The impact of stigma and discrimination on psychological distress in people with intellectual disability and access to health services: a mixed methods approach

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PhD Thesis, 2013

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Preface

In this thesis I present the findings of using a mixed methods approach to exploring the impact of stigma and discrimination on the lives of people with intellectual disability. The first chapter provides an overview of the conceptualisation of stigma and public attitudes towards people with intellectual disability, and discusses the findings of a systematic review into the experiences of stigma in people with intellectual disability and courtesy stigma in carers.

The second chapter reports the results of a cross sectional study of 229 participants with intellectual disability, investigating the impact of self reported stigma on psychological distress, quality of life, service use and adherence to treatment in people with intellectual disability. My interest in this study arose because of the relative dearth of research into the impact of stigma on health indicators in people with intellectual disability, when compared to other areas such as mental illness, particularly as stigma is increasingly being recognised as a determinant of health inequalities. I was interested in whether the findings from the mental illness literature about the impact of stigma on health outcomes were comparable and relevant to people with intellectual disability, given the presence of cognitive difficulties. The results of this study demonstrate that stigma has a deleterious impact on the wellbeing of people with intellectual disability. The findings are discussed in relation to previous studies, and the strengths and limitations of the study are considered.

The third chapter reports the results of a qualitative study exploring the barriers that Twenty nine participants (14 patient and carer dyads, and one carer) experienced in accessing health services for physical health problems. This study particularly focuses on the experience of discrimination from health services. Whilst the first study focuses on the impact of stigma on aspects of health, this study focuses on the factors that may prevent people with intellectual disability from receiving good quality of care from health services, particularly given the higher prevalence of health problems in this group. This thesis therefore raises two issues. Firstly, stigma may contribute to the development of health problems by increasing levels of psychological distress, and secondly, discrimination and other barriers may prevent people with intellectual disability from receiving the help that they require from health services, which may exacerbate health inequalities. In many ways the findings of the qualitative study are not surprising given the recent flurry of publications in this area, but it does reinforce and provide support to what is known already about the difficulties encountered by people with intellectual disability when accessing services. The strengths and limitations of the study are discussed.

In the final chapter, I summarise the findings of the studies and discuss potential clinical implications and directions for future research.

Acknowledgements

I am very grateful for the expertise and guidance provided by my supervisors Angela Hassiotis, Andre Strydom and Michael King, in completing this thesis. Their overwhelming support and confidence in me over the past five years has enabled me to flourish as a researcher.

In particular, I would like to thank Angela Hassiotis, who has provided me with invaluable career advice over the years and has been instrumental in helping me to achieve my goals. She has been an inspirational supervisor and role model. I hope to be able to inspire others in the same way as she has inspired me.

I would also like to express my gratitude to Katrina Scior who supervised the qualitative study. Her expertise, attention to detail and patience was much appreciated. Thank you also to Khadija Rantell who provided invaluable advice on the use of statistical techniques and the interpretation of data.

I am also grateful to all the professionals and service users who took part in the consultation groups and assisted in the piloting of the questionnaires. Thank you to Richard Lohan (Accessible Information Officer at Camden Learning Disability Service) who provided advice on the development of the accessible information sheets and questionnaires for the study.

Many thanks to all the Principal Investigators and Clinical Studies Officers who helped to recruit participants, from a number of sites in England. I would also like to thank admin staff, and all the staff who were involved in identifying suitable participants at community intellectual disability services, day centres, voluntary organisations and supported housing schemes. Not least of all, I would like to thank all the participants who took part in this study.

Finally, I would like to thank my husband for tirelessly supporting and encouraging me, and my son Raihan for being the sunshine in my life.

Abstract

Background

Self stigma has been associated with psychological distress, poorer adherence to treatment and is a barrier to help seeking behaviour in people with mental illness. Little is known about the impact of stigma on people with intellectual disability (ID). In addition, people with ID are more likely to experience disparities in accessing health care, possibly as a result of discrimination and inadequate knowledge of clinicians about the health needs of this vulnerable group.

Aims

1. To examine the association between self reported stigma and psychological distress, quality of life, treatment adherence and service use in people with ID

2. To explore experiences of health services by people with ID, particularly in relation to whether people have experienced discrimination from health services.

Methods

1. A cross-sectional study of 229 participants with mild to moderate ID, from 12 centres, was conducted to address the first aim. Data was analysed using a random effects regression model.

2. A qualitative study using semi-structured interviews, with 15 service use and carer dyads (29 participants), was used to examine the second aim. Data was analysed using thematic analysis.

Results

1. Self reported stigma was positively associated with psychological distress and higher service use, and negatively associated with quality of life. There was some

evidence that self reported stigma was associated with lower treatment adherence. Psychological distress mediated these relationships.

2. Half the participants had reported experiencing discrimination from health services. Accounts included negative staff attitudes and behaviour, and failure of services to make reasonable adjustments.

Implications

There is an urgent need to develop interventions that tackle self reported stigma and psychological distress in people with ID. Health services need to ensure that reasonable adjustments are made in order to reduce both direct and indirect discrimination of people with ID.

Chapter 1: Systematic Review of self reported stigma in people with intellectual disability and courtesy stigma in carers

Abstract

Background

People with intellectual disability frequently encounter stigma, prejudice and significant barriers that restrict their human rights. Stigma may also affect those who are closely associated with the person (courtesy stigma).

Aims

The aim of this review was to examine the literature on self reported stigma in individuals with ID and courtesy/affiliate stigma in family members.

Method

Four electronic databases were searched (Web of Science, PsychINFO, Pubmed and ERIC) between January 1990 and February 2012 (and updated in May 2013)

Results

Forty studies were included in the review (18 for self reported stigma and 22 for courtesy stigma). Most of the studies were qualitative or small descriptive cross sectional studies. Studies on self reported stigma revealed that people with intellectual disability were aware of being treated negatively but stigma awareness varied according to the extent to which individuals agreed with the label of having an intellectual disability, and the extent to which they were influenced by family members. Individuals often do not internalize the stigma associated with intellectual disability, which may enable individuals to maintain self esteem and hold similar aspirations to others in the community. Higher levels of self reported stigma are associated with lower self esteem, more negative social comparisons, more negative self evaluations and more psychiatric symptoms. Studies examining courtesy stigma report negative attitudes and behaviour from the public, resulting in the need to restrict activities outside of the home. In non-western cultures, mothers are often blamed for the child's disability and maybe marginalised by their family. Affiliate stigma is associated with increased self blame, increased care giving burden and psychological distress

Conclusion

There is a lack of studies examining self (internalised stigma) and large scale studies on the prevalence of self reported stigma or affiliate stigma. There is also a lack of longitudinal studies examining whether stigma has enduring effects on wellbeing and no studies of appropriate interventions for self or affiliate stigma in this group.

Section 1A: Introduction and conceptualisation of stigma

Introduction

People with intellectual disability are consistently identified as one of the least acceptable groups in society (Gordon et al, 2004; Nagata, 2007). Intellectual disability is defined by the World Health Organisation (2001) as “a condition of arrested or incomplete development of the mind, characterised by impairment of skills and overall intelligence in areas such as cognition, language, motor and social abilities, arising in the developmental period”. A recent meta-analysis estimated that the overall global prevalence of intellectual disability is approximately 1% (Maulik et al, 2011), with higher rates in low and middle income countries. Having a diagnosis of intellectual disability is associated with an excessive utilisation of public health resources in developed countries (Honeycut et al, 2004), although the costs arising from the burden of stigma is unknown (Pallab et al, 2011).

The stigma attached to intellectual disability: historical perspective

The stigma associated with having an intellectual disability is deeply rooted in history. Before the nineteenth century, people with intellectual disability, who were often referred to as “idiots”, were predominantly cared for by their families, and supported by local parishes in England. In the nineteenth century, society became less tolerant and held more negative attitudes towards those with disabilities. These changes were driven by the industrial revolution, changes in social reform (e.g. introduction of Elementary Education) and changes to the conceptualisation of the term “idiot” (Caine et al, 1998). People with intellectual disability became more visible, and were perceived to be a burden on their families and society as they were unable to work and contribute economically. People with intellectual disability were considered to lack the ability to “reason”, which was considered to be a defining characteristic of humanity, which led to the assertion that “idiots” were less than human (Goodley, 1996).

Institutions for people with intellectual disability were initially developed and managed by voluntary organisations with the aim of teaching skills and promoting productivity in selected individuals. However, the introduction of the Poor laws in

1834 led to the establishment of a large number of asylums where people with intellectual disability were admitted for life-long care, as they were viewed as being vulnerable and in need of protection (Gladstone, 1996; Jackson, 1996).

There were further changes in attitudes towards people with intellectual disability in the early twentieth century. The growing Eugenics movement viewed people with intellectual disability as being a threat to society. There were concerns that society would become contaminated if such individuals were permitted to reproduce. There was also a change in terminology to “mental deficiency”, which encompassed a number of different groups including people thought to be engaging in socially unacceptable behaviour, such as alcoholism and sexual misconduct. There was now a growing need to protect the public from people with intellectual disability, as well as the perception that such individuals required sheltering (Jackson, 1996). Legislative reforms led to the introduction of the 1913 Mental Deficiency Act, which gave powers that enabled “mental defectives” to be “certificated” and to live in segregated institutions (colonies), if deemed necessary. However, lack of funding meant that these measures were not fully implemented. The Act, however, permitted individuals to be cared for in the community under guardianship or licence. During the 1930s, sterilisation of individuals with intellectual disability took place in the UK and in other countries such as the USA.

During the Second World War, thousands of people with intellectual disability were assassinated as part of the Nazi eugenics regime. However, radical changes in attitudes and social reform were observed after the war. The introduction of the National Health Service in 1948 led to the reclassification of colonies as hospitals, and the introduction of the Mental Health Act in 1959 permitted the compulsory detention of people with intellectual disability in hospital. In the 1970s, over 60, 000 individuals were residing in institutions. However, in the 1960s and 1970s, there were a series of scandals reporting widespread abuse and neglect of individuals at these institutions, resulting in public outcry, and was a key driver of changes to social policy. Increasingly, people with intellectual disability were regarded as being less threatening to society. Research also suggested that people with intellectual disability who were previously considered to be “incurable” or not suitable for education, were able to develop skills with appropriate support. This led to advancements in social policy such as the 1971 White Paper “Better Services for the Mentally Handicapped”, which recommended an increase in community care and a shift in the responsibility for residential care from the National Health Service to local authorities. In addition, the philosophy of “normalisation” was advocated by Wolfensberger (1972) in the USA. This promoted the ideology that people with intellectual disability were valued citizens with the same rights to dignity, and opportunities for growth and development, as other members of the community, and that they should have access to accommodation that enabled them to lead “normal” and fulfilled lives. Changes in philosophy, alongside the hospital scandals of poor care, led to the process of deinstitutionalisation in the UK, and to the policy of community care. Wolfensberger also proposed that by increasing the public’s exposure to people with intellectual disability, stereotypes about people with intellectual disability could be challenged, leading to an increase in positive attitudes. This theory later became known as Social Role Valorisation (Wolfensberger, 1983).

Current situation

The number of people with intellectual disability residing in institutions fell dramatically in the 1980’s. The “Valuing People” white paper (Department of Health, 2001) and “Valuing People Now” (Department of Health, 2009) are strategies set out by the government to redress the inequalities experienced by people with intellectual disability in all aspects of their life by improving services. It emphasises the need to empower people with intellectual disability, and to maximise independence and social inclusion, including access to mainstream services such as health care. The rights of people with intellectual disability are further protected under the Disability Discrimination Act (1995) in the UK and the United Nations Convention on the Rights of Persons with Disabilities (2006).

However, despite substantial changes in government policies, people with intellectual disability continue to remain socially excluded, and encounter stigma, prejudice and major barriers that restrict their human rights (European Union Monitoring and Advocacy Programme report, 2005). There have also been recent reports of abuse at institutions for people with intellectual disability. A government inquiry, instigated by a BBC documentary highlighting numerous accounts of physical abuse and neglect of care of people with intellectual disability at Winterbourne view hospital, found a lack of clear leadership and accountability of senior managers (Flynn and Citarella, 2012). In addition, The Quality Care Commission had failed to act on concerns that had been raised. As a result of this inquiry, the government has made recommendations that everyone who has been placed at these institutions should be re-assessed and moved into more appropriate community placements where possible, with a view to reducing the number of inpatient units for people with intellectual disability.

MENCAP, a leading British organisation for people with intellectual disability surveyed 5, 000 people with intellectual disability about bullying and harassment (Mencap, 2000). Eighty eight percent reported bullying over the previous year, with 32% reporting bullying on a daily or weekly basis. Over 20% reported physical violence. A recent meta-analysis of the experience of violence over 12 months, found that people with disability were at greater risk of violence compared to those without (Hughes et al, 2012). The highest prevalence of violence was in people with mental illness (24.3%; OR 3.86) and those with intellectual impairments (6.1 %; OR 1.60). Hate crimes are often under reported and when they are reported, people with intellectual disability are often dismissed or their concerns are not taken seriously by the criminal justice system. Tackling disability hate crime is currently a national priority (Sheikh et al, 2010).

The Joint Committee on Human Rights (2008) has also highlighted the widespread denial of the fundamental human rights of people with intellectual disability by mainstream public services, including health services and the criminal justice system, and recommends fundamental changes in the way these services are delivered.

The public’s knowledge and attitudes towards intellectual disability

Public’s knowledge about intellectual disability

A recent systematic review by Scior (2011) provides a comprehensive summary of research into public knowledge and attitudes towards people with intellectual disability. Several studies consistently demonstrate that members of the lay public have a limited understanding of the concept of intellectual disability (Gordon et al, 2004), and that awareness and knowledge varies between respondents from different cultural and ethnic backgrounds. Knowledge about the prevalence of intellectual disability is often inaccurate (Alem et al, 1999; Tachibana, 2006; Tachibana & Watanabe, 2003), and one study found that only one in four people were able to recognise a person with intellectual disability from a vignette. Recognition was highest amongst White British participants compared to those from Asian and African backgrounds (Scior & Furnham, 2011). Knowledge is also associated with higher educational attainment (Aminidiv & Weller, 1995).

There are misconceptions about the aetiology of intellectual disability. In India, common explanations were “God’s will” or the fault of the parents (Madhavan et al, 1990) and in Tanzania, witchcraft was commonly cited as a cause by tribal leaders (Kisanji, 1995).

Public’s attitudes about intellectual disability

Studies examining social distance suggest that respondents are very unlikely to consider someone with intellectual disability as a friend (Gordon et al, 2004). Research on attitudes has focussed on four main factors (Henry et al, 1996) promoting inclusion, in line with the policy of “normalisation”: Empowerment (extent to which individuals are given the freedom to make their own life choices), Exclusion (extent to which respondents would like to exclude individuals with intellectual disability from society), Sheltering (extent to which individuals with intellectual need help keeping safe) and Similarity (extent to which individuals with intellectual disability share common goals). Empowerment and similarity are considered to be positive attitudes, and exclusion and sheltering are considered to be negative.

Attitudes towards people with more severe intellectual disability tend to be more negative compared to those with mild intellectual disability (Antonak et al, 1995) and are linked to perceptions about the ability and competence of people with intellectual disability. Attitudes in developed countries generally promote the inclusion of people with intellectual disability in society (Brayant et al, 2006; Henry et al, 2006). However, a significant minority oppose the integration of individuals with intellectual disability into mainstream education or work (Burge et al, 2007; Gilmore et al, 2003), either for the individual’s benefit, or because this would adversely impact others (Pace et al, 2010). Respondents from developed countries generally agree that people with intellectual disability share similar concerns and aspirations, but one study of German high school students found that agreement was low compared to Australian and Irish students (Eggert & Berrry, 1992). Negative attitudes are more likely to be associated with supernatural forces (Mulatu, 1999) and views about the condition being self inflicted (Panek & Jungers, 2008).

Socio-demographic factors are important in predicting attitudes towards people with intellectual disability. Individuals who are female (Downs & William, 1994; Oullette-Kuntz et al, 2003), younger (So-kum Tang et al, 2000; Yazbeck et al, 2004) and more educated (Yazbeck et al, 2004) tend to have more positive attitudes, although the effect of gender is inconsistent and diminishes once other variables are taken into account (Scior et al, 2010) A few studies of cross cultural comparisons suggest that some cultures may hold particularly negative attitudes. For example, Asian American students had more negative attitudes than Latin American or African students (Saetermore et al, 2001), and White British respondents were more positive towards people with intellectual disability compared to respondents from Hong Kong (Scior et al, 2010).

The most consistent factor associated with positive attitudes is having prior contact with someone with intellectual disability. In particular, positive attitudes are associated with having positive contact (Morin et al, 2013)

Knowledge and attitudes amongst health professionals

Several studies suggest that doctors often report that they have insufficient knowledge to treat people with intellectual disability. One study of Psychiatrists in Australia found that a third were reluctant to treat mental health problems in this group (Edwards et al, 2007). Inadequate training and education in intellectual disability is also cited by general practitioners as a reason for delivering inadequate care to this group (Cook et al 2000).

Health professionals may also hold negative beliefs and attitudes towards people with intellectual disability, which could potentially impact on the quality of care they provide for this group. One Australian study of health practitioners from different ethnic backgrounds found that intellectual disability was among the least accepted groups (Westbrook et al, 1993). One study found that nursing staff, working in a general hospital, were more likely to have less positive attitudes and more negative emotions towards patients with intellectual disability compared to those with physical disability (Lewis & Stenfert-Kroese, 2010). Psychiatry Residents are more likely to advocate sheltering rather than empowerment of people with intellectual disability if they have not completed a placement in intellectual disability (Ruedrich et al, 2008). Another study found that male Psychiatry Residents were more likely than females to advocate the exclusion of people with intellectual disability from community life; Female residents tended to favour empowerment and similarity. Psychiatry Residents also had higher scores on sheltering and exclusion, and lower scores on empowerment, compared to managers and professionals who worked with people with intellectual disability (Ouellette-Kuntz et al, 2003).

The conceptualisation of Stigma

1. Public Stigma

Defining Public stigma

Stigma is a process by which certain groups, such as those with mental illness or intellectual disability, are marginalised and devalued by society because their values, characteristics or practices differ from the dominant cultural group. Despite several decades of research into stigma, there continues to be debate about how stigma should be conceptualised. Goffman's (1963) characterisation of stigma as an "undesirable or discrediting attribute that reduces the status of the individual in society", has been argued by many to have limited utility in conceptualising health related stigma because of its outdated use of language, generalised application to a wide range of phenomena and focus on social interactions rather than political or structural aspects (Weiss et al 2006). Stigma is now regarded as a process, which is shaped by structural and cultural forces.

Link and Phelan (2001) argue that public or social stigma occurs through a number of different processes: Labelling (identifying characteristics as being different), stereotyping (assigning undesirable characteristics to these differences), separating (making a distinction between the normal group and labelled group), status loss, and finally, discrimination (devaluing, rejection and exclusion of the labelled group). They argue that for this to occur there must be an imbalance of power, fuelled by social, economic and political differences, that enables certain groups to become more dominant and to stigmatise others.

Corrigan and colleagues (Corrigan 2000, Corrigan & Watson, 2002) have also made contributions to our understanding of public stigma. Their social cognitive model comprises cognitive, behavioural and emotional aspects presenting as stereotypes, prejudice and discrimination. Stereotypes can have a useful function, as they can be an efficient way or organising collective information about particular cultural groups, and can be both positive and negative. Common negative stereotypes about mental illness or people with intellectual disability include beliefs about incompetence (e.g. inability to work or care for themselves), weakness of character (e.g. weakness of personality, judgement or irrationality) and dangerousness (violent, impulsive). Prejudice occurs when negative stereotypes are endorsed and combined with a negative emotional response towards a stereotyped group (e.g. “they frighten or disgust me”), and can lead to discrimination. Different types of prejudice can lead to different types of discriminatory behaviour, for example, anger may result in violence against the stigmatised group and fear may lead to avoidance or segregation of the stigmatised group.

Thornicroft et al (2007) also describe stigma as arising from three core problems: ignorance, arising from problems of knowledge; prejudice from problems of attitude; and discrimination as problems of behaviour. However, having greater knowledge does not necessarily lead to less prejudice. An increase in the public's knowledge about mental illness (e.g. mental illness has a biological aetiology) and a greater acceptance of professional help for mental health problems, has not been matched by more positive attitudes towards those with mental illness (Schomerus et al, 2012).

Thornicroft et al (2007) argue that stigma research in people with mental disorders (and other health disorders) should focus more on aspects of prejudice and discrimination, a view also held by proponents of the social model of disability. Traditionally disability has been viewed through a medical model, whereby disability is regarded as an individual tragedy, which has a physical or organic aetiology. However, over the last 30 years, the disability movement has argued that disability is socially constructed and imposed on individuals by society's failure to adjust and respond to people's needs, and it is therefore society that oppresses and marginalises people through social and structural barriers (Oliver, 1996). This has shifted the responsibility from the individual to society and has led to a move away from a focus on stigma to a greater consideration of discrimination, which can be addressed and tackled through the application of disability related policy (such as the Disability Discrimination Act in the UK). Nevertheless, it has been argued that the disability movement has excluded certain groups such as women and those with intellectual disability (Marks, 1999).

The impact of Public stigma and discrimination

Discrimination resulting from public stigma may take several forms. It may lead to withholding of help, avoidance, coercive treatment, and segregation (Corrigan & Watson, 2002). People from stigmatised groups, such as those with mental illness, frequently encounter discrimination that restricts opportunities in a number of domains including housing, education, employment, benefits, relationships with family and friends, and dating and marriage prospects (Time to Change, 2008; Social Exclusion Unit, 2008; Time to Change, 2009). Rates of employment are particularly low amongst people with intellectual disability and when paid work is available, it usually in the form of sheltered workshops (Bradock et al, 2005). A key barrier to community based employment is the belief that people with intellectual disability are “unemployable” (Shaw et al, 2004).

Research suggests that people with intellectual disability are aware of stigmatisation. One of the earliest studies include the work of Edgerton (1967) who found that individuals released from long stay institutions into the community, attempted to hide their disability due to their fear of being stigmatised. The experience of stigma in people with intellectual disability may involve overt acts of abuse or discrimination such as bullying or teasing. However, it is often more subtle, such as being denied the right to make choices as the person is considered incapable of making their own decisions, or having over-protective families who are reluctant to promote independence (Jahoda, 2010; Beart, Hardy, & Buchan, 2005; Jahoda, Cattermole, & Markova, 1988).

Discrimination may also occur from health professionals towards individuals with mental illness (Corker et al, 2013) and intellectual disability (Disability Right’s Commission, 2006; Mencap 2007). One reason for this is “physician bias”, as doctors (particularly psychiatrists) have contact with the most severe and serious cases, and less contact with individuals who have made a full recovery. This can lead to misconceptions about the prognosis of the condition, resulting in psychiatrists conveying an unoptimistic view about mental illness or intellectual disability to service users and carers. This may also perpetuate self stigmatisation (see below). In addition, “diagnostic overshadowing”, where symptoms due to physical health problems are attributed to the person’s mental illness or intellectual disability, can lead to delays in diagnosis and treatment of physical health problems leading to health inequalities (Disability Rights Commission 2006; Mencap 2007; Michael. 2008).

2. Self stigma

Self stigma, also known as internalised stigma occurs when individuals direct the stigmatised attitudes towards themselves (Corrigan & Watson, 2002; Corrigan et al, 2006; Corrigan et al, 2005; Ritsher & Phelan, 2004). Self stigma, like public stigma, comprises of stereotypes, prejudice and discrimination. Stereotypes such as “I am a weak person” are endorsed by the individual and lead to self prejudice in the form of negative emotional responses, such as low self esteem or self worth. Self prejudice can then lead to self discrimination through behavioural responses such as not seeking employment opportunities or avoiding social relationships. Self stigma only occurs when all three of the following occur: the individual must be aware of cultural stereotypes relating to the disorder, they must endorse these beliefs and apply these beliefs to themselves (Corrigan et al, 2009; Watson et al, 2007). Self stigma can occur in the absence of actual experiences of discrimination and arises due to the anticipation or fear of rejection or devaluation.

Factors influencing self stigma

However, not everyone with a stigmatising condition develops self stigma, even if they have experienced discrimination. Therefore there are factors that contribute to resilience. In some stigmatised groups, such as African Americans (Hoelter, 1983) or those with physical disability (Llewellyn, 2001), there may be increased self esteem. This maybe because they have reacted to stigma by protesting against the injustice caused by stigma and discrimination, and by focusing on positive attributes. Other groups may be indifferent to public stereotypes. One aspect that appears to be important is whether an individual identifies with a stigmatised group. Lack of identification with the stigmatised group may lead to indifference as he or she does not believe that the stereotypes apply to them, but identification with the group could lead to self stigma (Jetten et al, 1996), as it threatens self identity (Aronson & McGlone, 2009). However, if the stereotypes are considered to be illegitimate and unfair, individuals may react with righteous anger (Frable et al, 1997) and are likely to be proactive in campaigning for empowerment and equality.

3. Courtesy stigma

Stigma may also affect those who are closely associated, such as members of the family, friends and even professionals that work with the person. This is known as courtesy stigma (Birenbaum 1992, 1970). This may result in family members being teased, abused, blamed or considered responsible for the person’s disability (Larson & Corrigan, 2008). Family members may develop negative self evaluations and negative emotions such that they may withdraw or conceal their negative status from others. This process of self stigmatisation in family members has been described as affiliate stigma (Mak & Cheung, 2008).

Section 1B: Systematic Review

Aims and objectives of the review

There have been no published systematic reviews examining the body of literature on the experience of stigma by people with intellectual disability or courtesy and affiliate stigma in family members.

The aim of this systematic review is to summarise the findings of research into a) experience of stigma in people with intellectual disability (described in the review as self reported stigma), and b) courtesy stigma in the family members of people with intellectual disability. The specific aims are:

1. To identify the extent to which people with intellectual disability are aware of stigma and discrimination and the extent to which carers report courtesy or affiliate stigma
2. To identify whether self reported stigma and courtesy/affiliate stigma are influenced by psychological and social factors
3. To identify whether self reported stigma and courtesy/affiliate stigma are related to psychological distress (e.g. self esteem, care-giving burden, quality of life).

Method

Search Strategy

Studies covering the period from January 1990 to February 2012 were searched for using the electronic databases Web of Science, PsychINFO, Pubmed and ERIC (Proquest). The search terms “mental retardation”, “intellectual disability” and “learning disability” were combined separately (using AND as the bolean operator) with both “stigma” and “discrimination”. The above search terms were also combined with the search terms “affiliate stigma” and “courtesy stigma”. (The full list of search terms can be found in the appendix). Initially the titles of the articles and abstracts were reviewed and those that were not relevant were removed from the list. Full papers were obtained for the studies of interest and only studies that met the inclusion criteria were included in the review. In addition, the reference lists of all the included studies were searched to identify further relevant studies and some of the key journals on intellectual disability (Research in Developmental Disabilities, Journal of Intellectual Disability Research and Journal of Applied Research in Intellectual Disability) were also hand searched (last five years).

The search was updated in May 2013 to identify whether any new studies had been published since the original search and to identify any studies that had been missed by the earlier search.

Inclusion and exclusion criteria

Only studies of primary research examining the experience of stigma or discrimination from the perspective of individuals with intellectual disability, or the experience of courtesy or affiliate stigma in the informal carers of people with intellectual disability were included. Studies that did not specifically refer to people with intellectual disability were excluded (e.g. disabilities in general) and studies including less than ten participants were also excluded (to ensure some degree of methodological quality).

Carers included mothers and fathers and direct relatives of the individual with intellectual disability. Staff and other professionals such as teachers and health professionals were not included. Studies examining the attitudes of other groups towards people with intellectual disability and studies specifically examining the validation of stigma measures were excluded as these have been the subject of recent systematic reviews (Scior, 2011; Werner et al, 2012). Only studies in English and those studies where a full paper could be obtained were included. Both qualitative and quantitative studies were included.

Quality assessment and analysis

A structured questionnaire was used to extract information about the design of each study, sample size, selection of participants, the type of instruments or interviews used and their reliability and validity (if appropriate), the main findings, generalisability of findings and any methodological weaknesses. The included studies were analysed and synthesised using a thematic approach to identify key themes. The data was extracted by AA but consensus on the final inclusion, interpretation and synthesis of the studies was agreed by the research team.

Results

Results of search strategy

Figure 1.1 provides details of the search strategy and results, and the reasons for excluding studies.

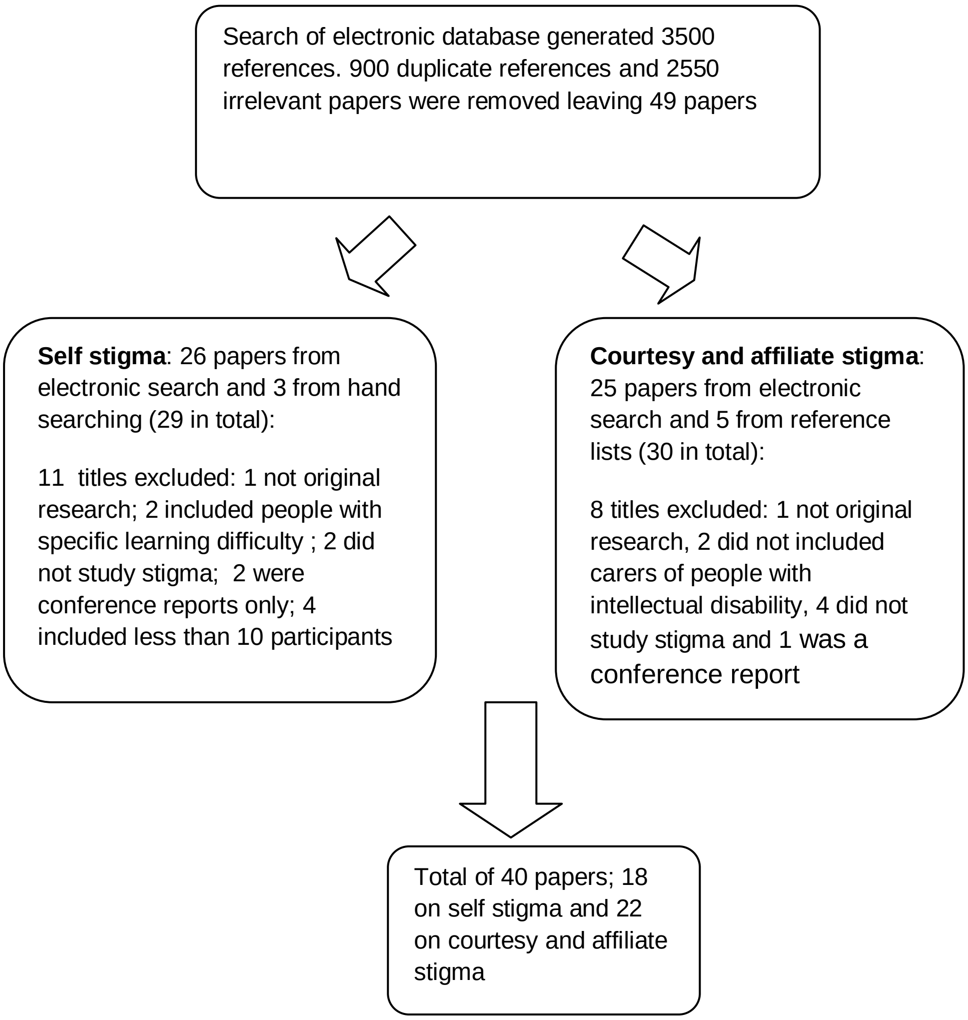
Overview of the studies included

A total of 40 papers were included in the review and an overview of the studies is provided in tables 1.1 and 1.2.

Eighteen studies examined self reported stigma in a total of 1891 people with intellectual disability (if the same sample was used in more than one study, this was only included once). Six used qualitative, nine cross sectional and three mixed methods. The majority of the studies were conducted in the UK (thirteen studies), one in the USA, two in Australia, one in Taiwan and one in Hong Kong.

Twenty two studies examined courtesy or affiliate stigma in a total of 1500 family members of people with intellectual disability. Eleven were qualitative, six were cross sectional, four used mixed methods and one was longitudinal. A variety of countries were involved; Taiwan (3), UK (4), USA (3), Hong Kong (2), Vietnam (2), Australia (1), Ireland (1), China (1) United Arab Emirates (2), India (1), Pakistan (1) and South Africa (1).

Figure 1.1: Flow diagram of search results



Search of electronic database generated 3500 references. 900 duplicate references and 2550 irrelevant papers were removed leaving 49 papers

Self stigma: 26 papers from electronic search and 3 from hand searching (29 in total):

11 titles excluded: 1 not original research; 2 included people with specific learning difficulty ; 2 did not study stigma; 2 were conference reports only; 4 included less than 10 participants

Courtesy and affiliate stigma: 25 papers from electronic search and 5 from reference lists (30 in total):

8 titles excluded: 1 not original research, 2 did not included carers of people with intellectual disability, 4 did not study stigma and 1 was a conference report

Total of 40 papers; 18 on self stigma and 22 on courtesy and affiliate stigma

Table 1.1: Overview of the studies examining self reported stigma in people with intellectual disability

Study	Design	Location	Sample	Method	Main findings	Limitations
Azmi et al.(1997)	Mixed methods	UK	21 adolescents and adults (14-44 yrs old; 14 male, 9 female) from South Asian communities.	Semi-structured interview covering 7 areas including ethnic and racial identity and stigma. 5 point rating scale used to assess global satisfaction in each area. content analysis used. 4 interviews coded by another rater to assess inter-rater reliability	Most identified themselves according the ethnicity rather than disability. Combined effects of racism and stigma.	Almost all participants lived in family homes.
Abraham et al (2002)	Cross-sectional study	UK	50 participants with mild/moderate ID, recruited from 3 day centres (28 female, 22 male aged 23-65).	IQ not assessed. Stigma Perception Questionnaire; self esteem scale	Stigma negatively correlated with self esteem	Small sample, limited generalisability. No information on ethnicity Multivariate analysis not conducted.
Chen & Shu (2012)	Qualitative	Taiwan	14 participants with mild/ moderate ID (aged 17-22, 8 males and 6 females) recruited from special educational programme at a high school	Semi-structured interviews examining experiences of stigma, views about stigmatising treatment and responses to treatment. Data analysed using thematic analysis. Validity assessed by two experts.	Students internalised stigma of ID.	Small sample. Participants recruited from one school. Those with autism excluded. Reliability of the coding frame not established.
Cooney et al (2006)	Cross-sectional study	UK	60 adolescents (aged 15-17) attending mainstream (28) and segregated schools (32)	Tested IQ. Stigma assessed using the “Experience of Stigma Checklist”, developed for study and the “modified life in school checklist”, (Aurora, 1987). Also analysed social comparisons with disabled and non disabled peers and future aspirations.	Mainstream group experienced more stigma, especially at school. No difference in social comparison scores and aspiration scores in the two groups. No relationship between stigma and future aspirations.	Low internal consistency of the stigma measures and social comparison scale and low response rate (50%).

Table 1.1: continued…

Study	Design	Location	Sample	Method	Main findings	Limitations
Cunningham & Glenn (2004)	Mixed	UK	78 Parents and 77 individuals with Down Syndrome (aged 17-24, 45 males, 32 females) recruited from the Manchester Down Syndrome cohort.	IQ assessed. Semi-structured interviews with factual answers used for parents. Structured questions with a few open ended questions used for individuals with DS. Reliability assessed by 2nd rater.	Awareness of disability associated with IQ. Only half recognised they had DS. Few described being distressed by experience of stigma.	Structured questions limited exploration of some issues.
Dagnan & Waring (2004)	Cross-sectional	UK	39 participants with mild/moderate ID (aged 23 to 65; 21 males, 18 females). 59 initially approached from 3 day centres and supported employment scheme	Stigma measured using the Stigma Perception Questionnaire. Evaluative Beliefs also measured.	Stigma correlated with negative self evaluations and negative social comparisons.	Small sample, limited generalisability, no control for confounding.
Emerson, 2010	Cross-sectional	UK	1273 participants with ID (45% of total sample) living at home or supported accommodation. Survey conducted in 2003-2004.	Secondary analysis of data. Examined responses to two questions on bullying and analysed association with wellbeing (4 questions) and self reported health (1 question), and whether association was modified by socio-economic factors	Self reported bullying was associated with poorer wellbeing and self reported health, and the association was stronger in people with lower levels of material or social resources.	IQ was not formally assessed. Only two items examining discrimination. Recall bias likely to affect responses, particularly to childhood bullying. The data does not identify that the bullying occurred as a result of ID.
Finlay & Lyons (2000)	Qualitative	UK	33 participants with mild/moderate ID (aged 18-65, 13 males, 20 females) recruited from 3 services	Semi-structured interviews about the way participants viewed themselves relative to others with and without ID. Questions embedded in stories being described by the person. Interviews were recorded and transcribed. Content analysis was performed and inter-rater reliability was assessed.	Upward comparisons (comparing themselves as unfavourable) were uncommon. Participants considered themselves to be better than other people with ID.	Did not examine experiences of stigma.

Table 1.1: continued…

Study	Design	Location	Sample	Method	Main findings	Limitations
Patterson, McKenzie, Lindsay (2012)	Cross-sectional	UK	43 recruited from a day centre (aged 20-66; 25 female, 18 men). Attempted to recruit everyone eligible (65 eligible).	IQ measured. Stigma measured using Stigma Perception Questionnaire. Also assessed self-esteem, psychiatric symptoms and social comparisons	Stigma negatively correlated with self esteem and negative social comparisons with the community (but not service users) and positively correlated with psychiatric symptoms.	Small sample, limited generalisability. Poor reliability of some of the measures (stigma questionnaire and social comparisons scale).
McDonald et al, 2007	Qualitative	USA	13 African American and Latino college students (mean age 13.6 yrs)	Semi-structured interviews. Interviews audio-taped and transcribed. Validity and reliability of coding frame assessed and disagreements resolved. Data were triangulated.	Ethnic identity considered to be important and most felt that their disability did not affect relationship their community.	Small sample size.
Petrovski & Gleeson, 1997	Cross-sectional study	Sydney, Australia	31 participants with mild ID (aged 18-41, 15 males, 16 females), recruited from a vocational agency	Stigma measured using the Stigma Perception Questionnaire. Also assessed self esteem, loneliness and aspirations.	Stigma negatively correlated with self esteem	Small sample size, limited generalisability, no control for confounding.
Szivos (1990)	Cross-sectional study and qualitative study	UK	50 participants with mild/moderate ID attending 4 further education classes and 3 work placements (aged 16-21; 30 males, 20 females)	IQ measured. Measured self esteem (questionnaire included 10 items on stigma), aspirations and expectations	Students who felt the most different had lower expectations. No differences in self esteem in those who worked and those who did not and those who were in more segregated settings thought they were more competent at work.	Stigma items were combined with self esteem items. Attempted to compare experiences of those who were in segregated and mainstream settings but not practicable. Small sample size and limited generalisability.

Table 1.1 Cont..

Study	Design	Location	Sample	Method	Main findings	Limitations
Szivos-Bach, 1993	Cross sectional study	UK	50 participants with mild/moderate ID from further education colleges (aged 16-21; 30 males, 20 females)	IQ measured. Stigma Perception Questionnaire, Self Esteem Scale	Stigma negatively correlated with self esteem.	Small sample, limited generalisability, no control for confounding.
Todd, 2000	Qualitative	UK	21 students from a school for children with ID (aged 16 yrs old).	Ethnographic study, based on observations and unstructured interviews with students and pupils over 2 year period.	Students did not consider themselves to be disabled and had little awareness of stigma.	Small sample size. Method used to analyse data not described.

Results: Self reported-stigma in people with intellectual disability

The following themes emerged from the analysis of studies on self reported stigma: the relationship between stigma and socio-demographic variables; the experience of stigma and discrimination in different settings; cultural factors; awareness of the intellectual disability label; psychological distress; and coping with stigma. The themes will now be discussed in more detail.

The relationship between stigma and socio-demographic variables

No studies have found a relationship between stigma and age (Cooney et al, 2006; Paterson, McKenzie & Lindsay, 2012; Szivos-Bach, 1993), stigma and gender (Cooney et al, 2006; Dagnan & Waring, 2004; Paterson, McKenzie & Lindsay 2012; Petrovski & Gleeson, 1997; Szivos-Bach, 1993) or between stigma and IQ (Cooney et al, 2006; Paterson, McKenzie & Lindsay, 2012; Szivos-Bach, 1993) possibly because of the small sample size of the studies.

The experience of stigma or discrimination in different settings

Eight studies have explored the experience of stigma in different settings. Four studies examined stigmatising experiences at school or college, three investigated experiences at work, one examined participants from different residential settings and one examined participants' experience of using banks. Four of these studies were cross-sectional, three were qualitative and one used mixed methods. Four of the studies were conducted in the UK, two in Australia and one in Taiwan and one in Hong Kong.

Emerson (2010) conducted a secondary analysis of results from a large population based study of 1273 participants with intellectual disability (aged over 16) residing in at home. Questions were asked about whether they had experienced bullying at school and whether people had been rude or nasty to them in the last 12 months.

Half the sample reported that they had been bullied at school and a third reported that they had been the recipient of bullying in the last 12 months.

Cooney et al (2006) surveyed 60 adolescents attending mainstream and segregated (special) schools and examined whether there were differences in the levels of stigma experienced by the two groups. Stigma experiences were measured using two scales. The “Stigma Experiences Checklist”, a 13 item, self report measure, that describes stigmatising treatment from key figures (parents, teachers, pupils) and the “Modified Life in School Checklist”, a 12 item self report measure (Arora, 1987). Students attending mainstream schools were more likely to report stigmatising treatment compared to those attending segregated schools, although both groups reported similar experiences outside the school environment. However, their experiences of stigma did not affect their future aspirations for a career, or optimism for the future, suggesting that experiences of mainstream schooling did not make individuals more aware of social limitations and barriers.

Larkin et al (2012) compared the nature of interpersonal conflicts in 26 college students with and without intellectual disability using mixed methods. They found that those with intellectual disability were more likely to report aggression and conflicts with strangers or people outside their peer group, compared to those without intellectual disability, who were more likely to report conflicts with a person close to them. The conflicts reported by young people with intellectual disability may be a direct result of stigmatisation. However, participants with intellectual disability were more likely to process cognitively and emotionally other peoples’ actions as negative and as personally directed, and to consider the perpetrator as “globally bad”, which may increase hostility towards others.

Chen & Shu (2012) interviewed 14 students with intellectual disability, attending mainstream schools, in Taiwan. Their study suggested that the students had internalised their stigmatised status. The possession of the handicapped identity card, which entitled the students to additional support, was regarded as a source of stigma and as validation that they were inferior to other students. Some students identified themselves as odd because of feelings of shame and embarrassment resulting from strange looks or stares from others, or as troublemakers because they invoked anger in teachers for being slow learners. The authors discuss the important value placed on educational ability in Taiwan and the consequent pressure that is placed on young people to succeed. This may result in students with intellectual disability being stigmatised even more than would be expected in other cultures that do not hold education in such high regard.

Li (2004) interviewed 18 adults from Hong Kong and found that the majority had experienced difficulties with finding employment due to the negative attitudes of employers towards people with intellectual disability. All had experienced problems at work, which included being reprimanded and having a poor relationship with other employees and employers. Half the participants reported possible discrimination and lack of social acceptance and misconceptions about their abilities. Petrovski & Gleeson (1997) found that the experience of stigma was associated with poor job satisfaction at work. Szivos (1990) surveyed 50 students and found that those who had mainstream work placements did not have higher expectations of achieving life goals than those who did not work, possibly because of a greater awareness of social limitations arising from more frequent contact with non- disabled peers.

Jahoda and Markova (2004) interviewed 28 adults who had recently moved from institutions into community settings (hospital group) and those who had recently moved from the family home to more independent forms of living (housing group). Awareness of stigma was apparent in both groups and included feeling isolated and being rejected and abused. The hospital group dissociated themselves from the institution and concealed their past in order to achieve acceptance, similar to the observations made by Edgerton (1967). For the housing group, living independently was a way of counteracting their stigmatised status. However, a few participants from both groups did not report stigma. Both groups expressed empathy for their peers but also a wish to escape from prejudice by distancing themselves from them. Stigma clearly affected the ability of the individuals to retain a positive sense of self.

One cross-sectional study of 94 participants with intellectual disability and 53 of their carers examined experiences with banks (Hayes & Martin, 2007). Carers were more likely to report that the individuals they supported experienced discrimination from banks than the individuals themselves. However, when people with intellectual disability made a complaint, it was more likely to be because of negative attitudes or negative treatment from bank staff. It was clear from the study that very few people with intellectual disability engaged in telephone or internet banking suggesting that there was a “digital divide” and that people with intellectual disability were being excluded from accessing such services due to the inaccessibility of these services.

Stigma and cultural factors

Two qualitative studies (one from the UK and the other from the USA) have explored the impact of cultural factors on the experience of stigma. Studies suggest that ethnic identity is important (Azmi et al, 1997; McDonald et al, 2007), and in some instances enabled participants to form a close bond with their community, despite the negative attitudes of their community towards disability (McDonald et al, 2007). However, Azmi et al (1997) found that young people from South Asian communities in the UK reported both racism (from the community, other service users and staff) and discrimination as a result of their disability, and that this double stigma had a profound impact on their lives. Some participants reported that the invisible nature of their disability was an advantage as it prevented them from being excluded from their community (McDonald et al, 2007).

Self reported stigma and awareness of the label of intellectual disability

Two studies from the UK investigated the relationship between awareness of having an intellectual disability and stigma. Cunningham & Glenn (2004) interviewed 77 people with Down Syndrome and their parents, using mixed methods. They found that only half of their participants were aware of having Down Syndrome or a disability. Thirteen percent (mainly male) had a negative emotional reaction (such as refusing to talk or appearing uncomfortable) when discussing the condition. A quarter of the sample were thought to be aware of the stigma associated with having a disability but only five participants described experiences of stigma as distressing. In general, the participants had high levels of self esteem. They found that awareness of Down syndrome did not correlate with their parent discussing the condition with them.

Todd (2000) conducted an ethnographic study of 21 students with intellectual disability and also found that the participants did not view themselves as “handicapped”, which for most meant a physical or sensory impairment, and that they held many typical aspirations such as finding a job and getting married. They had little awareness of their stigmatised status.

In both the studies, the individuals did not associate themselves with the label of disability and therefore had not internalised the stigma associated with the label.

Stigma and psychological distress

Nine studies (1579 participants) have investigated the relationship between self reported stigma and psychological distress. The definition of psychological distress included here were effects on self esteem, effects on aspirations, social comparisons with others and the presence of psychiatric symptoms. Eight studies were from the UK and one from Australia. All of the studies apart from one was quantitative. Six of the studies used Szivos-Bach’s 10 item measure of stigma (1993) or an earlier version of the scale and two studies used alternative questions or scales (Cooney et al, 2006; Emerson, 2010). Szivos-Bach’s stigma scale, which was originally developed for use by young adults with intellectual disability attending educational facilities (aged 16-21) assesses participants’ perception of being stigmatised (e.g. treated like a child, being made fun of) and is rated using a 5 point scale (never, sometimes, half the time, often, nearly and always). It has a good internal consistency (alpha 0.81) but its reliability and factor structure was challenged by Abraham et al (2002), who found that three items had poor test re-test reliability and the original factor structure could not be replicated.

Four studies have examined the relationship between how people with intellectual disability view themselves in relation to others (social comparisons) and the stigma they experience. Finlay and Lyons (2000) conducted a qualitative study of 33 adults with intellectual disability. Participants were more likely to consider themselves to be better than, or the same as others (including those without intellectual disability). These downward comparisons were mostly made with people who also had intellectual disability, usually on dimensions of good and bad behaviour and abilities, rather than on the basis of having an intellectual disability. Upward comparisons (presenting others in a favourable position) were uncommon. The identity of intellectual disability was not salient. The study suggests that in general, the participants regarded themselves positively and rejected their stigmatised status. Szivos-Bach (1993) also explored the nature of social comparisons and found contrasting results. She surveyed 50 young people with intellectual disability who were asked to identify four comparison figures: best friend, sibling, specific non intellectually disabled person ("other"), and their ideal self. Older siblings were considered as more superior, while younger ones were seen as inferior and "others" were perceived to be superior. Participants who perceived higher levels of stigma were more likely to perceive themselves as inferior to their comparison figures. These findings suggest that upward social comparisons may be the result of an awareness of stigma and that stigmatisation may begin at home, through social comparisons with siblings. Higher levels of stigma and more negative social comparisons were also found by Dagnan & Waring (2004). Patterson, McKenzie & Lindsay, (2012) found that higher levels of stigma were related to social comparisons with members of the community and not other service users (people with intellectual disability) mostly on the basis of feeling less attractive and less capable. However, social comparisons did not moderate the relationship between stigma and self esteem.

Four studies (Abraham et al; 2002; Patterson, McKenzie & Lindsay, 2012; Petrovski & Gleeson, 1997; Szivos-Bach 1990, 1993) all found that higher levels of stigma were associated with a lower self esteem. Szivos-Bach (1990, 1993) found that students who felt the most different or most stigmatised, were more likely to have lower aspirations in life. However, this finding was not supported by Cooney et al (2006) who found no relationship between stigma and aspirations. In addition, higher levels of stigma has been found to be associated with feelings of loneliness and poor job satisfaction (Petrovski & Gleeson 1997), more negative self evaluations (Dagnan & Waring, 2004) and more psychiatric symptoms (Patterson, McKenzie & Lindsay (2012). Emerson (2010) also found that participants who reported more bullying at school and in the last 12 months, were more likely to report lower wellbeing (e.g. “sometimes not happy”, “felling helpless”, “feeling left out” and “feeling sad”) and poorer self reported health. He found that the association between bullying and health was stronger in people who had lower levels of material or social resources.

These studies all suggest that stigma has a profound effect on psychological wellbeing by influencing how people view themselves in relation to others, lowering self esteem and making people vulnerable to mental health problems.

Coping with stigma

Few studies have specifically examined the coping strategies used by people with intellectual disability to manage stigma. Chen & Shu (2012) found that coping strategies used by students included avoidance such as concealing information about the possession of a handicapped card and managing and monitoring the behaviour of other classmates with intellectual disability when they were amongst mainstream students. Some students deliberately avoid forming relationships with non -disabled students without intellectual disability to avoid confrontation. Other students consciously promoted their skills and their ambition to learn new skills. Cunningham & Glenn (2004) found that strategies for maintaining a positive sense of self in individuals with Down syndrome included minimising their difficulties and believing that they could achieve competency if they worked harder.

Limitations of the studies

The qualitative studies included in the review generally had small samples, which ranged from 13 to 33. Most participants were recruited from one setting (e.g. educational settings). The method used to analyse the interviews was not stated by one study (Todd, 2000) and several studies did not examine the validity and the reliability of the coding frame (e.g. Jahoda & Markova, 2004; Li 2004;Todd, 2002). No study examined respondent validity.

Most of the mixed and quantitative studies employed convenience sampling, apart from three that attempted to approach everyone who was eligible (Cooney et al

2006; Emerson, 2010; Patterson et al, 2012). In addition, most of the studies recruited participants from one setting only, usually day centres or educational facilities, which may affect the representativeness of the findings. Only one study used a large representative sample (Emerson, 2010) but this was based on a secondary analysis of the data. The sample sizes for the other studies were small, ranging from 21 (Azmi et al, 1997) to 94 (Hayes & Martin, 2007), and the measure of stigma that was used by many of the quantitative studies had poor reliability (Abraham et al, 2002). Further details regarding the limitations are given in table 1.

Summary of findings: self reported stigma in people with intellectual disability

- The main themes were experience of stigma and discrimination in different settings, cultural factors, awareness of the label of intellectual disability, stigma and psychological distress and coping with stigma
- Stigma in different settings: Emerson (2010) found that half the sample of 1273 participants reported bullying at school. Cooney et al (2006) found that students attending mainstream schools were more likely to report bullying. Students in Taiwan who possessed a handicapped card reported feelings of shame and embarrassment (Chen & Shu, 2012). In Hong Kong, half the participants reported discrimination at work (Li, 2004). Mainstream work was not associated with higher aspirations (Szivos, 1990). Participants living in different residential settings described experiences of isolation, rejection and abuse and a need to distance themselves from peers
- Cultural factors: South Asians with intellectual disability reported double discrimination (Azmi et al, 1997)
- Awareness of label: Cunningham & Glenn (2004) found that only half the participants were aware of having Down Syndrome and only a quarter were aware of stigma
- Stigma and psychological distress: stigma was associated with lower self esteem, lower future aspirations, more negative social comparisons with others and more psychiatric symptoms such as depression.
- Coping strategies included avoidance of certain relationships, promotion of strengths and minimisation of difficulties.
- All of the studies except one (Emerson, 2010) were small studies using samples recruited from one setting. The measure of stigma used in the quantitative studies had poor reliability.

Results: Courtesy and affiliate stigma

Most of the studies of family carers have examined courtesy stigma. The studies mainly focus on the mothers’ views and perspectives as the mother is regarded as the main caregiver in most cultures. Only three studies explicitly stated that they had examined affiliate stigma (Mak & Kwok, 2010; Mak & Cheung 2008; Ntswane & Rhyn 2007). However, there were six other studies that investigated some aspects of affiliate stigma such as feelings of shame, embarrassment and distress, although the term affiliate stigma was not used (Baxter & Cummins 1992; Chang 2009; Green 2007, 2004, Perkins et al, 1992; Shin et al, 2006). The following themes emerged from the analysis of the studies on courtesy and affiliate stigma: being marginalised by the community; being marginalised by the family; courtesy or affiliate stigma and psychological factors in parents; courtesy or affiliate stigma in other family members; and how family carers cope with stigma. Table 1.2 provides an overview of the studies included in this section.

