with amenorrhoea for 5 years or more; non weight-bearing; poor diet; underweight; pre-pubertal)?

Further information.....

Part 3 – mental health

22. MENTAL HEALTH

a. Does the person have any known **mental health needs**, emotional or psychological problems, dementia or other psychiatric illness? ☐ ☐

b. If YES, specify the type of problem, illness or need, and any support the person receives

.....

c. [Give the **Modified PAS-ADD Checklist – The Glasgow Version** to the person's relative / support worker for completion. Use clinical judgement as to whether it should alternatively be administered as an interview e.g. relative / support worker cannot read.]

***How many ticks are there in the two right hand columns for Qs1-35? ☐ ☐ ☐

(Consider referral if 2 or more)

***Does the person have a positive score on any of the "at risk" Qs12, 18, 30, 31, or 32? ☐ ☐

(If YES, consider referral)

d. If the person scores 2 or above, or has a positive score for the "at risk" questions, ☐ ☐

but you are not referring to learning disabilities psychiatry, why not?

Symptoms are explained by physical illness = 1; Person already sees a psychiatrist = 2;
 Person declines referral = 3; Carer declines referral on person's behalf = 4; Other = 5 &
 specify.....

e. Further information.....

.....

23. PERVASIVE DEVELOPMENTAL DISORDERS

- a. Does the person have a **pervasive developmental disorder**, autism, Asperger's syndrome, [] or autistic spectrum disorder?
- b. If YES, specify
- c. Health professional's opinion: do you think the person might have an **autistic spectrum** [] **disorder**, even though this has not been previously identified?

N.B. Indicators include long-standing problems *out of keeping with the person's overall level of ability* in all the areas of:

- Impaired reciprocal social interaction (e.g. limited eye to eye gaze; limited feelings for others; difficulty making relationships or lack of interest in relationships)
- Impaired receptive or expressive language as used in social communication (includes abnormal use of language)
- Lack of empathy (e.g. abnormal responses to other people's emotions; lack of imaginative play / let's pretend)
- Restrictive, repetitive and stereotyped patterns of behaviour, interests and activities (e.g. unusual attachments to objects; touches, smells, tastes things inappropriately; repetitive behaviours such as hand flapping, spinning, tiptoe walking; rituals; unable to cope with change in routine)

If **YES**, ask the relative / support worker to complete the *Pervasive Developmental Disorder Questionnaire* (in addition to the *Modified PAS-ADD Checklist – The Glasgow Version*).

24. PROBLEM BEHAVIOURS

- a. Does the person have any **problem behaviours**, challenging behaviour or special needs [] related to behaviour?
- b. If **YES**, specify the type of behaviour
.....

Now ask if the person has any of the following specific types of problem behaviours. For any behaviour coded "yes" (= 1), complete each of the columns A - D, which refer to the points listed below.

- A** The behaviour is frequent, severe *or* chronic.
- B** The behaviour is *not* known to be a direct consequence of other psychiatric or physical disorders.
- C** i. The behaviour causes a significant negative impact on the person's quality of life, or on the quality of life of others e.g. restriction of lifestyle, social opportunities, independence, community integration, service access or choices or adaptive functioning
and / or
ii. The behaviour presents a risk to the health and / or safety of the person, and / or others.
- D** The behaviour presents across a range of personal and social situations (although it may be more severe or distressing in certain identified settings).

	Behaviour present?	A	B	C	D
Verbally aggressive behaviour	[]	[]	[]	[]	[]
Physically aggressive behaviour	[]	[]	[]	[]	[]
Destructiveness to property	[]	[]	[]	[]	[]
Self-injurious behaviour	[]	[]	[]	[]	[]
Sexually inappropriate behaviour	[]	[]	[]	[]	[]
Oppositional behaviour	[]	[]	[]	[]	[]
Excessively demanding behaviour	[]	[]	[]	[]	[]
Wandering behaviour	[]	[]	[]	[]	[]
Faecal smearing	[]	[]	[]	[]	[]
Pica / eating non-food substances	[]	[]	[]	[]	[]
Other & specify.....	[]	[]	[]	[]	[]

d. Further information.....
.....

Part 4 – social supports

Accommodation and support package

Who does the person live with? []

Lives alone = 1; Lives with partner = 2; Lives with parent/s = 3; Lives with other family carer = 4; Lives with other person / people = 5; Other = 6 & specify.....

Type of accommodation?

[]

Parental home = 1; Other family carer home = 2; Lives independently = 3;
lives independently with spouse / partner = 4; Supported group living = 5; Supported
living - individual = 6; Residential care = 7; Nursing home = 8; NHS accommodation = 9;
Other = 10 & specify.....

How many adults live at the person's home (including her / himself;
excluding support workers)?

[]

How many children (under 16 years) live at the person's home?

[]

If this is a family home, or supported living, ask: Is the flat / house privately owned or rented?

[]

Owner occupied = 1; Privately rented = 2; Rented from housing association = 3

If this is not a family home (i.e. it is supported living), ask:

How much paid support does the person receive?

[]

Part-times support (less than daily) = 1; Part-times support (daily)
= 2; 24 hour support, sleep-in nights = 3; 24 hours, waking night = 4;
24 hours, waking + sleep-in at night = 5

If < 24 hour support, number of hours of paid support / week?

[][][]

Which organisation provides the support package.....

How many whole time equivalents work here or how many hours of support
per week in the home?.....

Employment

For everyone, ask:

Has the person any regular arrangements for daytime activities or employment?

Over the last 2 years, did the person have any regular daytime activities or employment in which
she / he is no longer engaged?

Then ask about:

- *The type of provider.*

- *The duration the arrangement was / has been in place (to identify its duration if less than 2 year).*

- *The person's usual pattern of days or hours / week, to estimate the number of hours / week.*

Then calculate the estimated number of hours / week in each type of employment.

Then ask about each of the listed options, to see if it prompts identification of any other opportunities.

	Yes/No	Sector – NHS/SW/Private /Voluntary	Duration (if < 2 year)	Number of hours/week
Paid employment				
Paid employment, with support				
Voluntary work				
College course				
Day centre				
*1:1 support to access a day centre				
*1:1 day opportunities support				
Housewife/husband				
Retired				
Other & specify.....				

** Do not double count support – list 1:1 support here which is in addition to the care already listed above under “accommodation and support package” details.*

Tick here if the person has no employment in any of the above categories.

[]

Short breaks from home

If the person lives in a family home, ask:

Does the person have any regular arrangements for short breaks from home, or for respite care?

Over the last 2 years, did the person have any regular arrangements for short breaks from home, or for respite care, which she / he no longer uses?

For everyone, ask:

Does the person have any regular arrangements for breaks away from her / his usual home with family members or friends?

Over the last 2 years, did the person have any regular arrangements for breaks away from her / his usual home with family members or friends, which she / he is no longer uses?

Then ask about:

- *The type of provider.*

- *The duration the arrangement was / has been in place (to identify its duration if less than 2 year).*

- *The persons usual pattern of days or hours, to estimate number of days in last 2 years.*

Then calculate the estimated number of days in the last 2 years, for each type.

Then ask about each of the listed options, to see if it prompts identification of any others breaks.

	Yes/No	Sector – NHS/SW/Private /Voluntary	Duration (if<2 years)	Number of days in the last 2 years
Breaks with other family member/friend				
Respite care unit				
*1:1 support				
Other & specify				

* Do not double count support – list 1:1 support here which is in *addition* to the care already listed above under “accommodation and support package” and “employment” details.

Tick here if the person has no short breaks in any of the above categories []

PROFESSIONAL SUPPORTS

In the last 2 yrs, which of the following professionals have been involved in the persons care? *Ask about:*

- Current involvement with each listed professional group.
- Previous involvement in the last 2 years, which had now ended.

For each professional the person has / had contact with, ask:

- Where does / did the person see her / him? At own home, or the GP practice, or at the hospital?