Table 1.2: Overview of studies examining courtesy or affiliate stigma in family members

Study	Design	Location	Sample	Method	Results	Limitations
Baxter & Cummins (1992)	Longitudinal	Australia	131 parents (mother-father dyads) selected through random sampling of special schools and stratified sampling of households based on children's age. Second stage, 93 parents participated.	Interviews carried out at baseline and 7 years later. Measured parent perceived stress due to attitude of others towards child, types of stress inducing conditions and parental response to distress and willingness to take child to public places.	Stress was associated with negative reactions from the public, and only decreased slightly over time. Parents used three types of coping responses: not saying anything; moving away from the situation quickly and informing others.	30% of participants dropped out of second interview. Limited information about the demographics of the parents.
Chang (2009)	Qualitative	Taiwan	38 disability rights activists who had children with ID (22 mothers, 9 fathers, 3 siblings. 4 professionals). Recruited through snowballing techniques.	In depth interviews about the experience of courtesy stigma and the role and benefits of activism.	Mothers more likely to experience stigma compared to fathers. Participation in advocacy organisations helped parent obtain support and gave a new meaning to their lives.	The findings may be different in those who do not participate in advocacy groups. No validity or reliability checks.
Chou et al (2009)	Cross-sectional	Taiwan	350 female family carers (aged 55 or over) of people with ID (aged over 30). Comparison group were 66 carers of people with mental illness. Sample obtained through screening 2886 adults with ID and 576 female carers.	Stigma measured using the stigma domain of Caregiver Burden Scale (Song 2002). Also measured carer's health, social support and quality of life using validated and reliable scales.	Carers reporting higher levels of stigma reported more stress and effect more marked in carers of people with ID.	55% response rate. (aged 27-42). Views representative of older mothers

Table 1.2: Continued…

Study	Design	Location	Sample	Method	Main findings	Limitations
Crabtree (2007a)	Qualitative	UAE	15 carers of children with developmental disabilities (including ID and autism, aged 4-16) from 3 medical centres. Mostly women (7 Emirati, remainder Arab immigrants)	Examined experiences of stigma. Ethnographic study using in depth interviews over 10 months. Interviews conducted until data saturation was reached. Data coded into themes. Interpreter used.	Parents experienced stigma from the community and medical professions and also from members of the family.	Limited participation from fathers. Validity and reliability of coding frame not established.
Crabtree (2007b)	Qualitative	UAE	15 carers of children with developmental disabilities (including ID and autism, aged 4-16) from 3 medical centres. Mostly women (7 Emirati, remainder Arab immigrants)	Examined care-giving experiences and gender differences in how males and females with disability are viewed. Ethnographic study using in depth interviews over 10 months. Interviews conducted until data saturation was reached. Data coded into themes. Interpreter used.	Fathers were more likely to experience shame and disappointment. Females more likely to be subject to oppressive and sexist attitudes.	Limited participation from fathers. Validity and reliability of coding frame not established.
Edwardraj et al (2010)	Qualitative	India	8 focus groups with 68 women (29 mothers, 10 health workers, 16 teachers) recruited from tertiary centre form mental health needs, aged 20-50.	Semi-structured interviews covering perceptions of cause of disability and support from family and community, were audio-taped and transcribed and thematic analysis performed to generate themes. Two raters independently transcribed and translated interviews. Two raters derived themes.	Mothers experienced stigma from family members and the community.	Findings may not apply to other households. Fathers were excluded. Reliability of the coding frame not assessed. No information given about the children.

Table 1.2: Continued…

Study	Design	Location	Sample	Method	Main findings	Limitations
Fazil et al (2002)	Mixed methods	UK	15 Pakistani and 5 Bangladesh families interviewed (20 mothers, 16 fathers, 1 sibling, 2 grandmothers) referred by schools, nurses, health visitors and social workers.	Semi-structured interviews assessing social support and contact with professionals. Also used measures to assess psychological wellbeing, social support and self esteem.	Mothers reported being blamed for child's disability and experienced marital conflict and discord.	No discussion on how data were analysed both qualitatively and quantitatively. Stigma was not the focus of the study.
Green (2007)	Mixed	USA	81 mothers recruited from paediatric clinic. Fathers excluded. 7 mothers agreed to take part in qualitative study.	Perceived stigma measured using an adapted version of the Devaluation- Discrimination Scale . Also measured caregiver burden and perceived benefits of care giving	Perceived stigma associated with perceived care giver burden and emotional upset and distress and reduced benefits of caregiving.	No breakdown of what the disabilities were and how many had ID. Views of fathers not included.
Green (2004)	Cross-sectional	USA	81 mothers recruited from Paediatric clinic. Fathers excluded from analysis as small sample. All disabilities included	Perceived stigma measured using an adapted version of the Devaluation- Discrimination Scale. Also measured caregiver burden and attitude to future placement	Perceived stigma associated with increased care-giving burden, leading to more mothers considering residential placement.	No breakdown of what the disabilities were and how many had ID. Views of fathers not included.
Huang, Kellett, St John, 2012	Qualitative	Taiwan	15 mothers(aged 27-42) of children with Cerebral Palsy (aged 8 months to 14 yrs)	In-depth interviews transcribed verbatim and analysed in Chinese.	Experience of stigma from community and family members.	Small sample, not specific to ID. Mainly young mothers. Validity and reliability of coding frame not established.
Lim et al, 2013	Qualitative	China	14 mothers and 1 grandparent of children with severe ID and Rett's syndrome, recruited by random stratified sampling from a database.	Telephone interviews were conducted in Mandarin and translated into English. content analysis was performed.	Interviewees described stigmatising experiences from the community as well as family members	Small sample size. Mothers had post secondary school qualifications – may have better access to resources compared to mothers with less education. Validity and reliability of coding frame not established.

Table 1.2: Continued…

Study	Design	Location	Sample	Method	Main findings	Limitations
Mak & Kwok (2010)	Cross-sectional	Hong Kong	10 NGOs and 2 schools. 600 questionnaires sent. 188 responses included. 84% were mothers(88% children male; 37.8% had ID)	Stigma measured using Devaluation of Consumer Families Scale; Affiliate stigma measured using Affiliate stigma scale.	Courtesy and affiliate stigma were associated with parents blaming themselves and perceiving less control over stigma and cause of child's condition.	Low response rate, low proportion were carers of children with ID.
Mak & Cheung (2007)	Cross-sectional	Hong Kong	210 mothers (aged 24-58) of children with ID recruited from NGOs and self help groups and 108 carers of people with mental illness	Validation of the Affiliate stigma scale. Also measured caregiving stress and subjective burden	Affiliate stigma associated with greater subjective carer burden and lower perceived benefits of care giving.	Only mothers included.
Mirza et al. (2009)	Mixed methods	Pakistan	Random sample of tertiary care attendees and consecutive attendees to secondary care. 100 carers surveyed; 16 in depth interviews	Stigma assessed using Short Explanatory Model Interview (Lloyd, 1998). Also measured stress in carers.	Families experienced stigma from the community, preventing them from fully integrating with the community.	Stigma was not the main focus of the study.
Ngo et al, 2012	Mixed methods	Vietnam	70 parents (37 mothers, 33 fathers) of 37 children recruited from kindergarten and community health clinics. Most children also had physical disabilities.	Effect of stigma on restriction of social life assessed using a scale developed by authors "Restriction of Social Life Scale". Scale had open ended questions, which were transcribed and coded.	Higher severity of intellectual disability was associated with greater social restrictions arising from stigma. Five themes were identified: Core lived values, discredited (stigma), individual level discrimination, emotional reactions of caregiver, coping strategies	Some children with severe ID and challenging behaviour excluded. Also stigma scale was not previously validated. Results may not be generalisable to families of children with ID and no physical disability.

Table 1.2: Continued…

Study	Design	Location	Sample	Method	Main findings	Limitations
Ntswane & Rhyn (2007)	Qualitative	South Africa	12 mothers of children with ID, purposively selected .	Interviews explored mothers' experiences of parenting a child with ID. Analysed using a phenomenological approach	Mothers reported shame, anger, fear, frustration and disappointment at having a child with ID	Small size, only mothers interviewed.
Perkins et al (2002)	Cross-sectional	USA	36 children (18 boys, 18 girls; aged 9-17) with normal IQ who have mothers with ID	Stigma measured using own scale. Also measured attachment style, quality of maternal care-giving and self esteem in the child	Lower levels of stigma associated with secure attachment. Higher levels of stigma associated with mother being a cold or ambivalent care-giver.	Small size, use of non-validated instruments.
Power (2008)	Qualitative	Ireland	25 caregivers (18-30 yrs) recruited from voluntary organisations and local advertisements	Semi-structured interviews covering questions on the home and the public and access and use of services.	Carers experienced negative treatment from public and had to restrict activities outside of the home.	No information on the demographics of the carers. Validity and reliability of the coding frame not assessed.
Ryan, 2005	Qualitative	UK	17 mothers (24-50 yrs old) recruited from three non mainstream schools. Children aged 5-8. Only one female was non Caucasian	Combination of group and individual interviews (semi-structured). Interviews transcribed and coded.	Mothers reported structural constraints and being blamed for behaviour of younger children.	Small sample, most of the children were male. Limited generalisability to other ethnic groups.
Shin et al (2006)	Cross-sectional	Vietnam	106 mothers (mean age 35) and 93 fathers (mean age 38) of children with cognitive delay (aged 3-6)	Stigma measured using the Social Life Scale. Also examined parental stress and social support.	Parental stress not associated with stigma when other variables taken into account.	Poor reliability of stigma scale.

Table 1.2 Cont...

Study	Design	Location	Sample	Method	Main findings	Limitations
Todd & Shearn (1997); Shearn & Todd (1995)	Qualitative	UK	Parents of adults with ID living at home (aged 17-44; 18 females, 15 males) recruited from random selection of social services register and from local parents group	Ethnographic approach based on 18 months field work. In-depth interviews. Topics included management of courtesy stigma. Interviews were audio-taped and transcribed. Data analysis and collection of data occurred concurrently to derive new questions.	Stigma affected all family members. Restricted activities outside the home. Visibility of disability was an advantage.	Little information on the demographics of the carers (e.g. age, number, male/female).

Courtesy stigma

Being marginalised by the community

Four qualitative studies from the UK have reported family carers experiencing negative attitudes or responses from the public. Mothers report being blamed for younger children's disobedience, and disapproval and lack of acceptance of older children who behave inappropriately in public (Ryan 2005); being scrutinised, stared at or monitored in public (Ryan 2005, Todd & Shearn, 1997, Power 2008); and having to make excuses for the child's behaviour (Ryan 2005). The label of intellectual disability posed problems for all members of the family ("a stigma on the family"), including siblings (Todd & Shearn, 1997). Families were frequently faced with the dilemma of whether they should disclose their relative's disability to others due to fear of negative reactions. Most carers complained of having to restrict their activities and avoid public places. This often resulted in only a few places being regarded as tolerant of people with intellectual disability (Power 2008; Todd & Shearn 1997, Shearn & Todd, 1995,). Some parents reported that courtesy stigma increased over the years as their offspring matured or as the disability became apparent (Shearn & Todd, 1995). The visibility of the disability modified the expectations of others in that the public were more tolerant of those who had obvious features of disability (Todd & Shearn, 1997). However, some parents reported a reduction in stigma as their community became familiar with their offspring (Shearn & Todd, 1995).

Seven studies outside the UK (mainly non-western countries) also demonstrate the difficulties experienced by carers in interacting with others from their community. Three studies reported that parents avoided community exposure of the child: Crabtree (2007a) interviewed 15 mothers of children with intellectual disability and reported that mothers were reluctant to take the child out because of members of the public expressing disgust over the child's presence in public, or concerns that the child was dangerous. Lim et al (2013) interviewed 14 mothers and one grandmother of daughters with Rett's syndrome, in China, who complained that they were frequently met with odd stares and disapproval if they took their daughter into the community. Mirza et al (2009) used mixed methods to explore the views of 100 parents in Pakistan and 40% of parents reported concerns over taunting and teasing of their child in public. Some parents reported physically restraining the children at home to manage behavioural problems and to prevent community exposure. Ngo et al (2013) conducted a mixed methods study of parents of children with intellectual disability in Vietnam. Parents reported that they were snubbed by the local community who refused to allow their children to play with other non-disabled children, and they were not invited to social gatherings, which was an indication that they had not been accepted into the social network.

Lack of support from the community and isolation were reported by three studies. Edwardraj et al (2010) conducted focus groups of 68 participants (29 mothers, 17 community health workers and 16 teachers) in India. The mothers reported receiving little support from members of the community, who usually considered the child’s disability to be a consequence of the sins of their forefathers. They were confined to their homes, received little financial support from the government, and schools would frequently refuse to take the child. Many felt alone and unable to turn to others for help. Chang (2009) interviewed 38 parents, who were also disability activists, in Taiwan. Mothers bore the shame of public stigma more than fathers, and this sometimes led to them isolating themselves from friends and even from the disabled child. Ntswane & Rhyn (2007) found that affiliate stigma affected all 15 mothers who were interviewed in South Africa. They reported feelings of shame, anger, fear, frustration and disappointment. The availability of support was vital in that lack of support left mothers isolated from the outside world, while having support enabled mothers to integrate better into the community.

Medical professionals also discriminated children with intellectual disability by regarding them as “second class citizens” and refusing to treat premature children as their lives were not considered worth saving (Crabtree 2007a). Chang (2009) also found that medical professionals stigmatised parents and children with intellectual disability by failing to disclose the child’s disability to parents. This exacerbated the shame felt by parents.

Crabtree (2007a) found that parents of children with intellectual disability were not more tolerant of other children with intellectual disabilities. Some parents did not wish their child to attend segregated schools because of the fear that their child would "pick up bad habits" from other children.

Being marginalised by the family

As well as being excluded from society, six studies of non- western cultures suggest that family carers (mainly mothers) are marginalised within families after giving birth to a child with disability. In Arab, Bangladeshi, Pakistani, Indian and Taiwanese cultures, it was not unusual for family members to blame the mother for the child's disability (Chang, 2009 Crabtree 2007a; Edwardraj, 2010; Fazil, 2002). Chang (2009) found that stigma associated with having a child with intellectual disability was experienced by mothers and not fathers in Taiwan, as women were considered to be responsible for reproduction and it was their moral duty to produce healthy children. In fact, family members felt pity and sympathy towards the father for having to support his stigmatised wife and disabled child. Taiwanese mothers also reported pressure from their mother-in-laws, which included demands that they should give birth to another child without disability (Huang, Kellett & St John, 2012) and being made to feel invisible (Chang, 2009). Sometimes the mother's position was threatened with divorce or polygamy (Chang, 2009; Crabtree 2007, Fazil, 2002). Some parents even attempted to conceal the birth of the child from other family members (Chang, 2009; Crabtree, 2007a; Huang, Kellett & St John, 2012). Marital conflict, including domestic violence and constrained relationships with other members of the family often occurred following the birth of a child with intellectual disability (Chang, 2009; Fazil 2002 Huang, Kellett & St John, 2012). Edwardraj (2010) found that family members and relatives (from the father's side) provided little support to the mother and child because of lack of acceptance of the child, forcing some mothers to seek support from their own family. Chang (2009) reported that mothers were excluded from family events such as weddings because there were fears that the mother and the disabled child would bring misfortune to the newly wedded couple.

The burden of childcare was often placed on mothers due to fathers appearing unconcerned or distant (Edwardraj, 2010; Chan 2009; Crabtree, 2007a). Mothers therefore not only had to bear courtesy stigma but were overwhelmed with the responsibility of child care. Mothers in China relied on grandparents to assist with childcare, as they needed to work in order to contribute to the family income. However, grandparents were sometimes reluctant to care for a child with disability, and even nannies refused to look after a child with disability due to the fear of discrimination from their peers (Lim et al, 2013).

However, some women were able to gain acceptance by their family and their immediate community through religious devotion and piety and the belief that it was the will of God sent to test their character and resilience (Crabtree, 2007a).

Crabtree, (2007b) also examined gender differences in how males and females with disability were perceived by parents. Fathers were more likely than mothers to experience shame and embarrassment. Daughters particularly received differential treatment. Some fathers openly treated their disabled daughter differently to other siblings and would refuse to take the child to public places because of fear of stigmatisation. However, having a son with a disability often had a more serious psychological impact because of the cultural expectations placed on males to fulfil certain obligations and expectations. This often led to fathers and sometimes mothers, denying their son’s intellectual disability or refusing to accept the severity of the condition.

Courtesy or affiliate stigma and psychological factors in parents

Seven studies involving a total of 1229 participants have examined the relationship between stigma and psychological factors. Three of these studies were from Western countries (Baxter & Cummins, 1992; Green, 2007 & 2004) and five were from non- western countries (Chou et al, 2009; Mak & Kwok, 2010; Mak & Cheung, 2008; Ngo et al, 2013 and Shin et al 2006).

Mak & Kwok (2010) surveyed 188 parents and measured courtesy stigma using an adapted version of the 7 item Devaluation of Consumer Families Scale (Struening et al, 2001), which had a good internal consistency (alpha 0.86), and affiliate stigma using the 22 item Affiliate Stigma Scale, which measures cognitive, affective and behavioural domains (Mak & Cheung, 2008). Parents who had higher levels of courtesy and affiliate stigma perceived less control over the causes of their child's condition, behaviour and stigma, and were more likely to blame themselves and feel responsible for their child's disability. However, receiving support from friends (but not family or professionals) was related to less affiliate stigma and may be one approach to reducing the impact of affiliate stigma.

Two studies have examined the impact of affiliate stigma on stress in parents. Baxter & Cummins (1992) investigated the degree to which negative attitudes from the community were associated with stress in 131 parents of children. The parents were surveyed at baseline and after seven years. They found that the most distressing reactions were people staring at or ignoring the child, drawing attention to the child and treating the child differently from his or her sibling. There was a slight decrease in the level of distress these attitudes caused over time but in general, parents who were previously distressed, continued to be distressed. Overall, there was little change over the seven year period between the amount of stress parents felt and the types of reactions they found distressing, thus suggesting that the impact of stigma is pervasive. Shin et al (2006) examined whether the factors affecting stress were different in mothers than fathers of young children with cognitive delay. They measured affiliate stigma in 106 mothers and 93 fathers using "The Social Life Scale", which was developed for the study, and measures the extent to which social life experiences are limited due to stigma. Eighteen items cover aspects related to guilt, shame, reluctance to take child out to public places and reduced quality of life. Stress was found to be associated with stigma in both fathers and mothers. However, when potential confounding factors were considered, stigma was no longer associated with stress: Stress in mothers was associated with having a girl, a child with lower intellectual functioning and health conditions in the spouse; in fathers, stress was associated with lower socio-economic status and lower social support. Unlike the previous study, stress did not appear to be associated with stigma.

Ngo et al (2013) investigated the extent to which stigma imposed restrictions on the social life of 70 parents of 37 children, using a 12 item scale developed for the study

("Restriction of Social Life scale"). They found that a higher severity of intellectual disability was associated with more restrictions on social life, and parents' educational level was negatively associated with restrictions on social life. A third of the parents exhibited negative emotional reactions such as feeling sad or ashamed.

The effect of stigma on care giving burden and benefits of care-giving, were explored by Green (2007, 2004) and Mak & Cheung (2008). Green (2007) examined 81 mothers of children with varying disabilities including cognitive delay and impairment. Perceived stigma was measured using an adapted version of the "Devaluation Discrimination Scale" (Link et al, 1989). She found that mothers reported greater care-giving burden as a result of perceived stigma towards their child with disability. Perceived stigma was also associated with greater levels of emotional distress such as feelings of shame, guilt and worry and indirectly reduced the perceived benefits of care-giving by increasing the emotional stress of care giving. Mak & Cheung (2008) examined affiliate stigma in 210 mothers in Hong Kong, using their 22 item "Affiliate Stigma Scale". Affiliate stigma was not related to the age of the mother or the child, or the severity of the intellectual disability. However, mothers who had a child with a diagnosis of autism and intellectual disability were more likely to report affiliate stigma than mothers of children with only intellectual disability. Even after controlling for care-giving stress and demographic factors, higher levels of affiliate stigma were associated with greater subjective burden and fewer positive perceptions of care-giving (happiness, fulfilment and source of strength). The authors argue that affiliate stigma may be particularly salient in the Chinese community as having "face" and maintaining social norms is an integral part of Chinese culture.

Green (2004) found that mothers were more likely to consider residential placement of their child if they perceived higher levels of stigma. An increase in care giving burden mediated the relationship between stigma and residential placement. The child's age moderated the effects of the relationship between stigma and placement, such that the mothers of younger children were more likely to consider placing their child in residential care due to concerns over the impact of perceived stigma, even after controlling for demographic factors and care-giving burden.

Chou et al (2009) examined the impact of affiliate stigma on quality of life in 350 older mothers of adults with intellectual disability and 66 mothers of adults with mental illness (Chou et al, 2009) in Taiwan. Mothers reporting higher levels of affiliate stigma had a lower quality of life and this effect was more marked in carers of people with intellectual disability than in carers of people with mental illness. This relationship was reduced (but remained significant) after carer health and social support were taken into account suggesting that improving the health of older mothers and providing more social support may help to reduce the effects of affiliate stigma.

Experiences of other members of the family

Only one study examined affiliate stigma in other family members. Perkins et al (2002) explored the relationship between affiliate stigma in children who had mothers with intellectual disability, quality of maternal care-giving, attachment to the mother and self esteem in 36 children (who did not have intellectual disability). Stigma was measured using a 6-item measure developed by the authors comprising items assessing the extent to which the child goes out to public places with the mother and the extent to which s/he feels comfortable about having friends around. The scale had reasonable internal consistency (alpha 0.70), while its face validity was based on previously published literature. Lower perceptions of stigma in the child were associated with a secure attachment to the mother and the relationship between stigma and attachment was fully mediated by warm care-giving. Higher levels of stigma were associated with the perception of the mother as a cold or ambivalent caregiver. Self esteem in the child was not found to be related to secure attachment. This study suggests that warm care-giving may act as a barrier against the effects of stigma on mother child attachment and the authors suggest that mothers may benefit from parenting skills that focus on warm care-giving.

How family members cope with stigma

Ngo et al (2013) found that parents used secrecy, withdrawal and avoidance as coping strategies for managing the stigma. Baxter & Cummins (1992) investigated how parents responded to the negative attitudes of others. Stress in parents was associated with two types of responses: not saying anything even though they felt uncomfortable or angry (controlled affect), and moving away from the situation as quickly as possible (dissociation). Parents who responded by informing others of the child’s disability experienced less stress. In parents who responded by dissociation, there was a relationship between stress and unwillingness to take the child to places or gatherings involving strangers, particularly when the children were aged 10-12 years old compared to younger or older age groups. Parents who responded by educating others found it easier to cope when their child’s disability was known to others but parents who experienced difficulty in providing explanations were more stressed. However, the study suggested that use of verbal explanations may be helpful in reducing anxiety in some cases. Todd and Shearn (1997) also found that parents preferred to disclose rather than conceal the diagnosis of their offspring as this avoided misunderstandings and often acted as a preventative measure. Some parents even confronted others about responding inappropriately and advised them how to behave. Power (2008) found that parents used disclosure in order to shift the responsibility for behaving in conventional ways onto others in the community.

Power (2008) found that caregivers also used emotion focused approaches, which included denial of the individual’s disability, and behavioural and mental disengagement. Several studies also found that a common strategy used by parents was going to places that were considered to be more accepting of the person with intellectual disability such as support groups, day centres or more informal settings (Power, 2008; Shearn & Todd, 1995; Todd & Shearn 1997).

In other cultures, having faith in God helped mothers to cope (Crabtree, 2007, Edwardraj 2010). One’s individual faith, rather than organised religious support, was considered to be more helpful in India. However, a few of the participants revealed that they had lost their faith in God, although specific reasons for losing faith are not stated (Edwardraj, 2010). Participation in parent training programmes was considered helpful (Edwardraj, 2010). Chang (2009) found that parents who engaged in disability rights activism benefited from sharing experiences with others, and experienced less shame and even pride in parenthood, while mothers even gained respect and a heightened status in the eyes of members of the family. Mothers in particular who regularly volunteered in advocacy organisations regarded this work as an important part of their identity and it permitted them to negotiate more time for themselves from their family.

Limitations of the studies

The qualitative studies had sample sizes ranging from 12 (Ntswane & Rhyn, 2007) to 29 (Edwardraj et al, 2010). One study included participants with a range of different disabilities and did not state how many had intellectual disability (Huang, Kellet & St John, 2012). Most of the studies only examined the mother's perspective or had limited participation from fathers except one study that included mothers and fathers (Chang, 2009). In three of the studies, it was unclear how many of the participants were mothers or fathers (Power, 2008; Shearn & Todd, 1995; Todd & shearn 1997). Several studies did not assess the validity or reliability of the coding frame (Chang, 2009; Crabtree, 2007a & 2007b; Huang, Kellet & St John, 2012; Edwardraj, 2010; Power, 2008) and no study examined respondent validity.

All the quantitative and mixed methods studies used convenience sampling except three, which either screened the whole population (Chou et al, 2009) or used random sampling (Baxter & Cummins,1992; Mirza et al, 2009). The sample sizes ranged from 36 (Perkins et al, 2002) to 350 (Chou et al, 2009). Fathers were excluded from four studies (Green 2007 & 2004; Huang, Kellett, St John, 2012, Mak & Cheung, 2007). Three studies used a heterogeneous sample that included participants with other disabilities (Green, 2007 & 2004; Mak & kwok 2010). One study used a measure of stigma that had poor reliability (Shin et al, 2006), two studies used a measure of stigma that had been used in people with mental illness but had not been validated in carers of people with intellectual disability (Green 2007 & 2004) and one study used a new measure of stigma that had not been validated (Perkins et al, 2002). For further details about limitations of the studies, please refer to table 2.

Summary of the findings: courtesy and affiliate stigma in carers

- The main themes were: being marginalised by the community, being marginalised by the family, courtesy/ affiliate stigma and psychological factors, stigma experienced by other members of the family and coping with courtesy/affiliate stigma
- Studies of western and non western cultures found that families of intellectually disabled people experienced disapproval, lack of acceptance and scrutiny by their community, resulting in the restriction of activities. Lack of support and isolation were common. Studies on non western cultures reported that mothers were often blamed for the child's disability and were marginalised and excluded by the family. Mothers were also burdened with childcare.
- Higher levels of affiliate/courtesy stigma in carers are associated with increased blame and feelings of responsibility for the child's disability, increased care-giving burden and emotional distress. Baxter & Cummins (1992) found that stress associated with stigma did not change over a seven year period. Only one study investigated stigma in other family members: Perkins et al (2002) found that higher levels of affiliate stigma in children with mothers who had intellectual disability, was associated with perception of mother as a cold or ambivalent caregiver.
- Coping strategies include: not saying anything and moving away from the situation as quickly as possible, disclosure, going to places considered to be more accepting, having faith in God and engaging in disability rights activism.
- Limitations of the studies include small sample sizes, unrepresentative samples and use of measures that had not been validated or had poor reliability.

Discussion

Summary of findings

This systematic review summarises the main findings from primary research on the experience of stigma in individuals with intellectual disability or their family members. Most of the studies of participants with intellectual disability included in the review were small qualitative studies, or small scale descriptive cross sectional studies in often unrepresentative samples, apart from one study (Emerson, 2010). In addition, only two studies were conducted in non–western countries. The studies of courtesy/affiliate stigma were more diverse in terms of country of origin and the cross-sectional studies generally had larger sample sizes.

The studies on people with intellectual disability demonstrate that people are aware of stigma and can describe experiences of being treated differently or negatively. However, these experiences are not always attributed to the individual's intellectual disability. The studies reveal that many people with intellectual disability do not believe that they have an intellectual disability, and prefer to describe themselves on the basis of minor limitations such as not being able to read or drive a car. They therefore appear not to have internalised the label of intellectual disability and the stigma that is associated with it. When making comparisons with other service users, and even the general public, many people compare themselves favourably, have high self esteem and hold high aspirations such as working and getting married. Other studies not included in this review have shown similar findings (Taylor 2000, Jahoda, Markova & Cattermole 1988, Gibbons, 1985). This may be because of a lack of awareness of possessing a stigmatised identity, a lack of acceptance or it may be a mechanism by which individuals attempt to maintain self worth (Festinger, 1954). In addition, the minimisation of social difficulties and the promotion of strengths may be a coping mechanism employed by some individuals.

Beart et al (2004) explored possible explanations for why the identity of intellectual disability may not be salient. The level of awareness of disability and social identity may be influenced by poor cognitive development (Cunningham et al 2000) and denial may be used as a defence mechanism against the experience of stigma and as a way of dealing with the pain associated with the identity (Sinason 1992). Szivos and Griffiths (1992) suggest that when people become aware of the stigma of their identity, they experience a sense of loss and undergo stages of grief similar to those described by Kubler-Ross (1970). Todd and Shearn (1995, 1997) propose that the lack of awareness of the intellectual disability identity may stem from over-protection by significant others and lack of parental disclosure. Carers often avoid the use of intellectual disability label and a few actively concealed this information, fearing that it could upset the person they care for (Davies & Jenkins, 1997; Todd & Shearn, 1997). Zetlin & Turner (1984) found that parental disclosure and acceptance of the label of intellectual disability influenced how individuals with intellectual disability viewed their identity. Higher acceptance was associated with parents that disclosed compared to those that did not. If parents were ambivalent about disclosure, individuals were more likely to feel uncomfortable discussing their identity. However, Cunningham et al (2000) propose that a person’s awareness of stigma is not related to parental disclosure, but that the experience of feeling different comes about through social interaction with others. Gibbons (1985) suggests that there may be gender differences in the awareness of stigma. He found that women in the community were more likely to be aware of stigma, compared to men, especially those in institutionalised settings.

A greater awareness of stigma (and discrimination) was associated with lower self esteem, negative self evaluations, negative social comparisons and psychiatric symptoms. Therefore stigma can have a significant impact on psychological wellbeing. However, no study has explicitly studied the impact of self stigma, that is, no study has demonstrated that participants are aware of cultural stereotypes relating to intellectual disability, that participants endorse or agree with these stereotypes, and also apply these stereotypes to themselves. This is an area of research that requires further consideration, including the development of appropriate measures to measure stigma.

Given that all of the studies were cross sectional in design and many were small, unrepresentative samples, we cannot make assumptions about causality; reverse causality is possible wherein low self esteem and psychiatric symptoms result in a higher perception of stigma. Longitudinal studies examining the relationship between psychological distress and stigma in people with mental illness suggest that people continue to feel stigmatised, even after resolution of the original psychiatric symptoms and that higher baseline stigma is associated with lower psychological wellbeing at follow up periods (Lysaker, 2010; Lysaker 2007; Link et al 2001).

Almost all of the studies examining courtesy or affiliate stigma in family carers were qualitative studies or cross sectional studies and mainly focused on parents’ views, particularly the mother. Only one study specifically examined other family members’ views (Perkins et al, 2002). Most of the studies examined courtesy stigma and few studies explicitly examined affiliate stigma possibly because affiliate stigma is a relatively new concept. The studies included in this review highlight that family members are subjected to negative treatment not only by members of the community, but also by members of their family, particularly in studies of non western cultures. This frequently resulted in lack of support and isolation. There is evidence from six large studies to suggest that stigma also affects psychological wellbeing in parents and can lead to parental stress, increased care giving burden and a lower quality of life. One study also suggests that the impact of such stigma may be enduring (Baxter & Cummins 1992). The existence of social support and the use of disclosure and education may be helpful in combating stigma. The literature on cross cultural comparisons of courtesy or affiliate stigma is limited. Variations between and within countries (e.g. between rural and urban areas) in terms of ethnicity, level of education and how intellectual disability is defined and identified, may present challenges when conducting cross cultural comparisons.

Limitations of the review

There are several limitations of the review. The review did not include studies that were not in English, conference reports or proceedings or grey literature such as research dissertations.

Potential areas for further research

Further research is required into the process by which people with intellectual disability internalise the stigma associated with the label of intellectual disability and the social and clinical factors that are associated with stigma. More research is required on the consequences of stigma, such as the impact of stigma on other health outcomes. There is limited research on cross cultural comparisons of whether the prevalence of self stigma or affiliate stigma varies across different ethnic groups or countries. Further research is required into affiliate stigma, particularly in other members of the family such as siblings or the extended family. There is also a lack of large scale studies, in particular, population based prevalence studies of stigma in people with intellectual disability or their carers. There is also a need for longitudinal studies examining the impact of stigma on social and emotional wellbeing over time, and for interventions that specifically target the reduction of psychological distress associated with stigma in people with intellectual disability and their carers.

Conclusion

Stigma affects people with intellectual disability and their family members and has a deleterious impact on wellbeing. Most research is based on small unrepresentative samples, particularly in people with intellectual disability. Further research is required into the consequences of stigma, such as impact on psychological wellbeing and what strategies could be employed to help people with intellectual disability and their families cope with stigmatising experiences. At a national and global level, governments need to be more proactive in reducing the barriers encountered by people with intellectual disability, such as discrimination, through improving access to mainstream services, investing in programmes and adopting a national disability strategy. In particular, people with intellectual disabilities should be involved in the design and implementation of these strategies (The World Health Organisation, 2011).

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Chapter 2: The impact of stigma on psychological distress, quality of life, service use and treatment adherence in people with mild and moderate Intellectual disability: Results from a cross sectional study

Abstract

Background

Self stigma is associated with psychological distress, poor quality of life, lower utilisation of health services and a poorer adherence to treatment in people with mental illness. Little is known about the impact of stigma on these health outcomes in people with intellectual disability (ID).

Aims

1. To examine the association between self reported stigma and psychological distress, quality of life, treatment adherence and service use in people with ID

2. To examine the socio-demographic moderators of the relationship between ID and self reported stigma, and between self reported stigma and the outcome variables

3. To examine whether the relationship between self reported stigma and the outcome variables is mediated by psychological distress.

Methods

This is a cross-sectional study of 229 participants with mild and moderate intellectual disability, who were recruited from 12 centres across London and England. The primary outcome measure was psychological distress. Linear and multivariable regression analyses were used to analyse the relationship between self reported stigma and the outcome (dependent) variables.

Results

Older age was associated with self reported stigma. Self reported stigma was positively associated with psychological distress and higher service use (total

number of contacts with services, and contacts with community intellectual disability services and police) and negatively associated with quality of life. There was some evidence that stigma was associated with lower treatment adherence. All these relationships were mediated by psychological distress.

Conclusion

This study provides evidence that stigma may contribute to poor health indicators in people with intellectual disability, and may be a burden on services due to higher service utilisation.

Implications (discussed in chapter 4)

Services should consider screening people who may be at risk of psychological distress due to stigmatising treatment. Psychological support could be offered to those who have high levels of psychological distress. However no interventions have been developed to manage the effects of stigma. Interventions could focus on the development of resilience against the psychological consequences of stigma.

Section 2A: Introduction and overview of the literature

Introduction

1. Stigma as a determinant of health inequalities

Social determinants of health are the circumstances in which people are born, grow up, work and age, that are shaped by wider forces such as social and economic policies, which affect the distribution of power, money and resources at local, national and global levels (Commission on Social Determinants of Health (CSDH), 2008). These social determinants of heath can affect peoples' vulnerability to ill health and access to health care and resources, and may lead to health inequalities, which are avoidable, and unacceptable inequalities in health between groups of people between and within countries (CSDH, 2008). The conceptual framework for understanding the social determinants of health and key drivers of health inequalities (Solar & Irvin, 2007) suggests that policies, governance and cultural and societal norms and values, give rise to a hierarchy based on social position according to income, education, occupation, gender, race/ethnicity and other factors. These in turn, influence access to material wealth, psychosocial support and behavioural options that affect vulnerability to poor health.

A number of social determinants of health have been identified (WHO, 2003) including social gradients (lower socio-economic position associated with worse health), stress, early child development, social exclusion, unemployment, social support networks and availability of healthy food and transportation. Social exclusion is particularly relevant to the work on stigma. Inequalities in wealth, power and prestige of marginalised groups can lead to reduced freedom to participate in economic, social, political and cultural relationships, resulting in inequalities in accessing education, employment and health services. One of the recommendations to reduce health inequalities in the report by the CSDH (2008) includes the political empowerment and inclusion of marginalised groups.

Further support for the role of stigma as a social determinant of health inequalities is provided by Hatzenbuehler et al (2013). They advocate that stigma should be considered as a social determinant of health inequalities on population health. Firstly stigma affects several physical and mental health outcomes (Livingston & Boyd, 2010; Mak et al, 2007). Secondly, stigma reduces access to multiple resources (including structural, interpersonal and psychological) such as knowledge, power and prestige, that could reduce the impact of poor health; and lastly, it ensures that mechanisms that perpetuate health inequalities in certain groups continue to operate. These mechanisms include segregation, exclusion, discrimination and diminishing power.

A number of factors may mediate the relationship between stigma and health, which are discussed below.

Socio-economic status

A higher socio-economic status is associated with greater wealth, material resources, knowledge, power and social connectedness, which permit individuals to obtain a health advantage over individuals from lower socio-economic groups (Link & Phelan, 1995). Belonging to a stigmatised group such as those with mental illness, can reduce access to resources such as employment (Link & Phelan, 2006), housing (Link & Phelan, 2001), education (Link et al, 2004) and healthcare (Ross & Goldner, 2009), as well as reducing an individual's personal influence of power (Link & Phelan, 2001).

Social Isolation

Social isolation is common amongst individuals from stigmatised groups such as those with mental illness (Link et al, 1989) and may be linked to fear of rejection from friends and family. Social isolation may be a pathway through which stigma affects health outcomes (Kawachi & Berkman, 2001). For example, It may affect how rapidly health care is sought and obtained. There is evidence from studies that adjusting for social isolation may reduce the effects of stigma on health(Diaz et al, 2001; Hatzenbuehler et al, 2009;).

Psychological and behavioural responses to stigma

Managing a stigmatised identity requires the use of emotional regulation strategies.

Over time, the effort required to cope with stigma has a deleterious effect on the individual's psychological resources, which can lead to difficulties in emotional regulation, with negative impacts on physical and mental health (Miller et al, 2011; Repetti et al, 2002). Individuals who report higher levels of stigma are more likely to engage in maladaptive emotional regulation strategies such as rumination, which can increase psychological distress (Hatzenbuehler et al, 2009). Therefore emotional regulation processes may mediate the relationship between stigma and health. The experience of stigma can also lead to maladaptive coping behaviour such as smoking and excessive alcohol consumption (Paradies, 2006; Williams et al, 2008), which are independent risk factors of disease

Stress

Individuals from stigmatised groups may be exposed to stress resulting from discrimination, such as violence or bullying, or internal processes such as the expectation of rejection (Clark et al, 1999; Meyer, 2003). Stress secondary to stigma and discrimination has been associated with adverse physiological changes that can contribute to health problems such as changes to blood pressure and increased cortisol levels (Guyll et al, 2001; Townsend et al, 2011). Self reported discrimination is associated with poorer self reported health in people with intellectual disability (Emerson, 2010).

Rusch et al (2009a) have developed a model for cognitively appraising stigma related stress. This involves an individual estimating the potential harm arising from stigma, and then evaluating whether they have the personal resources to cope with threat. Stigma stress occurs if perceived harm exceeds their perceived coping resources. They found that higher levels of stress were associated with the perception of higher public stigma, increased sensitivity to rejection and holding the stigmatised group in low regard. These predictors remained significant after controlling for cognitive factors, depressive symptoms and diagnosis.

2. Research on stigma and health outcomes

Stigma and psychological distress in people with intellectual disability

In this thesis, psychological distress has been broadly defined as any factor or variable that has a potential negative impact of psychological functioning. It includes variables such as self esteem, quality of life and psychiatric symptoms. Research on the psychological impact of stigma in people with intellectual disability has been limited (see Chapter 1 section 1B). However, several studies have shown that stigma is correlated with lower self esteem (Abraham et al, 2002; Patterson et al, 2012; Petrovski & Gleeson, 1997; Szivos-Bach, 1990, 1993) symptoms of depression (Emerson, 2010; Petrovski & Gleeson, 1997; Patterson et al, 2012) and negative social comparisons with other people in the community (Dagnan & Waring, 2004; Patterson et al, 2012; Szivvos-Bach, 1993). Dagnan & Waring (2004) found that the relationship between stigma and social comparisons was mediated by negative self evaluations. Examining the mental illness literature provides further insight into the relationship between stigma and psychological distress.

People with mental illness

Studies have investigated the relationship between stigma and a number of psychological constructs such as self esteem, self efficacy (the confidence to manage different situations), mastery (the extent that an individual feels that they are in control of factors that affect their life), empowerment (power, community activism, righteous protest against discrimination, and control over future events), and quality of life.

Most of the studies examining self stigma have been in patients with schizophrenia, and have been cross sectional in design. Studies have consistently demonstrated a relationship between self stigma and psychiatric symptoms (Ahern et al, 2007; Corrigan et al, 2006; Link 1997, 1991, 1987; Lysaker et al, 2007; Meisser, 2007; Staring, 2009; Smith 2010), self stigma and self esteem (Corrigan et al, 2006; Link et al, 2001; Markowitz, 1998; Rusch et al, 2006; Wright et al, 2000) and between self stigma and quality of life (Bahm et al, 2008; Graf et al, 2004; Hsiung et al, 2010;

Rusch et al, 2006, Markowitz, 1998; Rosenfield, 1997; Staring et al, 2009). Stigma is also associated with hopelessness, lower empowerment and mastery and reduced self efficacy (Livingston & Boyd, 2010). The impact of self stigma does not appear to be related to diagnosis.

Longitudinal studies

Three studies have investigated the relationship between self stigma and psychological distress at one follow up time period (e.g. four months or 12 months), and found that stigma (including rejection experiences) were associated with depression at follow up, after controlling for baseline depressive symptoms (Link et al, 1997; Markowitz, 1998; Ritsher & Phelan, 2004). Actual experiences of discrimination were more important than perceived discrimination (extent to which an individual believes that the public would discriminate people with mental illness).

Link et al (2001) assessed whether stigma at baseline was associated with self esteem at six months and at 24 months. They found that perceived stigma was associated with self esteem at both time points after controlling for baseline depressive symptoms and self esteem.

In the above studies, stigma was only measured at one time point and therefore it was not possible to draw conclusions about whether levels of stigma have changed over time. Wright et al (2000) examined recently deinstitutionalised long stay psychiatric patients and followed them up at 12 months and 24 months after discharge. Feelings of self worth improved after discharge but self deprecation and stigma remained largely unchanged. There were no direct effects of experiencing rejection on positive self worth but rejection was associated with self deprecation at 12 months (but not at baseline or 24 months). This study suggests that experiences of stigma remain stable over time. The impact of stigma on self esteem was greatest at 12 months probably because of the stress of newly reintegrating into the community after a prolonged period of hospitalisation and more direct experiences of stigma.

Lysaker et al (2007a) found that stigma at baseline predicted anxiety and depression at 6 months but not positive or negative symptoms of schizophrenia. Positive symptoms at baseline predicted stigma levels at six months after controlling for baseline levels of stigma. Levels of stigma remained stable over the two time periods. There was no association between negative symptoms of schizophrenia and stigma, possibly because negative symptoms attract less attention than positive symptoms. This suggests that positive symptoms may make people with schizophrenia more susceptible to feeling stigmatised over time.

Lysaker et al (2010) examined the relationship between stigma and social anxiety at baseline and at 5 months and found that stigma was associated with social anxiety at both time points and that stigma (particularly discrimination experiences) predicted social anxiety at 5 months. In a further study (Lysaker, 2012) measures were taken at three time points. They found that stereotype endorsement and discrimination were stable over five to seven months but not over 12 months and although they were related at each time point, they did not predict each other over time. Discrimination did not predict levels of distress over time. Discrimination experiences and psychological distress did not appear to influence the degree of stereotype endorsement at different time points, suggesting that the endorsement of stereotypes may persist over time, and may be difficult to treat. This study suggests that stigma may fluctuate over time. However, the sample population of the studies are different, which may have influenced the findings.

In summary, the longitudinal studies suggest that treatment of symptoms does not alleviate internalised stigma and that levels of stigma remain stable over short periods. Stigma is related to psychological distress at different time points and baseline stigma is a predictor of distress at later time points, although these findings are not consistent. What is consistently reported is that actual stigma experiences appear to be more important than perceived stigma.

Stigma as a moderator in health outcomes

Stigma has been found to moderate the relationship between illness insight in people with schizophrenia and psychological functioning. Patients with high insight and minimal stigma have better psychological functioning than those with high insight and moderate stigma (Lysaker, 2007b; Staring 2009). Cavelti et al (2012) also found that stigma modified the relationship between insight and demoralisation. Higher levels of insight were associated with more demoralisation, and this relationship was stronger if higher levels of self stigma were present.

Mediators and moderators of the relationship between stigma and psychological distress

Self esteem and mastery

Rosenfield (1997) and Markowitz (1998) demonstrated that self esteem mediated the relationship between stigma and quality of life, whilst Hsiung et al (2010) found that mastery was a mediator between self stigma and quality of life. Maschiach-Eisenberger et al (2013) suggest that self esteem mediated the relationship between self stigma and hope, and Yanos et al (2008) propose that that self esteem mediated the relationship between self stigma and increased avoidant coping, active social avoidance and depressive symptoms.

Identity

Quinn & Chaudoir (2009), using structural equation modelling, found that centrality (how central the identity is to the person) and salience of identity (how often they think about the identity) were mediators in the relationship between anticipated stigma and psychological distress in college students with concealable identities.

Coping strategies

Link et al (1991) examined the effects of three coping strategies: secrecy (concealing their diagnosis); avoidance- withdrawal (limiting social interaction to those who accept the person’s condition) and educating others about their condition. They argued that coping strategies could be employed by individuals in order to reduce the effects of stigmatisation but such strategies could also exacerbate their situation. They found that secrecy and avoidance-withdrawal partly explained the relationship between stigma and psychological distress. Bos et al (2009) found that disclosure of a diagnosis had a moderating effect on stigma and psychological distress. Non disclosure of a diagnosis (particularly to colleagues) reduced the impact of stigma on psychological distress compared to disclosure. However, selective disclosure to close friends and family was associated with more social support and less stigma compared to disclosure to colleagues. Selective disclosure may help to protect self esteem, however, this must be weighed against the stress caused by concealing the diagnosis.

Ahern et al (2007) hypothesised that constructive responses to stigma (talking to friends and family, talking to the person mistreating them, educating others) would be associated with better mental health compared to unconstructive responses (avoidance, becoming angry). They found that the coping response of becoming angry was associated with poorer mental health and depression and that constructive responses were not associated with better psychological functioning.

Rusch et al (2009b) assessed three coping responses: devaluing the importance of work and education (an aspect that people with mental illness are likely to perform poorly in), making comparisons with other people with mental illness (in group comparisons) rather than the outside community, and blaming discrimination for setbacks and failures. Cognitive coping responses were not found to mediate the association between stigma related stress and self esteem or hopelessness.

In summary, the studies on coping resources suggest that responses such as withdrawal, secrecy and anger may partly mediate the relationship between stigma and psychological distress. However, selective disclosure may be beneficial.

Social support and group identification

Social support is a mediator between self stigma and quality of life (Hsiung et al, 2010). Verhaeghe et al (2008) found that peer support partly modified the negative relationship between stigma and self esteem. However, peer support was higher in those experiencing lower levels of stigma suggesting that those who perceive high levels of stigma may be less likely to form relationships with peers due to fear of stigmatisation, possibly as a way of denying their association with a stigmatised group as a mechanism to protect self esteem.

Rusch et al (2009b) found that a lower perceived group value (holding the stigmatised group with disregard) was associated with higher cognitive appraisal of stigma related stress. The authors concluded that targeting group value could help to reduce stigma related stress appraisal. Crabtree et al (2010) examined the relationship between group identification, stigma, social support and self esteem. They suggested that group identification could lead to stigma resistance, stereotype rejection and increased social support. Stigma resistance was also associated with increased social support. These three in turn predicted increased self esteem. However, group identification also lowered self esteem thus having both a positive and negative impact on self esteem.

In summary, social support is associated with higher self esteem, which may act as a buffer of the effects of stigma on self esteem. However, there are conflicting findings in relation to group identification. The studies suggest that improving the perceived value of the stigmatised group and identifying with a group may lead to improved social support and an ability to cope better with stigma.

Stigma and adherence to treatment

Studies of participants with mental illness have found that self stigma and lack of insight are associated with non compliance in those with schizophrenia (Tsang et al, 2009). Older adults with depression are more likely to discontinue outpatient treatment at three months as a result of perceived stigma, compared to younger adults (Sirey et al, 2001a). The same authors found that adherence to antidepressant therapy was associated with a lower perception of stigma, even after the effects of perceived illness severity were taken into account.(Sirey et al, 2001b). Possible reasons why antidepressants may be considered stigmatising include beliefs that people who take antidepressants are “weak” and unable to deal with their own problems (Interian et al, 2007), and concerns about the efficacy of treatment. These views may vary according to cultural factors. For example, one study found that Turkish people were more likely to advocate social or religious interventions for the treatment of depression compared to drugs (Ozmen et al, 2005). Those who held a biological attribution model of depression were more likely to continue treatment compared to those who do not (Cabassa et al, 2008), and refusing treatment may be an attempt to prevent being labelled with mental illness. Some individuals may hide the use of antidepressants from others in order to avoid stigma (Grime & Pollock, 2004).

Higher levels of self stigma have also been associated with lower adherence to psychosocial interventions such as vocational rehabilitation, social skills training, cognitive behavioural therapy and family therapy (Tsang et al, 2010).

The relationship between stigma and the adherence to treatment is an area that has yet to be investigated in people with intellectual disability and is a question that would merit further exploration.

Stigma and help seeking

Most of the literature on stigma and its impact on service use have focused on mental illness. Approximately 70% of people with mental health problems do not access mental health services, and this figure is likely to be higher in less developed countries. A number of factors are thought to contribute to this “treatment gap” including lack of knowledge about mental illness and treatability of mental illness, lack of knowledge about how to access treatment, concerns about prejudice against people with mental illness and fears over discrimination against people who are diagnosed with mental health problems (Henderson et al, 2013). Several studies have shown that stigma is a barrier to help seeking (e.g. Barney et al, 2006; Thornicroft**,** 2008). Better help seeking and utilisation of services has been found to be associated with better availability of information about services and lower self stigma (Evans-Lacko et al, 2012). Rusch et al (2009c) found that cognitions associated with resilience to stigma (rejecting stigma as unfair and group identification) were associated with willingness to use outpatient services, whereas higher levels of self stigma predicted more hospitalisation.

Help seeking is likely to be influenced by the type of psychiatric illness. Certain disorders such as psychotic illness and substance abuse are regarded as more stigmatising, and there may be fears about poor treatment and negative attitudes from health professionals.

Cultural factors are also important. Nadeem et al (2007) found that depressed women of immigrant African or Caribbean backgrounds, and US born Black or Latina women were less likely to seek treatment compared to US born White Women because of the fear of stigma. In older adults, Asian Americans and Latinos expressed greater shame and embarrassment about having mental illness compared to non-Latino Whites. Asian Americans expressed greater difficulty in seeking and engaging in mental health treatment (Jimenez et al, 2013). In addition, shame and stigma in the relatives of Asian American patients with severe mental illness was associated with longer treatment delays (Okazaki, 2000). Stigma, the fear of gossip, and discrimination by health, education and social care professionals were found to be significant barriers to the use of Child and Adolescent Mental Health Services by South Asian families in one Scottish city (Bradby et al, 2007).

The relationship between stigma and health seeking in people with intellectual disability has not been investigated.

The relationship between stigma and health outcomes in other conditions

Self stigma has been associated with a number of physical health conditions. In HIV patients, stigma has been found to be a partial mediator in the relationship between HIV sign and symptom severity and depressive symptoms (White et al, 2012). Depression is also associated with self reported discrimination amongst leprosy patients in Bangladesh (Tsutsumi et al, 2004), and perceived stigma amongst patients with refractory epilepsy has been found to have a negative impact on quality of life. (Viteva, 2013) Psychological distress arising from self stigma has also been reported in a number of genetic conditions such as Klinefelter syndrome (Turriff et al, 2011), Marfan's syndrome (Peters et al, 2005) and Sickle Cell Disease (Jenerette & Brewer, 2011). Studies of participants with speech impediments such as those who have undergone laryngectomy (Devins et al, 1994), and those with a stutter (Boyle, 2013) also report higher levels of psychological distress arising from stigma. Perceived stigma due to sensory impairment, such as hearing loss, has been associated with alterations in self perception (Wallhagen, 2010).

The relationship between stigma, socio-demographic factors and health outcomes

Racial and ethnic discrimination has been associated with a number of indicators of poor physical and mental health (Paradies, 2006; Williams & Mohammed, 2009; Williams & Neighbors, 2008). In a recent survey of European countries, discrimination due to age, disability and sexuality were found to be associated with lower self reported health (Alvarez-Galvez & Salvador-Carulla, 2013). Another study has also found that higher perceptions of age discrimination were associated with lower psychological wellbeing among middle aged African American women and European American women (Sabik, 2013).