- Is / was this through the NHS (*or* social work service)? If not, who is / was the provider (e.g. charity, or person pays / paid privately)?
 - How long does / did each appointment with the professional usually last?
 - How long has (did) the person see her / him for (to identify duration if less than 2 years)?
- Then calculate the estimated number of contacts during the last 2 year.*

	Yes / No	Domiciliary GP surgery/ Hospital	Sector - Public/ Private/ Voluntary	Length of appointment	Frequency of appointment	Duration (if < 2 year)	Estimated contacts over last 2 years
Dietician							
S<							
Physiotherapist							
Occupational Therapist							
Psychologist							
Podiatrist							
Community LD Nurse							
Epilepsy Nurse							

Practice Nurse							
GP							
Other Doctor & specify							
Social worker							
Care manager - unspecified							
Advocate							
Dentist							
Optician							
Complementary therapist & specify.....							
Other & specify							

Part 5 – sociology and geographic mobility

1. SOCIAL NETWORK QUESTIONS

For the last 7 days:

a. How many people has the participant been in contact with:

- i. At home? [] [] []
(Other tenants, flat-mates, residents, live-in partner, relatives at the same address, support workers)
- ii. Relatives whom she / he does not live with? [] [] []
- iii. At work (day centre, college)? [] [] []
- iv. Other friends? [] [] []
(Personal friends, family friends, people attending same club, leisure event, evening course)
- v. At a faith gathering, such as church? [] [] []
- vi. Other acquaintance [] [] []
(Neighbours, shopkeepers, more casual contacts, other non-professional workers who call into the home address)
- vii. Professionals? [] [] []
(Social workers, doctors, nurses, other health care professionals)

b. How many people has the participant had a confrontation or argument with, or an angry exchange? (Include any descriptions of bullying, harassment, abuse or aggression) [] []

c. How many people has the participant had a minor disagreement or problem with? [] []

d. How many people has the participant had an enjoyable social interaction with? [] []

In general:

e. Does the participant have someone whom she / he is particularly close to: a special relationship with a relative, partner or a best friend? Would that person regard the relationship as very close? (This excludes the expected level of interest and concern that a responsible support worker would have for a client) []

Yes = 1; Yes, several = 2; No = 3

f. How many people would the participant trust or tell a secret to? []

One = 1; Two – five = 2; Six or more = 3; Anyone (too trusting) = 4; No-one = 5

g. How often does the person visit friends or relatives for a meal? []

Never = 1; At least once a year = 2; At least monthly = 3; At least weekly = 4

h. How often does the person go out to meet friends or relatives
e.g. at the pub or someone's home? []

Never = 1; At least once a year = 2; At least monthly = 3; At least weekly = 4

i. How often does the person have friends or relatives to stay overnight at
her / his home? []

Never = 1; At least once a year = 2; At least once a month = 3

j. How often does the person stay overnight at a friend's or relative's home? []

Never = 1; At least once a year = 2; At least once a month = 3

k. Is the person on first name terms with any of her / his neighbours? []

Yes = 1; Yes, several = 2; No = 3

2. COMMUNITY

a. How often does the person go to a café or restaurant for a meal? []

Never = 1; At least once a year = 2; At least monthly = 3; At least weekly = 4

b. How often does the person go to the cinema to theatre? []

Never = 1; At least once a year = 2; At least monthly = 3; At least weekly = 4

c. How often does the person go to a shop or use other local amenities? []

Never = 1; At least once a year = 2; At least monthly = 3; At least weekly = 4; Every day = 5

3. SUPPLEMENTARY RURAL QUESTIONS

a. Is the participant well known in (location)? []

Yes, most people know or recognise participant = 1, Reasonably well known, but no more than anybody else = 2, No, not particularly well known = 3

b. If score = 1, on balance, does the participant think that this is a positive or negative thing? []

Positive = 1, Negative = 2, Not sure = 3

c. If the participant goes into town, will people stop and talk to them, or ask how they are on a regular basis? []

Yes, more than average = 1, Yes, but no more than anybody else = 2, No = 3

d. If score = 1, on balance, does the participant think that this is a positive or negative thing? []

Positive = 1, Negative = 2, Not sure = 3

e. Would the participant rather live in a place where nobody recognised them? []

(For example, in a big city where nobody knew who they were?)

Yes = 1, No = 2, Not sure = 3, No difference = 4

f. Would the participant rather live in a rural area (i.e. where they are now) or in a city? []

Rural = 1, City = 2, Not sure = 3, No difference = 4

g. On balance, would the participant be better off if they moved to the city? []

Yes = 1, No = 2, Not sure = 3, No difference = 4

h. Does the participant/carer think that they live in a beautiful part of Scotland? []

Yes = 1, No = 2, Not sure = 3

i. If yes, does the participant appreciate it? []

Yes = 1, No = 2, Not sure = 3

j. Does the participant/carer think that they live in a quiet part of Scotland? []

Yes = 1, No = 2, Not sure = 3

k. If yes, does the participant appreciate it? []

Yes = 1, No = 2, Not sure = 3

l. Does the participant/carer think that they live in a safe part of Scotland? []

Yes = 1, No = 2, Not sure = 3

m. If yes, does the participant appreciate it? []

Yes = 1, No = 2, Not sure = 3

n. What does the participant think are the advantages (if any) of living in a rural area?

o. What does the participant think are the disadvantages (if any) of living in a rural area?

p. What does the participant think would be the advantages (if any) of living in a big city?

q. What does the participant think would be the disadvantages (if any) of living in a big city?

r. In the interviewer's opinion, who answered the majority of the questions above/whose opinion do the answers most accurately reflect? []

The participant = 1, the carer = 2

Were there any disagreements between the participant and carer – for example if the participant thought they would be better off in a city, but the carer thought that they would be better off living where they are. []

Yes = 1, No = 2, Not applicable = 3. If Yes, describe:

4. Service access and availability questions

a. Do you think that there are enough services (e.g. care providers, day opportunities, learning disability nurses etc) available locally? []

Yes = 1, No = 2, Not sure = 3

b. Do you think that the participant would receive more services if they lived in a city? []

Yes = 1, No = 2, Not sure = 3

c. Whether or not you think that there are enough services, are you satisfied with the *quality* of the services that are available? []

Yes = 1, No = 2, Not sure = 3

d. Do you think that the *quality* of services would be better if the participant lived in a city? []

Yes = 1, No = 2, Not sure = 3.

5. Geographic Mobility questions

a. Where was the participant born? (NB Going to Glasgow for the actual birth itself but coming back to local area after immediate post-natal care counts as being born locally.) []

Local (Argyll and Bute) = 1, Glasgow = 2, Other Scotland = 3, Other UK = 4, Unknown = 5

Location _____

Would the interviewer rate this as urban or rural?

Urban = 1, Rural = 2, Not sure = 3, Postcode if known _____

b. Where did the participant spend their main childhood? []

Local (Argyll and Bute) = 1, Glasgow = 2, Other Scotland = 3, Other UK = 4, Unknown = 5

Location _____

Would the interviewer rate this as urban or rural?

Urban = 1, Rural = 2, Not sure = 3, Postcode if known _____

c. Where did participant first live when they left the family home, or started independent life []

Local (Argyll and Bute) = 1, Glasgow = 2, Other Scotland = 3, Other UK = 4, Unknown = 5, Not applicable (not yet left home or childhood placement) = 6.

Location _____

Would the interviewer rate this as urban or rural?

Urban = 1, Rural = 2, Not sure = 3, Postcode if known _____

d. Where has the participant spent their main adult life? []

(Score for location where the participant has spent the most time since leaving home or the age of 19). Local (Argyll and Bute) = 1, Glasgow = 2, Other Scotland = 3, Other UK = 4, Unknown = 5, Not applicable (under 25 years old) = 6.

Location _____

Would the interviewer rate this as urban or rural?

Urban = 1, Rural = 2, Not sure = 3, Postcode if known _____

e. Where did the participant live immediately before moving to the area? []

Local (Argyll and Bute) = 1, Glasgow = 2, Other Scotland = 3, Other UK = 4, Unknown = 5,

Not applicable (always lived in same place or town) = 6.

Location _____

Would the interviewer rate this as urban or rural?