Summary of research and Justification for the study

There is increasing evidence that stigma may be an important determinant of health inequalities. Studies of people with mental illness (and other stigmatising health conditions) suggest that self stigma has a negative impact on psychological wellbeing. Stigma impedes help seeking behaviour and utilisation of mental health services, and is associated with lower adherence to medication and psychosocial treatments. All these factors contribute to the delayed presentation of people with mental illness to mental health services, which may result in more coercive treatments (e.g. under the Mental Health Act), and delayed recovery and poorer prognosis, which in turn perpetuates the vicious cycle of stigma.

There have been a handful of studies examining the relationship between psychological distress (mainly self esteem) and stigma in people with intellectual disability, but most of these studies have had major limitations. There are no studies that have attempted to investigate the impact of stigma on service use and adherence to treatment in people with intellectual disability. If stigma is associated with higher levels of psychological distress, lower use of services and poorer treatment adherence, it may lead to poorer health outcomes such as anxiety and depression and increased morbidity from physical health problems.

Section 2B: Methods, Results and Discussion

Aims and objectives

The aim of this study was to investigate whether self reported stigma in people with intellectual disability is related to psychological distress, quality of life, adherence to treatment and service use in people with intellectual disability. In this study, self reported stigma refers to a combination of experiences of discrimination and being treated negatively or differently, and emotional reactions to discrimination. The term “self stigma” has not been used because it refers to the awareness, endorsement and application of cultural stereotypes to oneself (Corrigan et al, 2009), which is an area of research that has received little attention in people with intellectual disability, possibly owing to the difficulties of examining this concept in people with cognitive difficulties.

The primary objectives were:

1. To investigate whether self reported stigma in people with intellectual disability is associated with the outcome variables psychological distress (primary outcome), quality of life, adherence to treatment and service use, before and after controlling for the effects of confounding (severity of intellectual disability, socio-demographic and clinical variables)
2. To examine whether age, gender and severity of intellectual disability (mild or moderate intellectual disability modify the relationship between self reported stigma and the outcome variables.
3. To investigate whether psychological distress mediates the relationship between self reported stigma and the outcome variables

The secondary objectives were:

1. To explore if socio-demographic variables such as severity of intellectual disability (mild or moderate intellectual disability), age, ethnicity and physical health problems are associated with self reported stigma

2. To examine whether age, gender and ethnicity modify the relationship between severity of intellectual disability (mild or moderate intellectual disability), and self reported stigma,

Primary Hypotheses

1. Self-reported stigma will be associated with higher levels of psychological distress, lower quality of life and less frequent use of services. Self-reported stigma will be associated with lower adherence to treatments (medication, psychological and other types of treatment) in people with intellectual disability.

2. The relationship between self reported stigma and the outcome variables (psychological distress, quality of life, adherence to treatment and service use) will be modified by level of intellectual disability, age, and gender.

3. The relationship between self reported stigma and the outcome variables (quality of life, service use and adherence to treatment) will be mediated by psychological distress.

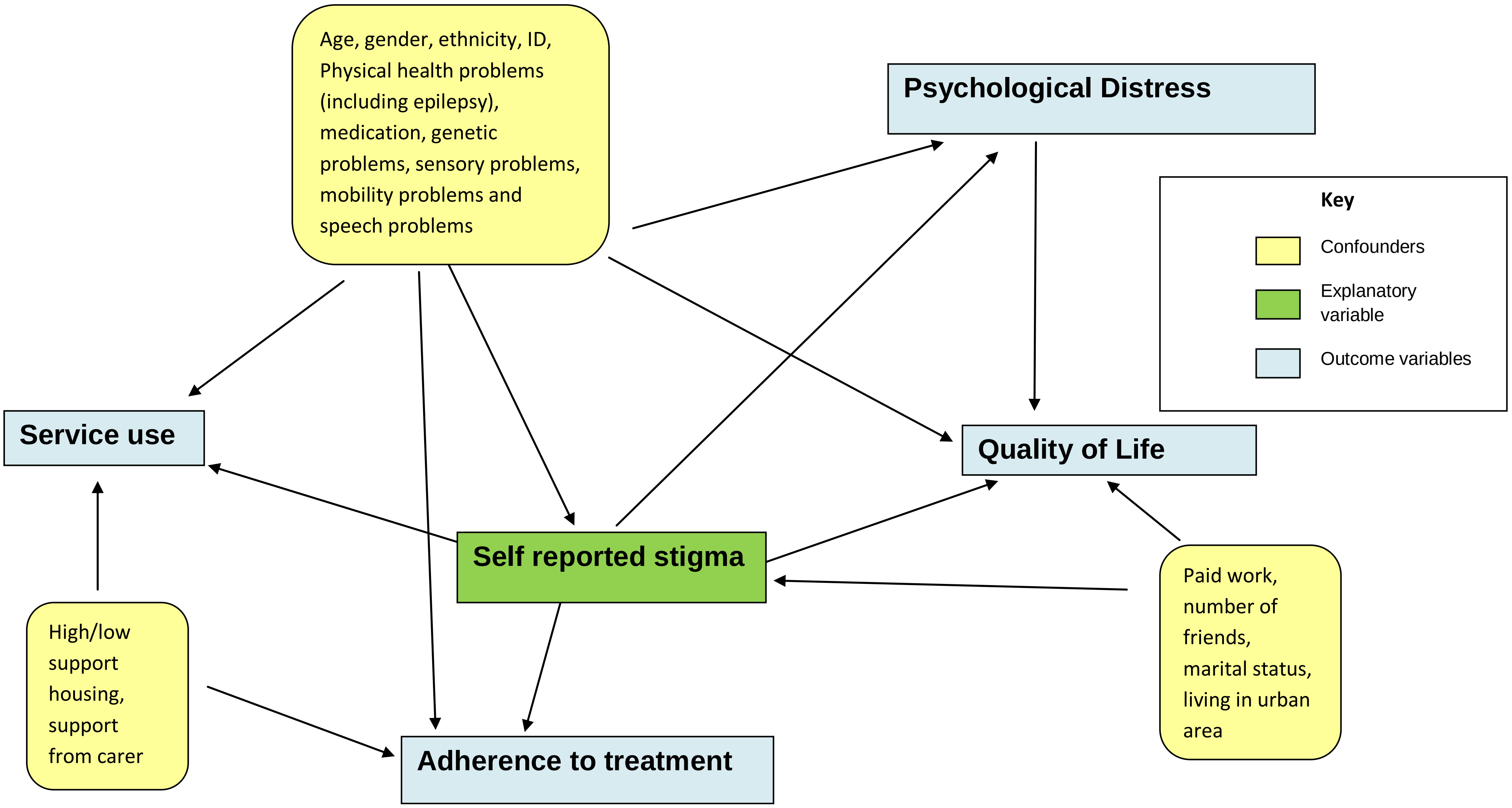
Secondary hypotheses:

1. Variables such as severity of intellectual disability, age, ethnicity and physical illness will be associated with self reported stigma. Specifically, having a moderate intellectual disability, being of older age, being from a non-White ethnic group and having physical illness, will be associated with more self reported stigma.

2. The relationship between severity of intellectual disability and self reported stigma will be modified by age, gender and ethnicity

Figure (2.1) is a causal diagram of the hypothesised relationship between self reported stigma and the outcome variables, and other variables that may be associated with stigma or the outcome variables (potential mediation by psychological distress is not shown). Some of these relationships may be bi-directional.

Figure 2.1. The hypothesised relationship between self reported stigma, outcome variables and potential confounders



Method

Funding and Ethical Approval

This study was funded by the Medical Research Council (MRC) as a three year Clinical Training Fellowship. Ethical approval was obtained from the West London Research Ethics committee (3) in November 2011 and Research and Development approval was obtained at all the participating sites. As the study was funded by the MRC, it was eligible for inclusion as a National Institute of Health Research Clinical Research Network "portfolio study", and was registered with the Mental Health Research Network (MHRN). The MHRN provided additional support with recruitment of participants, via Clinical Studies Officers, at sites outside of London. The study was conducted between February 2011 and February 2013.

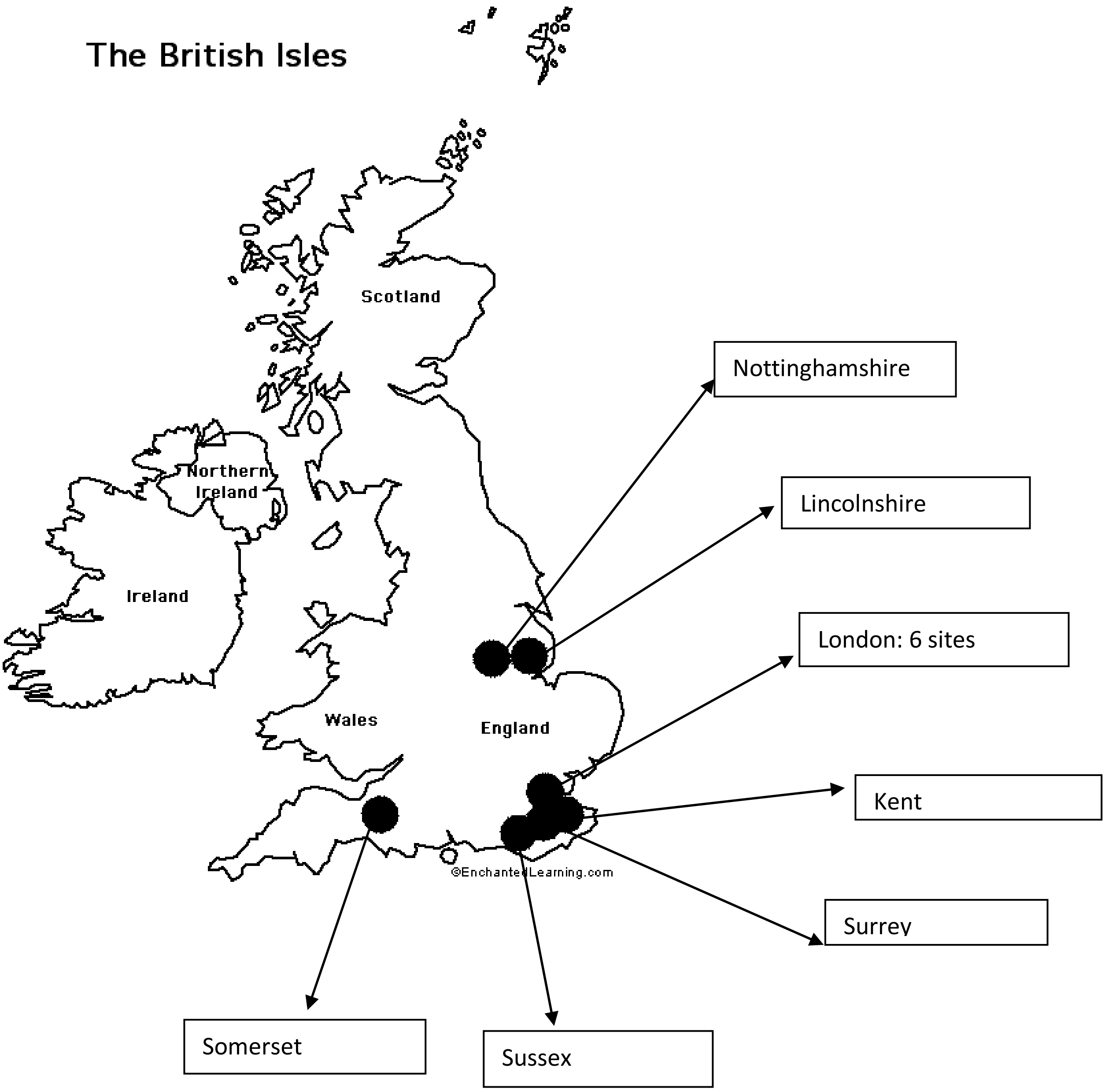
Participating sites

The study was conducted at five sites (see figure 2. 1) in North and East London (Camden, Islington, Waltham Forest, Tower Hamlets and Newham), one site in South East London (covering Bexley, Bromley and Greenwich) and six sites outside of London (Lincolnshire, Nottinghamshire, Somerset, Surrey, Sussex and Kent). The selection of centres was based on these sites expressing an interest to take part in the study and subject to obtaining local NHS Research and Development approval.

Recruitment

Participants were recruited from community intellectual disability services (CLDS), day centres, social clubs, supported accommodation and voluntary organisations that work with people with intellectual disability. In four of the participating sites (Camden, Islington, Nottinghamshire and South East London) it was possible to send out invitation letters to participants who were eligible for the study. Individuals who responded to the letter were contacted directly by the researcher. It was not feasible at other sites to use this approach as the number of eligible participants was not known. The other method of recruitment was via health and social care professionals, and support workers, who knew the individual well. Table A.2.1 (see appendix) provides a breakdown of the number of individuals recruited by each

Figure 2.2. Sites participating in the study



method, at each site. Individuals who were interested in the study were given an accessible information sheet (see appendix) and were required to give consent before entering the study.

Inclusion and exclusion criteria

Participants aged over 18 with mild or moderate intellectual disability were included in the study. Participants with a current diagnosis of mental illness were excluded because of the potential difficulty that participants could have in differentiating whether experiences of discrimination were due to intellectual disability or mental illness (an issue that was raised by the MRC funding panel). Individuals with poor verbal or comprehension skills, those unable to provide consent and individuals unable to speak English, were excluded from the study.

Piloting phase

In February 2011, two consultation groups were held, one with professionals and another with participants with intellectual disability, in order to obtain views on how two of the study questionnaires (Service Use and Adherence to Treatment) could be modified or adapted for the study. All the participants were given an information sheet and required to sign a consent form.

The first consultation group was comprised of eleven professionals (two psychologists, one counsellor, three nurses, one speech and language therapist, one psychiatrist, one social worker, one occupational therapist and one accessible information worker), seven were female and four were male, aged 21-56 (mean age 35), with an average experience of 11.6 years working with people who have intellectual disability. Eight were White British, two were White Other and one was Asian Other. The meeting was facilitated by AA and a research assistant, and was audio-taped. The key points that were discussed were recorded on a flipchart.

Following this consultation, the two questionnaires were modified with the input from an accessible information worker, and the adapted versions were presented to a group of participants with intellectual disability. There were five participants in the group, who knew each other well. They all had a mild intellectual disability. Three were female, four were White British and they were 38-56 years of age (mean age 46.4). The meeting was facilitated by AA and a Support worker who knew the participants well. The participants gave their opinion on whether they thought the questions were easy to understand and whether the illustrations accompanying the questions were appropriate. The discussion was audio-taped. Following this consultation, the questionnaires and interviews were further modified, with additional input from the accessible information worker and a speech and language therapist. The final versions were tested on 2 participants with mild intellectual disability (1 male and 1 female) and one with moderate intellectual disability (1 male).

Outcome measures

Primary Outcome measure: *Psychological distress*

The primary outcome (dependent variable) was Psychological distress, measured by the Clinical Outcomes in Routine Evaluation (CORE) 14 item version. This self report measure has been recently developed for people with intellectual disability (Brooks et al, 2013). It measures 14 symptoms relating to anxiety, depression and trauma on a 3 point likert scale (0=not at all, 1= sometimes and 2= a lot). The total score ranges from zero to 28, with higher scores indicating more psychological distress. Each item is accompanied by a symbol. Items include: “have you felt very very lonely”; “have you felt confused”; and “have you felt really scared or frightened”. It was developed for use in therapeutic settings, to be administered before, during and after psychological therapy, in order to assess treatment response. This instrument was selected because it is quick and easy to administer, It has been validated in people with intellectual disability and has specific items that are more relevant in this group (e.g. “I feel upset or frustrated with my learning disability”) and has good psychometric properties (test re-test reliability: rho 0.64); internal consistency: cronbach’s alpha 0.83). In this study, the internal consistency for the full scale, measured by cronbach’s alpha, was 0.83, which is the same as that reported by the authors of the scale.

Secondary Outcome measures

1. Quality of Life

Quality of Life was measured by the Quality of Life Questionnaire (Schalock & Keith 1993). This instrument is widely used and has been validated in people with varying levels of intellectual disability (mild to profound). It can be self administered or administered by staff and contains 40 items that are scored on a three point scale (1-3). It has 4 subscales, each with ten items: The “Satisfaction” subscale contains items such as “how much fun and enjoyment do you get out of your life” and “do you have fewer or more problems than other people”. The “competence/productivity” subscale contains items relating to work such as “do you feel that your job or other activities is worthwhile and relevant to yourself or others”. Participants who do not work are given a score of one for each of the items. The “empowerment/independence” subscale contains items such as “who decides how you spend your money” and “how much control do you have over things you do everyday, like going to bed, eating and what you do for fun”. The “social belonging/community integration” subscale contains items such as “do you have friends over to visit your home” and “how do your neighbours treat you”. The maximum score for each subscale is 30, with the total full scale score ranging from 40 to 120. Higher scores indicate a higher quality of life. The scale has good concurrent validity with the Life style Satisfaction scale (Harner & Heal, 1992; Rho 0.57) and good construct validity (e.g. convergent validity demonstrated by scores increasing with more independent living and higher IQ). It also has good psychometric properties (Full scale test re-test reliability: rho 0.87, inter-rater reliability between self report and staff ratings: Rho 0.73; Internal consistency: alpha 0.90). In this study, the internal consistency of the full scale, measured by cronbach’s alpha, was 0.87. The internal consistency for the subscales ranged from alpha 0.64 to 0.93, which are similar to that reported by the authors, apart from the empowerment subscale, which had a lower internal consistency (alpha 0.66 versus 0.82).

2. Service Use

At the time of conducting this study, there were no self report questionnaires on service use that have been developed for people with intellectual disability. In order to measure service use, questions were modified from the Client Services Receipt Interview (CSRI; Hallam et al, 2006). The modified questions were piloted with professionals and individuals with intellectual disability (see above) in order to develop a self report version. The modified questionnaire (see appendix) comprises questions about day time activities and the number of contacts with services over the last six months, including their General Practitioner and dentist, use of other primary care services (e.g. family planning clinics), contact with professionals at community intellectual disability services, hospital inpatient stays, hospital outpatient episodes, and contacts with police. A total score was calculated, which was the sum of all the contacts with community, hospital based services and the police in the last 6 months. For example, if the participant had visited the GP four times, had seen his social worker twice and had one Accident & Emergency visit in the last six months, the total score was calculated as seven. The calculation of a total score is not part of the original CSRI.. Participants were also asked if they had refused any service in the last 6 months and the reason for refusing services.

3. Adherence to treatment

There are currently no satisfactory instruments measuring adherence to treatment in people with intellectual disability. A self report rating scale was developed following piloting, as described above (see appendix), which measures adherence to medication (any regular medication), psychological therapies and other interventions (e.g. physiotherapy, speech and language therapy). Participants are asked questions about the frequency that medication or psychological (and other) sessions are missed, how often they need to be reminded to take medication or to attend their psychology (or other) sessions and how helpful they think the treatment is. Each question is rated 1-4 (1= poor adherence; 2 = satisfactory adherence; 3= good adherence; 4=excellent adherence). The range of scores is 3 to 12 for each subscale. A total score was not calculated as few participants were receiving all three types of treatment.

Other measures

Self reported stigma

Self reported stigma was measured using a questionnaire that was previously developed by AA and her supervisors (Ali et al, 2008). This self report instrument contains ten items with two subscales. The “Perceived Discrimination” subscale contains items that describe discrimination and negative treatment by others such as “people talk down to me”, “people on the street make fun of me” and “people treat me like a child”. The “Reaction to Discrimination” subscale describes emotional reactions to discrimination such as “the way people talk to me makes me angry” and “I worry about the way people act towards me”. The questionnaire does not require participants to report experiences over a particular time scale. Instead, participants are asked to report how they feel they are generally treated by others. The Items are rated “yes” (scored 1) and “no” (scored 0) and each item is accompanied by a photograph. The total score ranges from 0 to 10, with higher scores indicating higher levels of self reported stigma. The scale has good psychometric properties (Full scale internal consistency: cronbach’s alpha 0.84; 0.72 for “Perceived discrimination” subscale and 0.69 for “Reaction to discrimination” subscale; Kappa coefficients for test retest reliability ranged from 0.41 to 0.71). In this study, the internal consistency of the scale was slightly better than that previously reported (Full scale: alpha 0.87; Perceived discrimination subscale: alpha 0.82; Reaction to discrimination: alpha 0.74).

Demo-graphic and clinical data

A structured data collection form was used to collect demographic and clinical data. This was interviewer administered and included information on age, gender, ethnicity, marital status, previous education (whether they attended a mainstream school only or a special school), type of housing or accommodation, employment status, number of friends and whether they lived in a rural area (e.g. village), semi-urban (small town) or urban area (large town or city). Clinical data included information on health problems including history of epilepsy, genetic disorders, sensory problems (visual or hearing impairment), mobility problems and whether the participants were taking regular medication (e.g. anti-epileptic medication). Data on level of intellectual disability was based on information obtained from clinical records and not on formal IQ testing. The interviewer also rated the presence of any speech difficulties, according to how easy it was to understand the participant's speech.

Administration of questionnaires

For most of the sites in London, recruitment and data collection was conducted by AA. The Clinical Studies Officers based in South East London and sites outside of London were responsible for recruiting participants at these sites and for administering the questionnaires. They received training to ensure that the study questionnaires were administered appropriately. The questionnaires were administered face to face, either at the participant's home or another suitable setting (e.g. day centre or community intellectual disability service). Where possible, the questionnaires were administered with the support of a carer. Participants were supported to complete the questionnaires, such as reading the question out aloud, paraphrasing questions to improve understanding and explaining the response format. The administration time varied from 30 minutes to two hours depending on the level of support required. The average time was 45 minutes. Participants received a £20 gift voucher as an acknowledgement for their time and effort.

Sample size calculation

The minimum sample size of 171 was calculated, based on a regression analysis with a moderate effect size (f^2 0.15) and 15 predictors, at 90% power and 5% significance level.

Data cleaning and handling

The information obtained from the questionnaires was entered into a database on SPSS (version17). In order to ensure that the data had been correctly entered, 10% of the entries were randomly selected and checked for consistency. All the variables were checked to identify whether any of the observations were outside the expected categories or range of values (e.g. outliers). Prior to the main analysis, new variables were derived by grouping some the categories or values into smaller categories.

Missing data

Only a small number of variables had missing data (4.8% of the data were missing) and therefore missing data analysis and random multiple imputation techniques were not employed.

Analysis

Descriptive analysis

The data was analysed using SPSS (version 17) and Stata (version 10). Data for the whole sample and for individual centres was analysed descriptively. This included analysis of the number of participants and method of recruitment, and analysis of socio-demographic and clinical variables: mean age (SD and range); proportion with mild and moderate intellectual disability; gender; ethnic background; marital status; housing type, rural/ urban status, employment status, sensory problems, mobility problems, speech problems, health problems (including epilepsy), genetic problems and syndromes (e.g. Down syndrome, Cerebral Palsy) and medication (e.g. anti-epileptic).

The distribution of scores for each questionnaire was analysed using histograms. The mean, standard deviation and range of scores were obtained for all the questionnaires in the whole sample and for individual centres. The proportion of people responding to each item on the stigma questionnaire was analysed using Chi Square tests to identify whether the responses differed according to gender, age group and level of intellectual disability.

The relationship between self reported stigma and psychological distress was initially examined as categorical variables (although in the main analysis they were examined as continuous variables, see below). The purpose was to calculate the mean stigma score for clinically high and low levels of psychological distress. High levels of psychological distress were determined by the data reported by Brooks et al (2013) in their validation of the CORE-LD. The average total pre therapy psychological distress score was 12.6 and the inter-quartile range was seven to 14. Based on this information, the mean psychological distress score was dichotomised into two categories: a score of 13 or more was used to indicate clinically high levels of psychological distress and a score of 12 or less to indicate low levels of distress.

The mean psychological distress score was also calculated for each total stigma score (zero to ten). As there are currently no cut-off scores on the stigma questionnaire to indicate which scores would be clinically useful, the sensitivity and specificity were calculated for different stigma cut-off scores on the stigma questionnaire, using the dichotomised psychological distress variable as the gold standard. A receiver operating curve was plotted and the area under the curve was calculated to provide an indication of how good a test self reported stigma was in predicting clinically high levels of psychological distress.

Linear regression

Linear regression was used to examine the unadjusted relationship between self reported stigma, and the perceived discrimination and reaction to discrimination subscales, with psychological distress, quality of life and adherence to treatment. Linear regression was also used identified whether any of the socio-demographic or clinical variables were associated with self reported stigma or the outcome variables.

The number of total service contacts was analysed using negative binomial regression, which is used for count data that is not normally distributed and for over-dispersed observations (where the variance is greater than the mean). The association between self reported stigma and contacts with specific services such as primary care, community intellectual disability services, hospital based services and police, were also analysed using negative binomial regression. Logistic regression was used to investigate the relationship between self reported stigma and whether participants refused input from at least one service in the last six months. The relationship between each of the outcome variables was also analysed using linear regression analysis.

In all of the above analyses, multi-level modelling using a random effects model was used to take into account any effects that may have arisen from clustering (see below).

Clustered data

Participants who are recruited from the same centre are likely to be similar to each other compared to participants from other centres. Not adjusting for the presence of clustering can lead to small standard errors and to an over-estimation in the strength of relationship between the exposure and outcome. The effects of clustering was analysed using a random effects (multilevel) model, which explicitly models the similarity between individuals in the same cluster. The amount of clustering is measured using the intra-class correlation coefficient (ICC), which is the ratio of between cluster variance to the total variance. If the ICC is zero, then there is no evidence of clustering and if it is 1, then all the variance is explained by the clustering. If the likelihood ratio test is significant ($p<0.05$), then there is evidence of clustering. The ICC was examined for the random effects linear regression models. If the ICC is close to zero, the results of the random effects models are similar to that obtained from running a linear regression model.

Multivariate analysis

1. Exploring the socio-demographic variables that are associated with self reported stigma

The total score on the stigma questionnaire was entered as the dependent variable in the random effects regression model. Potential confounders (age, gender, level of intellectual disability and ethnicity), and all the variables that were related to self reported stigma in the linear regression analysis with p values of 0.2 or below, were then simultaneously added to the model. The variables that had p values equal to or less than 0.05 were identified as being independently associated with self reported stigma.

2. Exploring the relationship between self reported stigma and the outcome variables

In order to investigate whether the association between self reported stigma and psychological distress was altered by adjusting for potential confounding variables, multivariable regression analysis was carried out using a random effects model. Psychological distress was entered in the model as the dependent variable and self reported stigma was the independent variable. The corresponding regression coefficient and p value was recorded. The variables age, sex, ethnicity and level of intellectual disability were then added to the model as they were potential confounders, and any changes to the beta coefficient and p value were noted. Each variable that was associated with psychological distress in the linear regression analysis was then added separately, to identify whether it reduced the regression coefficient and had a significant confounding effect on the relationship between self reported stigma and psychological distress. Then all the variables associated with psychological distress were added to the final model, and the strength of the association between stigma and psychological distress was noted.

The analysis was repeated with the quality of life outcome measure and adherence to medication. Multivariable analysis of the relationship between self reported stigma and adherence to psychological treatment and adherence to other treatments was not performed due to the small number of observations in these groups. A random effects negative binomial regression model was used to investigate the relationship between self reported stigma and total number of service contacts, and between self reported stigma and individual services. A random effects logistic regression model was used to assess the relationship between self reported stigma and refusal of services.

All the analyses were repeated using the perceived discrimination and reaction to discrimination subscales of the stigma questionnaire. The results are presented as unadjusted and adjusted regression coefficients, 95% Confidence intervals and p values for Wald tests.

Regression diagnostics

For each regression model, regression diagnostics were carried out. The residuals were examined to identify whether they were normally distributed by inspecting an inverse normal plot. If the observations are normally distributed, then the plot is expected to be linear (see appendix Figure A.2.1). Multicollinearity (when variables are strongly correlated with each other) was assessed by examining the variance inflation factor for each model. Collinearity is present if the variance inflation factor (VIF) for a variable is greater than ten. Should this occur, the variable is then removed from the model and the VIF is re-calculated.

3. Investigating effect modification

Interaction effects were investigated to identify whether age, gender and ethnicity modified the relationship between intellectual disability and self reported stigma. Interaction effects were analysed using the unadjusted model (stigma, intellectual disability and interaction variable) and adjusted regression model (stigma, interaction variables and potential confounders).

Interaction effects were also investigated to identify whether intellectual disability, age and gender modified the association between self reported stigma and each of the outcome measures. Interaction effects were analysed using both unadjusted (outcome variable, stigma and interaction variable) and adjusted models for each outcome (outcome variable, stigma, confounders and interaction variables).

4. Exploring psychological distress as a mediator in the relationship between stigma and the outcome measures

A variable is considered to be a mediator if it fulfils the following criteria (Baron & Kenny, 1986):

a. The independent variable is associated with the dependent variable in the absence of the mediator

b. The independent variable is associated with the mediator

c. The mediator is independently associated with the dependent variable

d. The effect of the independent variable on the dependent variable is reduced after addition of the mediator to the model

The effect of psychological distress as a potential mediator in the relationship between self reported stigma and quality of life, self reported stigma and service use (total number of service contacts, and contacts with specific services) and self reported stigma and adherence to medication was investigated using the above criteria. Initially, regression analysis was used to confirm whether psychological distress was associated with these outcomes. Psychological distress was then included in the regression model with self reported stigma (and the potential confounders). If the regression coefficient for the relationship between self reported stigma and the outcome variable was reduced, then psychological distress was considered to be a mediator in the relationship. Psychological distress was considered to be a full mediator if the relationship between self reported stigma and the outcome variable became non significant, and a partial mediator if the relationship was reduced but remained significant.

Summary of methods and analysis

- The main aim of the study was to examine the relationship between self reported stigma and psychological distress, quality of life, service use and treatment adherence; to explore possible moderators of the relationship; and whether psychological distress is a mediator between self reported stigma and the outcome variables. The secondary aim was to examine whether socio-demographic factors such as severity of intellectual disability, age and physical illness were associated with self reported stigma
- The primary outcome was psychological distress, measured using the CORE-LD 14 item version. The Service Use questionnaire and Adherence to Treatment questionnaires were developed following some piloting work. Self reported stigma was measured using the Stigma Questionnaire, developed by the candidate in an earlier study.
- Participants with mild and moderate intellectual disability, with no current history of mental illness, were recruited from 12 sites in London and England from a number of different organisations. The main method of recruitment was direct approach by staff but in some sites, invitation letters were also sent out to eligible participants. Convenience sampling was used.
- Descriptive statistics were used to analyse the sample characteristics. The responses to the stigma questionnaire were analysed to identify whether responses differed according to level of intellectual disability, gender, age and ethnicity. The mean stigma scores were obtained for participants experiencing high and low levels of psychological distress, the mean psychological distress scores were examined for each score on the stigma questionnaire, and a ROC analysis was performed.
- Linear regression analysis was used to examine the unadjusted association between stigma and the outcome variables, and between other socio-demographic and clinical factors and the outcome variables. Multivariate regression analysis was carried out to examine the relationship between stigma and the outcome variables after adjusting for confounders. A random effects regression model was used to adjust for the effects of clustering.
- Analysis for interaction effects was performed to identify whether the relationship between stigma and the outcome variables were modified by level of intellectual disability, gender and age. Mediation analysis was performed to identify whether the relationship between stigma and the outcome variables was mediated by psychological distress

Results

Recruitment

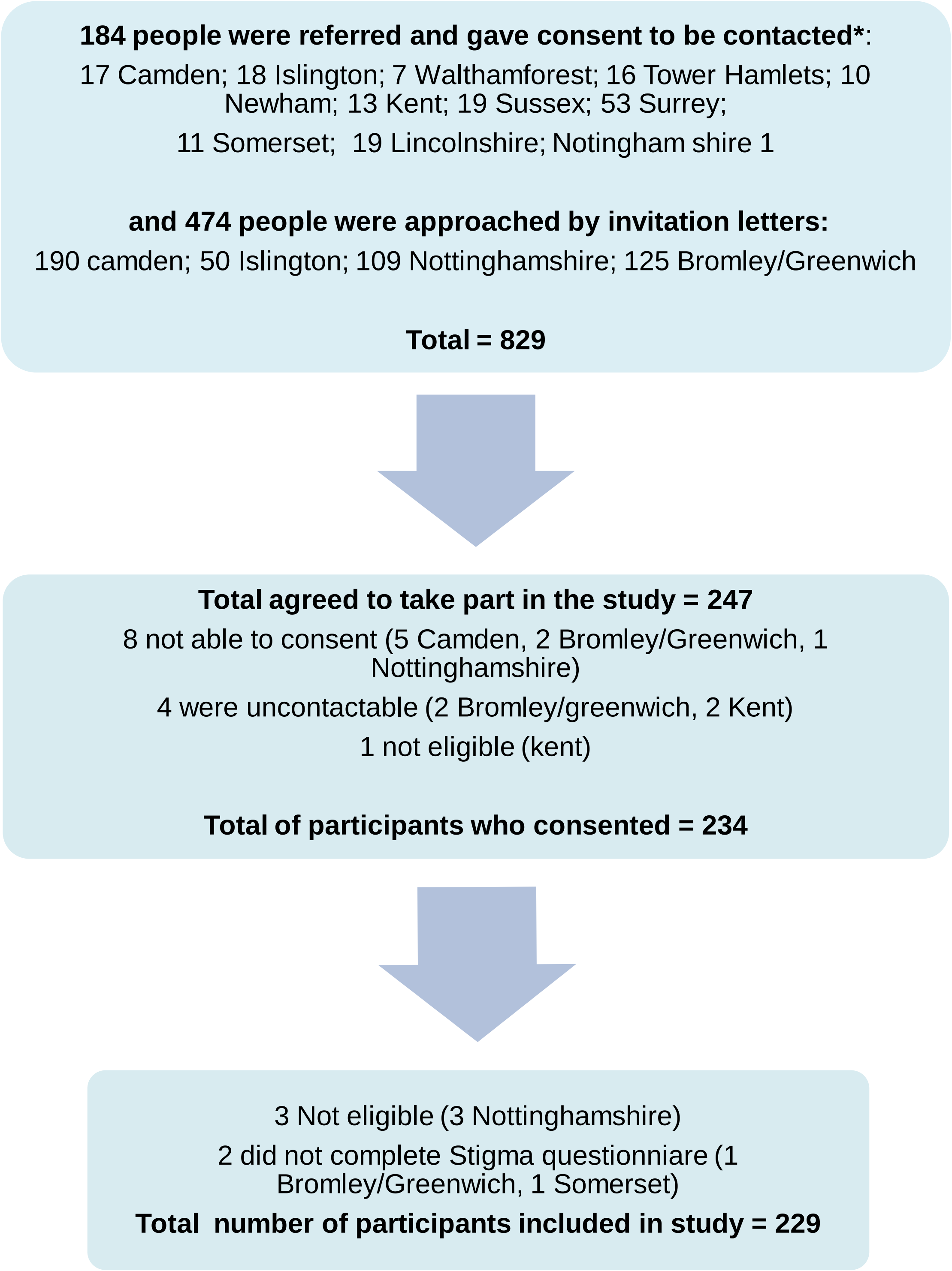
A total of 234 participants consented to take part in the study (see Figure 2.3 for recruitment flow chart). Three participants were later withdrawn as they did not strictly meet the eligibility criteria (had a current diagnosis of mental illness for which they were receiving treatment), and two were excluded from the analysis as they did not complete the stigma questionnaire, leaving a total of 229 participants. Seventy two participants were recruited from day centres (31.4%); 65 from voluntary organisations (28.4%); 48 by invitation letters (21.0%), 26 via staff at community intellectual disability services (11.4%) and 18 from supported housing schemes (7.9%). The method of recruitment varied according to the centre (See appendix Table A.2.1).

Characteristics of the participants

i. Socio-demographic characteristics

Table 2.1 describes the characteristics of the whole sample. The proportion of males to females was approximately equal (120 males; 52.4%); almost three quarters of the sample had a mild intellectual disability (165 participants, 72.7%) and the mean age of the sample was 40.9 years (SD 11.4; range 19-73). Eighty two percent of the sample was from White ethnic backgrounds, although in London, this figure was lower, reflecting a more ethnically diverse population (61.6%). The majority of the participants were single (62.9%) but 21 participants were married (9.2%); only five were in full time employment (2.2%) but 73 (31.9%) were in part time paid employment (either in competitive or sheltered employment). Fifteen participants were living alone with no support (6.6%); Ninety three participants were living with their family (40.6%); 42 were living in supported housing and 23 in residential homes. The majority of the participants had three or more friends (73.8%). One hundred and six participants regularly attended a day centre (46.3%), 62 (27.1%) attended a college. A third of participants regularly attended religious services (79; 34.5%), over a half attended social clubs (124; 54.2%) or leisure activities (135; 59.0%) and a fifth attended a group (e.g. advocacy group, health education group).

Figure 2.3: Recruitment Flow chart



184 people were referred and gave consent to be contacted*:

17 Camden; 18 Islington; 7 Walthamforest; 16 Tower Hamlets; 10 Newham; 13 Kent; 19 Sussex; 53 Surrey;

11 Somerset; 19 Lincolnshire; Notingham shire 1

and 474 people were approached by invitation letters:

190 camden; 50 Islington; 109 Nottinghamshire; 125 Bromley/Greenwich

Total = 829

Total agreed to take part in the study = 247

8 not able to consent (5 Camden, 2 Bromley/Greenwich, 1 Nottinghamshire)

4 were uncontactable (2 Bromley/greenwich, 2 Kent)

1 not eligible (kent)

Total of participants who consented = 234

3 Not eligible (3 Nottinghamshire)

2 did not complete Stigma questionniare (1 Bromley/Greenwich, 1 Somerset)

Total number of participants included in study = 229

*The exact number of people who were approached by staff at community intellectual disability services, voluntary organisations and supported housing is not known

The characteristics of the sample varied according to the centre (appendix Table A.2.2). The mean age ranged from 36.1 years (Tower Hamlets) to 44.9 years (in Camden); the proportion of males ranged from 20.0% (Bromley/Greenwich) to 80% (Newham); the proportion of people with moderate intellectual disability ranged from 11.1% (Somerset) to 87.5% (Kent) and in all the centres outside of London, almost all of the participants were from White ethnic backgrounds.

ii. Clinical characteristics

Seventy four participants had a sensory problem (32.3%; Table 2.2.2); 75 had problems with their speech (32.8%); and 24 (10.5%) had mobility problems. The majority had at least one physical health problem (64.6%), which included 39 people with epilepsy (17.0%). Twenty participants (8.7%) had a genetic disorder or a syndrome, including 12 with Down syndrome (5.2%).

Exploring the socio-demographic variables associated with stigma

i. Distribution of self reported stigma scores

Figure 2.4 shows the distribution of the total score on the stigma questionnaire. The total scores are not normally distributed. The most frequent scores are zero, one and two, with a further peak at five. There were similar numbers of people with scores between six and ten. The mean score was 4.2 (SD 3.3) in the whole sample (Table 2.2). The distribution suggests that there is a large group of participants who have experienced no or low levels of self reported stigma, but the fairly uniform distribution of scores suggests that self reported stigma is a common problem. This distribution of total scores is somewhat different to that obtained in the validation phase of the stigma questionnaire. The stigma scores were approximately normally distributed and the modal score was 10, with a mean of 6.5 (Ali et al, 2008). This difference in the distribution is likely to be due to differences in the study population: the stigma questionnaire was validated in a sample that included both people with and without mental illness, whereas this sample is comprised exclusively of people without mental illness.

The self reported stigma scores varied according to the centre (appendix Table A.2.3), with Lincolnshire and Camden reporting higher scores (6.05 and 5.41 respectively) and Sussex and Kent reporting the lowest (1.79 and 2.44 respectively).

Figure 2.4: The distribution of scores on the stigma questionnaire

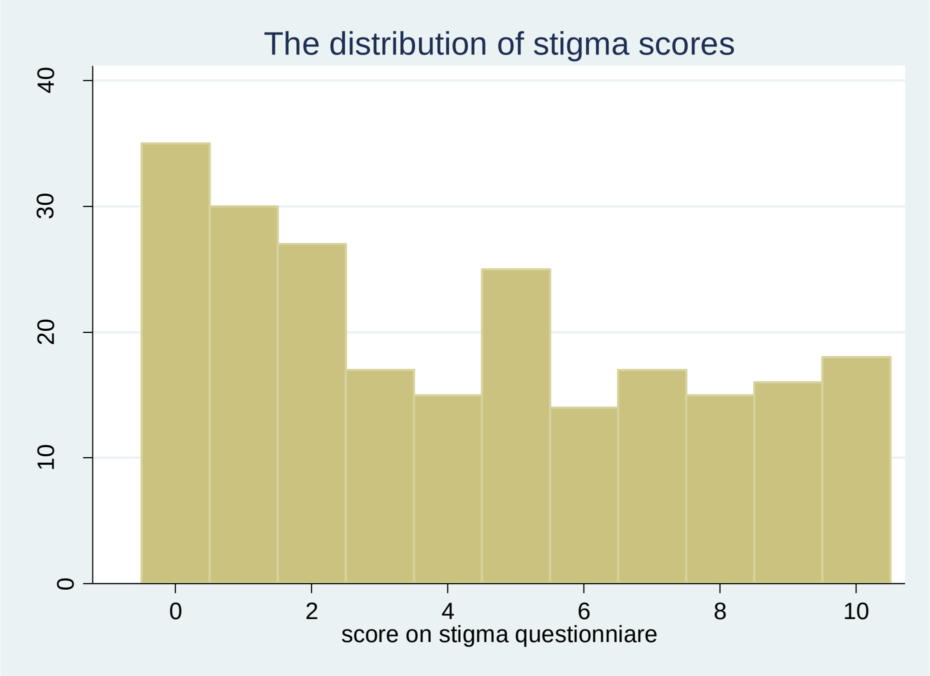


Table 2.1: Socio-demographic and clinical characteristics of the whole sample

Characteristic*	Numbers	Percentage
Gender:		
Male	120	52.4
Female	109	47.6
Intellectual disability:		
Mild	165	72.7
Moderate	64	27.9
Ethnicity (all groups)		
White British	171	74.7
White Irish	4	1.8
White Other	13	5.7
Mixed (White British/ Caribbean	3	1.3
Mixed (White British/African)	1	0.4
Mixed (White British/Asian)	2	0.9
Indian	3	1.3
Pakistani	3	1.3
Bangladeshi	12	5.2
Chinese	2	0.9
Black Caribbean	10	4.4
Black African	4	1.8
Black other	1	0.4
Ethnicity (combined)		
White	188	82.1
Other	41	17.9
Ethnicity (London): White	61	61.6
	38	38.4
(outside London): White	127	97.7
	3	2.3
Marital status		
Single		
Non-cohabiting	144	62.9
Cohabiting	44	19.2
Married	10	4.4
Separated	21	9.2
Divorced	1	0.4
widowed	7	3.1
	2	0.9
Employment		2.2
Full time paid work	5	24.9
Part time paid work (competitive)	57	7.0
Part time paid work (sheltered)	16	22.7
Voluntary work only	52	6.1
Unemployed, seeking work	14	26.6
Unemployed, not seeking work	61	7.9
Part time student only	18	1.8
Full time student only	4	0.9
Retired	2	

Table 2.1.....cont

Characteristic*	Numbers	Percentages
Housing		
Living with family		
Living with friend/other	93	40.6
Living alone	3	6.6
Supported housing (<24 hour support)	15	21.0
Supported housing (24 hour support)	48	21.0
Residential home	46	10.0
Nursing home	23	0.4
	1	1.3
Level of urban development		
Rural area	21	9.2
Semi-rural	60	26.3
Urban area	147	64.5
Friendship		
No friends	11	4.8
1-2 friends	49	21.4
3 or more friends	169	73.8
Friends with people without ID: yes	98	42.8
Sensory problems		
No sensory problems	155	67.7
Hearing problems	24	10.5
Visual problems	42	18.3
Hearing and visual problems	8	3.5
Any sensory problems	74	32.3
Speech problems		
No speech problems	154	67.3
Mild impediment	49	21.4
Moderate impediment	17	7.4
Severe impediment	9	3.9
Any speech problem	75	32.8
Health problems		
Epilepsy	39	17.0
Any physical health problem	148	64.6
Taking medication	126	55.0
Genetic disorders/syndromes	12	5.2
Down syndrome	2	0.9
Cerebral palsy	6	2.6
Other		
Any genetic disorder or syndrome	20	8.7

* age mean age 40.9, (SD 11.4), range 19-73

Table 2.2: Descriptive statistics for the exposure and outcome variables for the whole sample

Exposure/outcome	Mean	Standard deviation	Range
Stigma (full scale)	4.22	3.29	0-10
Perceived discrimination subscale	2.28	2.09	0-6
Reaction to discrimination subscale	1.94	1.48	0-4
Psychological distress	7.36	5.41	0-24
Quality of Life (full scale)	87.82	12.69	51-117
Satisfaction subscale	23.10	4.43	10-30
Competence subscale	18.98	7.08	10-30
Empowerment subscale	24.08	3.53	10-30
Social Belonging	21.64	3.81	10-30
Total service use	36.88	60.45	0-377
Adherence to medication	10.57	1.50	6-12
Adherence to therapy	9.85	1.97	6-12
Adherence to other treatments	10.47	1.91	5-12

ii. Responses to individual items on the stigma questionnaire

Thirty five participants (15.3%) obtained the lowest score of 0, which was the modal group and 18 obtained the highest score of 10 (7.9%). Table 2.3 shows the proportion of “yes” responses given to each item on the stigma questionnaire. Item 9 (I keep away from other people because they are not nice to me) and item 1 (people talk down to me) received the most “yes” responses (58.5% and 48.5% of the sample). Item 6 (people laugh at me because of the way I talk) and item 5 (People treat me like a child) received the fewest “yes” responses (31.9% and 32.3% respectively).

When the responses from participants with mild intellectual disability were compared to those with moderate intellectual disability (table 2.3), a significantly higher proportion of people with moderate intellectual disability rated “yes” to four items compared to those with mild intellectual disability (item 2: People on the street make fun of me, p=0.02; item 4: People laugh at me because of the way I look, p=0.001; item 5: people treat me like a child, p=0.05 and item 6: people laugh at me because of the way I talk, p=0.02).

When the responses from males and females were examined (Table 2.4), a significantly higher proportion of females rated “yes” to item 10 (I worry about the way people act towards me, p=0.002) and one item was borderline (item 5: people treat me like a child, p=0.06). When the responses were compared across different age groups (Table 2.5), increasing age group was associated with a higher proportion of “yes” responses to all the items (p<0.01 for almost all of these items) except for item 5 (people treat me like a child). Participants from White and non white backgrounds gave similar responses (Table 2.6.), apart from item 8 (People make me feel embarrassed) where a higher proportion of “yes” responses was given by those from a White background (p=0.04).

ii. Linear regression analysis of the relationship between the total stigma score and socio-demographic and clinical characteristics

The variables that had a strong association with self reported stigma (See appendix Table A.2.4) were age (older age associated with more stigma; p=0.001); health problems (having a health problem associated with more stigma; p=0.001) and sensory problems (having a sensory problem associated with higher levels of stigma, (p=0.01.). There was a moderate association between self reported stigma and being in paid employment (paid work associated with less stigma, p=0.02) and medication (being on medication associated with more stigma; p=0.05). There was a borderline association between self reported stigma and level of urban development (living in a semi-urban or urban area associated with more stigma than living in a rural area p=0.08).

Table 2.3: Comparison of responses to individual items on the stigma questionnaire given by people with mild and moderate intellectual disability

Item	**Total number of responses* (%)**	**Mild ID* Number (%)**	**Moderate ID* Number (%)**	**Chi Square (p value)**
1. People talk down to me	118 (48.47)	85 (51.52)	25 (40.32)	2.26 (0.13)
2. People on the street make fun of me	85 (37.12)	55 (33.33)	31 (50.00)	5.32 (0.02)
3. People on the street look at me in a funny way	106 (46.3)	71 (43.03)	34 (54.84)	2.53 (0.11)
4. People laugh at me because of the way I look	76 (33.19)	45 (27.27)	31 (50.00)	10.45(0.001)
5. People treat me like a child	74 (32.31)	47 (28.48)	26 (41.9)	3.74 (0.05)
6. people laugh at me because of the way I talk	73 (31.88)	46 (27.88)	27 (43.55)	5.07 (0.02)
7. The way people talk to me makes me angry	110 (48.03)	79 (47.88)	29 (46.77)	0.02 (0.88)
8. People make me feel embarrassed	100 (43.67)	67 (40.61)	32 (51.61)	2.22 (0.14)
9. I keep away from other people because they are not nice to me	134 (58.52)	99 (60.00)	35 (56.45)	0.24 (0.63)
10. I worry about the way people act towards me	98 (42.79)	30 (48.39)	30 (48.39)	0.94 (0.33)

* “yes” responses to each item

Table 2.4: Responses given by males and females to individual items on the stigma questionnaire

Item	Males* Number (%)	Females* Number (%)	Chi square (p value)
1. People talk down to me	54 (45.0)	57 (52.29)	1.22 (0.27)
2. People on the street make fun of me	44 (36.67)	42 (38.53)	0.08 (0.77)
3. People on the street look at me in a funny way	49 (40.83)	57 (52.29)	3.02 (0.08)
4. People laugh at me because of the way I look	39 (32.50)	37 (33.94)	0.05 (0.82)
5. People treat me like a child	32 (26.67)	42 (38.53)	3.68 (0.06)
6. people laugh at me because of the way I talk	40 (33.33)	33 (30.28)	0.25 (0.62)
7. The way people talk to me makes me angry	52 (43.33)	58 (53.21)	2.23 (0.14)
8. People make me feel embarrassed	47 (39.17)	53 (48.62)	2.08 (0.15)
9. I keep away from other people because they are not nice to me	68 (56.67)	66 (60.55)	0.35 (0.55)
10. I worry about the way people act towards me	40 (33.33)	58 (53.21)	9.22 (0.002)

* “yes” responses to each item

Table 2.5 Responses given by different age groups to individual items on the stigma questionnaire

Item	**Age 18-30*** **Number (%)**	**Age 31-45*** **Number (%)**	**Age 46-60*** **Number (%)**	**Age 60+*** **Number (%)**	**Chi Square test for trend (p value)**
1. People talk down to me	21 (36.21)	37 (46.84)	46 (55.42)	6 (85.71)	8.05 (0.01)
2. People on the street make fun of me	12 (20.69)	31 (39.24)	38 (45.78)	14 (57.14)	9.85 (0.01)
3. People on the street look at me in a funny way	17 (29.31)	32 (40.51)	50 (60.24)	6 (85.71)	17.94 (<0.001)
4. People laugh at me because of the way I look	8 (13.79)	30 (37.97)	35 (42.17)	2 (28.57)	9.10 (0.003)
5. People treat me like a child	15 (25.86)	23 (29.11)	33 (39.76)	2(28.57)	2.52 (0.11)
6. people laugh at me because of the way I talk	10 (17.24)	28 (35.22)	31 (37.35)	3 (42.86)	6.06 (0.01)
7. The way people talk to me makes me angry	19 (32.76)	40 (50.63)	46 (55.42)	4 (57.14)	6.51 (0.01)
8. People make me feel embarrassed	17 (29.31)	35 (44.30)	43 (51.81)	4 (57.14)	7.20 (0.01)
9. I keep away from other people because they are not nice to me	28 (48.28)	45 (56.96)	55 (66.27)	5 (71.43)	5.06 (0.03)
10. I worry about the way people act towards me	18 (31.03)	31 (39.24)	44 (53.01)	4 (57.14)	7.53 (0.01)

* “yes” responses to each item

Table 2.6: Responses given to individual items on the stigma questionnaire by participants from White and non-White backgrounds

Item	White* Number (%)	Non White* Number (%)	Chi Square (p value)
1. People talk down to me	92 (48.94)	19 (46.34)	(0.09 (0.76)
2. People on the street make fun of me	74 (39.36)	12 (29.27)	1.46 (0.23)
3. People on the street look at me in a funny way	89 (47.34)	17 (41.46)	0.47 (0.49)
4. People laugh at me because of the way I look	66 (35.11)	10 (24.39)	1.74 (0.19)
5. People treat me like a child	60 (31.91)	14 (34.15)	0.08 (0.78)
6. people laugh at me because of the way I talk	59 (31.38)	14 (34.15)	0.12 (0.73)
7. The way people talk to me makes me angry	90 (47.87)	20 (48.78)	0.01 (0.92)
8. People make me feel embarrassed	88 (46.81)	12 (29.27)	4.21 (0.04)
9. I keep away from other people because they are not nice to me	109 (57.98)	25 (60.98)	0.12 (0.72)
10. I worry about the way people act towards me	85 (45.21)	13 (31.71)	2.51 (0.11)

* “yes” responses to each item

iii. Multivariate analysis of the variables independently associated with self reported stigma

Table 2.7 (a) shows the results of the multivariate analysis of the variables that are independently associated with self reported stigma in the regression analysis. The only variable that was found to be strongly associated with self reported stigma, after adjustment of other variables, was age (older age associated with higher levels of stigma; p=0.01). There was a weak association with having a physical health problem (p=0.07) and being married or in a relationship (p=0.08).

The independent predictors of the two stigma subscales were analysed. Predictors of perceived discrimination were Intellectual disability (having a moderate intellectual disability was associated with more stigma; regression coefficient 0.60, P=0.05) and older age (regression coefficient 0.02, p=0.01). Older age was the only predictor of reaction to discrimination (p=0.05).

The relationship between self reported stigma and the outcome variables

i. Descriptive analysis of the outcome variables

Figure 2.5 shows the distribution of the scores on the measures of psychological distress, quality of life, total service contacts and adherence to treatment. Table 2.2 shows the mean scores for each of the outcome measures in the whole sample.

The mean total psychological distress score was 7.36 (SD 5.41) with the scores ranging from 0-24. This average score is similar to the mean scores reported by Brooks et al (2013) of their non clinical sample, and their post therapy clinical sample who had undergone psychological therapy.

The mean quality of life score was 87.82 (SD 12.69) with scores ranging from 51 to 117. Schalock & Keith (1993) reported mean scores for participants with mild and moderate intellectual disability as 90.9 and 83.4 respectively, which is consistent with the results of this study (mean score for mild intellectual disability=88.9 and moderate intellectual disability=84.7).

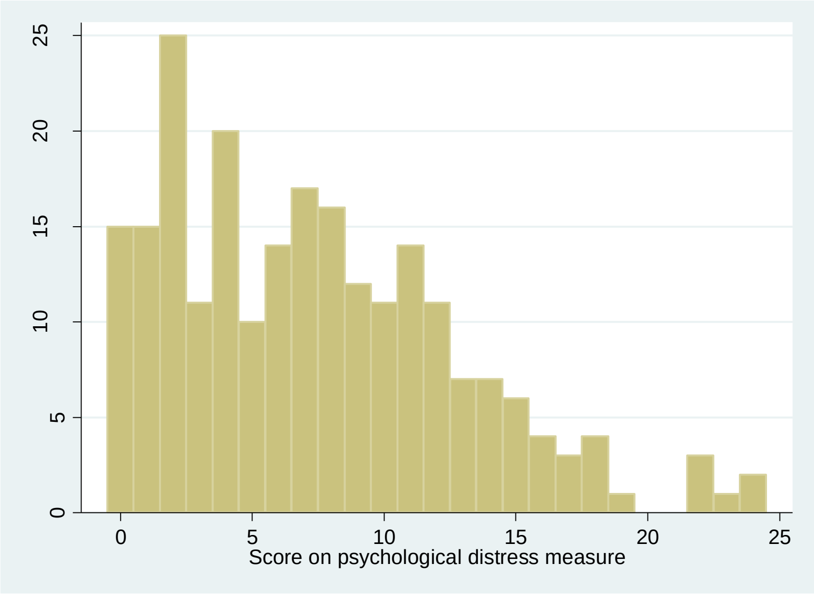
The mean total service contacts score was 36.88 (SD 60.45) with scores ranging from 0-377. The mean scores for each of the outcome variables varied according to the centre (appendix Table A.2.3).

Table 2.7 (a): Variables independently associated with self reported stigma following multivariate regression

Variable	Regression Coefficient	Standard error	95% Confidence interval	Wald test P value
Level of ID: Moderate ID **(reference group: mild ID)**	0.53	0.47	-0.40, 1.46	0.26
Gender: Female **(reference group: males)**	0.39	0.42	-0.44, 1.22	0.36
Age	0.05	0.02	0.01, 0.09	0.01
Ethnicity: Non White **(reference group: White)**	-0.14	0.59	-1.29, 1.01	0.81
Marital status: Married/cohabiting **(reference group: single/divorced)**	0.77	0.44	-0.10, 1.63	0.08
Urban development: Semi-rural	1.48	0.90	-0.28, 3.24	0.14
Urban	1.65	0.83	0.01, 3.29	
(reference group: rural)				
Employment: In paid work **(reference group: no paid work)**	-0.40	0.46	-1.29, 0.49	0.38
Number of Friends: One or two	-1.84	1.03	-3.88, 0.19	0.24
Three or more	-1.57	0.99	-3.50, 0.37	
(reference group: no friends)				
Physical health problems: Yes **(reference group: no)**	0.81	0.44	-0.05, 1.68	0.07
Sensory problems: Yes **(reference group: no)**	0.72	0.48	-0.22, 1.67	0.13

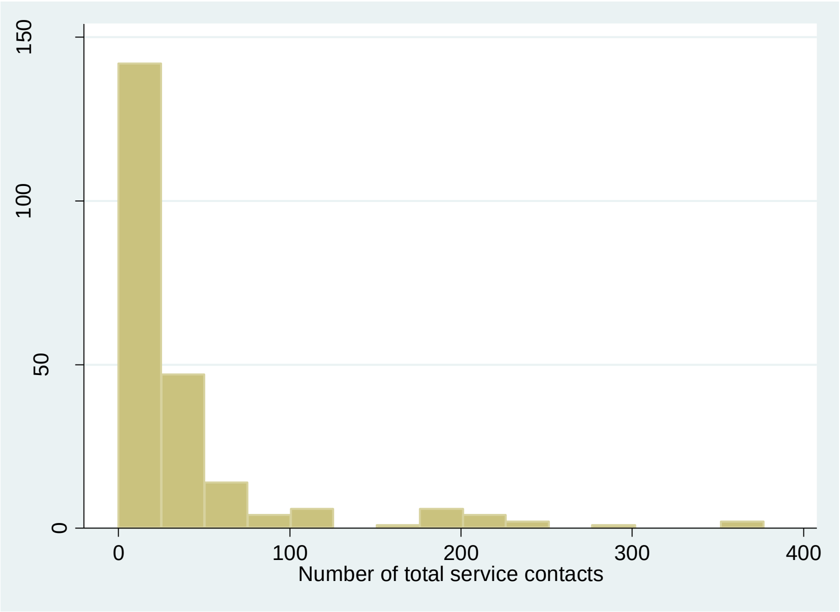
Figure 2.5: The distribution of scores on each of the outcome measures

(a) Histogram showing the distribution of psychological distress scores

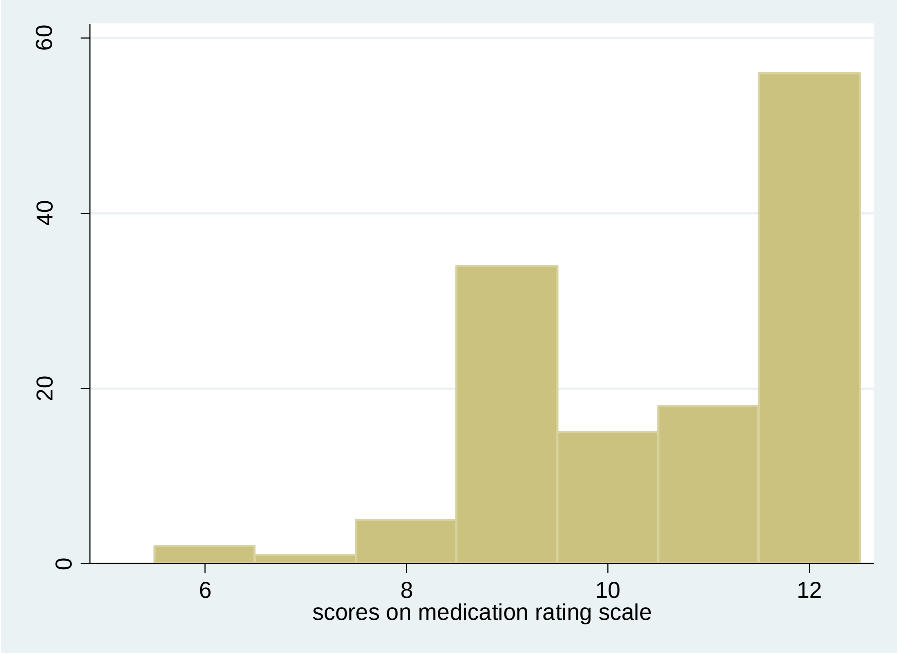


(b) Histogram showing the distribution of quality of life scores

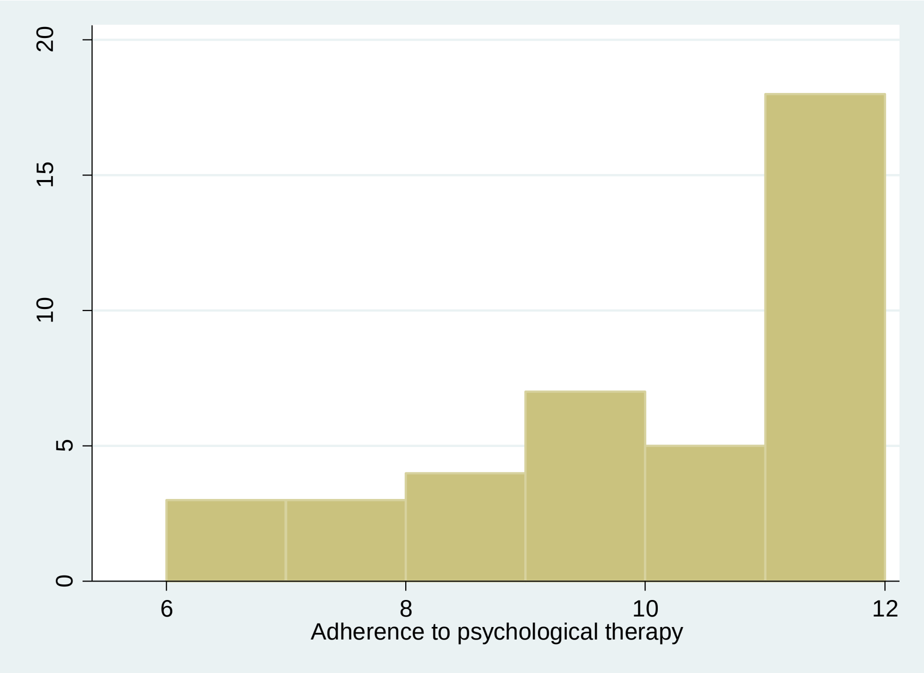
(c). Histogram showing the frequency of total service contacts in the last 6 months



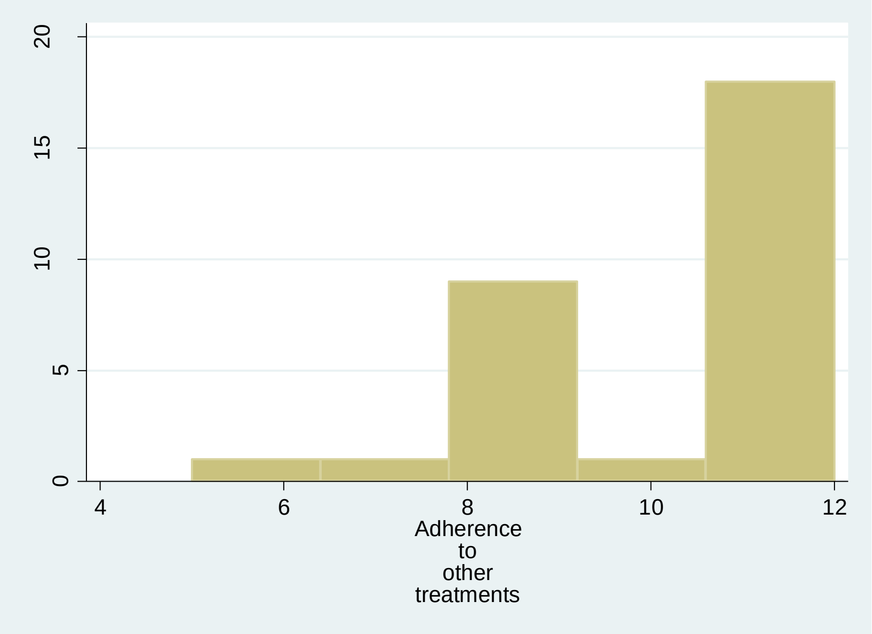
(d) Histogram showing the frequency of scores on the Adherence to medication rating scale



(e) Histogram showing the frequency of scores on the Adherence to psychological therapies rating scale



(f) Histogram showing the frequency of scores on the Adherence to other treatments rating scale



Service use

The highest proportion of participants had contacted their GP (68.1%) at least once in the last 6 months, compared to any other professional (see appendix Table A.2.5). This was followed by contact with a dentist (64.1%) and optician (51.5%). From the community intellectual disability teams, the most frequently contacted professionals were social workers, seen by 40.2% of participants and psychologists (21.0%). Over a third of the participants (37.1%) had attended a hospital outpatient clinic in the last six months (see appendix Table A.2.6) and 21.8% had attended Accident & Emergency. Almost a quarter of participants (23.6%) had contact with the police. Thirty seven participants reported that they had been the victim of crime (16.2%), four had offended (1.8%), 1 had been a victim and an offender and eight participants (3.5%) had witnessed a crime. Participants were also asked whether they had refused input from health or social services in the last six months. Only 18 participants (7.9%) replied that they had refused support.

Adherence to treatment

One hundred and thirty one participants were taking medication (57%); 40 (17.5%) had received some form of psychological therapy in the last 6 months (e.g. counselling, and arts therapies) and 30 (13.1%) had received other treatments (e.g. speech and language therapy or physiotherapy).

Psychological distress and stigma cut off scores

The mean stigma score was found to be 3.7 in the low psychological distress group (psychological distress score of 12 or less) and 7.1 in the high psychological distress group (psychological distress score of 13 or more; $t=6.35$, $p<0.001$). This suggests that a clinically significant level of psychological distress is associated with twice the level of self reported stigma compared to those who have low levels of psychological distress. Figure 2.6 shows the mean psychological distress scores that were obtained for each score on the full stigma questionnaire and for each of the subscales. A score of zero on the full stigma questionnaire generated a mean psychological distress score of 2.9, which is well below the mean for the whole sample. The mean psychological distress score increases to 7.8 on the full questionnaire with a self reported stigma score of three, which is just above the lower quartile of the pre-therapy scores reported by Brooks et al (2013). A score of nine results in a mean psychological distress score of 12.2, which is just below the average pre-therapy scores and a score of ten results in a psychological distress score of 13.7, which is near the upper quartile. Obtaining a maximum score of six on the perceived discrimination subscale results in a mean psychological distress score of 13.4 and obtaining a maximum score of four on the reaction to discrimination subscale produces a mean psychological distress score of 11.4.

Obtaining a stigma score between three to five is associated with a five and a half times increased odds of clinically high levels of psychological distress (unadjusted OR 5.6, 95% CI 1.4 to 21.5, p=0.01) compared to a score of 0-2; A score of six to eight is associated with a seven times increased odds (unadjusted OR 7.2, 95% CI 1.8 to 28.2, p=0.004), and a score of nine or ten is related to a thirty times increased odds of clinically high levels of psychological distress (unadjusted OR 29.7, 95% CI 7.8 to 112.5, p<0.001).

The sensitivity and specificity of four different cut-off points on the stigma questionnaire, alongside the Youden's index, are shown in table 2.7 (b). A cut-off of seven or more has the highest Youden's index (sensitivity + specificity -1) compared to other cut-off scores, indicating that this cut-off has the best sensitivity and specificity (Bewick et al, 2004). The corresponding Receiver Operating Characteristic (ROC) curve is shown in figure 2.6 (b). The area under the curve is 0.78, which indicates that self reported stigma scores are fair at predicting clinically high levels of psychological distress.

Figure 2.6 (a): The relationship between the stigma scores and mean psychological distress scores for the full stigma questionnaire and its subscales

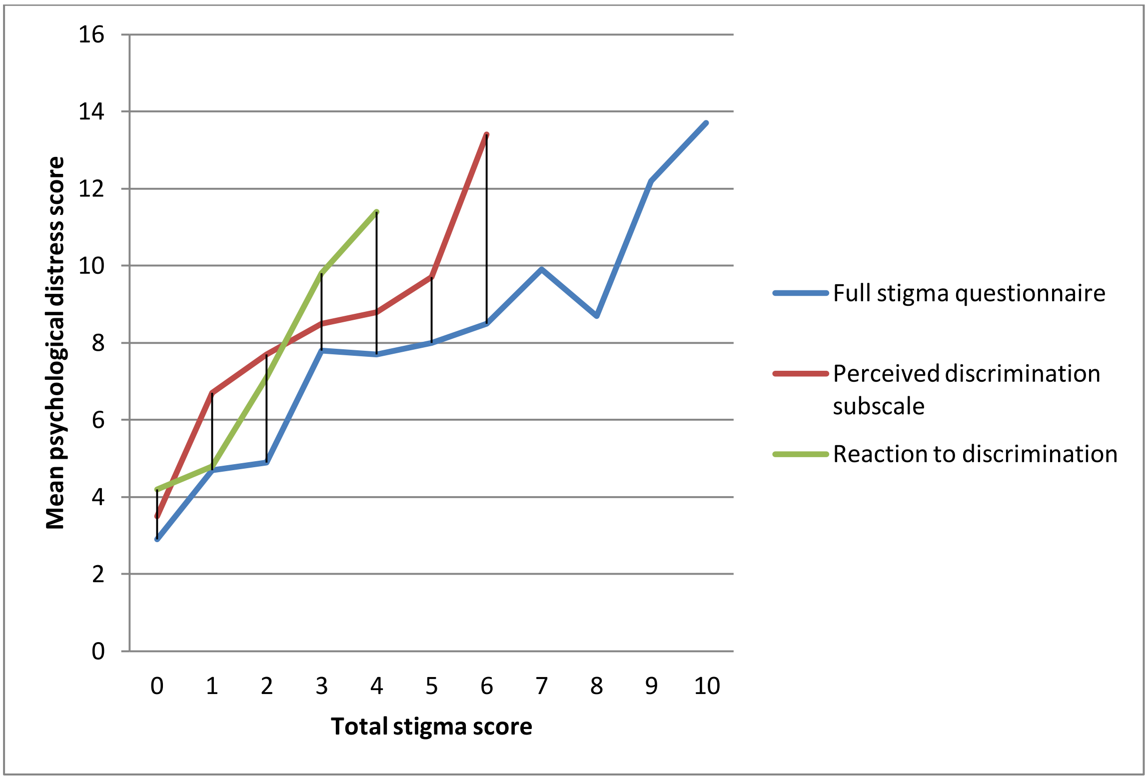
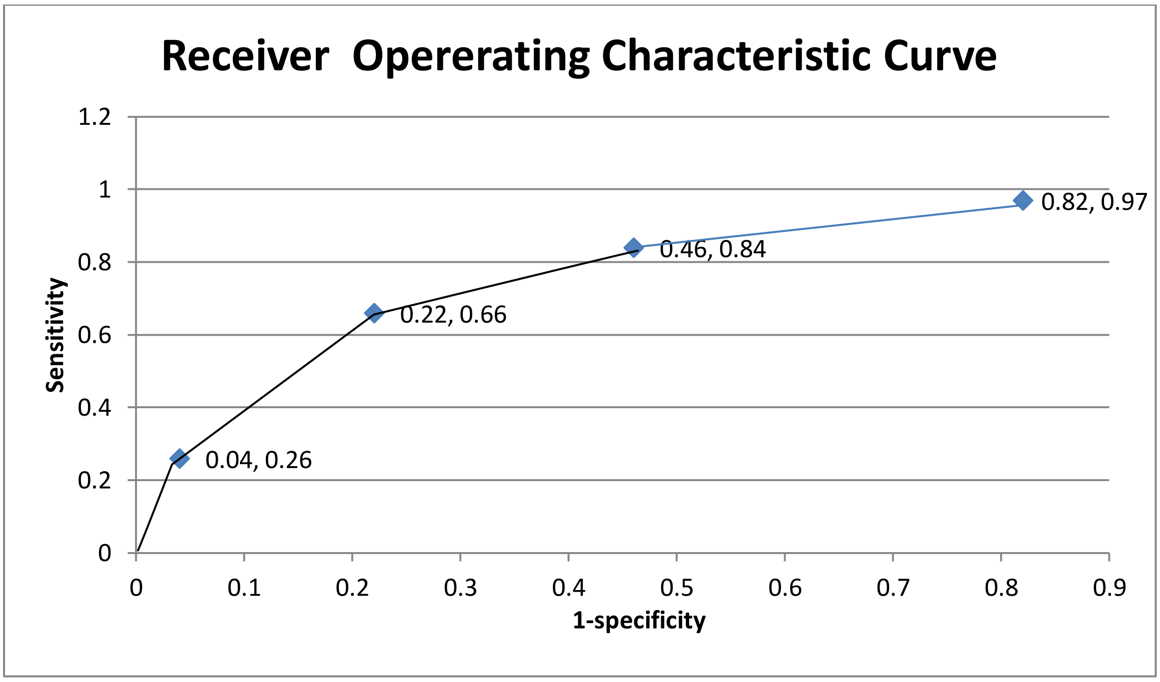


Table: 2.7(b) Sensitivity and specificity for different cut-off scores on the stigma questionnaire

Cut-off score	Sensitivity	Specificity	1-Specificity	Youden's index
1 or more	0.97	0.18	0.82	0.15
4 or more	0.84	0.54	0.46	0.38
7 or more	0.66	0.78	0.22	0.44
10	0.26	0.96	0.04	0.22

Fig 2.6 (b) ROC Curve for different cut off points on the stigma questionnaire



ii. Linear Regression analysis

In the linear regression (see appendix Table A.2.7), self reported stigma was strongly association with psychological distress (p<0.001). Both the perceived discrimination subscale and the reaction to discrimination subscale were also strongly associated with psychological distress (p<0.001). There was a positive association with health problems (having a health problem was associated with more psychological distress; p= 0.01) and an inverse relationship with paid work (being in paid work was associated with less psychological distress, p=0.02). There was a borderline association with gender (females reported more psychological distress, p=0.08), age (more psychological distress with increasing age, p=0.09) and level of urban development (participants from semi-urban and urban areas reported more psychological distress, p=0.09).

Quality of life

In the linear regression analysis, self reported stigma was strongly association with quality of life (p<0.001), with higher levels of stigma associated with a lower quality of life (see appendix Table A.2.8). The two stigma subscales were also strongly associated with quality of life (perceived discrimination subscale, p=0.001; reaction to discrimination subscale p<0.001). The variables that were also associated with quality of life were age (older age associated with lower quality of life, p=0.03), level of urban development (more urban areas associated with lower quality of life p=0.02), being in paid work (associated with higher quality of life, p<0.001), and having friends (compared to no friends, associated with higher quality of life, p=0.002). A borderline association was found with level of intellectual disability (moderate intellectual disability associated with lower quality of life, p=0.06) and housing (living with family or in 24 hour supported housing, compared to low support housing, was associated with lower quality of life, p=0.08).

Examination of the individual quality of life subscales found that stigma was strongly associated with the Satisfaction subscale (p<0.001) but only moderately associated with the Competence (p=0.05) and Empowerment subscale (p=0.05). There was no association between stigma and the social belonging subscale (p=0.96).

Service Use

i. Total service contacts

In the linear regression analysis, self reported stigma was associated with total number of service contacts (p=0.03); higher levels of stigma were associated with a higher number of contacts with services (See appendix Table A.2.9). Other variables associated with total number of service contacts were marital status (being married or in a relationship was associated with a higher number of contacts p=0.01), speech problems (having speech problems associated with more contact, p=0.03) and medication (taking medication associated with more contact, p=0.04). The perceived discrimination subscale was associated with total service contacts (p=0.02) but there was a weak association with the reaction to discrimination subscale (p=0.09).

ii. Contacts with primary care, secondary care and specialist services

Self reported stigma was associated with contacts with community intellectual disability teams; Higher levels of self reported stigma were associated with more contact (p=0.01), and being admitted to hospital with a physical health complaint (p=0.05). There was no association with contacts with primary care (p=0.12) or Accident and Emergency services (p=0.11). Participants who reported higher levels of stigma also reported more contact with the police (p<0.001). There was a borderline association between self reported stigma and refusal of input from at least one service in the last 6 months (p=0.07).

The perceived discrimination subscale was associated with higher contacts with Accident and Emergency departments (p=0.04), community intellectual disability services (p=0.004) and police (p=0.05) and with more admissions to hospital for physical health problems (p=0.04). The reaction to discrimination subscale was associated with contact with primary care (p=0.05) and the police (p=0.003). There was a no association between the stigma subscales and refusal of services.

Adherence to treatment

In the linear regression analysis self reported stigma was not associated with adherence to medication (p=0.18) or adherence to psychological treatment (p=0.21) but it was associated with adherence to “other” treatments (p=0.03). Adherence to medication (see appendix Table A.2.10) was associated with level of intellectual disability (with moderate intellectual disability associated with lower adherence, p=0.01), age (older age associated with better adherence, p=<0.001), marital status (being married or in a relationship associated with lower adherence, p=0.01), ethnicity (being from a non-White ethnic group was associated with less adherence, p=0.003). There was a borderline association with housing (living with family or in high support housing, was associated with poorer adherence compared to low support housing).

The relationship between the outcome variables

Table 2.8 shows the regression coefficients and p values for the associations between the outcome variables. Higher levels of psychological distress was associated with lower quality of life, higher total number of service contacts, lower adherence to medication, adherence to psychological treatment and adherence to “other” treatments (p values 0.01 or less). A higher quality of life was associated with lower total number of service contacts (p=0.03). A higher use of services was associated with poorer adherence to medication (p=0.01) and adherence to psychological treatment (p=0.05). A higher adherence to medication was associated with a higher adherence to “other” treatments (p=0.002).

The hypothetical direction of the relationship between each of the outcome variables is shown in figure 2.7. According to this theoretical model, higher levels of psychological distress results in a lower quality of life, higher service use and lower adherence to all types of treatment. Higher adherence to treatment results in a lower use of services and a higher use of services leads to a lower quality of life.

iii. Multivariate analysis of the relationship between self reported stigma and the outcome variables

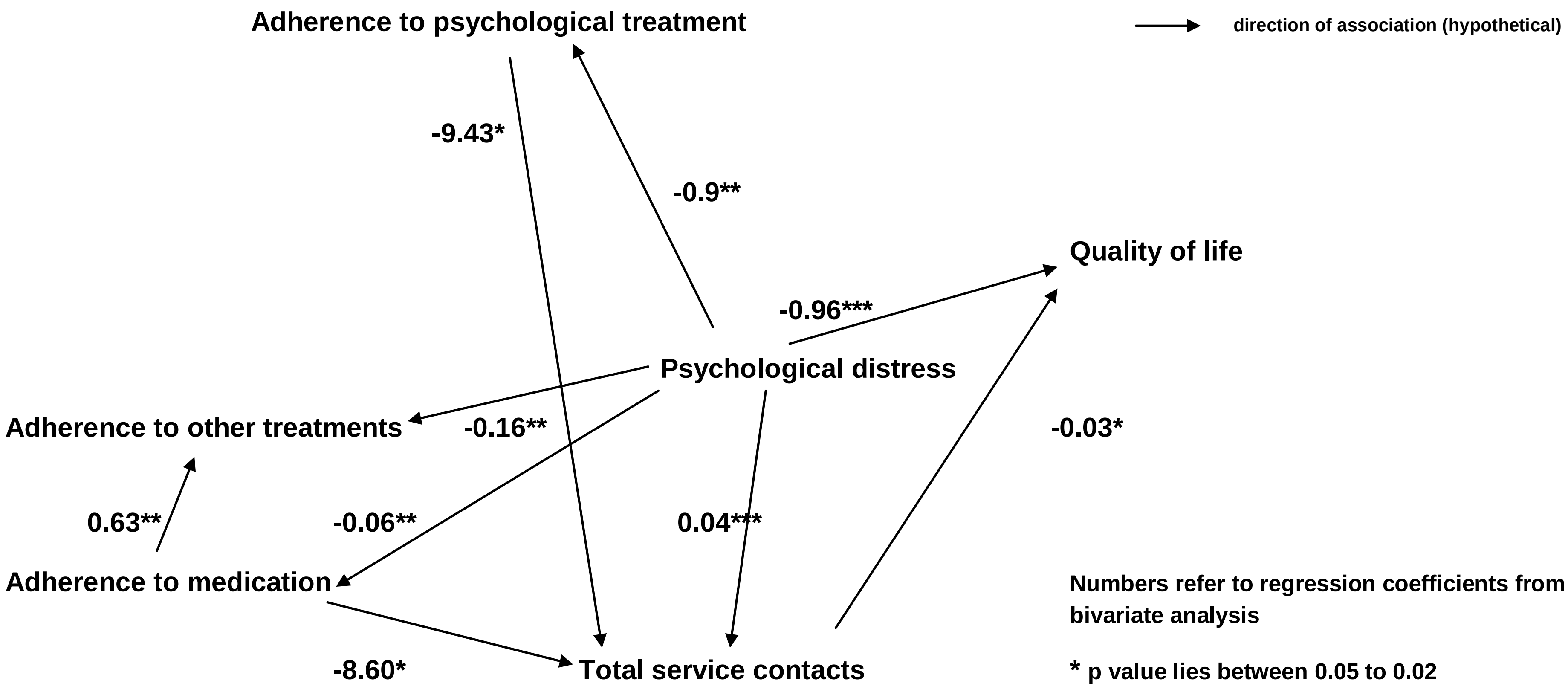
Psychological distress

Table 2.9 shows the results of the multivariate analysis. The intra-class correlation coefficient was zero, which indicated that there was no evidence of clustering by centre. The regression coefficient and the strength of association between self reported stigma and psychological distress changed very little following adjustment of potential confounders (age, level of intellectual disability, gender and ethnicity), and other variables that were associated with psychological distress (level of urban development, paid work, health problems and sensory problems). A one unit increase in the stigma score was associated with a 0.92 increase in the psychological distress score (adjusted analysis, p<0.001). Both of the stigma subscales were also strongly associated with psychological distress following adjustment of other variables ((see appendix Table A.2.11); Perceived discrimination subscale, p<0.001; Reaction to discrimination subscale, p<0.001)).

Table 2.8: The relationship between the outcome variables using linear regression

	Dependent/outcome variable					
	Psychological distress	**Quality of Life**	**Total number of service contacts**	**Adherence to medication**	**Adherence to psychological treatment**	**Adherence to other treatment**
Independent Variable	**Regression coefficients (p value)**	**Regression coefficients (p value)**	**Regression coefficients (p value)**	**Regression coefficients (p value)**	**Regression coefficients (p value)**	**Regression coefficients (p value)**
Psychological distress	-	-0.96 (<0.001)	0.04 (<0.001)	-0.06 (0.01)	-0.9 (<0.01)	-0.16 (0.01)
Quality of Life	-0.18 (<0.001)	-	-0.70 (0.03)	0.02 (0.14)	0.03 (0.26)	0.02 (0.46)
Total number of service contacts	0.02 (<0.01)	-0.03 (0.03)	-	-0.01 (0.01)	-0.01 (0.05)	-0.01 (0.15)
Adherence to medication	-0.82 (0.01)	0.93 (0.20)	-8.60 (0.02)	-	0.21 (0.45)	0.63 (<0.01)
Adherence to psychological treatment	-0.97 (<0.01)	1.02 (0.25)	-9.43 (0.05)	0.09 (0.45)	-	0.11 (0.62)
Adherence to other treatment	-1.29 (0.01)	0.46 (0.81)	-9.78 (0.15)	0.45 (<0.01)	0.17 (0.62)	-

Figure 2.7 Hypothetical relationship between the outcome variables (Linear regression analysis)



Numbers refer to regression coefficients from bivariate analysis

*** p value lies between 0.05 to 0.02**

**** p value lies between 0.001 and 0.01**

***** p value is less than 0.001**

Table 2.9. The relationship between self reported stigma and psychological distress after controlling for potential confounders and other variables

Variables	Regression coefficient	Standard error	95% Confidence interval	P Value
Unadjusted (stigma only)	0.94	0.09	0.77, 1.12	<0.001
Adjusted for confounders*	0.95	0.09	0.76, 1.13	<0.001
Adjusted for confounders and level of urban development	0.94	0.09	0.75, 1.12	<0.001
Adjusted for confounders and paid work	0.94	0.09	0.75, 1.12	<0.001
Adjusted for confounders and health problems	0.93	0.09	0.77, 1.12	<0.001
Adjusted for confounders and sensory problems	0.95	0.09	0.77, 1.14	<0.001
Adjusted for all the above variables**	0.92	0.20	0.73, 1.11	<0.001

* age, gender, level of ID and ethnicity

**age, gender, level of ID, ethnicity, level of urban development, paid work, health problems, sensory problems

Quality of life

The relationship between self reported stigma and quality of life was also unaffected following adjustment of confounders and other variables associated with quality of life (marital status, urban development, housing, paid work, and number of friends; Table 2.10). Paid work had the largest confounding effect (reduced regression coefficient by 24 units) but it did not alter the strength of the relationship between self reported stigma and quality of life. A one unit increase in the stigma score was associated with a decrease in quality of life of 0.69 units (adjusted analysis, p=0.001). The intra-class correlation coefficient was very close to zero indicating that there was no evidence of clustering by centre.

Table 2.10.The relationship between self reported stigma and quality of life after controlling for potential confounders and other variables

Variables	Regression coefficient	Standard error	95% Confidence interval	P Value
Unadjusted (stigma only)	-0.98	0.26	-1.48, -0.48	<0.001
Adjusted for confounders*	-0.88	0.26	-1.44, -0.42	<0.001
Adjusted for confounders and marital status	-0.93	0.26	-1.44, -0.42	<0.001
Adjusted for confounders and level of urban development	-0.82	0.26	-1.32, -0.32	<0.001
Adjusted for confounders and housing status	-0.90	0.26	-1.40, -0.40	<0.001
Adjusted for confounders and paid work	-0.64	0.21	-1.05, -0.23	0.002
Adjusted for confounders and number of friends	-0.90	0.25	-1.38, -0.41	<0.001
Adjusted for all the above variables**	-0.69	0.20	-1.09, -0.29	0.001

* age, gender, level of ID and ethnicity

** adjusted for age, gender, level of ID, ethnicity, marital status, level of urban development, housing status, paid work and number of friends

Self reported stigma remained strongly associated with the satisfaction subscale of the quality of life scale after adjustment (p<0.001; Table 2.11), and there was a moderate association with the empowerment subscale (p=0.04). Self reported stigma was no longer associated with the competence subscale. Both of the stigma subscales were also associated with quality of Life following adjustment of other variables (Perceived discrimination, p=0.003; Reaction to discrimination, p=0.001; see appendix Table A.2.12).

Table 2.11: The relationship between self reported stigma and the quality of life subscales after controlling for potential confounders and other variables

a. Satisfaction subscale Variables	Regression coefficient	Standard error	95% Confidence interval	P Value
Unadjusted (stigma only)	-0.55	0.08	-0.71, -0.39	<0.001
Adjusted for confounders*	-0.56	0.09	-0.73, -0.40	<0.001
Adjusted for all the variables **	-0.55	0.08	-0.72, -0.38	<0.001

b. Competence subscale Variables	Regression coefficient	Standard error	95% Confidence interval	P Value
Unadjusted (stigma only)	-0.28	0.14	-0.56, 0.004	0.05
Adjusted for confounders*	-0.20	0.15	-0.49, 0.08	0.17
Adjusted for all the variables **	-0.05	0.09	-0.23	0.60

c. Empowerment subscale Variables	Regression coefficient	Standard error	95% Confidence interval	P Value
Unadjusted (stigma only)	-0.14	0.07	-0.28, 0.00	0.05
Adjusted for confounders*	-0.13	0.07	-0.27, 0.001	0.05
Adjusted for all the variables **	-0.13	0.06	-0.25, -0.01	0.04

d. Social belonging subscale Variables	Regression coefficient	Standard error	95% Confidence interval	P Value
Unadjusted (stigma only)	-0.01	0.08	-0.17, 0.16	0.96
Adjusted for confounders*				
Adjusted for all the variables **				

* age, gender, level of ID, ethnicity

** age, gender, level of ID, ethnicity, marital status, level of urban development, housing status, paid work, number of friends

Service use

The strength of the relationship between self reported stigma and total number of service contacts was unaltered following adjustment of confounders and other variables (marital status, health problems, medication and speech problems; Table 2.12). No single variable had a strong confounding effect. A one unit increase in the stigma score was associated with an increase of log 0.04 in the number of total service contacts (adjusted analysis, p=0.01). The perceived discrimination subscale remained weakly associated with total service contacts after multivariable adjustment (p=0.06; see appendix Table A.2.13).

There was a strong association between self reported stigma and contacts with community intellectual disability services (Table 2.13 (c)), even after adjustment of confounders and other variables (p=0.02). A one unit increase in the stigma score was associated with an increase of log 0.07 in the number of contacts. A strong relationship was also retained between the perceived discrimination subscale and contacts with community intellectual disability services (p=0.004) after adjustment (see appendix Table 2.14 (c)).

The reaction to discrimination subscale was no longer associated with contacts with primary care after multivariable adjustment (see appendix Table 2.14 (a)). There was a weak association between the perceived discrimination subscale and contacts with Accident & Emergency departments (p=0.07; see appendix Table 2.14(g)).

Multivariable adjustment did not alter the relationship between self reported stigma and the police (p<0.001), with a one unit increase in stigma scores resulting in a log 0.20 increase in contacts with the police (Table 2.13 (g)). Both the stigma subscales also retained a strong relationship with number of contacts with police (perceived discrimination p<0.001; reaction to discrimination p=0.001; see appendix Table 2.14 (g)).

Table 2.12: The relationship between self reported stigma and total number of service contacts in the last 6 months after controlling for potential confounders

Variables	Regression coefficient	Standard error	95% Confidence interval	P Value
Unadjusted (stigma only)	0.04	0.02	0.01, 0.08	0.03
Adjusted for confounders*	0.05	0.02	0.01, 0.09	0.01
Adjusted for confounders and marital status	0.05	0.02	0.01, 0.08	0.01
Adjusted for confounders and health problems	0.04	0.02	0.01, 0.08	0.03
Adjusted for confounders and medication	0.04	0.02	0.01, 0.08	0.03
Adjusted for confounders and speech	0.05	0.02	0.01, 0.09	0.01
Adjusted for confounders and above variables**	0.04	0.02	0.00, 0.08	0.04

* age, gender, level of ID, ethnicity

** age, gender, level of ID, ethnicity, marital status, medication and speech problems (health problems not included as medication is a proxy for health problems)

The relationship between self reported stigma and hospital admission became non significant following adjustment of other variables (Table 2.13(e)). There was no longer an association between the perceived discrimination subscale and admission to hospital (p=0.28) following adjustment (Table 2.2.27 (e)).

There was a moderate relationship between self reported stigma and refusal of services (Table 2.14) after adjustment of other variables (p=0.04) A one unit increase in the stigma score was associated with a 17% increase in refusal of services. There was only a weak relationship between the stigma subscales and refusal of services after adjustment (see appendix Table A.2.15).

Table 2.13: The relationship between self reported stigma and contacts with specific services after controlling for potential confounders

a. Primary care contacts

Variables	Regression coefficient	Standard error	95% Confidence interval	P Value
Unadjusted (stigma only)	0.03	0.02	-0.01, 0.07	0.12
Adjusted for confounders*	0.02	0.02	-0.02, 0.07	0.26
Adjusted for all the variables **	0.01	0.02	-0.03, 0.06	0.50

b. Community health services contacts

Variables	Regression coefficient	Standard error	95% Confidence interval	P Value
Unadjusted (stigma only)	0.04	0.02	-0.00, 0.08	0.06
Adjusted for confounders*	0.03	0.02	-0.01, 0.07	0.15
Adjusted for all the variables **	0.02	0.02	-0.02, 0.06	0.32

c. Community intellectual disability service contacts

Variables	Regression coefficient	Standard error	95% Confidence interval	P Value
Unadjusted (stigma only)	0.07	0.03	0.01, 0.12	0.01
Adjusted for confounders*	0.08	0.03	0.03, 0.14	0.004
Adjusted for all the variables **	0.07	0.03	0.01, 0.13	0.02

* Adjusted for level of ID, gender and age

** Adjusted for level of ID, gender, age, marital status, medication and speech problems

Table 2.13 Cont...

d. Contacts with Accident & Emergency Department

Variables	Regression coefficient	Standard error	95% Confidence interval	P Value
Unadjusted (stigma only)	0.07	0.04	-0.02, 0.16	0.11
Adjusted for confounders*	0.07	0.04	-0.02, 0.16	0.11
Adjusted for all the variables **	0.05	0.04	-0.03, 0.14	0.23

e. Number of general hospital admissions

Variables	Regression coefficient	Standard error	95% Confidence interval	P Value
Unadjusted (stigma only)	0.11	0.06	-0.002, 0.23	0.05
Adjusted for confounders*	0.10	0.06	-0.02, 0.23	0.11
Adjusted for all the variables **	0.06	0.06	-0.06, 0.23	0.31

f. Number of outpatient clinic contacts

Variables	Regression coefficient	Standard error	95% Confidence interval	P Value
Unadjusted (stigma only)	0.05	0.04	-0.02, 0.12	0.17
Adjusted for confounders*	0.03	0.04	-0.04, 0.11	0.37
Adjusted for all the variables **	0.01	0.04	-0.07, 0.08	0.84

* Adjusted for level of ID, gender and age

** Adjusted for level of ID, gender, age, marital status, medication and speech problems

Table 2.13 Cont...

g. Contacts with police

Variables	Regression coefficient	Standard error	95% Confidence interval	P Value
Unadjusted (stigma only)	0.15	0.04	0.07, 0.23	<0.007
Adjusted for confounders*	0.19	0.04	0.11, 0.27	<0.001
Adjusted for all the variables **	0.20	0.04	0.11, 0.28	<0.001

* Adjusted for level of ID, gender and age

** Adjusted for level of ID, gender, age, marital status, medication and speech problems

Table 2.14: The relationship between self reported stigma and refusal of services (logistic regression) after controlling for potential confounders

Variables	Regression coefficient	Standard error	95% Confidence interval	P Value
Unadjusted (stigma only)	0.14	0.08	-0.01, 0.28	0.07
Adjusted for confounders*	0.17	0.08	0.01, 0.33	0.03
Adjusted for all the variables **	0.17	0.08	0.01, 0.34	0.04

* Adjusted for level of ID, gender and age

** Adjusted for level of ID, gender, age, marital status, medication and speech problems

Adherence to treatment

There was an association between self reported stigma and adherence to medication after adjustment for potential confounders (level of intellectual disability, age, gender and ethnicity, p=0.04; Table 2.15). However, the association became borderline after adjusting for other variables (p=0.08). Marital status had a significant confounding effect; being married, or in a relationship was associated with lower adherence to medication.

Table 2.15: The relationship between self reported stigma and adherence to medication, after controlling for potential confounders

Variables	**Regression coefficient**	**Standard error**	**95% Confidence interval**	**P Value**
Unadjusted (stigma only)	-0.05	0.04	-0.13, 0.02	0.18
Adjusted for confounders*	-0.08	0.04	-0.15, -0.00	0.04
Adjusted for confounders and marital status	-0.06	0.04	-0.14, 0.01	0.08
Adjusted for confounders and housing status	-0.07	0.04	-0.15, -0.00	0.04
Adjusted for all the above variables	-0.06	0.04	-0.14, 0.01	0.08

* adjusted for level of ID, age, gender and ethnicity

** adjusted for level of ID, age, gender, ethnicity, marital status and housing status

iv. Investigating interaction effects (effect modification)

Self reported stigma

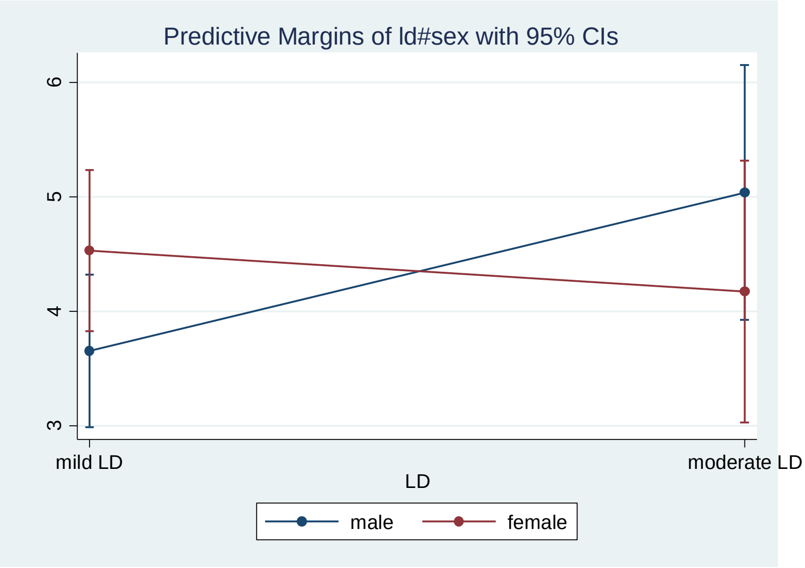
Ethnicity did not modify the relationship between self reported stigma and intellectual disability (Table 2.16). However, gender and age were both effect modifiers (p=0.05 and 0.04 respectively). Males with moderate intellectual disability reported higher levels of stigma compared to males with mild intellectual disability, and females with mild intellectual disability reported higher levels of stigma compared to females with moderate intellectual disability. This relationship is shown graphically in Figure 2.8. Older people with moderate intellectual disability reported higher levels of stigma than younger people with moderate intellectual disability. This can be visualised graphically using categorical age (figure 2.9).

Table 2.16 : Effect modification of the relationship between self reported stigma and intellectual disability by age, gender and ethnicity

Interaction term	Regression Coefficient	Standard error	95% Confidence interval	P value
ID x age				
Unadjusted	0.08	0.04	-0.01, 0.16	0.08
Adjusted*	0.09	0.04	-3.88, 1.66	0.04
ID x gender				
Unadjusted	-2.02	0.94	-3.86, -0.19	0.03
Adjusted*	-1.83	0.91	-3.61, -0.04	0.05
ID x ethnicity				
Unadjusted	-1.11	1.41	-3.88, 1.66	0.43
Adjusted*	-0.84	0.94	-3.51, 1.84	0.54

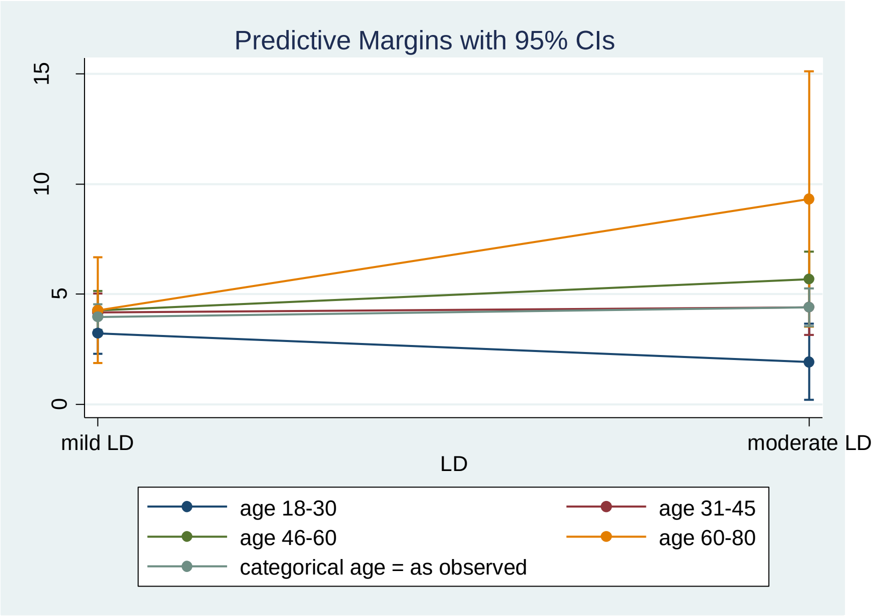
* adjusted for ID, age, sex, ethnicity, urban development, employment, sensory problems and health problems

Figure 2.8: Interaction effects between gender and intellectual disability on self reported stigma



Legend: Males with moderate ID reported higher levels of stigma compared with males with mild ID; the reverse was seen in females.

Figure: 2.9. Interaction effects between categorical age and intellectual disability on self reported stigma



Legend: Older participants with moderate ID reported more stigma compared to younger males with moderate ID. The effect of age in those with mild ID was similar for all age categories

Psychological distress

Intellectual disability, gender and age did not modify the relationship between self reported stigma and psychological distress in both the unadjusted and adjusted models (see appendix Table A.2.16).

Quality of life

The level of intellectual disability modified the relationship between stigma and quality of life in the unadjusted model ($p<0.001$ for interaction term) but this association became non significant after adjustment of confounders ($p=0.14$). Gender and age did not modify the relationship between stigma and quality of life (see appendix Table A.2.17).

Total number of service contacts

Intellectual disability, age and gender did not modify the relationship between self reported stigma and total number of contacts with services (see appendix Table A.2.18).

v. Psychological distress as a mediator

Psychological distress was strongly associated with quality of life, total number of service contacts, community intellectual disability service contacts, police contacts and adherence to medication (Table 2.17 (a)); Higher levels of psychological distress was associated with a lower quality of life ($p<0.001$) and a higher number of service contacts ($p<0.001$). Addition of psychological distress in the regression model (Table 2.17 (b)) resulted in the relationship between self reported stigma and the outcome variables becoming non significant, including quality of life ($p=0.47$, adjusted model), community intellectual disability service contacts ($p=0.52$, adjusted model), total number of service contacts ($p=0.70$, adjusted model) and adherence to medication ($p=0.60$, adjusted model). Psychological distress is therefore a full mediator in the relationship between self reported stigma and these outcome variables. Psychological distress was only a partial mediator in the relationship between self reported stigma and police contacts: it reduced the strength of the association but the relationship between self reported stigma and police contacts remained significant (p=0.02, adjusted model).