Urban = 1, Rural = 2, Not sure = 3, Postcode if known _____

f. How old was the participant when they moved to their current place/town? [][]

Always lived there = 0, Unknown = 99, Otherwise, code age to the nearest year = XXXX

If the above questions do not give an accurate picture of geographic mobility throughout the participant's life, use free text below to outline it further.

Part 7 – GP case note review

Date of first entry in GP notes or date of first registration with any GP?

[][][] / [][][] / [][][]

B. PROCEDURES AND INVESTIGATIONS

List all tests, investigations or procedures undertaken, with dates (regardless of the test outcome, include all tests, even those that have been repeated several times). Where there is more than one test of a certain type, underline the date of the most recent one. Check correspondence from secondary care also.

Test	Dates of tests of this type	Test results
Cervical smear		
Mammography		
Tetanus course and booster		
Polio course and booster		

Hepatitis B course and booster		
Flu jab		
ECG		
EEG		
Urine test		
Chest X-Ray		
Other:		

C. DEVELOPMENT AND ABILITY

1. Is there any documented **cause** of the person's learning disabilities? (Please tick)

- | | |
|--|--------|
| Unknown | 1 [] |
| Down's syndrome | 2 [] |
| Tuberous sclerosis | 3 [] |
| Eclampsia / ante-partum haemorrhage / complications of pregnancy | 4 [] |
| "Birth injury" | 5 [] |
| Meningitis / encephalitis | 6 [] |
| Fragile X syndrome | 7 [] |
| Head injury | 8 [] |
| Brain tumour | 9 [] |
| Hydrocephalus | 10 [] |
| Microcephaly | 11 [] |
| Phenylketonuria (PKU) | 12 [] |
| Prader-Willi syndrome | 13 [] |
| Smith-Magenis syndrome | 14 [] |
| Congenital rubella = 14 . . . | |
| Rett syndrome | 15 [] |
| Other = 16 & specify..... | |
| Unclear from GP notes = 88 | |

Any documented testing of the person's ability level?

Test type.....

Result.....

Date of test / person's age..... []

Mild learning disabilities (Mild learning disabilities= 1; Moderate learning disabilities = 2; Severe learning disabilities = 3; Profound learning disabilities = 4; No record of testing in last 10 years = 8; Person does not have learning disabilities = 9; No record ever = 7

D. MEDICATION

Drug name	Dose and frequency	Estimated start date	Reason for prescription

E PREVIOUS OPERATIONS (Asterix those which were undertaken in the last 12 months)

Operation type	Date	Reason	Outcome

--	--	--	--

F PREVIOUS AND CURRENT HEALTH PROBLEMS

(State diagnosis / type of illness; otherwise list possible diagnosis reported in notes or list symptoms)

Diagnosis / health problem	Date of first documentation	Outcome

G SERVICE USE

1. Number of GP consultations in the last 12 month period? [] []
(Exclude out-of-hours contacts from this count)

2. Number of GP consultations in the last 5 year period? [] [] [] []
(Exclude out-of-hours contacts from this count)

3. Number of primary care nurse consultations in the last 12 months? [] []

4. Number of primary care nurse consultations in the last 5 years? [] [] [] []

5. Number of out-of-hours emergency GP contacts in the last 12 months? [] [] []

(Count GEMS slips, also include entries from the person's own GP if there is an indication that these contacts were out-of-hours)

6. Number of out-of-hours emergency GP contacts in the last 5 years? [] [] []

(Count GEMS slips, also include entries from the person's own GP if there is an indication that these contacts were out-of-hours)

7. Number of A & E contacts in the last 12 months? [] [] []

8. Number of A & E contacts in the last 5 years? [] [] []

9. List the secondary care medical specialties that referrals have been made to in the last 12 month period, with date or estimated date of first appointment, and total number of follow up / return appointments per specialty

(Check correspondence: include DNAs where these are known. Count number of letters from secondary care, and check if letter is referring to one or several appointments)

Name of secondary care medical specialty	Date of first appointment or state if DNA	Number of follow up appointments in last 12 months

10. List the secondary care specialties with which the person has had hospital admissions during the last 12 months, giving admission and discharge dates (Check correspondence for discharge summaries).

.....

11. Number of hospital admissions in the last 12 months? [] [] []

12. How many days did the person spend in hospitals in the last 12 months? [] [] [] []

(Include the date of admission and date of discharge as full days)

13. List other non-medical referrals (including e.g. nurses, PAMS, audiology) or recommended contacts / resources in the last 12 months, giving dates. For each professional, indicate whether they work from the LD Service / Generic Secondary Service / Not Applicable / Not Known

H SOCIAL SUPPORTS

1. Do the notes contain *any* information about the person's lifestyle / support package? YES / NO

2. Is there specific reference in the notes to the person's type of accommodation? YES / NO

3. Is there specific reference in the notes to the person's support package? YES / NO

4. Is there specific reference in the notes to the person's work / day opportunities? YES / NO

5. Is there specific reference in the notes whether the person accesses respite care / natural breaks from a family home? NOT APPLICABLE / YES / NO

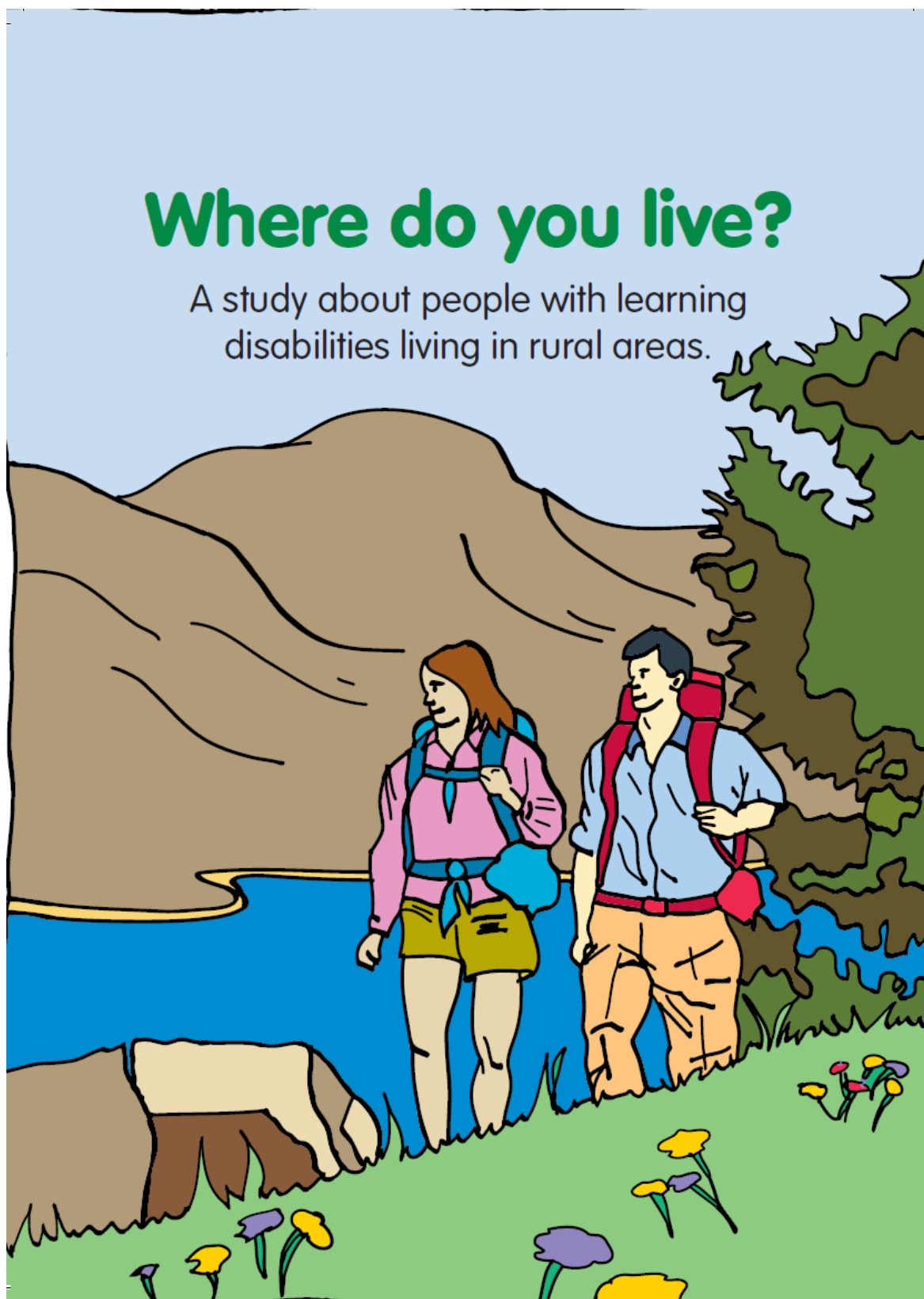
6. If YES to any of Q 1 -5, specify if this information came from a GP consultation, or which other source e.g. Care Manager's report, Community Learning Disabilities Nurse letter