The relationship between self reported stigma and the outcome variables, including mediation by psychological distress, is shown pictorially in Figure 2.10

Table 2.17 Psychological distress as a mediator in the relationship between self reported stigma and the outcome variables

a. Demonstrating the association between psychological distress and outcome (dependent) variables using regression analysis (adjusted for clustering)

Dependent variable	Independent variables	Regression Coefficient	Standard error	95% Confidence interval	P value
Quality of life	**Psychological distress**	-0.96	0.15	-1.24, -0.67	<0.001
Service Use: Total number of service contacts	**Psychological distress**	0.04	0.01	0.02, 0.06	<0.001
Contacts with Police	**Psychological distress**	0.11	0.02	0.07, 0.15	<0.001
Contacts with CLDS	**Psychological distress**	0.05	0.01	0.02, 0.08	<0.001
Adherence to medication	**Psychological distress**	-0.06	0.02	-0.11, -0.02	0.01

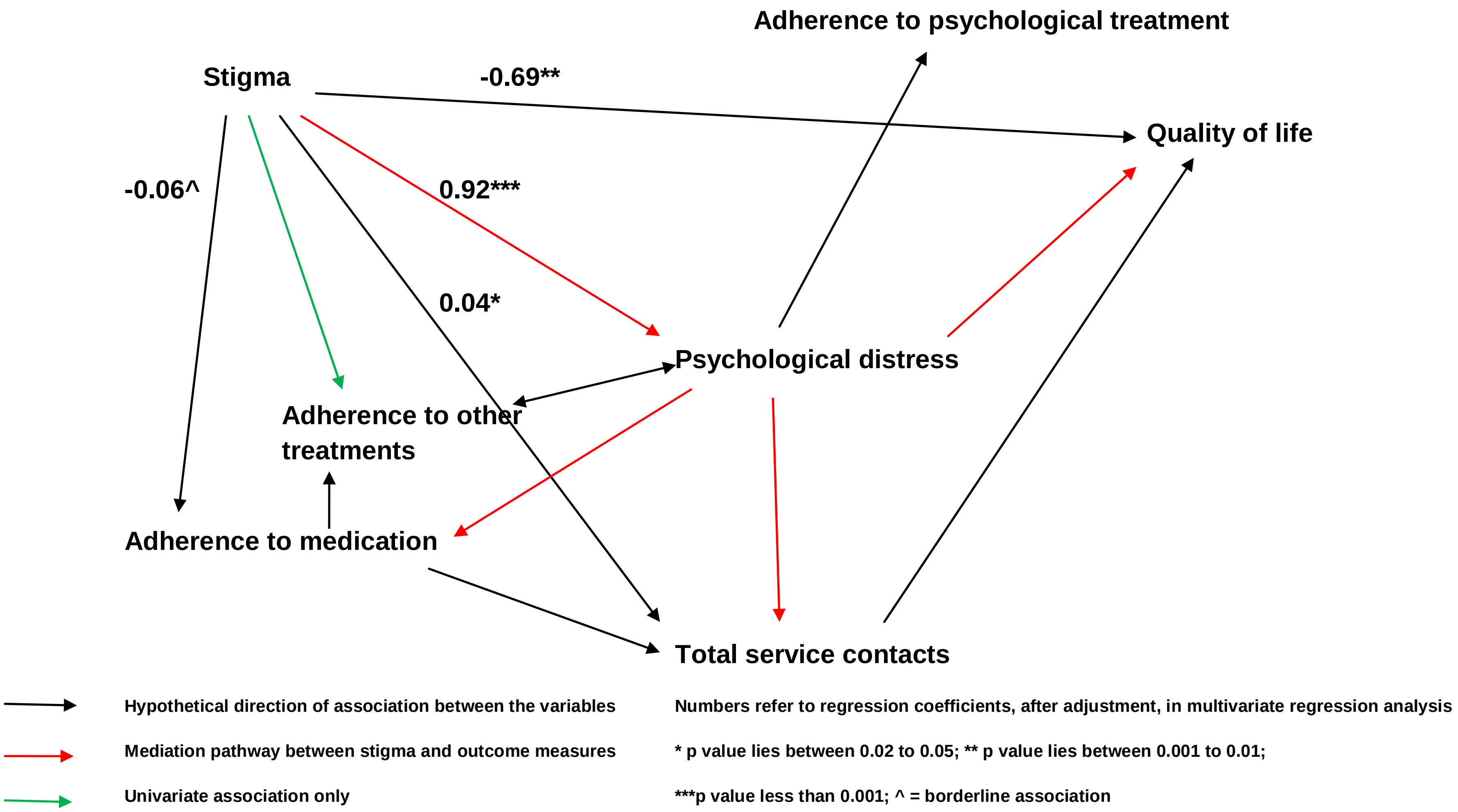
Table 2.17 cont..

b. Demonstrating that the association between stigma and outcome variables is reduced after including psychological distress in the regression model

Dependent Variable	Independent variables	Regression Coefficient	Standard error	95% Confidence interval	P value
Quality of life	**1.Unadjusted (stigma only)**	-0.98	0.26	-1.48, -0.48	<0.001
	2. Including Psychological distress	-0.12	0.29	-0.70, 0.45	0.68
	3. Including adjusted model	0.16	0.29	-0.28, 0.60	0.47
Service Use: Total number of service contacts	**1.Unadjusted (stigma only)**	0.04	0.02	0.01, 0.08	0.03
	2. Including Psychological distress	-0.00	0.02	-0.05, 0.04	0.91
	3. Including adjusted model	-0.01	0.02	-0.05, 0.04	0.70
Contacts with police	**1.Unadjusted (stigma only)**	0.15	0.04	0.07, 0.23	<0.001
	2. Including Psychological distress	0.06	0.05	-0.03, 0.15	0.21
	3. Including adjusted model	0.11	0.05	0.02, 0.21	0.02
Contacts with CLDS	**1.Unadjusted (stigma only)**	0.07	0.03	0.01, 0.12	0.01
	2. Including Psychological distress	0.02	0.02	-0.04, 0.08	0.52
	3. Including adjusted model	0.02	0.03	-0.04, 0.09	0.52
Adherence to medication)	**1.Unadjusted (stigma only)***	-0.05	0.04	-0.13, 0.02	0.18*
	2. Including Psychological distress	0.01	0.05	-0.08, 0.11	0.82
	3. Including adjusted model	-0.02	0.04	-0.11, 0.06	0.60

* P=0.08 for adjusted model, including confounders and other variables

Figure 2.10: Hypothetical relationship between self reported stigma and the outcome variables



Numbers refer to regression coefficients, after adjustment, in multivariate regression analysis

* p value lies between 0.02 to 0.05; ** p value lies between 0.001 to 0.01;

***p value less than 0.001; ^ = borderline association

Summary of the results section

- A total of 229 participants were included in the analysis. Participants with mild intellectual disability comprised three quarters of the sample.
- There were differences in the responses given to the Stigma questionnaire according to level of intellectual disability (those with moderate intellectual disability were more likely to report "yes" to questions on the perceived discrimination subscale) and age group (participants from older age groups were more likely to report "yes" to all the questions.
- Participants with clinically high levels of psychological distress (score of 13 or above) reported twice the level of stigma compared to those with low levels of psychological distress. A total stigma score above 9 is correlated with clinically high levels of psychological distress.
- Age was the main predictor of self reported stigma.
- Self reported stigma was positively associated with psychological distress and service use, after adjustment of confounders, and negatively associated with quality of life. Stigma was particularly associated with the satisfaction subscale of the quality of life questionnaire).There was some evidence that stigma was related to adherence to treatment but the number of people receiving treatment was small and therefore multivariate analysis was only performed on adherence to medication.
- Self reported stigma was particularly associated with higher use of community intellectual disability services and contacts with Police. Participants who reported higher levels of stigma were also more likely to refuse services that had been offered to them.
- Gender and age modified the relationship between level of intellectual disability and stigma. Level of intellectual disability, age and gender did not modify the relationship between self reported stigma and the outcome variables.
- Psychological distress mediated the relationship between stigma and quality of life, service use and adherence to treatment

Discussion

Summary of findings

This was a cross sectional study of 229 participants with mild and moderate intellectual disability from 12 centres in England.

The main objective of the study was to investigate the unadjusted and adjusted relationships between self reported stigma and psychological distress, quality of life, service use and adherence to treatment. The hypothesis that higher levels of self reported stigma would be associated with higher levels of psychological distress and a lower quality of life was supported by this study. A strong relationship was found between self reported stigma and these outcome variables. The hypothesis that higher levels of stigma would be associated with lower use of services was refuted by this study. In fact, higher levels of self reported stigma were moderately associated with a higher total number of contacts with services. Participants who reported higher levels of stigma were more likely to have contacts with community intellectual disability services and the police. However, participants reporting higher levels of stigma were also more likely to refuse at least one service offered to them in the last six months. The hypothesis that self reported stigma would be associated with lower adherence to treatment was only partially supported by the data. The number of participants who had received psychological treatment or “other” treatments was too small to carry out multivariate analysis, but in the unadjusted analysis, stigma was found to be related to poorer adherence to “other” treatments.

The second primary objective was to investigate whether there were any interaction effects. The study did not support the hypothesis that age, gender, and severity of intellectual disability modified the relationship between self reported stigma and the outcome variables.

The third primary objective was to investigate whether psychological distress was a mediator between self reported stigma and the outcome variables. The results support the hypothesis of psychological distress mediating the relationship between self reported stigma and quality of life, service use and adherence to treatment. Psychological distress was found to fully mediate the relationship between self reported stigma and quality of life, total number of service contacts, adherence to medication and contacts with the community intellectual disability team. Psychological distress was a partial mediator in the relationship between self reported stigma and contacts with police.

In addition to the primary objectives, the secondary objectives were to examine whether socio-demographic variables such as age, ethnicity and physical illness were associated with self reported stigma, and whether there were any interaction effects between level of intellectual disability and age, gender and ethnicity in the levels of self reported stigma. The results of the study support the (secondary) hypothesis that individuals of older age would report more stigma. This was demonstrated in the multivariate analysis, where the only independent predictor of self reported stigma was older age. There was partial support for the hypothesis that severity of intellectual disability would be associated with self reported stigma. When individual items on the stigma questionnaire were analysed as part of the descriptive analysis, participants with moderate intellectual disability were more likely to report perceived discrimination: that people on the street made fun of them, that people laughed at them because of the way they looked and talked, and that they were treated like children. In the regression analysis, the severity of intellectual disability was found to predict perceived discrimination, but not reaction to discrimination, which is consistent with the analysis of the individual items from the stigma questionnaire. There was a trend towards higher levels of self reported stigma in participants who were married or in a relationship, and those who had health problems.

The study findings support the hypothesis of age and gender modifying the relationship between severity of intellectual disability and self reported stigma, but not ethnicity. Males with moderate intellectual disability reported higher levels of self reported stigma compared to males with mild intellectual disability, and older people with moderate intellectual disability reported higher levels of stigma compared to younger people with moderate intellectual disability.

Results in the context of other studies

1. Self reported stigma and association with age, level of intellectual disability and other socio-demographic variables

The strong association of self reported stigma with age can be explained by cumulative adverse life events, including greater exposure to potentially stigmatising treatment increasing with age. This is reflected in the data, where older people (particularly the 60-80 age group) reported more stigmatising treatment. There may also be a period effect resulting from older participants having lived through a more stigmatising era. Deinstitutionalisation and government policies promoting the integration of people with intellectual disability in the community, and the promotion of equality and independence, are relatively recent changes. Participants from the older age group are more likely to have lived in institutionalised settings in the past, or may be currently living in residential settings, where certain types of stigmatising treatment are more common. In addition, they may be subject to additional age related discrimination. Previous published studies of people with intellectual disability have not found a relationship between stigma and age (Cooney et al, 2006; Paterson, McKenzie & Lindsay, 2012; Szivos-Bach, 1993). However, one unpublished study of almost 200 participants with intellectual disability in South Africa, using a modified and culturally validated version of the same stigma questionnaire, found that stigma was associated with age. However, in this study, stigma was associated with younger age. There may be cultural or political explanations for this difference. For example, in South Africa, younger people maybe more exposed to negative social interactions as they are more likely to access mainstream services such as education and employment, as services for people with intellectual disability may be less developed compared to the UK. One meta-analysis of studies of people with mental illness (without intellectual disability) found that both older and younger age was associated with self stigma (Livingston & Boyd, 2010), which is consistent with the above findings.

There was a trend towards physical health problems being related to self reported stigma. This may be because some types of physical health problems are also stigmatising. In the South African study mentioned above, there was a trend towards stigma being associated with “obvious additional disability”, which included physical illness as well as other potentially stigmatising features such as sensory problems, mobility problems and where the individual looked “noticeably different to other people”. The combination of stigma due to intellectual disability and stigma due to physical health problems may result in “double stigma”. Bahm and Forchuck (2008) found that individuals with both mental illness and physical illness reported higher levels of stigma compared to individuals with only mental illness**.** Double discrimination has been described in other groups with two or more stigmatising attributes such as those from ethnic minority groups who have intellectual disability (Azmi et al, 1997) mental illness (Gary, 2005) or who are gay (Zamboni & Crawford, 2007); suffering from a serious mental illness and obesity (Mizock, 2012) and substance abusers with HIV (Samilov, 2005).

It is not clear why there was a trend towards an association of stigma with marital status. This appears counter-intuitive as one would expect that being married or in a relationship would be a “normalising” experience that would reduce the experience of self reported stigma. One possible explanation is that being married increases awareness of social limitations due to the pressure of having to fulfil certain roles and expectations, such as looking after children or working, and individuals may receive more critical comments from their partners. In many cultures around the world, disabled men and women are expected to marry and have children. The findings in relation to stigma and marital status may partly explain the results of a large cross sectional study, which found that wellbeing in women with intellectual disability was associated with being single (Emerson & Hatton, 2008). In addition, studies of people with mental illness have found that one of the most common sources of discrimination is from family and close friends (Corker et al, 2013). Alternatively, the relationship between self reported stigma and marital status may be a spurious finding due to the large number of statistical analyses that have been performed.

Although the level of intellectual disability was not an independent predictor of self reported stigma, those with moderate intellectual disability were more likely to report certain types of stigmatising treatment, particularly those involving discriminatory treatment by the public. People with moderate intellectual disability often have more noticeable or visible distinguishing features that may alert members of the community or neighbourhood that they are “different”, making them the target of abuse or harassment. A recent qualitative study reported that participants with intellectual disability were treated unfairly when accessing the community and using public transport (McEvoy & Keenan, 2013).

Participants with moderate intellectual disability did not report more negative reactions to discrimination such as getting angry or avoiding others. One explanation for this is that people with intellectual disability may not internalise their intellectual disability (Cunningham & Glenn, 2000 and 2004; Finlay & Lyons, 1998; Jahoda et al, 1989; Todd, 2000), thus, although they may be able to describe experiences of negative treatment, they may not be able to relate these experiences to their intellectual disability identity. This may occur because of insufficient cognitive development (Cunningham & Glenn, 2000) to allow individuals to compare themselves to others, and to understand the actions of others. Previous studies did not find a relationship between IQ and stigma (Cooney et al, 2006; Paterson, McKenzie & Lindsay 2012, Szivos-Bach, 1993), possibly because these studies had a small sample size, and they did not distinguish between different dimensions of stigma (e.g. discrimination or emotional reactions).

The results of the study found no differences between males and females in self reported levels of stigma, which is similar to previous studies (Cooney et al, 2006; Dagnan & Waring, 2004; Paterson, McKenzie & Lindsay 2012; Petrovski & Gleeson, 1997; Szivos-Bach, 1993). However, males with moderate intellectual disability and females with mild intellectual disability were more likely to report stigma, which suggests that these individuals may be more susceptible to self reported stigma due to gender expectations. McDonald et al (2007) conducted a qualitative study, which found that having an intellectual disability had differential effects in males and females. In males, it diminished the positive effects of their masculinity (e.g. males regarded as less competitive), and in females it accentuated the negative effects of their femininity (e.g. females regarded as being more dependent, less competent).

The finding that older individuals with moderate intellectual disability also reported more stigma is perhaps understandable given that age is an independent predictor of stigma, and level of intellectual disability is a predictor of perceived discrimination.

2. The relationship between stigma, psychological distress and quality of life

Stigma was strongly associated with psychological distress. One large cross sectional study of 1273 participants with intellectual disability, also found that self reported bullying at school and self reports of people being nasty or rude in the last 12 months, was associated with “sometimes not feeling happy”, “feeling helpless”, “Feeling left out” and “feeling sad a lot” (Emerson, 2010). Other smaller studies have found a similar association between stigma and depressive symptoms (Paterson, McKenzie & Lindsay 2012, Petrovski & Gleeson 1997). This finding is also consistent with studies that have examined the effect of stigma on some aspect of psychological wellbeing in people with intellectual disability, most notably the association between stigma, self esteem and comparing oneself negatively to others (Dagnan & Waring, 2004; Cooney et al, 2006; Dagnan & Waring, 2004; Paterson, McKenzie & Lindsay 2012; Petrovski & Gleeson, 1997; Szivos-Bach, 1993).

Stigma was also negatively associated with quality of life. In particular, it was associated with lower life satisfaction, and there was a moderate association with lower empowerment (control over life). Previous studies have not examined the impact of stigma on quality of life in people with intellectual disability. However, studies in people with mental illness have found a similar association between stigma and quality of life (e.g. Lysaker, 2010; Yen et al, 2009).

Although both quality of life and psychological distress are measures of wellbeing (and both were found to be strongly associated with each other), it is important to distinguish that they measure different constructs. Verdugo et al (2012) identified three main factors in the assessment of quality of life in people with intellectual disability: Independence includes the domains of personal development (e.g. activities of daily living) and self determination (choices, decisions and personal goals); social, which includes the domains of interpersonal relationships (social networks), participation (social inclusion and community involvement) and rights (human and legal); and wellbeing, which includes emotional wellbeing (safety and security), physical wellbeing (health) and material wellbeing (financial status and employment). Quality of life can be viewed as a multidimensional construct that is influenced by both individual and environmental factors.

Psychological distress, on the other hand, is defined as a state of emotional suffering, characterised by symptoms of depression and anxiety (Mirowsky & Ross, 2002), that may have an impact on the individual's daily living and social functioning (Wheaton, 2007). It is often viewed as a transient phenomenon, in relation to a stressor. However, this has been disputed by some researchers who have found that psychological distress is moderately stable over the course of many years (Wheaton, 2007). Psychological distress is often considered to be a non specific psychiatric problem, but some researchers argue that if it is left untreated, it may lead to psychiatric problems such as depression (Horwitz, 2007).

People with intellectual disability may be more susceptible to becoming psychologically distressed as a result of stigma and discrimination due to the combined effects of multiple social adversities. Psychological distress is related to a number of different factors (Drapeau et al, 2012): These include: personality, in particular neuroticism, life events and childhood trauma, lack of valued roles, lower socio-economic status (income, education), fewer personal resources, including inner resources (self esteem, sense of control over one's life) and external resources (social network, social support). These are all common in people with intellectual disability and may be more common in this group compared to the general population (Emerson, 2013). Emerson (2010) found that the association between discrimination and psychological distress was stronger for people with lower levels of material and social resources.

3. The relationship between self reported stigma and service use and adherence to treatment

Contrary to previous studies in the mental health literature, higher levels of self reported stigma were found to be associated with a higher use of services, particularly contacts with community intellectual disability teams and police. This relationship was not explained by other factors such level of intellectual disability (e.g. those with moderate intellectual disability requiring more input because of higher support needs) or health problems. People with intellectual disability may be more likely to seek help compared to other stigmatised groups, because of fewer support networks, poorer coping and problem solving skills, and increased susceptibility to developing psychological distress following stressful events. In addition, there may be lower levels of stigma attached to services for people with intellectual disability, or that the psychological distress experienced by individuals outweighs the stigma associated with services.

However, higher levels of self reported stigma were also associated with refusal of at least one service in the last six months suggesting that help seeking behaviour does not necessarily mean that individuals will accept appropriate services. This finding echoes findings on help seeking behaviour in those with mental illness and other stigmatising conditions (Henderson et al, 2013).

The relationship between self reported stigma and service use may also be explained by reverse causality: people who use services such as community intellectual disability services are more likely to be psychologically distressed. They may also have greater awareness of their intellectual disability and therefore more likely to attribute the actions of others as being stigmatising. Or it is possible that services themselves are contributing to the stigmatisation of people with intellectual disability. Studies in the mental health literature have shown that service users frequently report discriminatory attitudes from health professionals (Henderson et al, 2012). Health professionals may hold similar discriminatory attitudes towards people with intellectual disability (Disability Right's Commission, 2006; Mencap, 2007 Michael, 2008).

People who reported higher levels of stigma also reported more contact with the police. The police may hold stigmatising attitudes towards people with intellectual disability. One survey by Mencap (2010) found that when people with intellectual disability contact the police, they frequently encounter patronising attitudes, including being ignored or dismissed as being a non credible witness. Consequently, many hate crimes against people with intellectual disability are not investigated. It is interesting to note that 16% of the sample in this study had reported contacting the police because they had been a victim of crime in the last six months. This figure is considerably higher than the figure of 5% reported by the general population in the British Crime Survey, during the period of 2012 to 2013 (Office for National Statistics, 2013), and supports previous evidence suggesting that this group are more likely to be the target of crime (Hughes et al, 2012; Mencap, 2000). The types of crimes committed against individuals with intellectual disability included verbal abuse, muggings and disability hate crimes. The relationship between stigma and police contacts was partially mediated by psychological distress, suggesting that people with intellectual disability may contact the police because of psychological distress arising from self reported stigma.

The association between self reported stigma and adherence to treatment is supported by the evidence from previous studies in the mental illness literature (Castaldelli-Mai et al, 2011; Tsang et al, 2010). Marital status was the main confounder in the relationship between stigma and adherence to medication. Counter-intuitively, being married was associated with poorer adherence to treatment. One would expect married individuals to have better treatment adherence, as shown in one study of people with physical illness (without intellectual disability) where being married was associated with better medication adherence and increased survival in patients with heart failure (Wu et al, 2012). However, one explanation is that being married increases the likelihood of being prompted or reminded to take medication, which was scored lower on the adherence rating scale compared to not needing to be reminded. It is also possible that the negative views of carers towards medication may influence medication adherence (Rasaratnam et al, 2004).

4. Psychological distress as a mediator between stigma and the outcome variables

Psychological distress was found to fully mediate the relationship between self reported stigma and quality of life. Studies (in people with physical health problems) have found that symptoms of depression and anxiety strongly predict quality of life (Chachamovich et al, 2010; Lukas, 2009). Self esteem in people with mental illness is a mediator in the relationship between self stigma and quality of life (Markowitz, 1998; Rosenfield, 1997).

The relationship between stigma and service use also appears to be fully mediated by psychological distress: people who report more stigma experience more psychological distress, which in turn leads to increased help seeking. In particular, increased psychological distress resulting from self reported stigma, is associated with more contacts with health and social care professionals at community intellectual disability services, and partially explains the increased contact with the police. No study has examined the role of psychological distress as a mediator in the relationship between stigma and service utilisation in people with intellectual disability. However, psychological distress is associated with more contacts with primary care in people with physical health problems (Donald et al, 2011; Kapur et al, 2005) and in patients with epilepsy, psychological distress is strongly associated with contacts with primary care, specialists and emergency departments (Lacey et al, 2009). Psychological distress is also a predictor of mental health visits to all types of professionals (including GPs) in the general population (Mills et al, 2012). The role of psychological distress as a mediator between self reported stigma and service use is therefore plausible.

Psychological distress was found to mediate the relationship between self reported stigma and adherence to treatment. Higher self reported stigma was associated with more psychological distress, which in turn was associated with poorer adherence to treatment. There are no studies that have explored psychological distress as a mediator between stigma and adherence to treatment. However, in studies of patients with physical health problems, higher levels of psychological distress are associated with poorer treatment adherence (Dima et al, 2013; Nahon et al, 2011). The relationship between psychological distress and adherence could be explained by increased forgetfulness (MacDonell, 2012), which could add to the cognitive difficulties encountered by people with intellectual disability in understanding and managing their medication regimes.

An interesting finding is that participants who reported more service use, also reported poorer adherence to medication, but this relationship could be explained by reverse causality and the variables being related to higher levels of stigma or psychological distress.

Strengths of the study

This is the first study to investigate the impact of stigma on a number of health and social outcomes in people with intellectual disability, including the role of psychological distress as a potential mediator in the relationship between self reported stigma and health outcomes. In addition, the effects of other potentially stigmatising attributes were examined such as mobility, speech and sensory problems. Whilst smaller studies have examined the effect of stigma on measures of wellbeing such as self esteem, no study has investigated the effects of stigma on service use and adherence to treatment. Apart from one large cross sectional study (Emerson, 2010), all the previous studies had a smaller sample (40-50 participants), were recruited from one setting, mainly daycentres, and used a measure of stigma that had poor reliability. Although Emerson's study (2010) had a large representative sample, it was based on a secondary analysis of data, and therefore the authors were constrained by the measures that were used in the original analysis. Only two items were used to measure discrimination, and it is not clear whether these items had been previously validated.

Additional strengths of this study include the following: The use of a valid and reliable measure of stigma that was specifically developed for use in people with intellectual disability and the use of self report measures, which enabled people with intellectual disability to have "a voice" and to report their own perspectives. Quite often, studies in people with intellectual disability use "objective" outcome measures based on the accounts provided by carers or professionals. Whilst these reports are very useful, it is questionable whether carers can accurately comment on someone's mental state or wellbeing. In addition, participants were recruited from a number of different settings (community intellectual disability services, day centres, voluntary organisations and supported housing) and from different regions, including rural and urban areas, making the findings of this study more generalisable than some of the previous studies.

Limitations

There are a number of limitations of the study and these are discussed below

i. Study design

This was a cross sectional study and therefore inferences about causality cannot be made. It is not possible to determine the direction of associations. It is therefore possible that the associations observed in this study can be explained by reverse causality: individuals who are more psychologically distressed are more likely to perceive the actions of others as being negative or discriminatory. The cross sectional nature of the study also means that it is not possible to identify whether levels of stigma and psychological distress remain stable or change over time.

ii. Sampling method

Convenience sampling was used to recruit participants, and therefore the sample may not be representative of people with intellectual disability living in the community. It was not considered practicable to approach everyone who was eligible for the study in each of the centres, because of limited time and resources. Only three centres had a list of potentially eligible participants, and in these centres, invitation letters were sent out to the eligible service users. However, response rates to the letters were low (less than 5% in each centre). In other centres, the wide variation in the provision of community services for people with intellectual disability meant that obtaining a list of potentially eligible participants proved more challenging. It is therefore possible that participants who had perceived more stigma or who were more psychologically distressed, were more likely to take part in the study. However, the £20 gift voucher that was given to participants for their time did incentivise some participants to take part in the study, and therefore the decision to take part (for at least some people) was less likely to be influenced by experiences of stigma or discrimination. Evidence for this is provided by the distribution of stigma scores: Ninety three participants scored two or less (out of ten) on the stigma questionnaire.

iii. Measurement of IQ

IQ was not formally measured and information on degree of intellectual disability was obtained from referrers and clinical notes. There is potential for disagreements to occur amongst professionals about the severity of an individual's intellectual disability, and this is a significant limitation. It was not considered practicable or feasible to conduct IQ tests, which on their own would not enable a diagnosis of intellectual disability to be made without an assessment of functional ability. Including an IQ test may have also deterred some participants from taking part. In addition, previous studies that have included a measure of IQ, did not find an association between IQ scores and stigma scores. This study suggests that there may be an association between moderate intellectual disability and discriminatory treatment, which may have occurred because of misclassification of some of the participants into the wrong group, although this is unlikely. Future studies should confirm this association by using IQ measures alongside measures of adaptive functioning.

iv. Sample size

Although this study has a relatively large sample, the proportion of participants receiving treatment, particularly psychological or other non pharmacological treatments, was quite small. This was largely because of the selection of participants without mental illness. The small number of participants receiving treatment meant that it was not possible to identify a relationship between self reported stigma and adherence to psychological and other treatments, and multivariate analysis could not be performed. The findings in relation to adherence to treatment should therefore be considered exploratory. In addition, what constitutes adherence to treatment may require further investigation. For example, accepting support from social services and support workers could also be regarded as adherence to treatment, but were not considered in this study.

iv. Measures

Participants with moderate intellectual disability may have found some of the measures more challenging to complete, for example the stigma questionnaire and the service use questionnaire. In order to assist participants in completing the study questionnaires, each question was read out to the participants, and rephrased if necessary. During the administration of the stigma questionnaire, participants were asked to give examples of situations where the stigmatising treatment may have occurred, in order to clarify understanding.

The study used a measure of adherence that had been developed for this study, and a measure of service use that had been modified into a self report version. Although both of these measures were developed through consultation with professionals and service users with intellectual disability, they had not been validated. All the measures that were used in the study relied on self reporting of events. In particular, the service use questionnaire may be subject to recall bias as participants were asked to recall how many times they had visited health and social care professionals over the last six months. People with intellectual disability often have an inaccurate sense of time, which may affect the accuracy of the information given about service use. It is for this reason that the stigma questionnaire did not ask participants to recall events within a particular time frame but asked how participants felt they were generally treated by others with respect to each of the questionnaire items. This does, however, mean that some of the stigmatising experiences are likely to be historical rather than recent events. However, a general sense of stigma is nonetheless useful as it reflects what the individual perceives at that moment in time. In future studies examining service use, it would be useful to obtain information from multiple sources including GP and health and social care records and carers' accounts.

As it was not always possible to verify information with carers or professionals, some of the information, such as the socio-demographic data and information about physical health problems, may have been under ascertained. Where there were concerns about the accuracy of the data, certain variables were not included in the analysis, or the data was reduced to binary outcomes (yes or no).

In addition, there is the possibility of acquiescence bias, or “yes saying” which is common amongst people with intellectual disability (Finlay & Lyons, 2002). This occurs due to a lack of understanding and the need to please the interviewer. This could lead to inaccurate findings. However, the distribution of responses on the stigma questionnaire, for example, suggests that participants with intellectual disability were only more likely to respond affirmatively to certain questions, rather than all the questions, which suggests that acquiescence bias is unlikely to have occurred.

v. Other variables not investigated

The association between stigma and the outcome variables may be explained by other variables that were not measured in the study, which are discussed below.

Social deprivation

In this study, social deprivation was not assessed. Emerson (2008) found that wellbeing was related to socio-economic status in people with intellectual disability. In a further paper, they found that the association between discrimination (bullying) with lower wellbeing and self reported health, was modified by material resources (having enough money to purchase goods such as food and clothes and to socialise) and social resources (contacts with relatives and friends). The association was stronger for people with lower levels of material or social resources (Emerson, 2010).

In the South African study discussed earlier, there was a trend towards area deprivation being associated with self stigma. However, Cooney et al (2006) did not find a relationship between stigma and socio-economic status. Although social class and area deprivation were not assessed, employment status was assessed in this study: being in paid employment was associated with lower levels of stigma, lower psychological distress and a higher quality of life in the linear regression analysis. Employment status was particularly important for the quality of life measure because the competence subscale measured satisfaction at work and those who were unemployed received a lower score.

Cooper et al (2011) investigated the effects of social deprivation in determining health inequalities and service access by adults with intellectual disability. They found that area deprivation was not associated with access to primary care services or hospital admissions. However, participants from more deprived areas used Accident & Emergency services more frequently and were less likely to use outpatient clinics. Future studies should examine whether area deprivation affects stigma, wellbeing and service use.

Self esteem and personality

Self esteem was not measured in this study. Previous studies in people with intellectual disability and people with mental illness have consistently shown a relationship between self esteem and stigma. Self esteem has also been found to mediate the relationship between stigma and psychological distress (Yanos et al, 2008). The relationship between self reported stigma and self esteem was not investigated in this study as it has been previously explored, and would have involved administering an additional questionnaire, placing further burden on participants.

Personality was also not assessed. Psychological wellbeing is inversely associated with neuroticism, and positively associated with extraversion and openness to experience (Furnham & Petrides, 2003). Studies suggest that personality difficulties may be more common in people with intellectual disability (Alexander & Cooray, 2003).

Life events

Stressful life events in the preceding year, is associated with affective and neurotic symptoms (Hastings et al, 2004), and also increased visits to the Accident & Emergency department in response to crisis (Lunski & Elserafi, 2011). It is not known to what degree recent life events contributed to psychological distress in this study and therefore it would be worthwhile measuring this in future studies.

Mental illness

Participants with a known diagnosis of mental illness were not included in this study. This resulted in a large proportion of individuals being excluded from this study as mental health problems are more common in this group compared to the general population (Cooper et al, 2007). Future studies could examine the impact of double stigma (having intellectual disability and mental illness) on health outcomes.

Statistical methods

A random effects regression model was used to identify whether there was clustering by centre. This approach can produce unreliable results if the number of clusters is small. At least 15 clusters are considered to be an ideal number (Kirkwood & Sterne, 2003) but only twelve clusters were included in this study. Statistical advice was sought from a medical statistician who advised that using a random effects model was a valid approach. The random effect models indicated that there was no evidence of clustering in the multivariate analyses. Bonferroni corrections have not been applied to the statistical analyses and if a p value of 1% was used to identify statistical associations (rather than 5%), the relationship between self reported stigma and service use would be non- significant. However, there were clearly stated a priori hypotheses regarding the proposed statistical analyses, and the results obtained appear to be hypothetically plausible.

The implications of the study and suggestions for future research are covered in chapter four.

Summary of discussion

- Age may be related to self reported stigma because of increased exposure to stigmatising treatment over time
- People with moderate intellectual disability were more likely to report discriminatory treatment, possible because their disability is more apparent to others
- People with intellectual disability may be more susceptible to psychological distress following discrimination because of the combined effects of multiple adversities, including poor coping skills and lack of social support, which in turn may lead to increased help seeking
- Self reported stigma is associated with increased use of services and is therefore an economic burden on services.
- Reverse causality may explain the association between self reported stigma and service use: participants who use more services may be more aware of their disability, and are therefore more likely to report stigma.
- The main strength of the study is that it examines the relationship between self reported stigma and multiple health outcomes is a relatively large sample recruited from multiple sites.
- There are a number of limitations including the cross sectional study design, the use of a non representative sample, the use of measures that had not been previously validates and IQ was not measured

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Chapter 3: Discrimination and others barriers to accessing health care: perspectives of patients with intellectual disability and their carers

Abstract

Background

People with intellectual disability have a higher prevalence of physical health problems but often experience disparities in accessing health care. In England, a number of legislative changes, policies and recommendations have been introduced to improve health care access for this population. The aim of this qualitative study was to examine the extent to which patients with intellectual disability and their carers experience discrimination or other barriers in accessing health services, and whether health care experiences have improved over recent years.

Method and main findings

Twenty nine participants (14 patient and carer dyads, and one carer) took part in semi-structured interviews. The interviews were audio-taped and transcribed and analysed using thematic analysis. Eight themes were identified. Half the participants thought that the patient had been treated unfairly or had been discriminated against by health services. There were accounts of negative staff attitudes and behaviour, and failure of services to make reasonable adjustments. Other barriers included problems with communication, and accessing services because of lack of knowledge of local services and service eligibility issues; lack of support and involvement of carers; and language problems in participants from minority ethnic groups. Most participants were able to report at least one example of good practice in health care provision. Suggestions for improving services are presented.

Conclusion

Despite some improvements to services as a result of health policies and recommendations, more progress is required to ensure that health services make reasonable adjustments to reduce both direct and indirect discrimination of people with intellectual disability.

Introduction

People with intellectual disability have a higher prevalence of health problems (Emerson & Baines 2010) and the median age of death is 25 years younger than the general population (Glover & Ayub, 2010). They are more likely to experience inequalities in accessing health care and to die from preventable causes, possibly as a result of institutional discrimination within health services (Disability Rights Commission, 2006; Mencap, 2007; Michael, 2008; NHS Health Scotland, 2004).

A number of qualitative (and mixed design) studies have explored the experiences of individuals with intellectual disability, and their carers, in accessing mainstream health services for physical health problems. Sixteen studies were identified from a review of the literature. Details of these studies and their main findings are shown on table 3.1. Nine studies were of experiences of primary care, two were of cancer screening and five were of experiences of hospitals. The findings are summarised below.

These studies have highlighted a number of barriers in accessing health care. These include: communication difficulties, resulting from individuals with intellectual disabilities being excluded from consultations (Ward et al, 2010; Wullink et al, 2009; Ziviana, 2004); failure of General Practitioners (GPs) to conduct health reviews, review medication (Langhan et al, 1994; Martin, Roy & Wells, 1997) and conduct blood tests and investigations (Langhan et al, 1994); lack of health promotion and screening (Broughton & Thompson, 2000; Langhan et al, 1994; Thornton, 1999; Ward et al, 2010); and inadequate knowledge of doctors about the health needs of people with intellectual disability (Fisher, 2005; Minnes & Steiner, 2009; Thornton, 1999; Ward et al, 2010), which has contributed to diagnostic overshadowing (Dinsmore, 2012; Minnes & Steiner, 2009; Webber et al, 2010; Ziviana, 2004). Diagnostic overshadowing occurs where signs and symptoms arising from physical or mental health problems are misattributed to the individual's intellectual disability, and can lead to delayed diagnosis and treatment.

In hospitals, concerns have been reported about the denial of basic needs such as lack of support during meal times (Fox & Wilson, 1999) or toileting (Fox & Wilson, 1999; Iacano & Davis, 2003; Webber et al, 2010); problems in the administration of medication (Iacano & Davis, 2003), and inadequate discharge arrangements (Dinsmore, 2012; Webber et al, 2010). In addition, studies have reported a lack of support offered to carers (Gibbs et al, 2008), disregard for information provided by carers (Dinsmore, 2012), and unrealistic expectations of carers to take on care giving responsibilities on the ward (Fox & Wilson 1999; Iacano & Davis, 2003).

Several studies concluded that patients with intellectual disability received suboptimal care, and were denied appropriate treatment (Fisher, 2005; Ward et al, 2010; Ziviana, 2004). Health professionals frequently exhibited negative attitudes and behaviour towards individuals with intellectual disability (Dinsmore, 2012; Ward et al, 2010; Webber et al, 2010), including questioning whether the person was worthy of surgical treatment, due to discriminatory judgements about the person's quality of life (Webber et al, 2010, Gibbs et al, 2008).

In England, a number of recommendations and initiatives to improve access to health services, for people with intellectual disability, were introduced following an independent inquiry into health care access (Michael, 2008; see Box 3.1.) This includes the requirement of health services to make reasonable adjustments to enable individuals with intellectual disability to access services, as stipulated by the Disability Discrimination Act (1995). The Act requires that information about treatment options, complaints procedures and appointments, are provided in an accessible format, and that any processes and procedures that may discriminate people with disability, either directly or indirectly, should be modified so that they are easier to use. Health services are also obligated to take steps to promote equality for people with intellectual disability and to ensure their needs are addressed even if that involves more favourable treatment.

In addition, since 2008, GPs in England have been incentivised to provide annual health checks for people with intellectual disability. Health checks have been shown to increase detection of serious unmet health needs such as cancer, dementia and heart disease. They also increase detection of minor problems such as sensory impairments, which are often treatable and can significantly improve the individual's quality of life (Hoghton et al, 2012; Robertson et al 2010).

Table 3.1: Summary of previous studies examining the experiences of physical health care

Study	Design	Location	Sample	Method	Main Findings
Broughton &Thomson (2000)	Mixed methods	UK	52 women with ID aged between 20 and 60 and 32 carers.	Semi-structured interview regarding the experiences of cervical screening	Most had never been screened. Screening was associated with feelings of anxiety in those not screened. Pain and discomfort reported by screened women. Carers reported need for preparation and procedure to be carried out by someone familiar. Need for staff to have knowledge of ID and effective communication.
Dinsmore (2012)	Qualitative	UK	Purposive sample of 5 participants with ID aged 8-51 and 9 carers recruited from voluntarily run day centres.	Semi-structured interviews regarding recent hospital experiences	11 themes identified including poor awareness of annual health checks among people with ID, poor involvement of carers in decision making and interpretation of signs and symptoms by clinicians, poor guidelines following discharge; Issues with administration of correct medication, lack of easy-access information and awareness of patient passports, poor flexibility and long waiting times and poor staff understanding and knowledge about ID.
Fisher et al. (2005)	Qualitative	USA	13 out of 30 directors of agencies working with people with ID (response rate 43%)	Semi-structured interviews on experiences of accessing health care.	4 themes: effects of stigma: differential treatment of people with ID including Sub-optimal care or denial of treatment by doctors due to behavioural and communication difficulties, poor understanding of ID by clinical staff, lack of adequate resources for provision of health care, inconsistent decision making: disagreements between family members, staff and health care providers about treatment.
Fox & Wilson (1999)	Qualitative	UK	Carers of 153 adults with ID attending day-centres contacted. 10 parents participated. Age of person with ID ranged from 20-49.	Semi-structured interview developed of hospital care over last 2 years.	Themes included lack of choice over bed placement, lack of activity on the ward, parents taking on nursing roles, feeding issues, toileting issues, nurses' attitudes.
Gibbs et al. 2008	Qualitative	UK	11 participants with ID aged 18-62 recruited from day centres and homes and14 carers recruited from various sources (e.g. advert).	Focus groups of experiences of hospital care	5 themes: feelings of anxiety and fear in service users and carer; Issues with comprehension and lack of communication facilitation (e.g. use of pictures). Limited involvement of carers and poor instructions following discharge; Practicalities (e.g. Issues with room placement on the wards and long waiting times leading to patient agitation, poor support for carers; Discrimination and negative comments, e.g. Refusal of surgery as doctors made assumptions about an individual's quality of life. Difficulties arranging admission; behavioural problems due to long waiting times

Table 3.1 cont...

Study	Design	Location	Sample	Method	Main Findings
Iacano & Davis, (2003).	Mixed methods	Australia	Participants recruited from 3 NGOs. 119 responses from carers and service users.11 agreed to also take part in a qualitative study	Questionnaire on experience of A&E and hospital wards	Difficulty in needs being met and communicating needs to hospital staff. Patients preferred having carer present during hospitalisation which was associated with having needs met. The majority of patients were given explanations for admission and instructions following discharge. Interviews: Overall positive perception of staff but issues with lack of understanding of ID. Over reliance and dependence on carers.
Jones et al. 2008	Qualitative	UK	6 participants with ID (aged 33-57) and19 paid carers.	Focus groups held with paid carers and semi-structured interviews held with service users regarding quality of care in primary care.	8 themes including: communication difficulties; long waiting times causing behaviour problems; service users concerned about wasting the doctor's time with trivial concerns; health education; dismissal of carers opinions and patient knowledge; attitudes and behaviour of primary care staff with reports of service users being spoken to like children, staff being frightened of service users and doctors not having time.
Langan et al. (1994)	Mixed	UK	81 carers selected based on random stratified sample of people with ID on a register. Also control group was selected to identify frequency in which health interventions were given.	Structured questionnaires on experience of primary care with verbatim quotes.	Themes included: not all carers had adequate training and some experienced difficulties managing challenging behaviour; issues about communication with doctor (e.g. carer being present, service user being spoken to); Views about medication with concern about lack of medication reviews; Limited health promotion and prevention. Lack of widespread screening; Carer's role in monitoring vision, hearing and dental care: inadequate levels of contact and instrumental role of carers in seeking contact.
Martin et al. (1997)	Mixed	UK	60 Service users, carers and service providers took part in a forum.104 carers completed questionnaires and 52 people with ID interviewed directly after a health check (out of 132).	Forum and questionnaires on the experiences of primary care and health checks	Concerns highlighted in the forum were: unequal access to health screening, focus on secondary care issues, neglect of primary prevention and health promotion, and missing out on local resources. Questionnaire responses: long term relationship with GP highly valued. General satisfaction with GP; Issues concerning communication with GP and their knowledge of ID services. Service users reported positive experiences; some reported issues on waiting times, accessibility and GP's attitude.

Table3. 1: cont...

Study	Design	Location	Sample	Method	Main Findings
Minnes & Steiner, 2009	Qualitative	Canada	17 parents of children with Fragile X, autism, and Down syndrome	Focus group about quality of health care	Fragile X group: health providers' lack of knowledge and interest often resulted in difficulties obtaining a correct diagnosis. Limited information regarding interventions; Autism group: difficulties in accessing services and dependence on diagnosis; Down syndrome group: issues with doctors' attitudes, diagnostic overshadowing and quality of care. Need for better services and deeper knowledge about conditions.
Truesdale-Kennedy et al. 2011	Qualitative	UK	Purposive sample of 19 women with ID (aged 31 to 50) who had received a breast mammography in last 12 months, recruited from a residential setting	Focus groups examining understanding of breast cancer and experience of mammography.	4 themes: understanding of breast cancer: limited knowledge about signs and symptoms, breast awareness, prevention and support sources; Experiences of breast mammography: most women reported positive attitudes. Feelings of fear and anxiety associated with a lack of understanding of the procedure, which was perceived as uncomfortable and painful. Presence of friendly staff and carers reduced anxiety; Barriers to attendance: fear and embarrassment; Solutions to barriers: providing information and emotional support and the use of user friendly leaflets and posters.
Tuffrey-Wijne et al. 2009	Qualitative	UK	Convenience and purposive sample of 13 participants with ID (Mean age 53) with a diagnosis of cancer and 10 were terminally ill.	Ethnographic study based on participant observation on quality of cancer care.	Main themes: dependence on others for decision making; Cancer diagnosis and treatment: Issues with delayed diagnosis due to communication difficulties. Over reliance on carers and poor involvement of patients; Capacity and understanding: Information given to participants about diagnosis and prognosis was controlled by carers. Clinicians lacked adequate communication skills; Staff's poor knowledge and communication skills in supporting people with ID, especially when person was dying.
Ward et al. 2010	Qualitative	USA	18 people with ID,41 parents/guardians,57 community support professionals and 26 health professionals. Sample recruited through disability agencies. Included am ethnically diverse sample.	Focus groups on quality of care received in primary care and outpatient clinics.	Main themes: difficulty in accessing health providers with ID experience. Patients often remained with paediatrician into adulthood. Issues with lengthy waiting times; lack of training of health care professionals, negative attitudes of health staff towards people with ID, incorrect labelling and diagnosis, lack of direct communication with the patient, language barriers; lengthy waits and rushed health care consultations, patients with behavioural problems and not receiving necessary investigations (e.g. screening).

Table 3.1 cont...

Study	Design	Location	Sample	Method	Main Findings
Webber et a. 2010	Qualitative	Australia	55 paid carers and family members looking after 17 residents with ID (aged 49-81) living in 13 groups homes.	Semi-structured interviews about hospital experiences.	Themes: discriminatory staff attitudes; Staff's poor knowledge of ID leading to unmet basic needs (e.g. feeding, toileting) ; lack of routines resulting in difficult behaviours; Failure to identify and treat pain even after request by carers; Issues arising between poor communication between staff, patients and carers; Issues with carers arising from early discharge and limited information on how to provide best care; Positive experiences associated with clear policies and resources addressing the needs of ID.
Wullink et al. 2009	Mixed	Netherlands	12 participants with ID, (middle aged). Participants were council members of 2 different organisations.	Similarities between Communication preferences of people with ID and professionals criteria used by doctors, was assessed. Focus group of people with ID was held.	Many similarities between the communication preferences of people with ID and the professional criteria. Two preferences did not fully meet the professional criteria: consultation time (sufficient time for consultations) and doctors talking to support workers, without seeking permission from people with ID. The communication criteria gave no information about handling triadic communication.
Ziviana et al. 2004	Qualitative	Australia	Purposive sample of five GPs, 3 adults with ID and 7 carers and 2 advocates.	Semi-structured interviews regarding participants' experiences of communication with their GPs	Themes: People with ID discussed communication difficulties with GP's. Consultations were often facilitated by carers. Health advocates: Concern about inequitable care for people with ID. Issues of diagnostic over-shadowing and over-prescription of medication for behavioural problems; Areas for improvement were communication skills, accessibility of services, waiting times and need for collaboration between all parties involved in the care of service users.

Gaps in the literature and rationale for the study

None of the identified studies examined experiences of healthcare across a range of different settings (e.g. primary care, secondary care and community services such as community intellectual disability teams), and no study specifically used service user and carer dyads in exploring experiences of health care. A focus on dyads allows an understanding of the individual needs of the participants, and the interactions and dynamics that occur between service users and their carers (Kendall et al, 2009). Dyads have not been previously used to examine people with intellectual disability's experiences of mainstream physical health services, although they have been used in the study of psychiatric services (e.g. Donner et al, 2010). In addition, many of the studies took place prior to new legislation and guidance on improving health care for people with intellectual disability, and therefore we know little about what impact these changes have had on improving healthcare. In order to provide new insight and contribute to existing literature, the experiences of people with intellectual disability and their carers, across a range of health services, were explored using patient-carer dyads.

Aims and objectives

The aim of this qualitative study was to examine the extent to which adults with mild or moderate intellectual disability (described in this study as "patients") and carers believe that their needs are being accommodated by health services. The objectives were to address the following questions:

1. What are patient's and carer's experiences of health services, including both positive and negative experiences, and to what extent do they believe they are receiving unfair treatment or are being discriminated against by health services?

2. What barriers are there to accessing help from health services?

3. How can health services continue to be improved so that they are more attuned and responsive to the needs of people with intellectual disability and their carers?

Method

Ethical Approval

Ethical approval was obtained from the West London Research Ethics committee (3) in November 2010. The study was conducted between May 2011 and September 2012.

Box 3.1: Key recommendations to improve health care access for people with intellectual disability in England (Michael, 2008).

1. Health services are required to make "reasonable adjustments" in accordance with disability equality legislation, and that effective systems are in place to deliver and monitor whether reasonable adjustments are being made

2. Health services should collect data (e.g. on whether the person has an intellectual disability) to enable health services to identify and track people with intellectual disability through care pathways

3. Commissioning of primary care services to provide annual health checks in 2008

4. Liaison staff to work with primary care to improve the quality of health care for people with intellectual disability across a range of health services

5. Establishment of the Learning Disabilities Public Health Observatory in (established in 2010). Their role is to publish reports on aspects of healthcare for people with intellectual disability such as progress of annual health checks and avoidable premature deaths

6. Undergraduate and postgraduate training for health professionals to include mandatory training in intellectual disability

7. Family and carers should be involved as partners in the provision of treatment and care. They should be provided with information, practical advice and service coordination

Recruitment

Dyads of a patient and their carer were recruited. As part of the recruitment process, community intellectual disability services, day centres and voluntary organisations were approached at eleven sites in the UK (5 in London and 6 outside London). The recruitment of participants was facilitated through members of staff at the different organisations who approached patients and carers, and through invitation letters or newsletters that were sent by some of the services giving information about the study. Some participants from difficult to reach groups such as ethnic minorities, were recruited through snow-balling techniques.

Half the sample was comprised of participants who responded to invitation letters or were approached by staff. The remainder were purposively selected on the basis of cultural and ethnic backgrounds and nature of health problems, in order to obtain a more diverse sample and a wider range of perspectives.

Inclusion and exclusion criteria

Participants with mild or moderate intellectual disabilities who were aged between18 and 65 were included in the study. The level of intellectual disability was not directly assessed but was based on information from clinical notes and information provided by the referrers. Participants unable to give informed consent were excluded. Both informal carers (e.g. relatives, friends) and paid carers were included. All of the carers had to know the person well (for at least 2 years). In order to be eligible for the study, both the carer and the patient with intellectual disability had to agree to participate in the study.

Procedures

Participants were required to give informed consent prior to participation in the study. Semi-structured interviews were conducted with patients with intellectual disability and carers separately, in order to give the patient an opportunity to voice their views and concerns. However, there was some flexibility in the procedures as some patients wanted their carers present at their interview, or their carers needed to be present in order to facilitate the interview due to complex communication needs. All the interviews were held at participants' homes apart from four that were held at a voluntary organisation. The interviews with the patients lasted between 20 and 45 minutes and the interviews with carers lasted between 30 and 60 minutes.

A structured data collection form was used to collect some basic socio-demographic and clinical data about the participants. Semi-structured interview schedules for patients and carers were used to prompt the researcher of questions or topics to explore. These were initially developed from the literature review but were then modified following input from health and social care professionals and individuals with intellectual disabilities at two consultation groups that were held at a community intellectual disability service at one of the main participating sites. The topics addressed in the interview schedule included any experiences of health services that were particularly memorable; positive and negative experiences of different types of health services (e.g. primary care, hospitals, dental care, community intellectual disability services); any experiences of unfair or discriminatory treatment; whether complaints were made; the impact of negative experiences on subsequent use of health services; the influence of legislative changes on healthcare experiences; and how health services could be improved so that they meet the needs of carers and patients with intellectual disability (see appendix for further details).

All the interviews, except two, were carried out by AA. The other two interviews were carried out by a clinical studies officer in Somerset. The interviews were audio-taped and field notes of the interviews were made. Complete data saturation was achieved with no new topics or themes emerging in the final few interviews. The interviews were transcribed verbatim. All the participants were given a £20 gift voucher to thank them for their time.

Sample characteristics

The total of 29 participants were made up of 14 patient and carer dyads and one single carer (patient declined to participate on the day). Six of the dyads were recruited from two inner London boroughs (Camden and Islington), five dyads (and 1 carer) were recruited from a borough in East London (Newham), one from a borough in South East London (Bromley) and two dyads were recruited from outside London (Somerset and Lincolnshire). Four of the dyads were recruited through snow-balling techniques.

The patients with intellectual disability were between 23 and 57 years of age; seven were male and seven female. Nine were of White Background, two were of Asian Indian and three were of Asian Pakistani origin, see Table 3.2). Ten had a mild intellectual disability and four had a moderate intellectual disability. Three of the patients had Down syndrome, one had cerebral palsy and two had autistic spectrum disorders. The patients had a range of health problems including epilepsy (2), hydrocephalus (2), sensory impairment (4), diabetes (2), hypertension (2), asthma (2) and mental health problems (3).

The carers were between 28 and 72 years of age. Most of the carers were mothers of the patients, apart from one who was a paid carer and three who were partners. Only one male carer took part. He was the patient’s partner and had borderline intellectual functioning. An advocate who knew the family well, and who was involved in facilitating access to health care, was present at interviews with five dyads. The advocate also assisted with interpreting where the carers or service users had difficulty understanding English.

Analysis

Analysis of the transcripts was performed using thematic analysis, based on the method described by Braun and Clarke (2006). For this study, an essentialist stance was taken, which reports the participants’ experiences as a reflection of reality. Initially the interview transcripts were read several times by the researcher in order to become familiar with the data. This was followed by coding of the data, using the software package NVivo (version 10). NVivo was used to manage the data set but the actual coding was done by the researcher. All transcripts were analysed to derive initial codes, which were applied to segments of the data and closely reflected the raw data (inductive analysis). Following this, all the data extracts relating to the same code were collated together. The third stage involved grouping the different codes into potential themes. The fourth stage involved reviewing the codes, and their grouping into themes with one of the supervisor (KS), who also independently coded four transcripts, in order to assess the validity of the coding frame and themes. Following this, some of the codes and themes were re-named and re-organised. A list of the final codes for each theme, and some examples of analysis, are presented in the appendix. Once the final coding frame was identified, the reliability of the coding frame was assessed by one of the supervisors (KS) using two transcripts. The average Cohen’s kappa coefficient was 0.82, indicating a good level of agreement between the two raters.

Table 3.2: Summary of socio-demographic and clinical information for all the dyads

Dyads	Interview details	Identification Number	Socio-demographic details
No.1	Conducted at home. Participants interviewed separately	Patient 1 (P1)	Male, aged 25, White British. Mild ID. Lives in family home
		Carer 1(C1)	Female, aged 72, White British, married. Mother of patient
No.2	Conducted at home. Carer present at interview with service user and facilitated interview	Patient 2 (P2)	Female, aged 26, moderate ID, White British. Lives in family home
		Carer 2 (C2)	Female, aged 52, White British, separated. Mother of patient
No.3	Conducted at home. Participants interviewed separately	Patient 3 (P 3)	Male, aged 24, White Other (Spanish). Mild ID. Lives at home
		Carer 3 (C3)	Female, aged 42, White Other (Spanish), married. Mother of patient
No.4	Conducted at home. Carer present at interview with service user	Patient 4 (P 4)	Male, aged 25, White Other (Mixed).Mild ID. Lives in family home
		Carer 4 (C4)	Female, aged 52, Irish, divorced. Mother of patient
No.5	Conducted at home. Carer present at interview with service user	Patient 5 (P 5)	Female, aged 28, White British. Moderate ID. Lives in family home
		Carer 5 (C5)	Female, ages 68, White British, Single. Mother of patient
No.6	Conducted at home. Participants interviewed separately	Patient 6 (P 6)	Female, aged 31, Irish. Mild ID. Lives in supported housing
		Carer 6 (C6)	Female, aged 60, Irish, married. Mother of patient
No.7	Conducted at home. Carer present at interview with service user	Patient 7 (P 7)	Male, aged 30, White British. Mild ID. Lives in supported housing.
		Carer 7 (C7)	Female, 28, White British, married. Paid carer
No. 8	Conducted at home. Carer present at interview with service user. Advocate present	Patient 8 (P 8)	Male, aged 57, Indian, married. Mild LD. Lives in family home
		Carer 8 (C8)	Female, aged 57, Indian, married. Wife of patient

Table 3.2 cont…

Dyads	Interview details	Identification Number	Socio-demographic details
No.9	Conducted at voluntary organisation. Interviews conducted separately	Patient 9 (P 9)	Female, aged 38, White British. Mild ID. Lives in family home
		Carer 9 (C 9)	Female, aged 54, White British, divorced. Mother of patient
No.10	Conducted at home. Interviews conducted separately. Advocate present at both interviews	Patient 10 (P 10)	Male, aged 42, Indian, married. Mild ID. Lives in family home
		Carer 10 (C10)	Female, aged 40, Indian, married. Wife of patient
No. 11	Conducted at home. Carer present at interview with service user. Advocate also present	Patient 11 (P 11)	Male, aged 29, Pakistani. Mild ID. Lives in family home
		Carer 11 (C11)	Female, aged 53, Pakistani, divorced. Mother of patient
No. 12	Conducted at voluntary organisation. Interviews conducted separately	Patient 12 (P12)	Female, aged 46, White British. Moderate ID. Lives with partner
		Carer 12 (C12)	Male, aged 52, White British, partner of patient
No. 13	Conducted at home. Interviews conducted separately. Advocate present at both interviews	Patient 13 (P13)	Female, aged 23, Pakistani. Moderate ID. Lives in family home
		Carer 13 (C13)	Female, aged 43, Pakistani, separated. Mother of patient
No.14	Conducted at home. Carer present at interview with service user. Advocate also present	Patient 14 (P14)	Female, aged 29, Pakistani. Mild ID. Lives in family home
		Carer 14 (C14)	Female, aged 57, Pakistani, married. Mother of patient
No. 15	Conducted at home with carer only	Carer 15 (C15)	Female, aged 52, Indian, married, mother of patient. Patient is 27 years old, had mild ID and lives in family home.