.....
.....
.....

List anything else from the GP notes that appears important or relevant, or any problems completing this form

.....
.....
.....

Appendix 5: Results booklet for participants



About the study

For the last 2 years, I have been collecting information about people with learning disabilities living in rural areas.

I travelled all around Oban, Lochgilphead and Campbeltown to speak with people.

I met people in resource centres or in their homes.

Sometimes they had family, or a friend or carer with them. Sometimes I met them on their own.

I asked lots of questions all about their lives. I asked about their health and what they do during the day. I also asked what they liked about where they lived.

People in Glasgow were asked lots of questions about their health and what they do during the day as well.

All of this information was collected together as part of a big study. Another word for this is "research".



What we found out

A lot of people with learning disabilities helped us by answering questions.

People from all around Oban, Campbeltown and Lochgilphead took part in the study. Lots of people in Glasgow also took part.

Everybody who took part was grown up, but some people were quite young, and some people were quite old. Men and women took part. Some people lived on their own, and some people lived with their families. Some people needed lots of help and support in their lives, and other people didn't need much help and support at all.

This shows that everybody with a learning disability can take part in research if they want to.

A lot of people said that they enjoyed taking part in the study.

The information that we have collected from this study will help other people with learning disabilities in the future.



Problems with health

Around half of the people that I spoke to had some sort of mental health problem.

This means problems with things like:

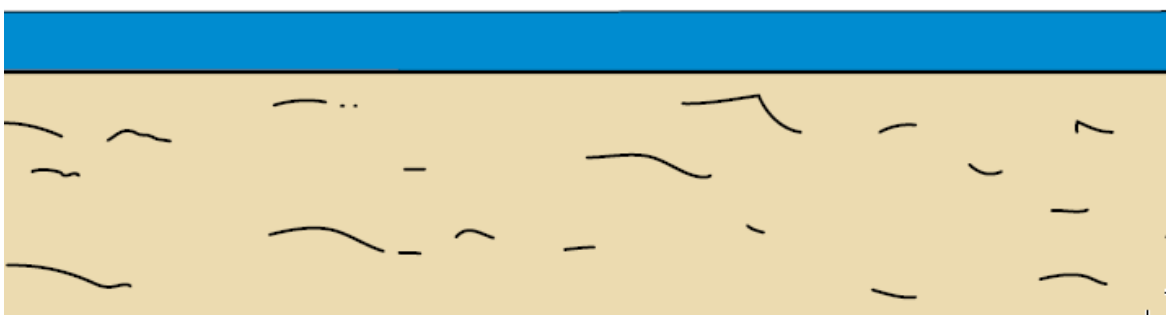
- Being depressed – feeling very unhappy
- Feeling anxious and scared
- Difficult behaviours – like hitting people or running away

This is important to know, as people with mental health problems often need help and support to make them feel better.

Most people had at least one problem with their physical health. Lots of people took medication (tablets) every day.

Most people lived a good healthy lifestyle: not many people smoked, and people didn't drink too much alcohol.

People living in Oban, Lochgilphead and Campbeltown had better access to doctors and hospitals than people living in Glasgow.