Results

Eight themes were identified relating to the three objectives and are grouped under: Barriers in health care access; discrimination from health services; and good practice (see Box 3.2). These themes are discussed in detail and illustrated with interview extracts below. The notation used in the brackets refers to the participant identification numbers shown in Table 1 (C denotes carers and P denotes patients).

Barriers to health care access

Theme 1: Problems with communication

Problems with communication were discussed by 12 patients with intellectual disability and 12 carers. Some patients felt ignored by clinicians during consultations or “were talked over” if their carer was present. Staff failed to modify and adapt their communication to the needs of the patient such as asking too many questions, speaking too quickly, giving too much information and not giving the person enough time to respond. Some patients with intellectual disability complained of not understanding what was being said, or not being understood themselves. Several carers reported that he patient’s communication difficulties or lack of confidence, affected their ability to express their concerns. Most patients found it helpful to have their carer or an advocate present at the consultation, in order to facilitate communication and understanding:

> *“I’d like to know what’s happening...I’d like to say something...I think the doctors like talking to the parent about what’s happened to the child, but I need to know. I think parents go first and daughter or son goes second about what’s happening, I need to know... I don’t want to be left behind and I want the doctors to speak to me and my mum together” (P5).*

> *“Sometimes if they talk to a stage where I don’t understand, my mother needs to tell me. You know, like it would have been better if they could explain it slowly for me...like the medication” (P4).*

Patients and carers reported not being adequately informed about diagnoses, procedures and medication regimes. This included failure of doctors to inform patients of potential side effects of medication, what to do in response to side effects, and lack of information about the dosing and duration of medication. Lack of information or understanding led to patients becoming frightened or feeling pressurised to have treatment.

> *P9: "And it was quite uncomfortable, because they put my legs in the stirrup"*
> *Interviewer: "Did they explain this to you before the operation?"*
> *P9: "No, No"*
> *Interviewer: "How did you feel?"*
> *P9: "Scary, and they gave me an epidural and I didn't like that because it made my legs go numb and I have problems with my legs."*
> *Interviewer: "Did they explain that they were going to do this before the procedure?"*
> *P9: "No, no. They didn't explain nothing really"*

> *"He does feel pressurised by them...he's had the operation, it hasn't worked. Now they're saying that they want to do it again. And he never went to the last appointment because he felt they were going to bully him into doing it" (C15; mother).*

Information was rarely provided in an accessible format that could be understood by patients with intellectual disability:

> *"No, they just said that I had to sign something... that was it, it was like a consent form. They gave me a little booklet beforehand but it wasn't like an easy read one" (SU9).*

Theme 2: Problems with accessing help

Problems with accessing help were discussed by eight patients with intellectual disability and 12 carers. Carers raised concerns about difficulties in accessing timely support, and of unmet health needs in the patient. Patients were denied GP home visits if they refused or could not attend the GP surgery; the GP was sometimes perceived to be unhelpful, particularly for social issues. For some carers, getting help from services only occurred during a crisis and was perceived to be a constant battle.

> *"I have to struggle to take him to the doctors or the hospital because he doesn't like to go...I explain to them that my husband refuses to come to the surgery and ask if someone can come and see him at home but they say they don't do home visits. They say take him to the hospital (C8; wife).*

Carers complained of the difficulty in obtaining information about what services were available, and lack of clarity about referral pathways and how services were structured. Obtaining help was compounded by disputes between services about eligibility issues and who should take responsibility for the patient. In the UK, community intellectual disability services are multidisciplinary services that provide expertise in health and social care issues that affect people with intellectual disability. In our study, five carers reported having no knowledge of these services or only being referred recently, suggesting inadequate transition from child to adult services, and their GPs failed to subsequently refer them to specialist services. Of note, in all of the five dyads, the participants were South Asians, which raises the question whether health services are meeting the needs of this group.

> *"When he left the hospital at the age of 16, he should have had a good transition to the adult services, but it didn't happen. It's not just to me but I see this happen to lots of people. They're not getting their support plans made, they seem to be slipping through the net" (C15; mother).*

> *"I think it's very confusing as to where services are and how it's structured. How you can access services and what is available to you. There's no clear*

> *thing that says if you're in this situation, this is what's available to you and this is what you can do...it's like an unknown world out the*re" *(C7; paid carer).*

Several carers who did not speak English as their first language reported that language was a significant barrier to accessing help. They were ignored at consultations, little consideration was given to their views and Information about the patient was frequently not shared with them. The language barrier also prevented some carers from accessing basic support such as assistance completing benefit forms. Many health services failed to provide these carers with an interpreter, which perpetuated their feelings of marginalisatio*n.*

> *"I have been to many meetings with the doctors but because my English isn't good, I couldn't say what I wanted to say. They never had a translator there at the meetings for me" (C8; wife)*

Theme 3: Problems with how health professionals relate to carers

Nine carers and one patient with intellectual disability reported problems in the relationship between health professionals and carers. Carers criticised staff for not sharing information or consulting them about clinical decisions. The carer's knowledge of managing the patient's health problems was often disregarded by staff. Carers who were proactive in managing the patient's health care were regarded as "pushy" or over-protective. One paid carer reported feeling like a "piggy in the middle" between hospital staff and the relatives of the service user:

> *"We were sort of piggy in the middle kind of thing, going from him, speaking to his mum, and speaking to social services and trying to find out information from the hospital. It was very difficult to find out information from the hospital... And we are asking questions and they are very secretive, um, I understand the confidentiality aspects of it, but somebody needs to know what's happening" (C7; paid carer).*

> *"I had no idea when he could come home. I said to the nurse several times don't let the doctor (talk to him without me) 'cause of the time thing...I was*

> *livid, because I'd been there all night long with him and...I was none the wiser" (C4; mother).*

Carers reported not receiving copies of clinic letters and therefore had to ensure they attended appointments where important decisions were going to be made, which was not always practicable. Some carers felt embarrassed when their presence at appointments was questioned by staff who failed to understand why an adult may need to be accompanied:

> *"And then when you go in with your son they always look at you if to say God what sort of mother's like that, going in with a man that size." (C4; mother).*

Theme 4: Complexity of the health care system and lack of support for carers

Challenges in negotiating complex health care systems were discussed by 15 carers and nine patients with intellectual disability. Carers thought that it was important to be proactive, as they could not rely on health services taking the initiative in ensure that the patient's needs were met. Consultations were pressured for time. In particular, it was difficult to address concerns within the constraints of the ten minute slot allocated with the GP, which meant that this had to be carefully managed. Some patients with intellectual disability found it difficult to use a telephone based system. Mobility problems or cost of transportation made it difficult for some patients to attend hospital appointments. Carers had learned to manage the health care system over a number of years by acquiring knowledge of how different systems worked. Being articulate and knowledgeable about the patient's health problems was an advantage and usually led to more positive health experiences but carers also reported feeling intimidated because of lack of knowledge and being unable to question clinical decisions.

> *"I've had to learn it as a whole technique of how to manage it, what to do about it...So you have to learn to play the game, and that means information, using your own experience" (C5; mother).*

Several carers declared that managing the health care needs of the patient was emotionally draining and resulted in stress, poor emotional wellbeing, and exacerbation of health problems in the carer. Sometimes this led to certain health needs in the patient remaining unmet. Some carers had little support from family or services. Others were able to obtain valuable assistance from voluntary or advocacy groups.

> *"I think it's put a ceiling on what I can cope with so, for example, her teeth and her feet and toes. I think that's gone on longer untreated because I just can't cope with it any more. Any more appointments, any more processes, any more people to relate to, any anything" (C5; mother).*

> *"It's been very detrimental to my health, the last few years, the way he's been because it's not easy seeing your child suffering from a life threatening condition and not being supported" (C15; mother).*

Carers reported that they did not have the time or the confidence to make complaints. One carer reported that she had instigated a complaint four years ago but had not been resolved. Two carers reported that when they complained about poor medical care received by their loved ones, they received a minor acknowledgement that mistakes had occurred but no further action was taken. One carer reported that she had asked a solicitor to investigate further but could not afford the legal costs to pursue the case further. Patients were unlikely to complain because they did not know what the procedures were, or did not think that it would make a difference, or were worried that complaining could have an adverse impact on future care.

> *"We...put one in through the complaints system in 2008 and they then said we'll pass it on to the GP so it's the GP and now we're complaining about the GP...I know that when someone has life threatening and brittle asthma, like he has, they should be on a proper care path way because they suffer from co-morbidity issues. We've tried to get that from him and it's never happened" (C15; mother)*

> *"I don't know who to go to and would they listen" (P9).*

Discrimination from health services

Theme 5: Substandard care of people with intellectual disability

Twelve patients with intellectual disability and 14 carers gave examples of poor health care provision, including distressing or traumatic experiences. In many of the examples that were given, it is likely that the experiences were not specific to people with intellectual disability and that other patient groups could have had similar experiences, such as the elderly or those with physical disability. Examples included poor continuity of care such as inadequate follow up and being reviewed by a different doctor each time, leading to the prescription of incorrect medication and to unnecessary investigations; lack of adequate discharge arrangements from hospital such as an occupational therapy assessment of the home; and investigations and treatments being delayed or lacking altogether. Sometimes carers had to be persistent in negotiating with the clinicians for investigations to be conducted. In one case, the carer alleged that the patient's behavioural difficulties were misattributed to her intellectual disability, resulting in the doctors refusing to investigate further. This led to a serious medical diagnosis (spinal cord compression) being missed, culminating in permanent irreversible neurological damage.

> *"They were ignored all of the time they were in there. It took about eight weeks for a diagnosis and in that time they were trying to get them back home, sort of not looking into anything else, assuming that it was them not being compliant. But actually there was a serious underlying problem, in which they didn't do a ...an MRI scan" (C7; paid carer).*

Concerns were also reported about the neglect of basic needs on hospital wards, such as staff not responding to requests of support to use the toilet because they were too busy. Sometimes this had long term consequences for the patient.

> *"Too busy to see to you right now, If you pressed the buzzer...it would be a couple of hours until somebody came round...Or if they wanted to go to the*

> *toilet...it wasn’t for another hour, an hour and a half until somebody came back to do that. The result of that has been reduced continence...they were left to just soil themselves. And now that’s become a habit, and now they’re back in their own home, it’s a thing we’ve got to work on” (C7; paid carer).*

Half the participants thought that the patient had been discriminated against or treated poorly because of their intellectual disability.

> *“My Nan sort of had diabetes as well, but you could see the way they talked to her and the way they talked to me, it was completely different” (P9).*
>
> *“But I do feel, I never thought of it before, but would a man at 23 have had all...he wouldn’t have had the same treatment. I think of my brother for instance, if something like that happened to him he wouldn’t put up with that” (C 4).*

Some participants acknowledged that patients with intellectual disability were inadvertently treated poorly because staff had misjudged, or had limited awareness of the patient’s abilities and needs. Few health services made reasonable adjustments to accommodate the person’s needs, such as the provision of additional support when patients were admitted to hospital.

> *“I can’t remember which hospital it was but they gave him the menus but he didn’t know how to complete the menus...no one explained to him... so when his dinner came it was like a slice of toast...they just gave him the menu and left him to it. Two minutes of someone sitting there saying, do you want a hand mate”(C 4; mother).*
>
> *“Another time when she stayed in hospital... she had quite an upsetting time...they didn’t provide her with a box to put her (insulin) needles in what so ever, so she left them on the table and a nurse pricked herself and she wasn’t very nice to her about it and that obviously upset her...She can appear very*

> *capable and very normal and they just sort of take that for granted without really knowing her and finding out her needs" (C9; mother).*

In some circumstances, both carers and patients with intellectual disability did not think they were treated differently, and acknowledged that at times, everybody was treated poorly. However, the patient's lack of understanding about their care meant that they were likely to perceive their treatment differently and more negatively compared to someone without the same difficulties.

> *"The thing is we've had some terrible things happen...um... but I don't know if you'd say that they've been worse because of his difficulties... anybody would have experienced it, but for him I think it was more traumatic, so to be fair I don't think in most cases we were treated differently but because of his lack of understanding it, it upset him more" (C4; mother).*

Many participants reported reluctance about returning to hospitals or GP surgeries because of the poor treatment that they received. Some patients were able to change their hospital to one which was perceived to be better. Some patients simply refused to attend appointments but others felt that they had no choice but to return to the service.

> *"Well you stop using them...you think they weren't helpful last time, what's the point in going and sometimes you have to work on your thinking and say well give them another chance. Like you do with the GP, you have a barrier wall but you still have to go, but for some people the barrier stays up for such a long time and they miss out and that's wrong" (C15; mother).*

Theme 6: *Problems with staff attitudes, knowledge and behaviour*

Five patients with intellectual disability and nine carers recalled incidents when health staff had been impolite or unfriendly towards them. Accounts included being spoken to in an abrupt or condescending manner, staff appearing unwelcoming, using insulting language or appearing disinterested.

> *“It’s like, (they) come into your room for just a second and they talk to you sometimes like you’re a five year old” (P7).*

> *“One of the hospitals, I was waiting around to see a chiropodist and I was waiting for two hours, so I asked the receptionist and I said when am I going to be seen. She said well they keep putting you down on the bottom of the list, they look at your file and keep on putting you down on the bottom of the list, it’s like they don’t want to see you” (P9).*

> *“It’s like you’re not really there and sometimes they don’t even look at you and acknowledge you properly. It’s like everything else is much more important than anything else you have to say… I felt like they sort of look down on you a bit, it was like we know what we’re doing, you don’t need to know” (C7; paid carer).*

Several carers remarked that they were surprised and astounded at the lack of knowledge that some members of staff had about conditions associated with intellectual disability such as epilepsy:

> *“Well it’s a seizure, and he stood there, actually solid, like that, and there was a nursing assistant walking past, and I said he’s seizing, and she said, no he’s not…Their only knowledge of a seizure is the sort when you roll around on the floor, so I thought they’re very ignorant about it...I didn’t think that nurses wouldn’t know what seizures looked like. It just never dawned on me” (C4; mother).*

> *“He probably doesn’t know or isn’t interested about learning difficulties, he’s a medical practitioner...I don’t know if as a doctor, if he’s heard about autism and Asperger’s syndrome, perhaps they’re difficult, but you kind of think I wonder if they had because they’re certainly not helping him out in anyway” (C1; mother).*

Good practice

Theme 7: Examples of good practice and improvements in services

Twelve patients with intellectual disability and 13 carers discussed examples of good practice from health services. Higher levels of satisfaction were associated with staff who had gone “beyond the call of duty” to accommodate the needs of patients.

> *“She actually went for an overnight stay and she got very distressed because she went there and she had forgotten her injection...she was so distressed about it so I said go to the ward and explain to them, and when they did, they were so nice... And obviously they could see her needs, they took the time to show her around where she would be staying, and they made another appointment, and you know, she was a different person then because she knew they understood” (C9; mother).*

Other examples included good communication skills, friendly and helpful staff and situations where both the patient and carer felt respected. There were also a few examples of the health care system being flexible and accommodating towards the needs of people with intellectual disability, such as offering longer appointments.

> *“It was the first time that a doctor had ever spoken directly to her and although they’ve always been really nice and helpful, he actually just addressed her only and then only looked at me for support, you know, if she was struggling for an answer. And I just thought he was absolutely amazing, he was so respectful to her and that was really good” (C2; mother).*

There were examples of good care being provided, including GP health checks (completed for half the patients participating), with GP surgeries taking the initiative to arrange these, and the provision of health promotion strategies by community services. There were also examples of good transition of care from children to adult services, good continuity of care, examples where help was obtained quickly and services providing support to carers and patients with intellectual disability. A few carers also commented that there were aspects of health care that were improving, although there was still some way to go:

> *"I think that's (inpatient care) got better because they give you a care plan and you answer loads of questions and I think that's got better, saying that we had the menu thing so that means no one actually looks at the care plan" (C4; mother).*

When participants were asked whether they thought that health care had improved in recent years, some responded that either their experience had remained unchanged or had become worse. A few thought that legislative changes in the UK such as the Disability Discrimination Act and the Mental Capacity Act were confusing and did little to improve or clarify things.

> *"I do think it's all paper work, and you know, you have guidelines to go by and they're sort of fixed on them and um, they have to be aware of them obviously and I don't know if they really stick to them. I think it's all about ticking boxes" (C9; mother).*

Theme 8: Suggestions for improving care

Eight patients with intellectual disability and nine carers provided suggestions for improvement. Several participants commented that health services could be improved if they provided information in an accessible and easy to read format, or if patients were provided with a health passport or a communication book that enabled clinicians and carers to communicate changes in the treatment plan. Several of the carers commented that services needed to make reasonable adjustments to accommodate the needs of people with intellectual disability. This included people with intellectual disability being invited to see a ward prior to a surgical procedure, and being prioritised in some instances, to avoid having to wait too long during appointments. Other carers suggested computer records should highlight that the person has an intellectual disability in order to alert staff.

> *"I think yeah, one of the things would be, when you go into a doctor's surgery, as far as I know if a person's diabetic, it comes up, why not have the same sort of thing, this person has got a learning disability... why not flag it up and maybe there's somewhere they can sit, or to think, perhaps it doesn't matter if you let them go in before someone else, if the situation is stressful" (C1; mother).*

Several participants suggested that staff needed to have better knowledge and training in communication skills and conditions that are relevant for people with intellectual disability. Several participants thought it was important that staff had better awareness of individual needs, including more person centred care.

> *"I think it's all down to understanding people really, you know because everyone's so individual and their needs are so individual and unless people are aware of their needs. You know it's easy to mark someone with special needs but do they know their special needs, the most important thing is awareness" (C9; mother).*

A few people suggested that this training would be best delivered by involving patients or carers. Suggestions were also made about having access to a hospital liaison or link nurse with expertise in intellectual disability, who could give advice to clinicians, or patients should be provided with an advocate.

> *"Maybe go on courses to learn how to treat people with disabilities properly. Maybe have training sessions with a person with disability actually involved so they know how to treat them...I think it would be good because the way I've been treated, I don't want other people treated the same. I don't think it's right" (P9).*

> *"There should be somebody in every hospital, where some adult or a child with a learning disability is admitted, someone who is an expert could go and assess the situation and may be stay with the person if they haven't got someone and be their advocate and someone who actually knows what autism is like and what dyspraxia's like so they can" (C4; mother)*

Comparing themes between patients and carers

Between group comparisons

The themes that were most reported by patients were problems with communication and examples of good practice, followed by the substandard care of people with intellectual disability, and problems with the complexities of the health care system. For carers, the most prevalent themes were complexities of the health care system and lack of support for carers, and the substandard care of people with intellectual disability. The least reported themes for both patients and carers were problems with staff attitudes, knowledge and behaviour and problems with how health professionals relate to carers.

Box 3.2: Summary of themes and subthemes

Topic A: Barriers to health care access

- Theme 1. Problems with communication
- Theme 2. Problems with accessing help
- Theme 3. Problems with how health professionals relate to carers
- Theme 4. Complexity of the healthcare system and lack of support for carers

Topic B: Discrimination from health services

- Theme 5. Substandard care of people with intellectual disability
- Theme 6. Problem with staff attitudes, knowledge and behaviour

Topic C: Good practice

- Theme 7. Examples of good practice and improvements in services
- Subtheme 8. Suggestions for improvement

Comparing the agreement in the themes within individual dyads

The number of themes that were referred to by both the carer and patient with intellectual disability in each dyad was compared (Table 3.3). Reference was made to at least six themes by both the carer and patient in four dyads (dyads 3, 4, 7 and 9). Agreement within the dyads in the themes did not necessarily mean agreement in the accounts given by the patient or the carer. For example, in dyad 1, both the carer and patient with intellectual disability commented that the GP’s communication skills were inadequate. However, the patient reported that accessing support had been uncomplicated, whereas his carer reported that eligibility issues had made it difficult to access services. Further examples are given in Table 3.3. Eight dyads showed agreement in accounts, three showed disagreement in accounts and three were mixed (both agreements and disagreements).

Table 3.3: Examples of agreement and disagreement in the accounts given by carers and patients within each dyad

Dyad number	Number of themes referred to by patient	Number of themes referred to by carer	Number of themes referred to by both carer and patient	Examples of agreement in accounts by carer and patient	Examples of disagreement in accounts by carer and patient
1	5	8	5	Poor communication skills of GP	Accessing help perceived to be easy by patient and difficult by carer; patient satisfied with health check but carer dissatisfied.
2	2	6	2	High levels of satisfaction with health services; staff perceived as friendly and respectful	None
3	7	7	6	None	Patient reported negative attitudes of health professionals and staff not modifying communication skills
4	7	7	6	Distressing experiences in hospital; poor knowledge of staff about epilepsy/ID; staff failing to modify communications skills; staff not consulting with carer	None
5	3	8	3	Staff not talking directly to patient; examples of good practice and friendly/helpful staff	None
6	6	4	4	Positive experiences of primary care and community services	None
7	7	8	7	Staff not spending time with patient on ward and not respecting patient; patient and carer not informed/consulted.	Patient dissatisfied with length of hospital admission but carer thought this enabled discharge arrangements to be made

Table 3.3 continued...

Dyad number	Number of themes referred to by patient	Number of themes referred to by carer	Number of themes referred to by both carer and patient	Examples of agreement in accounts by carer and patient	Examples of disagreement in accounts by carer and patient
8	5	5	4	None	Patient satisfied with input from primary care but carer dissatisfied (GP refusing home visits, not investigating health complaints)
9	7	7	6	Satisfaction with primary care; less satisfied with hospital care; examples or poor care and good practice.	None
10	6	5	4	None	Patient satisfied with input from primary care but carer dissatisfied (difficulty in arranging home visits, concerns not taken seriously by GP and carer not consulted)
11	6	4	4	Poor experience of inpatient care and Accident and Emergency department.	Some services perceived to be better by carer and advocate but not by patient
12	2	4	1	Positive experience of primary care and community services	None
13	1	7	1	Health professionals failing to talk directly to patient and not involving patient in discussions	None
14	3	5	3	Satisfied with care received from primary care and hospital services	None

Discussion

Summary of findings

In this study, the experiences of health care for physical needs were examined from the perspective of patients with intellectual disability and their carers. A number of patients felt that they were discriminated against, or treated differently because of their intellectual disability. Some of these experiences were due to direct discrimination resulting from negative staff attitudes towards patients and carers and failure to treat patients with respect and dignity. Other experiences were due to indirect discrimination arising from lack of staff awareness of patients' needs, and health services failing to accommodate the needs of people with intellectual disabilities.

Barriers in accessing health services included communication difficulties experienced by patients with intellectual disability due to staff failing to speak directly to them or failing to modify their communication skills; problems accessing services due to lack of information about the availability of local services; poor transition of patients from child to adult services; failure of GPs to refer patients to specialist services; and failure to provide interpreters to non English speakers. Other barriers included lack of support and involvement of carers in health care decisions.

Many of the participants reported examples of good care and improving practice, such as being invited for health checks, suggesting that some of the initiatives to improve health care access have been successful, although further progress was required. A number of suggestions were made about improving care, including the provision of more training for staff in communication and awareness of the needs of patients with intellectual disability; services making reasonable adjustments to support people with intellectual disability such as the provision of accessible information, use of a health passport or communication book; and measures to improve staff attitudes towards people with intellectual disability.

Results in the context of other studies

Many of the findings of this study are similar to that reported by previous studies, and are discussed below

Barriers to healthcare access:

Problems with communication

The patients with intellectual disability in this study were particularly concerned about the failure of doctors to communicate directly to them and to involve them in decision making. Other studies have reported similar findings (Jones et al, 2008; Wullink et al, 2009; Ziviana, 2004). Very few people in this study were given information in an accessible format, which have also been reported in other studies (Dinsmore, 2011; Gibbs et al, 2008). There were a number of times when informed consent was clearly not obtained prior to a medical procedure. Langhan et al (1994) found that only about 65% of carers thought the GP was very good at explaining health conditions to a person with intellectual disability or gave them enough time.

Problems accessing help

Five patients with intellectual disability (third of the sample) had not been referred (or experienced delays in referral) to specialist services for people with intellectual disability, and that their carers had little knowledge of such services. Ziviana (2004) also reported that GPs failed to refer patients to appropriate services. Possible reasons for this include GPs lacking knowledge of resources and services relevant for people with intellectual disability (Martin, Roy & Wells,1997), GPs not being aware of the individual’s intellectual disability even though keeping a record of everyone with intellectual disability is part of the Quality and Outcomes Framework**,** and issues related to work load.

About half the participants in this study reported that they had health checks by their GP. This is similar to UK national statistics of 49 per cent of people with intellectual disabilities receiving a health check between 2010 and 2011 (Emerson et al, 2011). Dinsmore (2012) identified that one of the barriers to uptake was lack of awareness of the benefits of a health check amongst individuals with intellectual disability.

South Asians were particularly likely to experience problems in accessing health care. The problems were compounded by language difficulties, which made some carers feel that they were being excluded from consultations. A number of carers reported that services did not routinely use interpreters. One carer reported that she was denied an interpreter because staff thought she was undeserving as she had not bothered to learn to speak English. Such families are often deprived, isolated, and experience racism, language barriers and high levels of stress, and are less likely to be knowledgeable about intellectual disability and services (Mir et al, 2001). Ward et al (2010) also reported the failure of services to provide interpreters and translators to Spanish and Haitian participants in their study.

Problems with how health professionals relate to carers

A number of carers reported dissatisfaction with the lack of information that was provided to them by health professionals, particularly on hospital wards, or the lack of involvement in clinical decisions. These issues have also been reported in previous studies (Dinsmore, 2011; Gibbs et al, 2008; Webber et al, 2010). One paid carer in this study reported that staff were particularly reluctant to share information with her as she was not a relative, even though she was the patient’s primary carer. Paid carers may therefore encounter additional difficulties where services are reluctant to disclose information because of confusion around confidentiality and who should have access to information.

Complexity of the health care system and lack of support for carers

Patients with intellectual disability frequently rely on their carers to identify health problems and to facilitate access to health care, particularly where there are communication difficulties affecting the expression of needs. Carers who were more proactive, articulate and had good knowledge of health conditions were more likely to be able to access appropriate health care. They were also more likely to complain if they were dissatisfied with services. However, carers who were less articulate and less knowledgeable were more likely to rely on health professionals to actively identify and manage the service user's health problems. This meant that health problems were often not identified or treated. Minnes & Steiner (2009) also reported that carers frequently had to be proactive in getting the right support. Low educational attainment and limited knowledge in carers is also likely to affect whether individuals with intellectual receive the right care (Ziviana, 2004).

Several carers in our study reported health problems, including depression. McGrother et al (1996) reported that carers of people with intellectual disability had a 40 per cent higher prevalence of health problems, and were four times as likely to be suffering from depression, compared to the general population. Some of the family carers in our study admitted that this meant less urgent health needs in the patient were ignored and therefore remained unmet. Some carers reported that they had no access to emotional and financial support, and that carer assessments by social services had been delayed or not offered.

Carers from a South Asian background were particularly likely to report lack of support. Families from minority ethnic communities may encounter double discrimination as a result of having a member with intellectual disability, and having to endure racial discrimination and culturally inappropriate forms of care (Azmi et al, 1997; O'Hara, 2003). The stigma of having a child with intellectual disability may lead to carers feeling marginalised by their community, and even being blamed for the child's disability by their own families (Fazil et al, 2002).

There are also misconceptions among service providers that South Asian carers are more likely to be supported by members of the extended family (Ahmad & Atkins, 1996), which may be a reason why support is not always offered. In fact, studies show that these carers receive little support from their families, and that other types of informal support, such as that provided by support groups, temples or mosques play only a minor supporting role (Hatton et al, 1998; Hatton et al, 1997; Emerson &

Robertson 2002). In addition, health professionals may hold negative or discriminatory attitudes towards this group. South Asians are more likely to receive a delayed diagnosis for medical problems because their concerns are disregarded. Views about consanguineous marriages causing genetic problems, and even intellectual disability, may result in health professionals appearing unsympathetic. This may alienate families and make them reluctant to approach health services for assistance (Butt & Mirza, 96; Baxter 98, Mir et al, 2001).

Discrimination from health services:

Substandard care of people with intellectual disability

Many of the participants reported accounts of poor care, although some of these difficulties were not specific to people with intellectual disability. Although there were only a few examples where participants perceived overt discrimination, there were many examples of indirect discrimination resulting from services failing to make reasonable adjustments to accommodate the needs of people with intellectual disability. Examples included not being able to read food menus and lack of assistance with toileting. These issues have also been reported by other studies (Fox & Wilson, 1999;Iacano & Davis, 2003; Webber et al, 2012). Other studies have also reported carers' concerns about the neglect of people with intellectual disability on hospital wards (Gibbs et al, 2008).

There was at least one example of diagnostic overshadowing where the carer specifically stated that investigations were not performed because clinicians attributed the patient's difficulties to her behavioural problems. This patient in fact had spinal cord compression, which is a medical emergency. Delays in treatment led to this individual experiencing permanent neurological impairment and to a significantly poorer quality of life. There were other examples where patients did not receive investigations or had experienced delays in treatment. Diagnostic overshadowing has been reported in other studies (Dinsmore, 2012; Disability Rights Commission, 2006; Webber et al, 2010).

It is therefore not surprising that a recent survey by the General Medical Council of 1084 health professionals (ICM poll of doctors- unpublished research) found that 45% of doctors and a third of nurses had reported that they had witnessed a person with intellectual disability being treated with neglect or lack of dignity, or had received poor quality of care. In addition, 39% of doctors and a third of nurses believed that people with intellectual disability were discriminated by the NHS.

Problems with staff attitudes, knowledge and behaviour

There were a number of examples reported by patients with intellectual disability and their carers of inappropriate staff attitudes. Lewis & Stenfert-kroese (2010) found that general hospital nursing staff reported less positive attitudes and more negative emotions in response to caring for people with intellectual disability compared to patients with a physical disability. Other studies have reported a lack of empathy and staff who were indifferent to the needs of people with intellectual disability (Dinsmore, 2012; Webber et al, 2010). There were also concerns about the lack of staff knowledge about issues relevant to people with intellectual disability, similar to previous studies (Dinsmore, 201; Iacano & Davis, 2003; Webber, 2010).

Good Practice:

Examples of good practice

There were some examples of services making reasonable adjustments, such as providing longer appointment slots, and inviting patients to see the ward before surgery. Webber et al (2010) found that positive experiences were associated with hospitals that had clear policies, resources and systems in place to address the needs of people with intellectual disability, including effective discharge planning and provision of training to staff (Webber et al, 2010).

Suggestions for improvement

Many of the suggestions for improvements were for practices that should already be implemented by health services. These included the use of a communication passport, having a liaison nurse at hospitals that provided advice and expertise on intellectual disability, and better training for staff. Other studies have made similar recommendations (Dinsmore, 2011;Langhan, 1994; Ziviana, 2004; Webber et al, 2010). None of the participants mentioned that they had spoken to a liaison nurse during recent hospital admissions.

The survey conducted by the General Medical Council of over a 1000 health professionals (ICM poll of doctors- unpublished research) also reported that a third of health professionals had not received training on how to make reasonable adjustments for patients with intellectual disability, and over half the doctors and 68% of nurses reported that they needed specific training on how the care of someone with intellectual disability should be modified to meet the needs of patients with intellectual disability. Other studies have also reported that nurses and therapists frequently lack knowledge and confidence when caring for people with intellectual disability (McConkey & Truesdale, 2000; Sowney & Barr, 2006, 2007).

Strengths and limitations of study

The use of dyads has provided a rich and detailed picture of health experiences from different perspectives, including similarities and differences in perspectives. Although efforts were made to conduct separate interviews with patients and carers, the carer was present in half of the interviews with patients, which may have influenced the nature of the issues that were discussed. In joint interviews, carers were advised to allow patients to voice their opinions and not to interrupt where possible. Another disadvantage of joint interviews is that personal or sensitive information may be divulged by one participant, which could put the other participant at unease. However, in separate interviews there is also the possibility that confidentiality may be compromised, for example if the patient is informed about discussions that took place with their carer (Eisikovitis & Koren, 2010; Kendall et al, 2009). To prevent the breach of confidentiality, neither the carer nor the patient was given information about the other person’s interview.

This study found that in over half the dyads, carers and patients agreed with each other in the themes and accounts that were given. The comparability of findings between two or more groups may be considered as a form of triangulation, which is an assessment of whether the findings are valid. However, some researchers regard triangulation as an approach to ensuring that data collection and analysis is comprehensive and reflexive, rather than as a test of validity (Mays & Pope, 2000). There were some disagreements in the accounts given by carers and patients. One explanation is that the differences in opinion reflect the different roles and experiences of patients and carers. The patient's level of cognitive development will also influence the extent to which he or she is able to process and internalise their health care experiences and differentiate between good and inadequate healthcare.

A further strength of the study is the relatively large sample size, as previous qualitative studies investigating health experiences have included fewer participants. Patients from a range of different backgrounds with mild or moderate intellectual disability, and varying physical and mental health needs, were included, which provided a diverse sample and a range of different perspectives. There was a relatively large sample of participants from the South Asian community, and the study provides further insight into the experiences of this group. Participants were also recruited from a number of different settings and locations.

One of the limitations of this study is that almost all of the carers were female and were largely informal carers (parents and partners). The health experiences of male carers and paid carers may be very different. There were no participants from Black African or Caribbean backgrounds or Chinese backgrounds, and the views of service users with severe and profound intellectual disability were not considered in this study. The issues raised in this study were also influenced by the interview schedule, which may have limited the exploration of other issues. In addition, the participants who agreed to take part in the interviews may have had more health problems and more negative experiences of health care. Some caution also needs to be given to interpreting that incidents of poor care were due to the patient's intellectual disability. In the absence of experimental research, we can only conclude that these were perceptions rather than conclusive evidence. It should also be noted that the primary researcher's professional and personal background (South Asian, female psychiatrist) would have subjectively influenced the research questions and the analysis of the data, and this is discussed in the next section.

Reflexivity: My reflections about the conduct of the study

My motivations, assumptions and interests (personal and professional) have substantially influenced this study from the nature of the research questions, the development of the interview schedule, the data that was collected to how the transcripts were analysed and interpreted.

Pre-research stage

My professional role as a psychiatrist for people with intellectual disability has exposed me to some of the difficulties that this group encounter. On several occasions I became concerned about the poor quality of medical care that my patients had received from primary care or secondary care and I found myself advocating on their behalf. I particularly remember one young gentleman with autism, attention deficit hyperactivity disorder and severe learning disability, who had lost a significant amount of weight due to excessive vomiting. His family eventually took him to the Accident & Emergency department where the medical team reluctantly admitted him to one of the wards. However, when I visited him several days into the admission, I was astonished to find that not a single investigation had been conducted, including a blood test. His mother had received little information or support, and it was apparent that his placement in a side room was to prevent him from disturbing staff and other patients, rather than for his own benefit. After some lengthy discussions with the medical team who were quite dismissive and very eager to discharge the patient, they eventually agreed to arrange some investigations. Experiences such as this made me question whether health services were equitable for people with intellectual disability, and to what extent health professionals exhibited discriminatory practices. At around the same time, there were a number of reports (DRC, 2006 and Mencap 2007) that highlighted the inequalities experienced by people with intellectual disability in accessing health services.

These views undoubtedly shaped the research question, and to some extent the interview schedule that was developed. In addition, having a medical background meant that thematic analysis as a form of analysis was more intuitive to me, than more interpretative forms of analysis, which require more knowledge of sociological theories. I also held some assumptions and preconceptions about what the data would reveal, and made conscious effort not to allow these to interfere with the data collection phase and analysis of the data.

Data collection phase

During the data collection phase, there were a number of issues that could have influenced the nature and quality of data. The use of dyads made it more challenging to recruit participants into this study, as sometimes individuals with intellectual disability agreed to be interviewed but they could not identify a suitable carer, or carers agreed and the service user did not. However, the £20 gift voucher did incentivise some participants to take part, although this meant that some participants only took part for the voucher and not because they wanted to express their opinion, which resulted in the interviews being quite short and lacking in depth of material.

Some participants were motivated to take part because they believed that this study could lead to potential improvements in health services. One carer was keen to explain that she did not want to waste her time speaking to me if nothing happened. It was difficult to manage such expectations, especially since I could not guarantee that this study would be published, let alone influence health policy.

I was consciously aware of the possibility of a power imbalance between myself and the participants, particularly given my professional background. I tried to ensure that a non judgemental approach was used. I was also not responsible for the clinical care of the participants with intellectual disability, which could have led to some participants feeling coerced into taking part.

My background as a female of South Asian background had a number of advantages. I was able to reach participants of South Asian background who would not normally have participated in research. They were able to trust me and thought that I was sympathetic and understanding of their circumstances. Being female allowed many women to talk freely and openly to me, which they may not have done if I was male. Conversely, there were some disadvantages of being female and South Asian. Males (particularly South Asian males) were more reluctant to talk to me, possible because of cultural factors relating to the disapproval of females and males mixing. In addition, my prior knowledge of some of the issues that may affect South Asians might have led to me being less thorough in my questioning. There were also times when I was reticent about asking certain questions because I assumed it would be “too sensitive”.

There were several challenges during the process of interviewing. It was not always easy to ensure free flowing conversation, particularly when the respondent gave short answers. This was particularly an issue in the interviews with participants who had intellectual disability. I found myself frequently using closed questions as it was difficult to elicit responses using open questions. I also had to be conscious of the possibility of suggestibility and acquiescence bias during these interviews.

Managing interviews where the carer was present at the patient’s interview, also presented challenges. Some carers were keen to voice their opinion, and this may have deterred some patients from volunteering information. There was one interview where the carer was so keen to help that she took over the entire process and started to ask all the questions. I felt somewhat redundant, and was able to appreciate how some patients with intellectual disability must feel when they are ignored during consultations.

When I reviewed the audio-recordings, I was disappointed by my performance in the first couple of interviews. In these interviews, I had frequently interrupted the participant, and failed to recognise opportunities to explore certain issues further. I was disappointed because as a psychiatrist, I am expected to be a good listener, and I had clearly not utilised my listening skills. However, I was quite anxious during the early interviews and my interview skills did improve notably as I became more experienced in conducting them.

One of the carers disclosed after the interview that she had been having some marital problems, and interpersonal difficulties with her children. She had no one to turn to and had felt isolated. I listened to her concerns and provided some general advice about where to seek help but I felt powerless to help her. I was quite overwhelmed by some of the difficulties that many of the carers faced. Many were single mothers, or had very little support, were living in extreme poverty or had been ostracised by their community. Despite these challenges, they somehow managed to remain grounded. I was particularly inspired by one South Asian carer who acted as an advocate for some of the other South Asian carers. She provided support to other carers on a voluntary basis, but it was clear that this support had made an immeasurable difference to the lives of these women. Before they met her, one carer declared that she had not been able to get carer's allowance because no one had supported her to complete the application form. It made me appreciate the importance of acts of kindness. I enjoyed listening to the stories and narratives that each participant contributed.

Participating in research can also affect participants. One carer reported that after I had advised her to consult her GP about her husband's health needs and that he had not received input from services after attending a special school, the GP, who had previously been quite dismissive of the family, finally carried out a home visit. It appears in this case that the GP was not aware of the participant's intellectual disability. She thanked me and said she was grateful for the advice. I contemplated how many other families were in a similar situation because they simply did not have access to the right information. Another carer, after listening to her daughter talk about her desire to be spoken to directly by doctors and to be informed about health care decisions, came to the realisation that she had been over protective. It struck me how surprised she was to hear her daughter express such a strong opinion, and the emotional effect that this had on her. She was determined to make amends at future appointments.

Analysis and interpretation of the data

The process of analysis was laborious and quite frustrating at times. I did not have the time to send the transcripts to all the participants for checking. I only achieved this for a third of the participants. In addition, at the time of writing the thesis, the results have not been discussed with the participants, although I plan to provide feedback in the form of an accessible leaflet. This may have affected the validity of the findings.

There were some differences of opinion in the way the codes and themes should be identified and named, which meant that the data had to be re-analysed a couple of times. However, my supervisor and I were mostly able to agree on a consensus, and I appreciated the support and guidance that I received. I did struggle to identify new and novel themes and insights into patient and carer experiences of health care, but I think this was largely because of the data that I had, and because there have been a number of recent publications on this topic. I believe that my results reflected the data, and the validity and reliability analyses support this. However, there is still likely to be some subjectivity in the analysis and interpretation of the data, resulting from personal experience, biases and assumptions.

I was surprised by the number of people who made positive comments about accessing health care. I had the preconceived notion that more participants would be dissatisfied with health care access, and that there would be more incidents of discriminatory treatment. Perhaps this reflected changes in healthcare professionals' attitudes and awareness of the needs of people with intellectual disability. However, I also felt that some participants had low expectations of health services, and perhaps were not fully aware of what services were available for them.

The process of conducting qualitative research, analysing, interpreting and writing up the results made me appreciate the amount of time and effort that is required to ensure that the process is rigorous and transparent. In many ways, I found the qualitative study more challenging than the cross sectional study, perhaps because it was outside my "comfort zone" as I had limited previous experience. However, I have gained new skills that I hope will give me the confidence to conduct qualitative research in the future.

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Chapter Four: Summary of results, implications of findings and future directions for research

Summary of Results

Two studies were completed as part of this PhD project. Both of the studies examined an important aspect of stigma and discrimination. The first study was a cross sectional study that explored the relationship between self reported stigma in participants with intellectual disability and a number health outcomes. This study demonstrated that higher levels of self reported stigma was associated with higher levels of psychological distress, a lower quality of life, and a higher utilisation of services, particularly community intellectual disability services and contacts with the Police. There was also some evidence supporting the association between higher levels of self reported stigma and poorer adherence to medication. The relationship between stigma and the outcome variables appear to be mediated by psychological distress. However, participants reporting higher levels of stigma were more likely to refuse at least one service offered to them in the last six months, which may suggest that although self reported stigma is associated with higher service utilisation, the services offered to individuals with intellectual disability may be perceived to be inappropriate by these individuals, which may lead to the excessive use of other services. For example, individuals may make frequent contact with their social worker or community nurse but fail to engage with day services. The association between self reported stigma, service use and adherence to treatment requires further investigation in order to identify the different mechanisms at work.

The second study was a qualitative study exploring the extent to which people with intellectual disability and their carers experience discrimination and other barriers when accessing services for physical health problems. The study suggests that although some aspects of care had improved as a result of government legislation and initiatives (e.g. number of people receiving health checks), there were still reports of poor quality of care. In particular, there were a number of examples of indirect discrimination by the failure of services to make reasonable adjustments, such as failing to provide accessible information and longer appointment times and lack of individualised care. In addition, other barriers, such as clinicians failing to modify their communication skills to suit the needs of patients, and failure to provide interpreters to non English speaking carers, may be contributing to indirect discrimination. There were also a few examples of direct perceived discrimination from health professionals and accounts of negative attitudes and behaviour from health professionals. It is perhaps surprising that self reported stigma was not associated with use of mainstream health services such as primary care and hospitals in the cross sectional study (apart from a borderline association between perceived discrimination and Accident & Emergency department visits). Instead, self reported stigma was associated with more visits to community intellectual disability services. One reason for this may be that service users who access these services are more aware of their disability (e.g. through accessing daycentres where they interact with people with intellectual disability). Alternatively, health and social care professionals at community intellectual disability services may be contributing to the stigmatisation of people with intellectual disability (e.g. by talking to service users in a condescending way or being over protective). However, it is more likely that people with intellectual disability who report higher levels of stigma, are using these services because of increased psychological distress. It is therefore reassuring that people who are experiencing psychological distress are accessing community intellectual disability services, rather than making more frequent visits to their GP or Accident & Emergency Department, who may be less equipped to deal with the needs of this group, and could exacerbate feelings of discrimination. It is therefore paramount that community intellectual disability services take a central role in understanding and managing the psychological distress associated with stigma, and ensure that they provide appropriate and acceptable services.

Implications of the Cross sectional study

This study suggests that stigma and discrimination against people with intellectual disability, who do not have identified mental health problems, is associated with poor health outcomes such as lower psychological wellbeing. The findings of this study provide further support that stigma may be a contributory factor in the aetiology of health problems, and should be regarded as a social determinant of health inequalities. There is evidence from longitudinal studies (of people without intellectual disability) that bullying and victimisation may have enduring effects on mental health and wellbeing. One study found that children who were bullied or victimised at school had an increased risk of later psychiatric hospitalisation and were more likely to be prescribed psychotropic medication. This association remained in females after controlling for severity of symptoms (Sourander et al, 2009). The effects of stigma on psychological wellbeing in people with intellectual disability may therefore persist, even after a reduction in the levels of self reported stigma.

This study also suggests that self reported stigma may be a burden on services in terms of costs arising due to frequent contacts with staff. Stigma may reduce adherence to treatment and therefore contribute to inadequate treatment response and delay recovery in individuals, which may also result in additional costs to services. Some individuals may also refuse services that they require. The effects of stigma on these health outcomes are mediated by psychological distress. It is therefore paramount that services become better at identifying people experiencing psychological distress as a result of stigma. The implications of the study are summarised in Box 4.1.

Service users' experiences of stigma and discrimination are frequently not discussed by health and social care professionals, and rarely considered to be an important contributory factor in their presentation of mental or physical health problems (Craig et al, 2002). This may be because professionals find it uncomfortable to talk about this particularly sensitive topic and may be concerned about service users' reactions to their enquiry. One study found that only nine out of 31 professionals regularly spoke to their service users about their intellectual disability. Twenty one respondents thought service users may find it difficult to talk about their disability (Craig et al, 2002). It may be necessary to provide training and support to health professionals in order to increase their confidence in engaging in such conversations.

The stigma questionnaire and a screening measure for psychological distress could be used to identify individuals at risk. These individuals could then be offered a further assessment of their wellbeing, and those with moderate to high levels of psychological distress resulting from self reported stigma, could then be offered therapeutic assistance in the form of counselling and psychological therapy.

Currently, there have been no studies of interventions to reduce the impact of stigma in people with intellectual disability. Studies of stigma reducing interventions in people with mental illness have used a number of different approaches including individual and group based psycho-education, cognitive behavioural therapy, social skills training or a combination of different strategies. Interventions have focussed on two different approaches. One approach has been to modify the self stigmatising beliefs and attitudes of the individual, and the second approach has been to enhance the skills in coping with self stigma by improving self esteem, empowerment and help seeking behaviour. The second approach has become the preferred approach (Mittal et al, 2012). Interventions in people with intellectual disability could also focus on the development of resilience through improving self esteem, empowerment and the development of appropriate coping strategies. However, further research in this area is warranted. Such interventions could prevent individuals from developing mental health problems such as depression, and could help reduce excessive utilisation of services in the future. In addition to interventions aimed at reducing the psychological distress associated with stigma, anti-stigma campaigns need to be directed at the public in order to reduce social stigma towards people with intellectual disability. These could include more targeted interventions directed at specific groups such as health professionals, police officers or school children.

Implications of the Qualitative study

The qualitative study has highlighted the need for further improvements to health services in order to facilitate better access to health care for people with intellectual disability. In particular, the study suggests that discrimination of health services towards people with intellectual disability is one of the key barriers affecting access.

Key areas that need to be tackled include improving the knowledge and attitudes of health professionals towards people with intellectual disability and reducing indirect discrimination through the provision of reasonable adjustments to services. Although there were some examples of services making reasonable adjustments, such as provision of longer appointment slots, and inviting patients to visit the ward before surgery, further progress needs to be made to ensure that health services are tailored to individual patient needs. Adjustments that could be incorporated by mainstream services include easy read (accessible) clinic letters, and information on medication and procedures; the use of a communication or health passport to communicate health needs and treatment changes; allocation of longer appointment slots or offering the first appointment and making appointment booking systems easier to use.

There is an urgent need to improve the training provided to doctors and health care staff on communication skills and issues relevant to people with intellectual disabilities. This may be achieved through schemes that promote local champions, who are responsible for developing an expertise in intellectual disability and for training others. One positive example of training is the online module in intellectual disability produced by the General Medical Council in the UK, which is aimed at providing doctors with the knowledge and skills required to effectively communicate and treat people with intellectual disability (GMC, 2012). This resource is freely available and could be used more widely as a teaching aid for health professionals across a range of disciplines. Training sessions for hospital staff can improve knowledge and confidence when caring for patients with intellectual disability (McMurray & Beebee, 2007). Nurses who have had specific training about intellectual disability and who have experience of working with this group are more likely to have positive attitudes towards patients with intellectual disability (Slevin, 1995; Slevin & Sines, 1996). There is evidence that undergraduate lectures on intellectual disability for medical students can improve knowledge about intellectual disability. However, one recent study found that there were no changes in attitudes from the start to the end of the course (Sinai et al, 2013), suggesting that more innovative methods of teaching are required, including face to face contact with individuals with intellectual disability.

The study also identified the need to address the following issues (summarised in box 4.1.):

1. Better support for carers. In particular, social services need to be more proactive in conducting assessments of carers' needs, and in alleviating the burden placed on carers. General Practitioners also need to actively identify and treat health problems in carers resulting from carer stress.

2. Better support for ethnic minorities and non English speakers. Health services need to ensure that they provide culturally sensitive forms of care and provide interpreters in order to reduce the inequalities caused by language barriers.

3. Improvements in referral pathways to specialist services. There is a need for more effective transition arrangements between child and adult services, and for more resources to be available to carers, including information translated into other languages, about the availability of local services.

4. Improvements in the uptake of health checks. Although more GPs are offering health checks, uptake of health checks could be improved by promoting increased awareness of the benefits of health checks amongst people with intellectual disability (Dinsmore, 2012)

5. Improving the experience of patients with intellectual disability at hospitals through liaison models of working. A wider adoption of liaison nurses at hospitals may help to improve care. Liaison nurses can assist the clinical team in the care and management of patients and by providing support to carers. Alternative models include training nurses so that they act as link nurses who are then able to support other nurses caring for patients with intellectual disability, or extending the role of community intellectual disability nurses so that they work closely with health professionals at hospitals. Another approach involves commissioning a team that is dedicated to improving access to hospitals for people with intellectual disability, such as the Birmingham Acute Hospital Liaison Project. There is evidence that such an approach can reduce anxiety in patients with intellectual disability and improve the confidence of health professionals in providing care for patients (Glasby, 2002).

Inequity in accessing healthcare for people with disability is a global issue. Recently the World Health Organisation published its “World Report on Disability” (2012). The report makes several recommendations on improving access to health care. Many of these recommendations have already been implemented in the UK in relation to people with intellectual disability, and this study suggests that they have had some impact on improving access to health care for people with population. It is important to share this experience with other countries that may be in the process of implementing similar changes, but also to implement these changes more widely so that they are considered for other populations that experience significant barriers to equitable health care, either due to cognitive or communication impairments, or complex health needs. However, one of the lessons learnt so far is that long term commitment is required from both government and health organisations, alongside measures to enforce and evaluate the successful implementation of strategies.

Future Research

Research on stigma in people with intellectual disability remains a relatively under-researched area, when compared to stigma research in other fields such as mental illness or HIV. Further research is required in order to understand whether people with intellectual disability experience self stigmatisation, as described in the mental illness literature (Corrigan et al, 2009; Watson et al, 2007). Using this framework, in order for self stigmatisation to occur, people with intellectual disability would need to be aware of cultural stereotypes relating to intellectual disability, agree with these stereotypes and endorse them. It would be interesting to investigate whether this model of self stigma is valid in this group, given the presence of cognitive difficulties. We therefore need to develop a model for understanding self stigma in people with intellectual disability.

This study provides some evidence for the impact of stigma on several important health outcomes. However, a larger study using a more representative sample, is required, preferably one that is longitudinal. This could be done by administering the stigma questionnaire routinely in clinical practice, for example by clinicians at community intellectual disability services. An ideal study would be one that followed up young children with a diagnosis of intellectual disability over the course of a life time. This would enable researchers to examine how the label of intellectual disability impacts on experiences of stigma and discrimination, and the influence of potential moderating factors. For example does accepting or refusing the label of intellectual disability, or carers' willingness to discuss intellectual disability, modify the relationship between stigma and psychological distress. A longitudinal study would provide more information on whether the effects of stigma were pervasive.

Other health outcomes that were not assessed in this study but may be useful to assess in future studies include the impact of stigma on health such as cardiovascular disease and self reported health, financial costs to services and carer burden and quality of life. It may also be useful to examine the potential confounding effects of social deprivation, life events and personality factors in the relationship between stigma and health outcomes. Further research needs to be conducted on the impact of stigma on adherence to treatment, as only limited evidence was provided by this study.

The impact of stigma on people with mental illness and intellectual disability requires investigation. This group may experience double discrimination as a result of two stigmatising conditions. This could be assessed by comparing health outcomes in participants with intellectual disability and mental illness and those without mental illness. More research is also needed in understanding the experiences of people with severe intellectual disability.

As stigma may also affect others who are closely associated with the person, research is needed to understand whether courtesy or affiliate stigma in carers is associated with similar health outcomes. It would be important to identify whether there is an association between affiliate stigma in carers and self stigma in the individuals that they care for. For example, are carers who perceive higher levels of stigma, more likely to be over protective and avoid labels such as intellectual disability, resulting in lower self reported stigma, or is higher affiliate stigma also associated with higher self reported stigma?

In this study, most of the participants were known to intellectual disability services. The views of those not known to services, for example, because they do not wish to be associated with intellectual disability services or do not identify with the label, have not been represented. A future study could examine participants identified from a primary care sample.

There are no published studies of stigma reducing interventions in people with intellectual disability. There is an urgent need to develop effective interventions that help people with intellectual disability cope with the psychological distress of stigma. Interventions that enhance self esteem and resilience may be the way forward.

It is not enough to tackle self stigma on its own, and interventions that can help to diminish public stigma, alongside policy changes, are also required. There have been no large scale national interventions to reduce public stigma against people with intellectual disability as there have been with mental illness. However, lessons can be learnt from campaigns such as “Time to change”. This was a 20 million pound campaign in England with several aims: to improve public awareness and attitudes, and reduce discrimination towards people with mental illness; to give people with mental illness the knowledge, confidence and assertiveness to challenge discrimination; and the provision of physical activity and other opportunities to breakdown discrimination and to improve wellbeing.

The campaign was targeted at the general population and at specific groups (e.g. employers and medical students). It included a social marketing campaign which promoted contact between people with and without mental illness. Annual surveys were conducted between 2008 and 2009. The effects of the campaign were modest. There were improvements in the public’s intended behaviour but no changes in knowledge or reported behaviour (Evans-Lacko et al, 2013a). The proportion of people with mental illness who experienced no discrimination increased by 2.8%, which was a significant change but less than the 5% target (Corker et al, 2013). Social contact was found to have a positive effect on attitude change (Evans-Lacko et al, 2013b). The economic evaluation of the social marketing campaign suggests that it was cost effective (Evans-Lacko et al, 2013c. There was some improvement in employers’ attitudes towards mental illness but anti-stigma training provided only short term effects in medical students (Friedrich et al, 2013).

Campaigns such as Time to Change suggest that targeting specific groups and increasing social contact between the public and the stigmatised group can improve attitudes. A number of studies have shown that direct contact with people who have intellectual disability can improve attitudes (Rillotta & Nettelbeck, 2007; Roper, 1990). However, large scale interventions employing direct contact may be unfeasible, and there is evidence that indirect contact using film clips may be effective in improving attitudes in the short term (Smedema et al, 2012; Walker & Scior, 2013). In particular, film clips based on "protest", highlighting the immoral injustice of stigma, may be more effective (Walker & Scior, 2013).

Advocacy groups such as Mencap have been working with the police and justice system to improve how people with intellectual disability are treated and how hate crimes are investigated ("Stand by me"). This appears to be particularly important given the positive association between self reported stigma and contacts with the police. Future interventions that promote positive social contact could target other groups such as school children, teachers and health professionals. We have seen from the qualitative study that health professionals may hold negative attitudes towards people with intellectual disability, which may explain the poor quality of healthcare received by this group. It would be important to emphasize principles such as inclusion and similarity and to dispel myths that people with intellectual disability cannot enjoy a good quality of life.

Longitudinal qualitative studies, where participants are interviewed several times over several months or years, may provide more insight into current practice and whether access to health services is improving for patients with intellectual disability and their carers. Large scale cross sectional studies on healthcare access would provide more representative data on the prevalence of discrimination and other barriers preventing healthcare access, and could be used to plan local health services.

Box 4.1: Self reported stigma in people with intellectual disability and implications for services

General issues

- Increase awareness amongst health and social care professionals about the impact of stigma on psychological wellbeing and health
- Development of appropriate interventions to reduce psychological distress associated with stigma
- Reduce social/public stigma towards people with intellectual disability through large scale campaigns or targeting of specific groups such as school children and Police officers

Community Intellectual Disability Services

- Training of staff about the consequences of stigma and how to approach discussions with patients/ service users
- More open discussion with service users about experiences of discrimination such as bullying and impact on self esteem and psychological wellbeing
- Use of questionnaires to identify service users who may at risk of psychological distress due to stigma
- Provision of psychological therapy or other types of support in order to reduce psychological distress associated with stigma

Box 4.2: Areas where further improvements are required in order to improve access to health

1. General issues

- Provision of training for clinical and reception staff on communication skills
- Specific training of clinicians on intellectual disability, including addressing diagnostic overshadowing and negative attitudes and discrimination. Ideally delivered by service users and carers
- Ensure services are culturally sensitive and interpreters are available if required
- Services should make sure they have appropriate policies and procedures in place to make reasonable adjustments where required (e.g. longer appointment times, accessible information, use of communication passports)

2. Primary care services

- Increase awareness of annual health checks amongst people with intellectual disability
- Improve information about availability of local resources and services, especially to ethnic minority groups
- Ensure that service users with intellectual disability are identified (particularly from ethnic minority groups) and are referred to community intellectual disability services

3. Community services

- Ensure effective transition from child to adult services
- Improve clarity about how services are structured and referral pathways
- Resolve disputes over eligibility issues quickly
- Carer's assessments to be provided more regularly, with provision of feedback

3. Hospital/ inpatient services

- Clinic letters and discharge letters to be copied to named carer
- Carers should be consulted and involved in decisions about service user's care
- Involvement of liaison nurse where available
- Ensure appropriate discharge arrangements are made

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Appendix

Search terms for literature review (Section 1B)

Learning disability/disabilities AND stigma
Learning disability/disabilities AND discrimination
Mental retardation AND stigma
Mental retardation AND discrimination
Intellectual disability/ disabilities AND stigma
Intellectual disability/ disabilities AND discrimination
Intellectual impairment AND stigma
Intellectual impairment AND discrimination

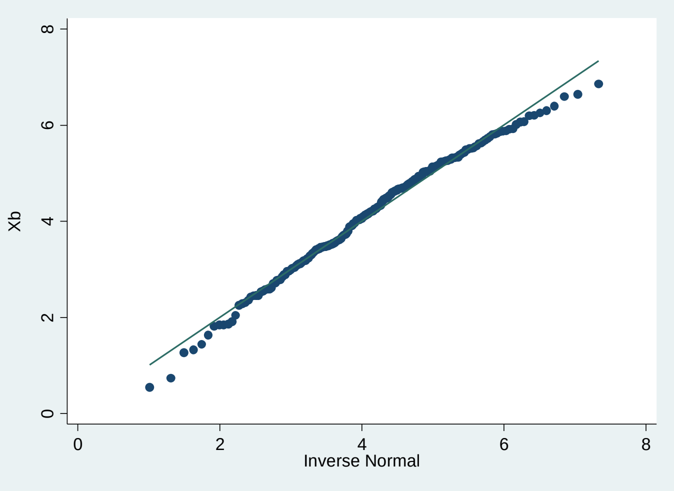
Stigma AND family
Stigma AND carers
Courtesy stigma AND family
Courtesy stigma AND carers
Affiliate stigma AND family
Affiliate stigma AND carers
Courtesy stigma AND learning disability/disabilities
Courtesy stigma AND intellectual disability/ disabilities
Courtesy stigma AND mental retardation
Courtesy stigma AND intellectual impairment
Affiliate stigma AND learning disability/disabilities
Affiliate stigma AND intellectual disability/ disabilities
Affiliate stigma AND mental retardation
Affiliate stigma AND intellectual impairment

Additional Results

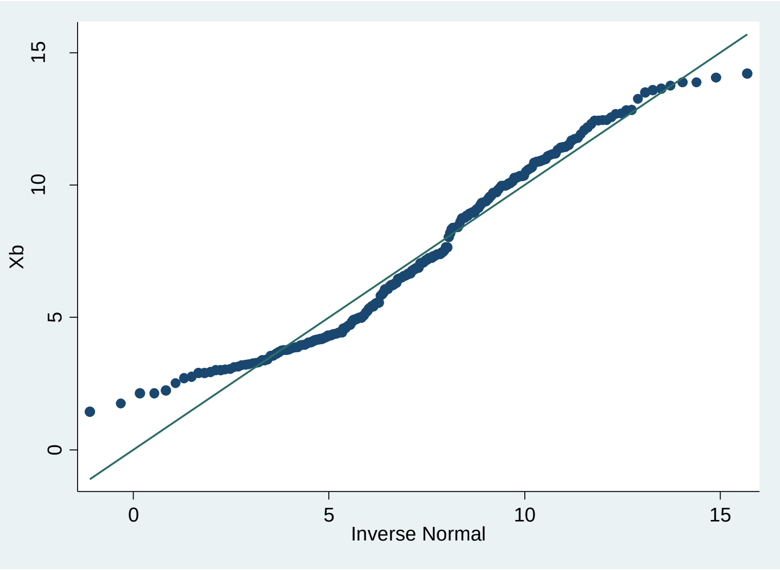
1. Cross-sectional study

Figure A.2.1: Regression diagnostics

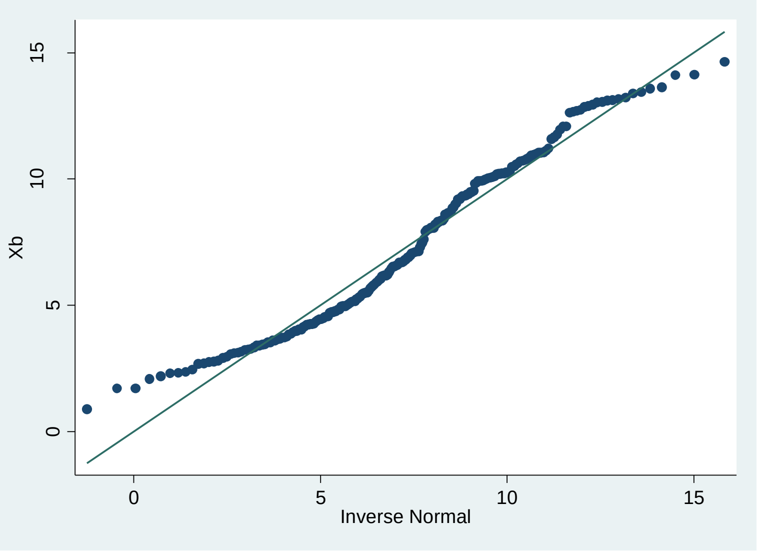
1. Assessing whether residuals are normally distributed: Inverse normal plot of stigma as dependent variable (full model)



2. Assessing whether residuals are normally distributed: Inverse normal plot of psychological distress as dependent variable (full model)



3. Assessing whether residuals are normally distributed: Inverse normal polt of Quality of life as dependent variable (full model)



4. Assessing whether the residuals are normally distributed: inverse normal plot of Adherence to medication rating scale (full model)

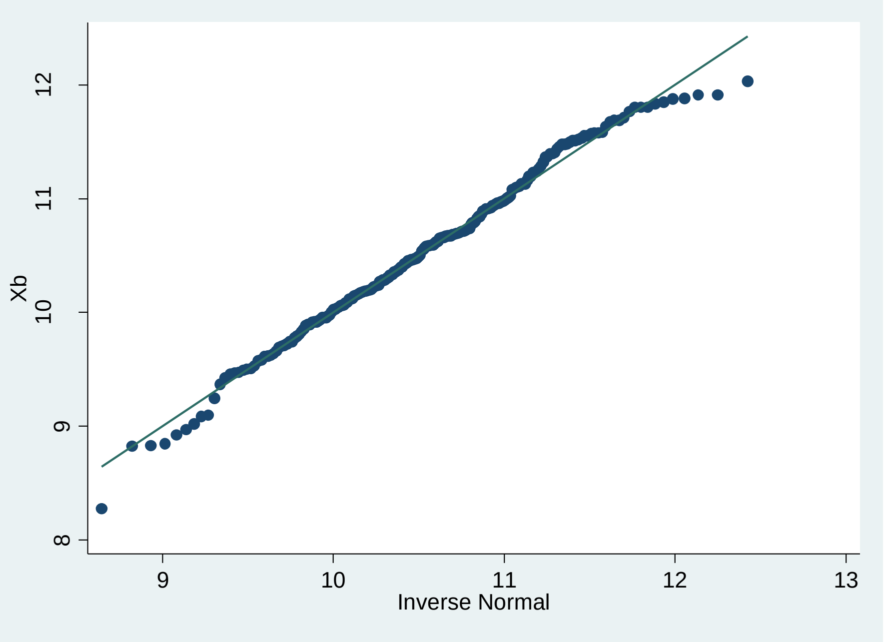


Table A.2.1 The number of participants recruited by each method at each centre

Centre	Total Number of participants (%)	Invitation letters Number (%)	CLDS* Number (%)	Voluntary organisations Number (%)	Day centres Number (%)	Supported housing Number (%)
Camden	35	16 (45.7)	7 (20.0)	12 (34.3)	0	0
Islington	21	3 (14.3)	0	14 (66.7)	0	4 (19.1)
Waltham Forest	7	0	0	2 (28.6)	5 (71.4)	0
Tower Hamlets	16	0	0	2 (12.5)	14 (87.5)	0
Newham	10	0	0	7 (70.0)	0	3 (30.0)
Bromely/ Greenwich	10	10 (100.0)	0	0	0	0
Kent	9	0	9 (100.0)	0	0	0
Sussex	19	0	3 (15.8)	9 (47.4)	0	7 (36.8)
Surrey	53	0	0	0	53(100.0)	0
Somerset	10	0	4 (40.0)	6 (60.0)	0	0
Lincolnshire	19	1 (5.3)	2 (10.5)	13 (68.4)	0	3 (15.8)
Nottinghamshire	20	18 (90.0)	1(5.0)	0	0	1 (5.0)

* CLDS = community intellectual disability services

Table A.2.2: Socio-demographic variables by centre

Centre	Mean age (SD)	Male Gender: Number (%)	Moderate ID Number (%)	White ethnicity Number (%)
Camden	44.9 (11.1)	18 (51.4)	6 (17.1)	23 (65.7)
Islington	38.2 (11.2)	13 (61.9)	0	14 (66.7)
Waltham Forest	37.9 (9.1)	5 (71.4)	3 (42.9)	4 (57.1)
Tower Hamlets	36.1 (9.9)	9 (56.3)	3 (18.8)	7 (43.8)
Newham	40.3 (12.8)	8 (80.0)	2 (20.0)	3 (30.0)
Bromley/Greenwich	43.9 (12.0)	2 (20.0)	4 (40.0)	10 (100.0)
Kent	38.6 (13.4)	7 (77.8)	7 (87.5)	9 (100.0)
Sussex	38.2 (12.0)	7 (36.8)	1 (5.3)	19 (100.0)
Surrey	40.4 (11.3)	23 (43.4)	20 (37.8)	51 (96.2)
Somerset	38.0 (7.8)	7 (36.8)	1 (5.3)	10 (100.0)
Nottinghamshire	43.1 (12.3)	8 (80.0)	2 (20.0)	19 (95.0)
Lincolnshire	44.5 (10.8)	8 (42.1)	6 (31.6)	19 (100.0)

Table A.2.3: Descriptive statistics for the exposure and outcome variables by centre

Centre	Stigma Mean (SD)	Psychological distress Mean (SD)	Quality of Life (full scale) Mean (SD)	Satisfaction subscale Mean (SD)	Total service use Mean (SD)
Camden	5.14 (3.51)	8.43 (6.18)	85.91 (12.82)	21.17 (5.23)	59.49 (91.72)
Islington	3.38 (2.91)	6.05 (4.70)	90.14 (12.23)	22.43 (4.15)	72.14 (99.20)
Waltham Forest	2.86 (3.13)	7.86 (5.76)	90.43 (11.94)	25.86 (2.79)	63.14 (94.44)
Tower Hamlets	3.69 (2.47)	8.63 (7.32)	84.44 (13.29)	23.75 (4.65)	22.6 (17.67)
Newham	3.40 (2.84)	5.60 (5.38)	91.4 (14.77)	24.8 (5.14)	13.2 (10.43)
Bromley/Greenwich	4.0 (2.49)	7.0 (4.47)	90.75 (11.14)	23.75 (5.06)	48.2 (31.68)
Kent	2.44 (2.74)	5.67 (5.12)	81.13 (11.72)	23 (3.34)	39.22 (57.3)
Sussex	1.79 (2.07)	5.63 (3.74)	94.53 (14.67)	23.89 (3.84)	11.47 (9.54)
Surrey	4.96 (3.37)	7.09 (4.96)	88.47 (11.56)	23.57 (3.95)	22.43 (30.21)
Somerset	3.2 (2.49)	10.37 (6.19)	94.2 (13.38)	23.7 (4.27)	22.6 (17.67)
Nottinghamshire	4.85 (3.39)	7.2 (5.08)	87.17 (8.15)	24.16 (3.35)	27.55 (27.26)
Lincolnshire	6.05 (3.91)	10.37 (6.19)	79.05 (12.24)	21.26 (5.03)	22.16 (16.92)

Table A.2.4: Linear regression analysis of the variables associated with self reported stigma using linear regression

Variable	Regression Coefficient	Standard error	95 % Confidence interval for coefficient	P value
Level of ID: Moderate ID **(reference group: mild ID)**	0.67	0.49	-0.30, 1.63	0.17
Gender: Female **(reference group: males)**	0.70	0.43	-0.13, 1.53	0.10
Age	0.06	0.02	-0.02, 0.20	0.001
Ethnicity: Non White **(reference group: White)**	-0.37	0.60	-1.54, 0.81	0.54
Marital status: Married/cohabiting **(reference group: single/divorced)**	0.62	0.46	-0.28, 1.52	0.17
Urban development: Semi-rural	2.12	0.97	-0.21, 4.02	
Urban	1.91	0.93	0.10, 3.73	0.08
(reference group: rural)				
Housing: Living with family	-0.52	0.52	-1.54, 0.51	
24 hour supported housing	-0.25	0.56	-1.36, 0.86	0.61
(reference group: low support)				
Support from a carer: Has carer **(reference group: no carer)**	0.69	0.55	--0.39, 1.78	0.21
Employment: In paid work **(reference group: no paid work)**	-1.02	0.45	-1.91, -0.13	0.02
Education: Special school **(reference group: mainstream school)**	0.37	0.56	-0.73, 1.46	0.51
Number of Friends: One or two	-2.14	1.06	-4.22, -0.05	
Three or more	-1.76	1.0		0.13
(reference group: no friends)				
Physical health problems: Yes **(reference group: no)**	1.38	0.43	0.53, 2.23	<0.001
Medication: On regular medication **(reference group: no medication)**	0.81	0.42	-0.01, 1.64	0.05
Epilepsy: Yes **(reference group: no)**	0.14	0.56	-0.97, 1.24	0.81
Sensory problems: Yes **(reference group: no)**	1.25	0.48	0.37, 2.14	0.01
Speech problems: Yes **(reference group: no)**	-0.08	0.09	-1.01, 0.86	0.87
Mobility problems: Yes **(reference group: no)**	-0.21	0.69	-1.57, 1.16	0.77
Genetic problems: Yes **(reference group: no)**	0.07	0.02	-1.42, 1.56	0.92

Table A.2.5: Contacts with community professionals and services in the last 6 months

Professional or service	At least one contact Number (%)	Range of number of contacts	Mean number of contacts (SD)
GP	156 (68.12)	0-36	2.22 (4.24)
Nurse (GP surgery)	125 (54.59)	0-36	1.50 (3.90)
District nurse	9 (3.93)	0-24	0.34 (2.50)
Learning Disability nurse (CLDS)	33 (14.41)	0-30	1.20 (4.33)
Psychology (CLDS)	48 (20.96)	0-48	2.38 (7.11)
Occupational Therapist (CLDS)	22 (9.61)	0-24	0.32 (1.77)
Physiotherapist (CLDS)	25 (10.92)	0-180	1.88 (13.02)
Speech and Language therapist (CLDS)	15 (6.55)	0-24	0.36 (2.38)
Social worker (CLDS)	92 (40.17)	0-60	1.83 (5.38)
Dietician	35 (15.28)	0-24	0.52 (2.15)
Dentist	148 (64.62)	0-12	1.10 (1.51)
Optician	118 (51.52)	0-12	0.71 (1.24)
Chiropodist	89 (38.86)	0-24	1.62 (3.6)
Family planning clinic	13 (5.67)	0-2	0.07 (0.28)
Parenting service	3 (1.31)	0-64	0.61 (6.02)
Health visitor	0	0	0
Midwife	0	0	0
Advocate	43 (0.19)	0-24	0.82 (2.54)
Support worker	44 (19.21)	0-360	12.07 (46.7)

Table A.2.5 cont...

Professional or service	At least one contact Number (%)	Range of number of contacts	Mean number of contacts (SD)
Welfare officer	14 (6.11)	0-5	0.11 (0.53)
Job centre	51 (22.27)	0-100	1.66 (8.63)
Housing officer	30 (13.10)	0-8	0.30 (0.99)
Meals on wheels	3 (1.31)	0-24	0.14 (1.62)
Respite	24 (10.48)	0-24	0.38 (2.33)
Police	54 (23.58)	0-7	0.45 (1.06)
Other	10 (4.37)		

Table A.2.6: Contacts with hospital based services in the last 6 months

Professional or service	At least one contact Number (%)	Range of number of contacts	Mean number of contacts (SD)
Outpatient clinics	85 (37.11)	0-6	0.50 (1.01)
Investigations	85 (37.11)	0-5	0.46 (0.77)
Accident & Emergency department	50 (24.02)	0-5	0.27 (0.62)
Inpatient admission	26 (11.35)	0-3	0.13 (0.38)

Table: A.2.7: Linear regression analysis of the variables associated with psychological distress

Variable	Regression Coefficient	Standard error	95 % Confidence interval for coefficient	P value
Stigma score	**0.94**	**0.09**	**0.77, 1.12**	**<0.001**
Level of ID: Moderate ID	**0.25**	**0.81**	**-1.35, 1.84**	**0.76**
(reference group: mild ID)				
Gender: Female	**1.26**	**0.71**	**-1.32, 2.65**	**0.08**
(reference group: males)				
Age	**0.05**	**0.03**	**-0.01, 0.12**	**0.09**
Ethnicity: Non White	**-0.26**	**0.96**	**-2.14, 1.61**	**0.79**
(reference group: White)				
Marital status: Married/cohabiting	**1.03**	**0.76**	**-0.46, 2.53**	**0.17**
(reference group: single/divorced)				
Urban development: Semi-rural	**1.66**	**1.36**	**-0.10, 4.32**	
Urban	**2.59**	**1.25**	**0.14, 5.04**	**0.09**
(reference group: rural)				
Housing: Living with family	**-0.20**	**0.88**	**-1.92, 1.51**	
24 hour supported housing	**-1.26**	**0.94**	**-3.10, 0.58**	**0.33**
(reference group: low support)				
Support from a carer: Has carer	**-0.88**	**0.83**	**-2.51, 0.75**	**0.29**
(reference group: no carer)				
Employment: In paid work	**-1.72**	**0.75**	**-3.19, -0.26**	**0.02**
(reference group: no paid work)				
Education: Special school	**-0.08**	**0.95**	**-1.95, 1.79**	**0.93**
(reference group: mainstream school)				
Number of Friends: One or two	**-2.46**	**1.80**	**-6.00, 1.07**	**0.26**
Three or more	**-2.76**	**1.68**	**-6.05, 0.52**	
(reference group: no friends)				
Physical health problems: Yes	**2.04**	**0.73**	**0.60, 3.48**	**0.01**
(reference group: no)				
Medication: On regular medication	**0.57**	**0.72**	**-0.84, 1.97**	**0.43**
(reference group: no medication)				
Epilepsy: Yes	**-0.98**	**0.96**	**-2.87, 0.90**	**0.31**
(reference group: no)				
Sensory problems: Yes	**1.29**	**0.76**	**-0.21, 2.78**	**0.09**
(reference group: no)				
Speech problems: Yes	**-0.89**	**0.77**	**-2.40, 0.62**	**0.25**
(reference group: no)				
Mobility problems: Yes	**-0.81**	**1.18**	**-3.12, 1.49**	**0.49**
(reference group: no)				
Genetic problems: Yes	**-0.93**	**1.26**	**-3.41, 1.55**	**0.46**
(reference group: no)				

Table A.2.8: Linear regression analysis of the variables associated with quality of life

Variable	Regression Coefficient	Standard error	95 % Confidence interval for coefficient	P value
Stigma score	-0.98	0.26	-1.48, -0.48	<0.001
Level of ID: Moderate ID	-3.71	1.95	-7.52, 0.11	0.06
(reference group: mild ID)				
Gender: Female	-1.87	1.67	-5.18, 1.44	0.27
(reference group: males)				
Age	-0.17	0.07	-0.31, -0.02	0.03
Ethnicity: Non White	-1.63	2.32	-6.19, 2.92	0.48
(reference group: White)				
Marital status: Married/cohabiting	2.44	1.80	-1.10, 5.97	0.18
(reference group: single/divorced)				
Urban development: Semi-rural	-9.67	3.56	-16.64, -2.70	
Urban	-7.30	3.44	-14.03, -0.56	0.02
(reference group: rural)				
Housing: Living with family	-4.59	2.04	-8.59, -0.58	
24 hour supported housing	-2.05	2.21	-6.39, 2.29	0.08
(reference group: low support)				
Support from a carer: Has carer	-2.25	2.12	-6.40, 1.91	0.29
(reference group: no carer)				
Employment: In paid work	15.88	1.44	13.06, 18.69	<0.001
(reference group: no paid work)				
Education: Special school	0.05	2.22	-4.30, 4.40	0.98
(reference group: mainstream school)				
Number of Friends: One or two	3.29	4.09	-4.73, 11.31	0.002
Three or more	9.33	3.83	-4.73, 16.85	
(reference group: no friends)				
Physical health problems: Yes	-1.34	1.76	-4.79, 2.10	0.44
(reference group: no)				
Medication: On regular medication	-1.42	1.68	-4.72, 1.87	0.40
(reference group: no medication)				
Epilepsy: Yes	0.82	2.22	-3.54, 5.17	0.71
(reference group: no)				
Sensory problems: Yes	0.85	1.80	-2.68, 4.38	0.64
(reference group: no)				
Speech problems: Yes	-2.47	1.91	-6.22, 1.28	0.20
(reference group: no)				
Mobility problems: Yes	-0.62	2.78	-6.06, 4.82	0.82
(reference group: no)				
Genetic problems: Yes	0.77	3.02	-5.15, 6.70	0.80
(reference group: no)				

Table A.2.9: Linear regression analysis of the variables associated with total number of service contacts

Variable	Regression Coefficient	Standard error	95% Confidence interval	Wald test P value
Stigma score	0.04	0.02	0.01, 0.08	0.03
Level of ID: Moderate ID (reference group: mild ID)	0.08	0.13	-0.19, 0.34	0.58
Gender: Female (reference group: males)	0.03	0.12	-0.20, 0.25	0.83
Age	-0.00	0.01	-0.01, 0.01	0.43
Ethnicity: Non White (reference group: White)				
Marital status: Married/cohabiting (reference group: single/divorced)	0.31	0.12	0.07, 0.55	0.01
Urban development: Semi-rural	0.14	0.27	-0.39, 0.67	0.82
Urban	0.16	0.27	-0.35, 0.67	
(reference group: rural)				
Housing: Living with family	-0.18	0.14	-0.46, 0.10	0.37
24 hour supported housing	-0.02	0.15	-0.32, 0.28	
(reference group: low support)				
Support from a carer: Has carer (reference group: no carer)	0.07	0.14	-0.22, 0.35	0.63
Employment: In paid work (reference group: no paid work)	-0.05	0.12	-0.30, 0.19	0.67
Education: Special school (reference group: mainstream school)	0.10	0.15	-0.20, 0.40	0.50
Number of Friends: One or two	-0.05	0.29	-0.62, 0.53	0.55
Three or more	0.11	0.28	-0.43, 0.65	
(reference group: no friends)				
Physical health problems: Yes (reference group: no)	0.20	0.12	-0.04, 0.44	0.10
Medication: On regular medication (reference group: no medication)	0.24	0.12	0.01, 0.47	0.04
Epilepsy: Yes (reference group: no)	0.12	0.15	-0.18, 0.41	0.43
Sensory problems: Yes (reference group: no)	0.18	0.12	-0.06, 0.41	0.15
Speech problems: Yes (reference group: no)	0.27	0.13	-0.03, 0.52	0.03
Mobility problems: Yes (reference group: no)	0.16	0.19	-0.21, 0.52	0.39
Genetic problems: Yes (reference group: no)	-0.16	0.21	-0.58, 0.25	0.44

Table A.2.10. Linear regression analysis of the variables associated with adherence to medication

Variable	Regression Coefficient	Standard error	95% Confidence interval	Wald test P value
Stigma score	-0.05	0.04	-0.13, 0.02	0.18
Level of ID: Moderate ID (reference group: mild ID)	-0.77	0.30	-1.36, -1.76	0.01
Gender: Female (reference group: males)	0.04	0.27	-0.48, 0.57	0.87
Age	0.04	0.01	0.02, 0.06	<0.001
Ethnicity: Non White (reference group: White)	-1.02	0.35	-1.70, 0.06	0.003
Marital status: Married/cohabiting (reference group: single/divorced)	-0.70	0.27	-1.23, -0.18	0.01
Urban development: Semi-rural	0.23	0.52	-0.79, 1.25	0.69
Urban (reference group: rural)	-0.05	0.48	-0.99, 0.90	
Housing: Living with family	-0.69	0.32	-1.30, -0.06	0.09
24 hour supported housing (reference group: low support)	-0.22	0.32	-0.84, 0.40	
Support from a carer: Has carer (reference group: no carer)	0.34	0.32	-0.28, 0.95	0.28
Employment: In paid work (reference group: no paid work)	0.30	0.30	-0.29, 0.89	0.32
Education: Special school (reference group: mainstream school)	-0.34	0.36	-1.04, 0.36	0.34
Number of Friends: One or two	0.57	0.63	-0.66, 1.80	0.35
Three or more (reference group: no friends)	0.80	0.59	-0.35, 1.95	
Physical health problems: Yes (reference group: no)	0.23	0.39	-0.54, 1.00	0.56
Epilepsy: Yes (reference group: no)	0.19	0.30	-0.40, 0.78	0.53
Sensory problems: Yes (reference group: no)	-0.16	0.28	-0.71, 0.39	0.57
Speech problems: Yes (reference group: no)	-0.21	0.31	-0.82, 0.39	0.49
Mobility problems: Yes (reference group: no)	0.34	0.36	-0.36, 1.04	0.34
Genetic problems: Yes (reference group: no)	-0.40	0.48	-1.35, 0.55	0.41

Table A.2.11. The relationship between psychological distress and the stigma subscales after controlling for other variables

a. Perceived discrimination subscale

Variables	Regression coefficient	Standard error	95% Confidence interval	P Value
Unadjusted (perceived discrimination subscale only)	1.38	0.15	1.09, 1.66	<0.001
Adjusted for confounders*	1.38	0.15	1.08, 1.70	<0.001
Adjusted for all the variables **	1.33	0.15	1.03, 1.66	<0.001

b. Reaction to discrimination

Variables	Regression coefficient	Standard error	95% Confidence interval	P Value
Unadjusted (reaction to discrimination subscale only)	1.90	0.21	1.50, 2.31	<0.001
Adjusted for confounders*	1.87	0.22	1.44, 2.29	<0.001
Adjusted for all the variables**	1.79	0.22	1.36, 2.22	<0.001

* age, gender, level of ID and ethnicity

**age, gender, level of ID, ethnicity, urban development, paid work, health problems and sensory problems

Table A.2.12: The relationship between the stigma subscales and quality of life after controlling for other variables

a. Perceived discrimination subscale

Variables	Regression coefficient	Standard error	95% Confidence interval	P Value
Unadjusted (perceived discrimination subscale only)	-1.36	0.40	-2.15, 0.58	0.001
Adjusted for confounders*	-1.16	0.41	-1.95. -0.36	0.004
Adjusted for all the variables **	- 0.95	0.32	-1.58, -0.32	0.003

b. Reaction to discrimination subscale

Variables	Regression coefficient	Standard error	95% Confidence interval	P Value
Unadjusted (perceived discrimination subscale only)	-2.06	0.58	-3.20, -0.93	<0.001
Adjusted for confounders*	-1.97	0.58	-3.12, 0.83	0.001
Adjusted for all the variables **	-1.46	0.45	-2.35, -0.57	0.001

* age, gender, level of ID, ethnicity

** age, gender, level of ID, ethnicity, marital status, level of urban development, housing status, employment status, number of friends

Table A.2.13: The relationship between the stigma subscales and number of total contacts with services

a. (i) Perceived discrimination subscale and total number of contacts with services

Variables	Regression coefficient	Standard error	95% Confidence interval	P Value
Unadjusted (Perceived discrimination subscale)	0.06	0.03	0.01, 0.12	0.02
Adjusted for confounders*	0.08	0.03	0.02, 0.13	0.01
Adjusted for all the variables **	0.06	0.03	-0.00, 0.11	0.06

a. (ii) Reaction to discrimination subscale and total number of contacts with services

Variables	Regression coefficient	Standard error	95% Confidence interval	P Value
Unadjusted (Reaction to discrimination subscale only)	0.07	0.04	-0.01, 0.15	0.09
Adjusted for confounders*	0.08	0.04	0.00, 0.17	0.04
Adjusted for all the variables **	0.06	0.04	-0.02, 0.15	0.13

* Adjusted for level of ID, gender and age

** Adjusted for level of ID, gender, age, marital status, medication and speech problems

Table A.2.14: The relationship between the stigma subscales and contacts with specific services

a. (i) Perceived discrimination subscale and Primary care contacts

Variables	Regression coefficient	Standard error	95% Confidence interval	P Value
Unadjusted (Perceived discrimination subscale)	0.03	0.03	-0.03, 0.10	0.28
Adjusted for confounders*	0.03	0.03	-0.03, 0.10	0.28
Adjusted for all the variables **	0.01	0.03	-0.05, 0.08	0.70

a. (ii) Reaction to discrimination subscale and Primary care contacts

Variables	Regression coefficient	Standard error	95% Confidence interval	P Value
Unadjusted (Reaction to discrimination subscale only)	0.09	0.05	0.00, 0.18	0.05
Adjusted for confounders*	0.08	0.05	-0.02, 0.17	0.11
Adjusted for all the variables **	0.06	0.05	-0.04, 0.15	0.22

b. (i) Perceived discrimination and Community health services contacts

Variables	Regression coefficient	Standard error	95% Confidence interval	P Value
Unadjusted (Perceived discrimination subscale only)	0.08	0.04	-0.003, 0.17	0.06
Adjusted for confounders*	0.07	0.05	-0.02, 0.16	0.12
Adjusted for all the variables **	0.06	0.05	-0.03, 0.15	0.21

* Adjusted for level of ID, gender and age

** Adjusted for level of ID, gender, age, marital status, medication and speech problems

Table A.2.14: Cont...

b. (ii) Reaction to discrimination and Community health services contacts

Variables	Regression coefficient	Standard error	95% Confidence interval	P Value
Unadjusted (Reaction to discrimination subscale only)	0.04	0.02	-0.00, 0.08	0.06
Adjusted for confounders*	0.03	0.02	-0.01, 0.07	0.15
Adjusted for all the variables **	0.02	0.02	-0.02, 0.06	0.32

c. (i) Perceived discrimination and Community intellectual disability service contacts

Variables	Regression coefficient	Standard error	95% Confidence interval	P Value
Unadjusted (Perceived discrimination subscale only)	0.12	0.04	0.08, 0.20	0.004
Adjusted for confounders*	0.14	0.04	0.05, 0.22	0.002
Adjusted for all the variables **	0.12	0.04	0.04, 0.21	0.01

c. (ii) Reaction to discrimination and Community intellectual disability service contacts

Variables	Regression coefficient	Standard error	95% Confidence interval	P Value
Unadjusted (Reaction to discrimination subscale only)	0.09	0.06	-0.02, 0.21	0.12
Adjusted for confounders*	0.11	0.06	-0.01, 0.23	0.07
Adjusted for all the variables **	0.09	0.07	-0.04, 0.21	0.17

* Adjusted for level of ID, gender and age

** Adjusted for level of ID, gender, age, marital status, medication and speech problems

Table A.2.14 Cont...

d. (i) Perceived discrimination and Contacts with Accident & Emergency Department

Variables	Regression coefficient	Standard error	95% Confidence interval	P Value
Unadjusted (Perceived discrimination subscale only only)	0.14	0.07	0.01, 0.27	0.04
Adjusted for confounders*	0.15	0.07	0.01, 0.28	0.03
Adjusted for all the variables **	0.12	0.07	-0.01, 0.25	0.07

d. (ii) Reaction to discrimination and Contacts with Accident & Emergency Department

Variables	Regression coefficient	Standard error	95% Confidence interval	P Value
Unadjusted (Reaction to discrimination subscale only)	0.06	0.10	-0.13, 0.25	0.55
Adjusted for confounders*	0.05	0.10	-0.14, 0.24	0.59
Adjusted for all the variables **	0.01	0.12	-0.21, 0.24	0.91

e. (i) Perceived discrimination and number of general hospital admissions

Variables	Regression coefficient	Standard error	95% Confidence interval	P Value
Unadjusted (Perceived discrimination only)	0.19	0.09	-0.01, 0.37	0.04
Adjusted for confounders*	0.17	0.10	-0.02, 0.37	0.08
Adjusted for all the variables **	0.11	0.10	-0.09, 0.30	0.28

* Adjusted for level of ID, gender and age

** Adjusted for level of ID, gender, age, marital status, medication and speech problems

Table A.2.14 Cont...

e. (ii) Reaction to discrimination and number of general hospital admissions

Variables	Regression coefficient	Standard error	95% Confidence interval	P Value
Unadjusted (Reaction to discrimination only)	0.19	0.13	-0.07, 0.45	0.16
Adjusted for confounders*	0.15	0.14	-0.18, 0.37	0.28
Adjusted for all the variables **	0.10	0.14	-0.18, 0.37	0.49

f. (i) Perceived discrimination and number of outpatient clinic contacts

Variables	Regression coefficient	Standard error	95% Confidence interval	P Value
Unadjusted (Perceived discrimination subscale only)	0.09	0.05	-0.01, 0.20	0.09
Adjusted for confounders*	0.07	0.06	-0.04, 0.18	0.23
Adjusted for all the variables **	0.05	0.06	-0.06, 0.16	0.37

f. (ii) Reaction to discrimination and number of outpatient clinic contacts

Variables	Regression coefficient	Standard error	95% Confidence interval	P Value
Unadjusted (Reaction to discrimination subscale only)	0.06	0.08	-0.10, 0.22	0.47
Adjusted for confounders*	0.03	0.08	-0.14, 0.19	0.70
Adjusted for all the variables **	0.02	0.08	-0.15, 0.18	0.82

* Adjusted for level of ID, gender and age

** Adjusted for level of ID, gender, age, marital status, medication and speech problems

Table A.2.14 cont...

g. (i) Perceived discrimination and contacts with police

Variables	Regression coefficient	Standard error	95% Confidence interval	P Value
Unadjusted (Perceived discrimination subscale only)	0.22	0.06	0.10, 0.34	<0.001
Adjusted for confounders*	0.29	0.06	0.17, 0.41	<0.001
Adjusted for all the variables **	0.29	0.06	0.17, 0.42	<0.001

g. (i) Reaction to discrimination and contacts with police

Variables	Regression coefficient	Standard error	95% Confidence interval	P Value
Unadjusted (Reaction to discrimination subscale only)	0.18	0.07	0.04, 0.32	0.01
Adjusted for confounders*	0.28	0.10	0.10, 0.47	0.003
Adjusted for all the variables **	0.34	0.10	0.14, 0.54	0.001

* Adjusted for level of ID, gender and age

** Adjusted for level of ID, gender, age, marital status, medication and speech problems

Table A.2.15: The relationship between the stigma subscales and refusal of services

(i) Perceived discrimination subscale and refusal of services

Variables	Regression coefficient	Standard error	95% Confidence interval	P Value
Unadjusted (stigma only)	0.20	0.11	-0.03, 0.42	0.09
Adjusted for confounders*	0.17	0.08	0.01, 0.33	0.03
Adjusted for all the variables **	0.23	0.13	-0.02, 0.48	0.07

(i) Perceived discrimination subscale and refusal of services

Variables	Regression coefficient	Standard error	95% Confidence interval	P Value
Unadjusted (stigma only)	0.28	0.17	-0.06, 0.62	0.10
Adjusted for confounders*	0.34	0.18	-0.02, 0.70	0.06
Adjusted for all the variables **	0.34	0.19	-0.05, 0.70	0.09

* Adjusted for level of ID, gender and age

** Adjusted for level of ID, gender, age, marital status, medication and speech problems

Table A.2.16: Effect modification of the relationship between self reported stigma and psychological distress by level of intellectual disability, gender and age

Interaction term	Regression Coefficient	Standard error	95% Confidence interval	P value
Stigma x ID				
Unadjusted	-0.09	0.20	-0.48, 0.30	0.65
Adjusted*	-0.14	0.21	-0.56, 0.28	0.51
Stigma x gender				
Unadjusted	-0.08	0.18	-0.43, 0.27	0.66
Adjusted*	-0.08	0.19	-0.02, 0.01	0.44
Stigma x age				
Unadjusted	-0.01	0.01	-0.02, 0.01	0.44
Adjusted*	-0.01	0.01	-0.02, 0.01	0.46

* adjusted for level of ID, gender, age, ethnicity, level of urban development, paid work, health problems and sensory problems

Table A.2.17: Effect modification of the relationship between self reported stigma and quality of life by level of intellectual disability, gender and age

Interaction term	Regression Coefficient	Standard error	95% Confidence interval	P value
Stigma x ID				
Unadjusted	1.79	0.53	-17.74, -5.66	<0.001
Adjusted*	0.67	0.45	-0.56, 0.28	0.51
Stigma x gender				
Unadjusted	-0.77	0.51	-1.77, 0.23	0.13
Adjusted*	-0.28	0.39	-0.04, 0.49	0.48
Stigma x age				
Unadjusted	-0.01	0.01	-0.04, 0.02	0.49
Adjusted*	0.003	0.02	-0.03, 0.04	0.86

* Adjusted for level of ID, gender, age, ethnicity, marital status, level of urban development, housing, paid work and number of friends

Table A.2.18: Effect modification of the relationship between stigma and total number of service contacts by level of intellectual disability, gender and age

Interaction term	Regression Coefficient	Standard error	95% Confidence interval	P value
Stigma x ID				
Unadjusted	0.06	0.04	-0.02, 0.14	0.13
Adjusted*	0.04	0.04	-0.04, 0.12	0.29
Stigma x gender				
Unadjusted	-0.04	0.04	-0.11, 0.14	0.25
Adjusted*	-0.04	0.04	-0.11, 0.03	0.26
Stigma x age				
Unadjusted	-0.001	0.002	-0.004, 0.003	0.90
Adjusted*	-0.001	0.002	-1.27, 0.31	0.75

* Adjusted for ID, age, gender, ethnicity, marital status, medication and speech problems

2. Qualitative study: List of final codes and themes

Topic A: Barriers to healthcare access

Theme 1: Problems with communication

Service user with ID talked over or completely ignored
Staff giving mixed messages
Staff failing to modify their communication skills
Service user with ID wanting to be spoken to
Service user has difficulty understanding staff
Information not in accessible format
Failure of staff to pick up on non verbal communication
Service user not given information about diagnosis
Need for advocate to help with communication
Lack of confidence in service user affects communication
Service User feeling pressurised to have treatment
Communication problems affecting expression of needs
Health professionals not explaining things to service user

Theme 2: Problems accessing help

Carer lacking knowledge about health screening
Fighting to get input from services
Getting help only in a crisis
Hard to get hold of staff
Waiting to hear from services
Not being informed of local services or resources
Lack of help from GP
Not getting the right help from services
Referral being blocked
Poor transition of care from child to adult services
Poor liaison or communication between services
Disputes over responsibility for service user
Delay in getting help or being referred
Language barrier
Lack of provision of interpreter
Budget cuts to services

Theme three: problems with how healthcare professionals relate to carers

Piggy in the middle
Carer perceived as being over protective
Not sharing information with carer
Disregarding carer's knowledge
Carer not consulted
Carer’s presence questioned

Theme four: Complexities of the healthcare system and lack of support for carers

Carer having to be proactive
No support from services
Learning to manage the system
Feeling intimidated by the system
Carer burden of chasing the system
Everything is pressured for time
Advantage of being articulate
Coping strategies used to deal with carer stress
Service user not having ownership of care
Lack of time or confidence to complain
Confronting clinician about care
Problems with appointments system
Problems travelling or cost of travelling to appointments
Feeling treated like a number
Encouraging independence versus needs being unmet
Attending service perceived as better
Not knowing how to complain
No point in complaining
Worried about consequences of complaining
Unsatisfactory response to complaint

Topic B: Discrimination from health services

Theme five: Substandard care for people with ID

Treated poorly because of ID
Service user not respected
Service user feeling distressed or traumatised
Poor administration or monitoring of medication
Failure to read notes or incorrect information in notes
Service user not given time or space
Neglect of basic needs
Wrong medication given
Lack of holistic care
Staff not spending time with patient
Lack of confidentiality or privacy
Inadequate discharge arrangements
Failure to make reasonable adjustments
Lack of staff awareness of person’s needs
Early or delayed discharge
Delayed diagnosis or treatment due to Challenging behaviour
Investigations or treatment delayed or lacking altogether
Staff too busy to attend to service user's needs
Having to wait around during appointments

Healthcare experience not getting better
Loss of results or investigations
Treatment experienced differently due to service user’s lack of understanding
Poor continuity of care
Reluctance to use service again

Theme 6: Problems with staff attitudes, knowledge and behaviour
Unreliable staff
Staff being rude or unfriendly
Staff being judgemental
Inadequate staff knowledge about people with ID

Topic C: Good practice

Theme 7: Examples of good practice
Support from services
Service user and carer feel respected
Satisfactory response to complaint
Not treated differently because of ID
Medication explained
Helpful or friendly staff
Health promotion offered
Gradual improvements in care over recent years
Legislation not helpful
GP health checks offered
Good transition of care from child to adult services
Good continuity of care
Good communication
Help needed is provided
Getting help quickly
Carer is consulted
Staff acting beyond the call of duty
System is flexible or accommodating

Theme 8: Suggestions for improving care
More training of staff
More time given to service users
Providing more accessible information
Prioritising people with LD
Making reasonable adjustments
Liaison or link nurse
Improving staff attitudes towards people with LD
Improving awareness of person's needs
Health passport or communication book
Ensuring carer is consulted

Examples of analysis

Reviewing the themes and checking that the themes work in relation to the codes

Theme 1: Problems with communication

Code: Service user with ID talked over or completely ignored

Example 1

RESPONDENT: it's the same thing. It's the one where sometimes, um, when they realise, or when I talk over him, which I have to sometimes in the end to get to the point..um..then they totally ignore him. (C4)

Example 2

INTERVIEWER: Could you tell me about an experience that he or you have had from health services that has been particularly memorable?

RESPONDENT: I think the most memorable ones are going to be the bad ones, but a lot of the issues are around what he was saying about spending time with people and explaining things properly, and also possibly not speaking directly to him. So when he visited the dentist, they often speak to the carer rather than the patient and that often makes me feel bad (C7).

Example 3

INTERVIEWER: A couple of more questions. We spoke about hospitals. What were the ward rounds like, so when the doctors came round to see you?

RESPONDENT: They just talked to the nurses and then go away.

INTERVIEWER: they didn't speak to you directly?

RESPONDENT: No they just said this patient needs whatever medication.

INTERVIEWER: They didn't ask you how you were feeling or explain things to you?

RESPONDENT: No. No.

INTERVIEWER: What about in clinics, do they talk to you directly, or do they speak to whoever is with you?

RESPONDENT: They talk to whoever's with me, they don't talk to me.

(P9)

Example 4

INTERVIEWER: How does that make you feel when they don't talk to you?

RESPONDENT: It annoys me because they're talking to someone else and not me. They don't think that I can answer the questions.

INTERVIEWER: Have you ever confronted the doctors about this?

RESPONDENT: Well I did on the last kidney appointment when they were talking to mum and like not to me. And I was trying to explain my things across and he was just talking over me.

INTERVIEWER: Did you ask the doctor to speak to you?

RESPONDENT: yeah

INTERVIEWER: And did that make a difference?

RESPONDENT: No, he just ignored me.

(P9)

Example 5

INTERVIEWER: Do they talk to you and listen to what you have to say?

RESPONDENT: I sit there and say nothing and they talk about me

INTERVIEWER: So the doctors don't say anything to you?

RESPONDENT: No

INTERVIEWER: Would you like them to talk to you?

RESPONDENT: yes, I would.

INTERVIEWER: And do you like the way they talk to you?

RESPONDENT: I'd like to know what's happening..I'd like to say something..I think the doctors like talking to the parent about what's happened to the child, like a cold..but I need to know. I think parents go first and daughter or son goes second about what's happening, I need to know.

INTERVIEWER: So you think that doctors always talk to your mum and you're not given enough information about what's going on?

RESPONDENT: yeah.

(P5)

Example 6

INTERVIEWER: Does the doctor try to speak to her directly?

RESPONDENT: No he never tries, he only speaks to me

INTERVIEWER: Does he examine her?

RESPONDENT: He examines her but he never says anything to her. It's always with me and then I say everything.

INTERVIEWER: How long have you known this doctor?

RESPONDENT: 26 years

(C13)

Example 7

INTERVIEWER: When you go to see the doctor, does he talk to you or your mum?

RESPONDENT: He talks to my mum

INTERVIEWER: Does he ever talk to you? Does he say hello, how are you?

RESPONDENT: No

INTERVIEWER: He never talks to you?

RESPONDENT: Never.

(P13)

Code: Health professionals not explaining things to service user

Example 1

INTERVIEWER: Could you tell me about an experience that he or you have had from health services that has been particularly memorable?

RESPONDENT: I think the most memorable ones are going to be the bad ones, but a lot of the issues are around what he was saying about spending time with people and explaining things properly, and also possibly not speaking directly to him. So when he visited the dentist, they often speak to the carer rather than the patient and that often makes me feel bad (C7).

Example 2:

RESPONDENT: yeah, but obviously there were still problems like he wasn't respected and fully informed. I did speak to him a couple of times while he was in the hospital. Like he said he would ring the office because he felt lonely there and scared that he didn't know what was going on. He did phone me up a couple of times, didn't you, in the office and he was quite stressed that he wasn't getting informed, didn't feel supported that end and obviously this end it was quite stressful for us to hear him in that situation (C7)

Example 3:

RESPONDENT: but what they did was, which we weren't aware of, they had to go in and they obviously had to put her legs in stirrups so that affected her quite badly because of her hip problem. Now whether they could have done it another way we weren't really asked so that was a bit of a disappointment

INTERVIEWER: So that was a complete surprise and not explained before the procedure?

RESPONDENT: No it wasn't

(C9)

Example 4:

RESPONDENT: And it was quite uncomfortable, because they put my legs in the stirrup.

INTERVIEWER: Did they explain this to you before the operation?

RESPONDENT: No, No.

INTERVIEWER: How did you feel?

RESPONDENT: Scary, and they gave me an epidural and I didn't like that because it made my legs go numb and I have problems with my legs.

INTERVIEWER: Did they explain that they were going to do this before the procedure?

RESPONDENT: No, No. They didn't explain nothing really. Because they weren't suppose to put me to sleep because I've got sleep apnoea and they out me to sleep so I felt sick afterwards because of the anaesthetic.

(P9)

Example 5

INTERVIEWER: What were your hospital admissions like? You mentioned the one about kidney

RESPONDENT: They're all exactly the same

INTERVIEWER: In what way have they been the same?

RESPONDENT: Basically they don't explain things properly. They don't know how to treat..they don't have good customer care or patient care. They don't treat the patients right.

(P9)

Example 6:

INTERVIEWER: And do you like the way they talk to you?

RESPONDENT: I'd like to know what's happening..I'd like to say something..I think the doctors like talking to the parent about what's happened to the child, like a cold..but I need to know. I think parents go first and daughter or son goes second about what's happening, I need to know.