What do people like to do?

People did lots of things during the day. Some people had jobs. Some people went to college. A lot of people went to their local resource centre.

Almost everybody in Oban, Lochgilphead and Campbeltown had at least one supported activity with other people each week. A lot of people in Glasgow had nothing to do during the week.

Almost everybody in Oban, Lochgilphead and Campbeltown had been on holiday recently. Only half the people in Glasgow had been on holiday.



Good things about living in a rural area

Almost everybody living in Oban, Lochgilphead and Campbeltown would rather live there than in a big city like Glasgow.

Good things about living in a rural area are:

- It is quiet and safe.
- Everybody knows everybody else. People would stop and help you if you were lost or if you had an accident.
- There are lots of good things to do in rural areas - like horse-riding, going for walks, and kayaking.
- It is easier to get to know people because it is small.
- People are nicer than in big cities like Glasgow.
- It is a beautiful place to live.
- It is nice because people stop and talk to you if you go into town.



Bad things about living in a rural area

Even though most people were very happy living where they were, they thought that there were bad things as well as good things about living there.

Bad things about living in a rural area are:

- There are lots of things that you can't do – like ten-pin bowling, going to big shops, ice-skating and going to music shows.
- Sometimes you have to go to Glasgow to see specialist doctors; Glasgow is a long way away. The journey can be difficult.
- People with who need to use a wheelchair sometimes have problems – for example, they can't use the swimming pool in Campbeltown.
- Even in rural areas there are still things like noise, fighting, alcohol and drugs.
- Some people said that they had been bullied, and it was harder because everybody in a small town knew them.





Thank you very much to all of the people who took part in this study.

If you want more information about the study, please contact me:

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Appendix 6: Qualitative sub-study topic guide

These guided questions were used in the qualitative component of the thesis. The exact wording of the questions depended on the interviewee, and the questions were not necessarily asked in the order below.

1. In general, how did you find the process of asking people to take part?
2. Did you have any problems?
3. If there were any difficulties, where do you think that they arose?
4. Were people generally enthusiastic and keen, or was it hard to get people to be interested?
5. Was it helpful if I had met the participants beforehand, so that at least they knew who I was?
6. What sort of worries and objections to taking part did people have?
(Differentiate between objections by participants, and objections by next-of-kin.)
7. Did you tell people that I was a doctor - and do you think that this made any difference to how keen they were to take part?
8. Did you tell them that I was a psychiatrist? (Or did they know already?) Do you think that this made any difference? Were people worried about the mental health/psychiatry bit of the survey.
9. Do you think that it would have been different if you had worked in a city (like Glasgow)? Why/in what way?
10. Were people able to understand my “information pack”? Did they know what to do with it? Do you think that some people were keen, but didn’t have the support to help them fill out the reply slip?

Appendix 7: Original thematic index

1. Participant factors

- a. Interview anxiety
- b. Worry about negative feedback
- c. The concept of research
- d. Choice and consent
- e. Apathy
- f. Amount of work involved

2. Research and process factors

- a. The recruitment process: repetition, meeting people informally, the lone researcher
- b. Supplementary information
- c. Timing
- d. Communication difficulties
- e. Apparent interest and enthusiasm at first contact is not enough.
- f. Participants feedback

3. Qualities of the researcher

- a. Role perception
- b. Researcher fixed attributes
- c. Researcher personal attributes
- d. Degree of formality
- e. How the researcher is presented to the participant

4. Previous experience

- a. Experience of research - participants
- b. Experience of research - families and carers
- c. Experience of research - Participants and carers
- d. Experience of health and healthcare

5. Locality factors

- a. Culture of the area
- b. Geographic dispersion
- c. Relationship with professionals
- d. Relationship with client
- e. Economic factors

6. Families and carers

- a. Suspicion
- b. Fear of change
- c. Over-assessment
- d. Negative consequences
- e. Amount of work involved
- f. No perceived benefit

7. Recruiters

- a. “Active recruitment”
- b. Promoting free choice
- c. Multiple approaches

8. Motivators

- a. Participant motivators
- b. Recruiter motivators