INTERVIEWER: So you think that doctors always talk to your mum and you're not given enough information about what's going on?

RESPONDENT: yeah.

(P5)

Example 7:

RESPONDENT: No, I was frightened, I was nervous and I didn't know what was going on. It was my carers that told me what was going on, what was happening. Coz I rang my carers and my mum up a lot and when you tell the nurse, they said well we'll get in touch with your social worker, and sometimes it would take five hours. The OT was ok but the nurses didn't tell you anything (P7)

Example 8:

RESPONDENT: The dentist at (name of place), that's got a lot to be desired because they don't talk to me calmly.

INTERVIEWER: This is the previous dentist that you went to see? What happened there?

RESPONDENT: They weren't telling me what they were doing on my teeth and they transferred me to the dentist in (name of place) just like that. And I hate gas, and they said they would put me to sleep with gas and oxygen and that really scared me.

Code : Staff failing to modify their communication skills

Example 1

RESPONDENT: yeah, yeah...and they don't want to modify their language. He's quite able, he is able. If you use, you know modify your language and don't use double negatives. (C4)

Example 2

RESPONDENT: it's the same thing. It's the one where sometimes, um, when they realise, or when I talk over him, which I have to sometimes in the end to get to the point..um..then they totally ignore him. Or..um..they keep talking to him and asking him questions and he is giving totally ridiculous answers but they keep talking to him. Coz I don't think they know the point you can actually..I suppose they feel awkward too, coz they don't know either..yeah (C4).

Example 3:

INTERVIEWER: When they do come round during their ward rounds, do they explain to you what's going on?

RESPONDENT: I can't understand sometimes but I get the gist, not all the gist but when they're on their own, I get the whole idea

INTERVIEWER: So when they have a 1:1 conversation, you find it easier, rather than when there are lots of people?

RESPONDENT: They don't understand what you're talking about half the time.

INTERVIEWER: So when they're talking to you, do they check that you've understood what they've said?

RESPONDENT: Sometimes yes but sometimes no. Cos I know a couple of people with low attention and he's not that clever and he wouldn't understand what to do.

Mum: Do you find also that they tell you a lot of stuff and they say do you understand? Maybe you did bits of it and not other bits. You know when they tell you loads of stuff and right at the end they say did you understand?

RESPONDENT: It's too much information. Do it simply and it's more easier to understand. Not a long thing, it goes beyond my attention...where it's beyond me...it needs to be at a slow speed, the right pace for me. When I'm at the doctor's, I always feel like, what did he do, what did he talk about?, I can't remember. Sometimes I go blank.

INTERVIEWER: Do you feel quite a lot of pressure when you're with doctors?

RESPONDENT: Sometimes..sometimes I go blank. If he did say something to me, the fella, I would forget straight away.

INTERVIEWER: What would help? Would it help if they wrote it down for you or gave you something to take away?

RESPONDENT: Yeah, something like that. But it would be better if the pace was slower, someone can understand what's going on.(P4)

INTERVIEWER: Did you think they were explaining things to you properly?

RESPONDENT: Sometimes they said things too quickly. Couldn't understand.

INTERVIEWER: Did they make an attempt to explain things differently, like using information sheets or pictures?

RESPONDENT: they were making notes and they were talking so quickly.

INTERVIEWER: Did they take time to explain what was going to happen?

RESPONDENT: No.

(P3)

Questionnaires for the cross sectional study

Structured Data collection form for stigma study

Patient ID:

Centre:

1. **Gender** Male ☐ Female ☐

2. **Age:**

3. **LD severity**: Mild ☐ Moderate ☐

4. **Ethnicity**

White: British ☐ Irish ☐ other ☐

Mixed: White/ Black Caribbean ☐ White /Black African ☐

White and Asian ☐ Other ☐

Asian/British Asian: Indian ☐ Pakistani ☐

Bangladeshi ☐ Other ☐

Black/Black British: Caribbean ☐ African ☐ Other ☐

Chinese/other: Chinese ☐ Other ☐ specify……………

5. **Marital status**

Married ☐ Cohabiting ☐ Partner (not cohabiting) ☐

Widowed ☐ Divorced ☐ Separated ☐ single ☐

6. **Living situation**

Family home ☐ Lives alone (has tenancy -no support) ☐

Supported housing - less than 24 hour support ☐

supported housing - 24 hour support ☐

Residential home – 24 hour support ☐

Nursing home ☐ Other ☐

7. **Number of people living with participant?** ……………………………..

8. **Main carer**

None ☐ Parent ☐ Other relative ☐

Friend ☐ Paid carer ☐ Other ☐

9. **Number of children:**

Number of children living at home:

10. **Previous education**

Attended mainstream school only ☐

Attended special school ☐

11. **Employment**

Full time (paid) ☐ part time (paid) ☐ charity/voluntary ☐

Unemployed, seeking work ☐ unemployed, not seeking work ☐

Retired ☐ Housewife/House husband ☐

Full time student ☐ Part time student ☐

Other ☐

If in paid employment – type of job or occupation ……………………………

12. **Benefits**

Disability Living Allowance ☐ Income support ☐

Job seekers allowance ☐ Widows allowance ☐

Housing benefit ☐ State pension ☐

None ☐ Other ………………………

13. **Relationships**

Number of close friends: None ☐ Two or less ☐

More than 2 ☐

Any friends without LD? Yes ☐ No ☐

14. **Sensory problems**

Hearing problems: one ear ☐ both ears ☐

problems with vision: one eye ☐ both eyes ☐

none ☐

15. **Mobility problems**

Wheel chair user ☐ walking stick/frame ☐

No adaptations required ☐ other ☐

16. **Speech abnormalities** (rated by interviewer)

None ☐

minor (minor difficulty understanding speech) ☐

Moderate (half the words difficult to understand) ☐

Severe (most of the words are difficult to understand) ☐

17. **Health problems** (diagnosed by GP)

Cancer ☐ if yes specify ……………………..

Diabetes ☐ Heart attack/angina ☐

High blood pressure ☐ Other heart problems ☐

Asthma ☐ Bronchitis/emphysema ☐

Stomach/digestive problem ☐ Bowel problems ☐

Bladder problems/incontinence ☐ Arthritis ☐

Other bone/joint problem ☐ Stroke ☐

Epilepsy ☐ Migraine/headaches ☐

Infections ☐ Other ☐ Specify………………

None ☐

18. **Known genetic disorder/syndrome**

No ☐ Yes ☐

Specify ………………………..

19. **Medication**

List all medications and doses (if available)

The Stigma questionnaire

Participant ID:

These questions are about how people act towards you because you have a learning disability

please read each question and tick one of the boxes

	yes 	**no** 
1. people talk down to me		
2. people on the street make fun of me		
3. people on the street look at me in a funny way		

	yes 	no 
4.people laugh at me because of the way I look		
5. people treat me like a child		
6. people laugh at me because of the way I talk		
7. the way people talk to me makes me angry		
8. people make me feel embarrassed		

	yes 	no 
9. I keep away from other people because they are not nice to me		
10. I worry about the way people act towards me		

Total Score ……………………………

CLINICAL **CORE-LD**
OUTCOMES in Patient id:
ROUTINE
EVALUATION -
LEARNING
DISABILITIES

HOW DO YOU FEEL?

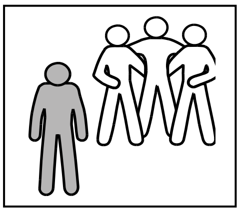
This form has 14 questions about how you have been **OVER THE LAST WEEK**

People with a learning disability helped make these questions.

Please tick the box that fits how you feel.

Over the last week……..

1.

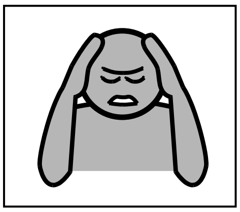


Have you felt very very lonely?
Have you felt really alone

☐ ☐ ☐

Not Some A lot
At all times

2.

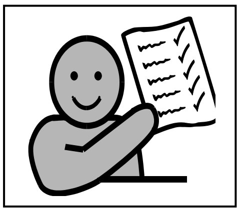


Have you felt confused?
Has it been hard to think straight?

☐ ☐ ☐

Not Some A lot
At all times

3.



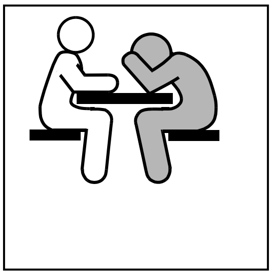
Have you felt happy with the things you have done?

☐ ☐ ☐

Not Some A lot
At all times

Over the last week…….

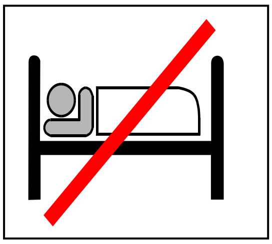
4.



Have you found it hard to say how you feel?

Not At all
Some times
A lot

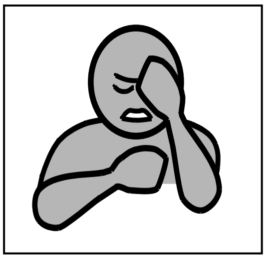
5.



Have you had difficulty getting to sleep or staying asleep?

Not At all
Some times
A lot

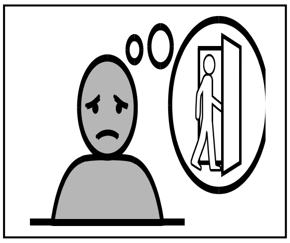
6.



Have you felt frustrated or upset with your learning disability?

Not At all
Some times
A lot

7.



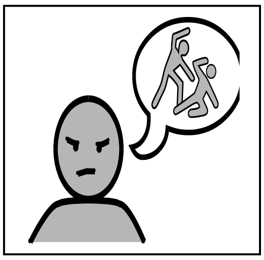
Have you felt sad about people you have lost?
For example family, staff, friends

Not At all
Some times
A lot

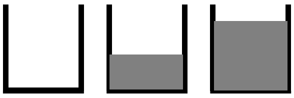
Over the last week……..

8.

R

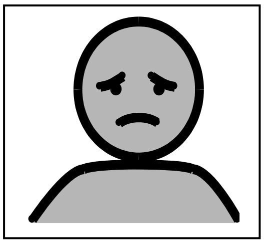


Have you threatened or shouted at someone?

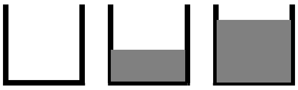


Not At all **Some times** **A lot**

9.

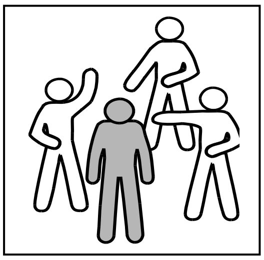


Have you felt unhappy?



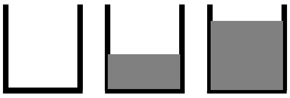
Not At all **Some times** **A lot**

10.



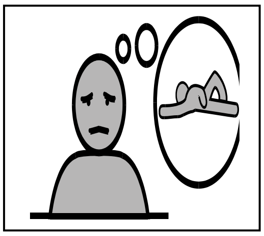
Have you felt people are getting at you?

Have you felt people were picking on you?



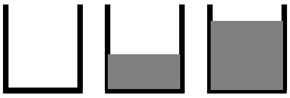
Not at all **Some times** **A lot**

11.



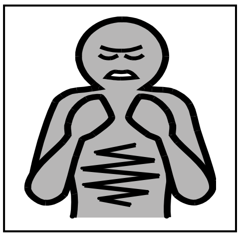
Have you thought about ending your life?

Have you wanted to be dead?



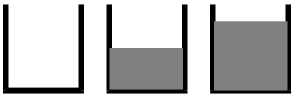
Not at all **Some times** **A lot**

12.



Have you bottled up angry feelings?

Have you felt ready to blow inside?

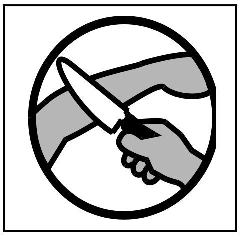


Not at all **Some times** **A lot**

Over the last week........

13.

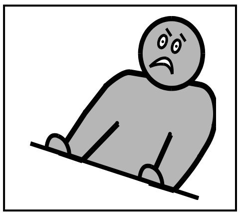
R



Have you hurt yourself on purpose? eg. cutting, picking, hitting yourself, not taking tablets, drinking lots of alcohol

☐ Not At all
☐ Some times
☐ A lot

14.



Have you felt really or frightened?

☐ Not At all
☐ Some times
☐ A lot

Total Score ☐ **Mean** ☐ **Total Clinical Score** ☐

Thank you for doing this questionnaire

Scoring – all questions except question3:

Not at all = 0 Sometimes = 1 A lot = 2.

Question 3 only
Not at all =2 Sometimes = 1 A lot = 0

Add together the item scores. Divide by the number of questions completed to get the mean score, multiply by 14 to get the total clinical score.

Quality of Life Questionnaire

Robert L. Schalock, Ph.D., and Kenneth D. Keith, Ph.D.

Person's Name ____ Age ________________ Gender____________________

Person's Program ____ Evaluator _________________________ Test Date __________________

Scale	**Rater-1** (If Applicable)	**Rater-2** (If Applicable)	**Average Rater or Self-Report** (Numbers in Circles)	**Percentile**
Satisfaction	____________	____________	____________	____________
Competence/Productivity	____________	____________	____________	____________
Empowerment/Independence	____________	____________	____________	____________
Social Belonging/ Community Integration	____________	____________	____________	____________
Total Score	____________	____________	____________	____________

Questions		Answer Alternatives			Record Score Here
		3 Points	2 Points	1 Point	
SATISFACTION					
1.	Overall, would you say that life:	Brings out the best in you?	Treats you like everybody else?	Doesn’t give you a chance?	
2.	How much fun and enjoyment do you get out of life?	Lots	Some	Not much	
3.	compared to others, are you better off, about the same, or less well off?	Better	About the same	Worse	
4.	Are most of the things that happen to you:	Rewarding	Acceptable	Disappointing	
5.	How satisfied are you with your current home or living arrangement?	Very satisfied	Somewhat satisfied	Unsatisfied or very unsatisfied	
6.	Do you have more or fewer problems than other people?	Fewer problems	The same number of problems as others	More problems than others	
7.	How many times per month do you feel lonely?	Seldom, never more than once or twice	Occasionally, at least 5 or 6 times a month	Frequently, at least once or twice a week	
8.	Do you ever feel out of place in social situations?	Seldom or never	Sometimes	Usually or always	
9.	How successful do you think you are, compared to others?	Probably more successful than the average person	About as successful as the average person	Less successful than the average person	
10.	What about your family members? Do they make you feel:	An important part of the family	Sometimes a part of the family	Like an outsider	

TOTAL SCALE SCORE -- SATISFACTION

Questions	Answer Alternatives			
	3 Points	2 Points	1 Point	
COMPETENCE/PRODUCTIVITY				
11. How well did your educational or training program prepare you for what you are doing now?	Very well	Somewhat	Not at all well	
12. Do you feel your job or other daily activity is worthwhile and relevant to either yourself or others?	Yes, definitely	Probably	I'm not sure, or definitely not	
Note: *If a person is unemployed, do not ask Questions 13-20. Score items # 13-20 "1".*				
13. How good do you feel you are at your job?	Very good, and others tell me I am good	I'm good, but no one tells me	I'm having trouble on my job	
14. How do people treat you on your job?	The same as all other employees	Somewhat differently than other employees	Very differently	
15. How satisfied are you with the skills and experience you have gained or are gaining from your job?	Very satisfied	Somewhat satisfied	Not satisfied	
16. Are you learning skills that will help you get a different or better job? What are these skills?	Yes, definitely (one or more skills mentioned)	Am not sure, maybe (vague, general skills mentioned)	No, job provides no opportunity for learning new skills	
17. Do you feel you receive fair pay for your work?	Yes, definitely	Sometimes	No, I do not feel I am paid enough	
18. Does your job provide you with enough money to buy the things you want?	Yes, I can generally buy those reasonable things I want	I have to wait to buy some items or not buy them at all	No, I definitely do not earn enough to buy what I need	
19. How satisfied are you with the benefits you receive at the workplace?	Very satisfied	Somewhat satisfied	Not satisfied	
20. How closely supervised are you on your job?	Supervisor is present only when I need him or her	Supervisor is frequently present whether or not I need him or her	Supervisor is constantly on the job and looking over my work	

TOTAL SCALE SCORE – COMPETENCE/PRODUCTIVITY

Questions		Answer Alternatives 3 Points	2 Points	1 Point	Record Score Here
EMPOWERMENT/INDEPENDENCE					
21.	How did you decide to do the job or other daily activities you do now?	I chose it because of pay, benefits, or interests	Only thin available or that I could find	Someone else decided for me	
22.	Who decides how you spend your money?	I do	I do, with assistance from others	Never on my own	
23.	How do you use health care facilities (doctor, dentist, etc.)?	Almost always on my own	Usually accompanied by someone, or someone else has made the appointment	Never on my own	
24.	How much control do you have over things you do every day, like going to bed, eating, and what you do for fun?	Complete	Some	Little	
25.	When can friends visit your home?	As often as I like or fairly often	Any day, as long as someone else approves or is there	Only on certain days	
26.	Do you have a key to your home?	Yes, I have a key and use it as I wish	yes, I have a key but it only unlocks certain areas	No	
27.	May you have a pet if you want?	Yes, definitely	probably yes, but would need to ask	No	
28.	do you have a guardian or conservator?	No, I am responsible for myself	Yes, limited guardian or conservator	Yes, I have a full guardian	
29.	Are there people living with you who sometimes hurt you, pester you, scare you, or make you angry?	No	Yes, and those problems occur once a month or once a week	Yes, and those problems occur every day or more than once a day	
30.	Overall, would you say that your life is:	Free	Somewhat planned for you	Cannot usually do what you want	

TOTAL SCALE SCORE – EMPOWERMENT/INDEPENDENCE

Questions	Answer Alternatives			Record Score Here
	3 Points	2 Points	1 Point	
SOCIAL BELONGING/				
31. How many civic or community clubs or organizations (including church or other religious activities) do you belong to?	2-3	1 Only	None	
32. How satisfied are you with the clubs or organizations (including church or other religious activities) do you belong to?	Very satisfied	Somewhat satisfied	Unsatisfied or very unsatisfied	
33. Do you worry about what people expect of you?	Sometimes, but not all the time	Seldom	Never or all the time	
34. How many times per week do you talk to (or associate with) your neighbors, either in the yard or in their home?	3-4 times per week	1-2 times per week	Never or all the time	
35. Do you have friends over to visit your home?	Fairly often	Sometimes	Rarely or never	
36. How often do you attend recreational activities (homes, parties, dances, concerts, plays) in your community?	3-4 per month	1-2 per month	Less than 1 per month	
37. Do you participate actively in those recreational activities?	Usually, most of the time	Frequently, about half the time	Seldom or never	
38. What about opportunities for dating or marriage?	I am married, or have the opportunity to date anyone I choose	I have limited opportunities to date or marry	I have no opportunity to date or marry	
39. How do your neighbors treat you?	Very good or good (invite you to activities, coffee, etc.)	Fair (say hello, visit, etc.)	Bad or very bad (avoid you, bother you, etc.)	
40. Overall, would you say that your life is:	Very worthwhile	Okay	Useless	

TOTAL SCALE SCORE –

SOCIAL BELONGING/COMMUNITY INTEGRATION

Adherence rating scale

Participant ID:

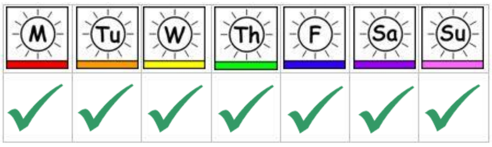
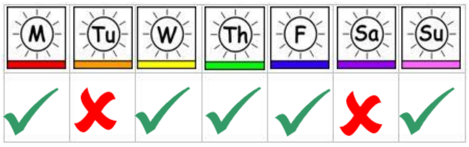
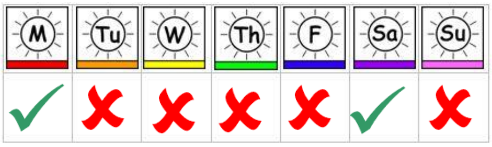
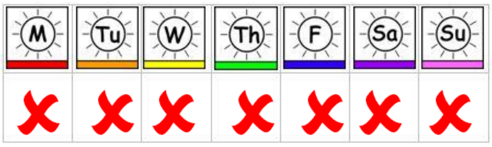
Please can you fill in this form. The information you give is confidential

1. are you on any medication?

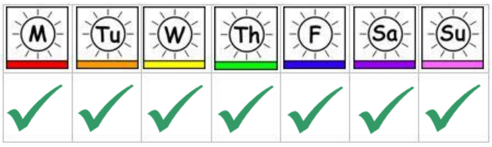
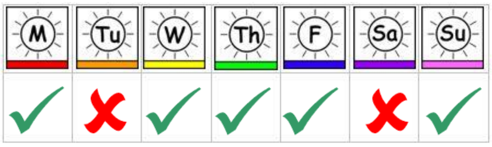
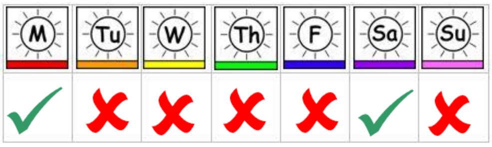
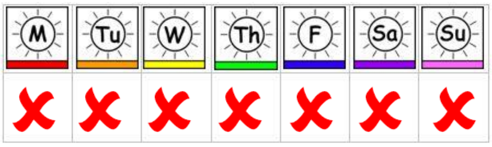
✓ **yes** ☐

✗ **no** ☐

2. if yes, how often do you take the medication?

	how often	**tick one box** ✓	rating
 M Tu W Th F Sa Su ✓ ✓ ✓ ✓ ✓ ✓ ✓	I take the medication **everyday**		4
 M Tu W Th F Sa Su ✓ ✗ ✓ ✓ ✓ ✗ ✓	I take the medication on **most days**		3
 M Tu W Th F Sa Su ✓ ✗ ✗ ✗ ✗ ✓ ✗	I take the medication **sometimes**		2
 M Tu W Th F Sa Su ✗ ✗ ✗ ✗ ✗ ✗ ✗	I **never** take this medication		1

3. how often do you need to be reminded to take the medication?

	reminders	**tick one box** ✓	Rating
	I **don't** need reminders		4
	I need reminders **sometimes**		3
	I need reminders **most days**		2
	I **always** need reminders		1

4. does the medication help you?

	help	**tick one box** ✓	rating
✓ ✓	It **always** helps me		4
✓	I helps me **most** of the time		3
?	It helps me **sometimes**		2
✗	It **doesn't** help me		1

Total score ………………..

Average rating (total score /3)…………

Adherence rating scale – psychological therapy

in the last 6 months

1. did you take part in any talking therapy (e.g. counselling)

✓ **yes** ☐

✗ **no** ☐

2. did you take part in art, dance or music therapy

✓ **yes** ☐

✗ **no** ☐

3. if yes, which one?

4. If yes, how often did you go to the sessions?

	How often	**tick one box** ✓	rating
	I went to **every** session		4
	I went to **most** sessions		3
	I went to **some** of the sessions		2
	I went to **none** of the sessions		1

5. how much did you need to be reminded to go to the sessions?

	reminders	**tick one box** ✓	rating
M Tu W Th F Sa Su ✓ ✓ ✓ ✓ ✓ ✓ ✓	I **didn't** need reminders		4
M Tu W Th F Sa Su ✓ ✗ ✓ ✓ ✓ ✗ ✓	I needed reminders **sometimes**		3
M Tu W Th F Sa Su ✓ ✗ ✗ ✗ ✗ ✓ ✗	I needed reminders **most days**		2
M Tu W Th F Sa Su ✗ ✗ ✗ ✗ ✗ ✗ ✗	I **always** needed reminders		1

6. did the sessions help you?

	help	**tick one box** ✓	rating
✓ ✓	they helped me **alot**		4
✓	they helped me **most** of the time		3
?	they helped me **sometimes**		2
✗	they **didn't** help me		1

Total score ....

Average rating (total score /3)............

Adherence rating scale – other help

In the last 6 months
1. did you get any other help (e.g. nursing, OT, physiotherapy)

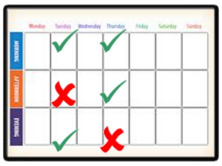
✓ **yes** ☐

✗ **no** ☐

2. if yes, what help did you get

……………………………………….

3. how often did you go to the sessions? (add more sheets if needed)

	How often	**tick one box** ✓	rating
	I went to **every** session		4
	I went to **most** sessions		3
	I went to **some** of the sessions		2
	I went to **none** of the sessions		1

4. how much did you need to be reminded to go to the sessions?

	reminders	**tick one box** ✓	rating
M Tu W Th F Sa Su ✓ ✓ ✓ ✓ ✓ ✓ ✓	I **didn't** need reminders		4
M Tu W Th F Sa Su ✓ ✗ ✓ ✓ ✓ ✗ ✓	I needed reminders **sometimes**		3
M Tu W Th F Sa Su ✓ ✗ ✗ ✗ ✗ ✓ ✗	I needed reminders **most days**		2
M Tu W Th F Sa Su ✗ ✗ ✗ ✗ ✗ ✗ ✗	I **always** needed reminders		1

5. did the sessions help you?

	help	**tick one box** ✓	rating
✓ ✓	They helped me **a lot**		4
✓	they helped me **most** of the time		3
?	they helped me **sometimes**		2
✗	They didn't help me		1

Total score …………………

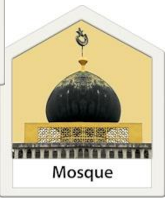
Average rating (total score /3)…………

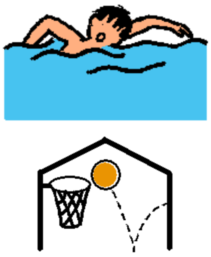
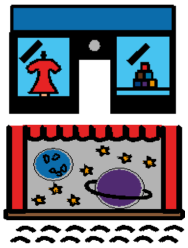
Service Use Questionnaire

Patient ID: **completed with carer:**

Please fill in this form. The information you give is private

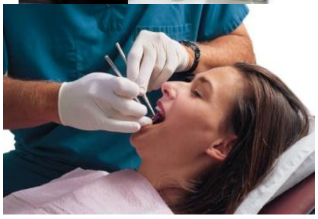
1. which of these day time activities have you done in the last 6 months?

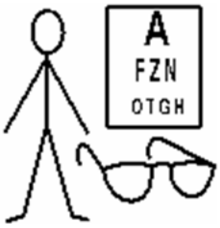
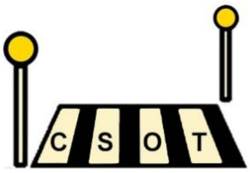
	activity	**how often do you do this?** **tick one box** ✓				
		once a week or more	**every 2 weeks**	**once a month**	**less than once a month**	**never**
	day centre					
	college					
 	religious activity (church, mosque, temple)					

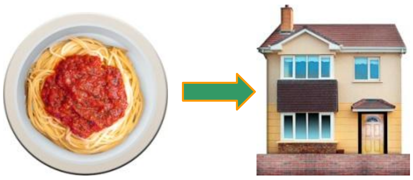
	Activity	how often do you do this? Tick one box ✓				
		once a week or more	every 2 weeks	once a month	less than once a month	never
	social clubs					
	voluntary work					
	leisure activities (swimming gym, horse riding)					
	one to one activities (e.g. shopping, cinema)					
	Other					

2. have you had contact with any of these services or professionals in the last 6 months?

	professional or service	**yes** ✓	**no** ✗	**how many times?**
	GP			
	nurse at GP surgery			
	district nurse			
	learning disability nurse			
	psychologist or counsellor (or other therapist)			
OT	occupational therapist			

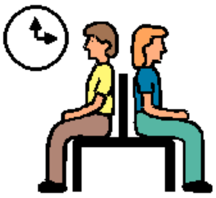
	professional or service	**yes** ✓	**No** ✗	**how many times?**
	physiotherapist			
	speech and language therapist			
	dietician			
	social worker or care manager			
	dentist			
	chiropodist or podiatrist			
	Advocate			

	Professional or service	**yes** ✓	**no** ✗	**how many times?**
	optician			
	family planning clinic or sexual health clinic			
	parenting service			
	health visitor			
	Midwife			
	community support worker			
	welfare rights officer			

	professional or **service**	**yes** ✓	**no** ✗	**how many times?**
	job centre or employment service			
	housing advisor			
	meals on wheels			
	respite care			
ℹ	other ……………….			

Hospital Based services

3. have you used any of the following services in the last 6 months?

	Service	**yes** ✓	**no** ✗	**reason for using service**	**how long for?**
	outpatient clinic				
	Tests (x-ray, blood test)				
	day hospital				
	accident and emergency				
	stayed overnight on medical ward				
ℹ	Other..........				

Police contact

4.In the last 6 months, have you had any contact with the police? 	**yes** ✓	no ✗
If yes, how many times did you have contact with the police? what was the reason? (were you the victim, a witness or offender)		

Refusal of services

	yes ✓	no ✗
5. have you said no to any help from services in the last 6 months? 		
were any of these services offered by **the learning disability service?** CLDS 		

Which services did you say **no** to?  what was your **reason** for saying **no** to the service? 	**tick one box** **did not need it** ☐ **too busy** ☐ **appointment time/date not suitable** ☐ **did not get on with staff** ☐ **no support to attend** ☐ **worried about what other people may think** ☐ **other** ☐ **……………..**

Interview Schedules for the qualitative study

Participant ID:

Version 2, 10/05/2011

Semi-structured interview schedule for participants with Intellectual Disability

1. Introduction

Thank you for taking part in this interview. I would like to find out what you think about the care you have got from health services, particularly if you think you've been treated badly or unfairly or have been bullied, or may be you've felt that people don't care. For example, a few times when I've gone to see my GP, I felt like she didn't really listen to what I had to say and I felt rushed so I didn't tell her everything I wanted to say. Maybe you've had the same happen to you.

Everything you say is confidential – no one else will know what you have said, (including your key worker or carer). We may use what you say to write a report but we will not use your name.

A) Service contacts and satisfaction

1. Would you like to talk about any particular experiences with health staff that you've had?

2. Which health staff do you normally see? (To make process more engaging and collaborative create a visual brainstorm of the professionals he/she has contact with, which can then be used throughout the interview)

Do you see any staff at the learning disability service (nurse, speech and language therapist, occupational therapist , psychiatrist etc)

How often do you see your GP?

Do you see anyone else at the GP surgery (e.g. nurse)?

Do you use any other services in the community (e.g. family planning clinics)

Do you go to your local hospital for any appointments? Who do you see?

Do you see an optician or a dentist?

Do you see any other health staff? (E.g. district nurse, podiatrist/chiropodist)

ii) How do you get on with the health professionals you see?

For each professional :

What do you think about the way they talk to you?

Do you think that he/she listens to what you have to say

If you have a problem how helpful are they?

Did you have any problems getting referred to this person (did the person see you quickly or did you have to wait a long time to see them?)

Can you give an example of when you were happy with him/her?

Were there any times when you were not happy with them? Can you tell me about this?

How could things be better/what could this person do better?

iii) Have you ever stayed overnight at the hospital?

– If yes: how long were you there?

Why were you there?

What was it like?

Were you happy with the way you were treated by staff?

Were you given enough information? Were things explained to you?

Could you take part in ward round/meetings?

Did the learning disability liaison nurse (link nurse) visit you?

Were there any things that you were happy about? Can you tell me about these?

Were there any things that you were not happy about?

B. Stigma and discrimination

Do you think you have ever been treated badly or differently by a health professional because you have a learning disability?

If yes - Could you tell me more about this?

How did that make you feel?

How do you feel about seeing this person again/ using this service (e.g. clinic) again?

Did you think about making a complaint (check if they generally know about the right to complain and procedures)

Did you talk to other people about this? If not, why not? Did they give you any support?

Has this experience changed your mind about using health services again? In what way?

C. Improving/developing services

How could health services treat people with learning Disability better?

What extra help would you like when you go to the local hospital or GP practice?

What could staff do better?

Do you think any changes need to be made to the facilities? If yes – what changes need to be made?

Is there anything else you would like to tell me?

Thank you for taking part

Here is my name and contact number – you can call me if you have any questions about the study

Version 2, 10/05/2011

Semi-structured interview schedule – carers

1. Introduction

Thank you for agreeing to be interviewed. The purpose of the interview is to find out about your views on the experience and quality of care that the person you care for, has received from health services, particularly if you think that he/she has been treated unfairly or badly because of his or her learning disability. I am also interested in what your experience has been from health services, as a carer, and how health services could be improved.

Anything you say in the interview will be treated confidentially. Your comments may appear in published work but you will not be named or identified.

1. Main questions/probes

A Service contacts

i. Can you tell me about any experiences that X or you have had that were particularly memorable? (good or bad experiences)

ii) What types of health services (private, voluntary or NHS) has X had contact with?

Does X have contact with his/her GP or practice nurse?

Does X have any input from the learning disability service?

Does X have input from dentists/opticians/podiatrists?

Does X have outpatient appointments with any doctors?

Has X received any treatment as an inpatient?

Has X had any private consultations or treatment?

ii) For each of these services, can tell me about the quality of the service that X received?

What was the nature of the contact?

How was X treated by the staff?

What did you think about the appropriateness of the facilities?

In your opinion, did X receive appropriate investigations or treatment?

Were there any positive things about that experience?

Were there any negative things about that experience?

How were you treated as X's carer?

Were you given enough information about what was going on?

What opportunities were you given to ask questions/ become involved in the care?

What could they have done better? What improvements would you like to see?

B Stigma and discrimination

Have you or X ever experienced discrimination or unfair/unequal treatment from health services compared to other people?

Could you describe what happened?

How do you think X felt?

How did it make you feel?

How do you feel about using that service again?

Did you make a complaint? Were you aware of procedures regarding making a complaint?

What impact has it had on your use of health services on X's behalf (if any)?

C Improving/developing services

How do you think that health services could be improved so that they meet the needs of people with learning disability?

What concerns, if any, do you have about the way health staff/professionals treat people with learning disability and their carers?

Are there any areas that staff could be trained better in?

What do you think are the most important aspects that need to be improved?

Has legislation such as the Mental Capacity Act, Discrimination Act or the recent Equality Act made a difference?

Have you noticed any changes over the last few years about the way X has been treated by the NHS?

Is there anything else you would like to talk about that we haven't mentioned?

Check that you have covered list of questions and prompts

Thank you for your time.

Here is my name and contact number in case you would like to talk about the project later.

Structured data collection form for qualitative interviews
Participant ID:

Information about service user

1**. Gender** Male ☐ Female ☐

2. **Age:**

3. **LD severity**: Mild ☐ Moderate ☐

4**. Ethnicity**

White: British ☐ Irish ☐ other ☐

Mixed: White/ Black Caribbean ☐ White /Black African ☐

White and Asian ☐ Other ☐

Asian/British Asian: Indian ☐ Pakistani ☐

Bangladeshi ☐ Other ☐

Black/Black British: Caribbean ☐ African ☐ Other ☐

Chinese/other: Chinese ☐ Other ☐ specify……………

5**. Marital status**

Married ☐ Cohabiting ☐ Single ☐

Widowed ☐ Divorced ☐ Separated ☐

6. **Living situation**

Family home ☐ Lives alone (has tenancy -no support) ☐

Supported housing - less than 24 hour support ☐

supported housing - 24 hour support ☐

Residential home – 24 hour support ☐

Nursing home ☐ Other ☐

7. **Number of people living with participant?** ……………………………..

8. **Main carer**

None ☐ Parent ☐ Other relative ☐

Friend ☐ Paid carer ☐ Other ☐

9**. Sensory problems**

Hearing problems: one ear ☐ both ears ☐

problems with vision: one eye ☐ both eyes ☐

none ☐

10. **Mobility problems**

Wheel chair user ☐ walking stick/frame ☐

No adaptations required ☐ other ☐

11. **Physical Health problems** (diagnosed by GP)

Cancer ☐ if yes specify ……………………..

Diabetes ☐ Heart attack/angina ☐

High blood pressure ☐ Other heart problems ☐

Asthma ☐ Bronchitis/emphysema ☐

Stomach/digestive problem ☐ Bowel problems ☐

Bladder problems/incontinence ☐ Arthritis ☐

Other bone/joint problem ☐

Stroke ☐ Epilepsy ☐

Migraine/headaches ☐ Infections ☐

Other ☐ Specify………………

None ☐

13. **Mental Health problems (diagnosed by GP)**

Depression ☐ Anxiety Disorder ☐

Biplolar disorder ☐ Psychotic disorder ☐

ASD ☐ Other ☐

Specify ………………..

12. **Known genetic disorder/syndrome**

No ☐ Yes ☐

Specify ………………

13. **Medication**

List all medications and doses (if available)

Information about carers:

Participant ID:

1**. Gender** Male ☐ Female ☐

2. **Age:**

3**. Ethnicity**

White: British ☐ Irish ☐ other ☐

Mixed: White/ Black Caribbean ☐ White /Black African ☐

White and Asian ☐ Other ☐

Asian/British Asian: Indian ☐ Pakistani ☐

Bangladeshi ☐ Other ☐

Black/Black British: Caribbean ☐ African ☐ Other ☐

Chinese/other: Chinese ☐ Other ☐ specify……………

4**. Marital status**

Married ☐ Cohabiting ☐ Single ☐

Widowed ☐ Divorce ☐ Separated ☐

5**. Relationship with service user**

Parent ☐ Sibling ☐ Son/daughter ☐

Other relative ☐ Friend ☐ Paid carer ☐

Other ☐ specify ……………………………..

6. **Does carer Care for any one else?**

Yes ☐ No ☐

If yes, who else …………………………………………..

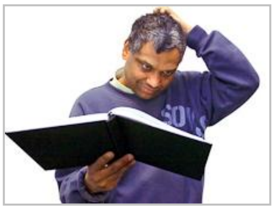
7. **Number of years carer has known service user?**..............................

Information sheets and consent forms

Service user information sheet- Cross sectional study

Camden NHS
Primary Care Trust

A study to find out if being treated unfairly causes stress in people with learning disability

	my name is Afia Ali
	I am a Doctor
 	I am writing to ask if you want to help me

to help you understand this letter you can

- ask someone to read it for you

- talk to your carer about it

- you can ask me questions

What is my work about?

finding out how you are treated by other people because you have a learning disability

I want to find out if being treated badly or unfairly:

	• makes you feel sad or stressed
	• stops you from taking your medication
	• stops you from using services for people with learning disability like the daycentre
	• affects your quality of life

Why do I want to see you?

	I want to talk to you • because you are between 18-65 years old • because you have a mild or moderate learning disability

	• The information you give can help to make things better for people with learning disability
What will happen to me if I take part?	
   	we can not include anyone with serious mental health problems in the study If you agree to take part, I will ask you some questions and fill in a form you will only need to say "yes" or "no" to most of the questions the interview will last for about 1 and a half hours

we can meet at a place you know

you can ask your carer or key worker to come to the meeting

Do you have to take part?

you can tell me **“Yes”** if you want to take part.

you can tell me “**No**” if you do not want to take part

if you say no it will **not** change the care you get

if you decide to take part, I will ask you to sign a consent form

you can stop taking part at any time

What happens after you have seen me?

	I will give you a gift voucher for £20 for your time and help
  	if you tell me it’s **OK**, the information you give will be confidential I will not talk to anyone else about you I will not use any information with your name and address but if you tell me about something where you may be in danger, I will have to tell your key worker or the duty social worker

If you want to talk to me	
	• you can call me if you have any questions about the study • you can call me if you are not happy with the study my telephone number is 0758 003 7907
Thank you for looking at this	
This research project has been reviewed by the West London Research Ethics Committee, who are there to make sure you are treated well.	

Service users consent form- cross sectional study

Camden NHS
Primary Care Trust

Participant Identification Number:

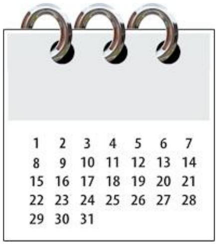
A study to find out if being treated unfairly causes stress in people with learning disability

		No	Yes
Please answer tick one box		✗	✓
	I have read the information sheet about the research		
	I can understand the things the information sheet told me		
	I was able to ask questions if I wanted to		

		✗	✓
	I understand that it is my choice to take part in this study		
	I understand that I can say **No** at any time if I want to stop		
	I understand that It will not change the care I get		

my name

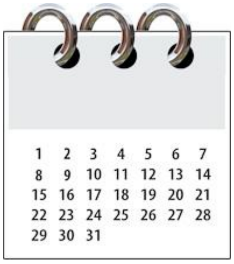
my signature



date

researcher's name

signature



date

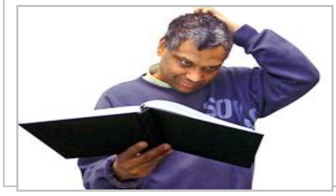
One copy will be given to the participant, one copy will be kept by the researcher and one copy will be stored in the medical file

Camden NHS
Primary Care Trust

Version 2, 15/11/2010

Service User Information sheet – qualitative study

A study about experiences of health services by people with learning disability

	my name is Afia Ali
	I am a Doctor
 	I am writing to ask if you want to help me to help you understand this letter you can

- ask someone to read it for you

- talk to your carer about it

- you can ask me questions

What is my work about?

my work is about:

- finding out how people with learning disability have been treated by health services

I want to find out if you were treated well

or if you were treated badly

I want to find out if staff treat you differently because you have a learning disability

- this could be by your family doctor or GP surgery

- it could be by staff at the accident and emergency department at the hospital

- it could be by the ambulance service

- it could be by staff on the hospital ward

- it could be by the nurses or doctors at the clinic

Why do I want to see you?

I want to talk to you:

- because you are 18-65 years old
- you have a mild to moderate learning disability
- and you have a carer

I want to find out how you and your carer have been treated by health services

- I will also talk to your carer

we would like to talk to you and your carer if you want to take part and your carer does not, we will talk to you only

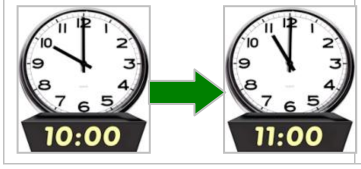
the information you give can help to make health services better for people with learning disability

What will happen to me if I take part?

you will take part in an interview

I will ask you some questions about the way you were treated by health services

the interview will be recorded



the interview will last for about 1 hour

	we will meet at a place you know
Do you have to take part?	
	you can tell me **“Yes”** if you want to take part.
	you can tell me “**No**” if you do not want to take part
	if you say no it will **not** change the care you get
	if you decide to take part, I will ask you to sign a consent form

if you decide to take part, you can stop at any time

What happens after you have seen me?

I will give you a gift voucher for £20 for your time and help

If you tell me it’s **OK**,

the information you give will be confidential

- I will not talk to anyone else about you

  	- the audiotape will be stored in a locked cabinet - the audiotape will be destroyed as soon as the study is over - I will not use any information with your name and address but if you tell me something serious and you may be in danger, I will have to tell your key worker or the duty social worker
If you want to talk to me	
	you can call me if you have any questions about the study

	you can call me if you are not happy with the study my telephone number is 07580037907
Thank you for looking at this	
This research project has been reviewed by the West London Research Ethics Committee 3 who are there to make sure you are treated well.	

Camden NHS
Primary Care Trust

Version 1, 13/08/2010

Service User Consent form – qualitative study

Participant Identification Number:

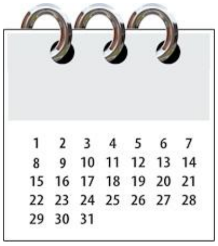
A study about experiences of health services by people with learning disability

		No	Yes
Please answer tick one box		✗	✓
	I have read the information sheet about the research		
	I can understand the things the information sheet told me		
	I was able to ask questions if I wanted to		

		✗	✓
	I understand that it is my choice to take part in this study		
	I understand that what I say will be recorded		
	I understand that I can say **No** at any time if I want to stop		
	I understand that It will not change the care I get		

my name

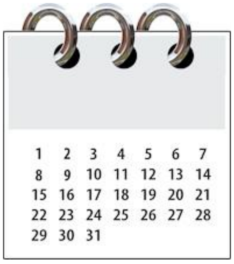
my signature



date

researcher's name

signature



date

One copy will be given to the participant, one copy will be kept by the researcher and one copy will be stored in the medical file

Date 15/11/2010, Version 2

Carers information sheet – qualitative study

Stigma and health outcomes in people with learning disability: interview with service users and carers about experiences of health care

We would like to invite you to take part in our research study. Before you decide, we would like you to read this information sheet, which will explain the purpose of the study and what it would involve for you. The researcher will go through the information sheet with you and answer any questions you may have. It may be helpful for you to talk to someone else about the study.

Part 1 will tell you about the purpose of the study and what will happen to you if you decide to take part.

Part 2 will give you information about how the study will be conducted.

1. What is the purpose of the study?

People with learning disability have significant health needs but often experience difficulties in accessing appropriate help from health services.

We would like to find out if people with learning disability experience stigma and discrimination from health services such as from the General Practice (GP) surgery, from the Accident and Emergency Department, from inpatient hospital wards, outpatient services or any other National Health Service (NHS) facility or service. We are interested in both positive and negative experiences of health services.

We would like to improve the experiences that people with learning disability have from health services. This study will give us some ideas about how services could be improved so they are better at serving the needs of this vulnerable group.

2. Why have I been invited?

You have been invited because you are a carer of someone with a learning disability, and you have known the person for at least 2 years. We are interested in the views of people with learning disability and the views of their carers. We would like to interview both yourself and the person you care for as it will give us a more complete picture of peoples' experiences of health services. Therefore, both you and the person you care for will need to give consent to participate in the study, otherwise we will not be able to include you in the study. It does not matter if you are a paid carer or a family member, as long as you know the person well. We would like to interview 15 people with learning disability and their carers, a total of 30 people.

3. Do I have to take part?

It is up to you to decide if you would like to take part. If you agree to take part, you will be asked to sign a consent form. You are free to leave the study at any point and do not have to give a reason. This would not affect the standard of care you receive from the team.

4. What will happen to me if I take part?

We will ask you to take part in an interview with the researcher. This interview may last between 1 hour and 1 and a half hours. To help us record what you say, the interview will be audio-taped. The researcher may also take some written notes. We can carry out the interview at a place that is convenient for you. We will also ask you for some personal information such as your age and ethnicity. We will only hold one interview and there will be no follow up.

5. Expenses and payments

We will give you a gift voucher for £20, at the end of the interview, as a thank you for your time and effort and for any inconvenience this study may have caused you.

6. What will I have to do?

You will be asked to take part in an interview, where we will ask you some questions about your views on the way health services have responded to the needs of the person you care for. We will also ask you about your views on how services could be improved.

7. What are the possible disadvantages or risks of taking part?

Peoples' experiences of stigma and discrimination is a very sensitive topic and it may invoke some unpleasant memories and emotions. If you think you may you experience such problems then you should think carefully about whether it would be appropriate to participate.

8. What are the possible benefits of taking part?

The study may not directly benefit you or the person you care for but it may improve how people with learning disability are treated by health services in the future.

9. What if there is a problem?

Part 2 will tell you what to do if you are not happy with the way you were treated during this study.

10. Will my taking part in the study be confidential?

Yes. We will follow ethical and legal practice, and any personal information you give us will be kept confidential. The details are included in part 2.

If the information in part 1 interests you and you are thinking about taking part, please read part 2 before making a decision

Part 2

1. What will happen if I don't want to carry on with the study?

If you decide to withdraw from the study, for example midway through the interview, we will use the information that you have provided up to that point.

2. What if there is a problem?

If you have concerns about any aspect of the research project, you should contact the researcher at the number below, who will try to answer any queries you have. If you remain unhappy and wish to complain formally, you can contact the Learning Disability service at the number below and they will give you details about how to make a complaint.

Camden Learning Disability Service: 0207 974 3737

3. Will my taking part in the study be kept confidential?

Any information collected about you during the course of the study will be kept confidential and will be stored in a secure place. Only the researcher will have access to this information. The audiotape will initially be stored in a locked cabinet within a locked room. The recording will be transcribed but no personal information will be used to identify you. The audiotape will be destroyed as soon as the study is over. Published data will be anonymous and no personal information will be included that could identify you.

4. What will happen to the results of the study?

We intend to publish the results in a scientific journal. The results will also be published in the learning disability service newsletter for service users and carers. Where possible we will also arrange to speak at service user and carer forums. If you are interested in finding out more and obtaining a copy of the published reports, please contact the researcher who will be able to provide you with this information. You will not be identified in any report or publication.

5. Who is organising and funding the research

The research is being funded by the Medical Research Council and is being sponsored by University College London.

6. Who has reviewed the study?

All research in the NHS is looked at by an independent group of people called the Research Ethics Committee, in order to protect your interests. This study has been reviewed and given a favourable opinion by the West London Research Ethics Committee 3 .

7. Further information and contact details

If you would like further information about this study, would like to discuss issues about participating in the study or would like to know who to approach if you are unhappy with the study, please contact the researcher (Dr Ali) at the number below:

Telephone: 0207 679 9587

If you are unsure about whether you should participate in this study, you may wish to discuss this study with a health professional that you know.

If you decide to participate in the study, you will be given a copy of this information sheet and a signed consent form to keep.

Camden NHS
Primary Care Trust

Carers Consent Form – qualitative study

Centre number:

Patient identification number:

Name of researcher: Dr Afia Ali

Title: Stigma and health outcomes in people with learning disability: interview with service users and carers about experiences of health care

Please initial box

1. I confirm that I have read and understood the information sheet dated 27/10/2010 (version 1) for the above study. I have had the opportunity to consider the information, ask questions and my questions have been answered satisfactorily	☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without any medical care or legal rights being affected	☐
3. I understand that any information I give will be kept confidential and my personal details will be protected	☐
4. I understand that the interview will be tape recorded	☐
5. I agree to take part in the study	☐

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Name of participant	Date	Signature
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Name of researcher	Date	Signature

A copy will be given to the participant, one copy will be kept in the research file and original copy will be kept in the medical notes

Ethics Approval Letter

West London REC 3
Room 4W/12, 4th Floor West
Charing Cross Hospital
Fulham Palace Road
London W6 8RF
Telephone: 020 3311 7282
Facsimile: 020 3311 7280

Dr Afia Ali
Medical Research Council (MRC) clinical research fellow
University College London
Department of mental health science
2nd floor Charles Bell Building
67-73 Riding House street, London
W1W 7EJ

25 November 2010

Dear Dr Ali

Study Title:	**The impact of perceived stigma on psychological distress, treatment concordance, service use and quality of life in people with intellectual disability**
REC reference number:	**10/H0706/84**

Thank you for your letter of 17 November 2010, 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.

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, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where the only involvement of the NHS organisation is as a Participant Identification Centre (PIC), management permission for research is not required but the R&D office should be notified of the study and agree to the organisation's involvement. Guidance on procedures for PICs is available in IRAS. Further advice should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*	
Interview Schedules/Topic Guides	1 (Carers)	13 August 2010	
Interview Schedules/Topic Guides	1 (Participants with Intellectual Disability)	13 August 2010	
Questionnaire: CORE-10			
Advertisement	2	15 November 2010	
Response to Request for Further Information		17 November 2010	
Participant Information Sheet: Service User Information Sheet 2	2	15 November 2010	
Letter of invitation to participant	1	13 August 2010	
REC application	58402/158298/1/251	14 October 2010	
Participant Consent Form: Service User Information Sheet 3	1	13 August 2010	
Participant Consent Form: Professionals	1	13 August 2010	
Questionnaire: CSRI			
Questionnaire: Quality of Life Questionnaire			
Questionnaire: Compliance Rating Scale			

Questionnaire: PSID			
Letter to Clinicians	1	13 August 2010	
Letter from Funder: MRC		12 March 2010	
CV Academic Supervisor: Angela Hassiotis		15 October 2010	
Participant Consent Form: Carers	1	13 August 2010	
Participant Information Sheet: Service User Information Sheet 1	2	15 November 2010	
Letter of Invitation to Carer	1	17 November 2010	
Covering Letter		15 October 2010	
Letter from Sponsor		07 October 2010	
Protocol	2	17 November 2010	
Evidence of insurance or indemnity		06 September 2010	
Referees or other scientific critique report	MRC Panel Comments	27 July 2009	
Referees or other scientific critique report	MRC Peer Reviews (5 Reviews)	27 January 2010	
Investigator CV		15 October 2010	
Participant Information Sheet: Service User Information Sheet 3	2	15 November 2010	
Participant Information Sheet: Professionals	1	13 August 2010	
Participant Consent Form: Service User Information Sheet 1	1	13 August 2010	
Participant Consent Form: Service User Information Sheet 2	1	13 August 2010	
Participant Information Sheet: Carers	2	15 November 2010	

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.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

10/H0706/84	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely

Dr Sabita Uthaya
Chair

Email: louise.moran2@imperial.nhs.uk

Enclosures:	"After ethical review – guidance for researchers"
Copy to:	*Mr Dave Wilson*

Publications from thesis

Ali A, Scior K, Ratti V, Strydom A, King M, Hassiotis A (2013). Discrimination and other barriers to accessing health care: perspectives of patients with mild and moderate intellectual disability and their carers. *PLoS One*, 8(8), e7U855

Ali A, Hassiotis A, Strydom A, King M (2012). Self stigma in people with intellectual disability and courtesy stigma in family carers: A systematic Review. *Research in Developmental Disabilities,* 33, 2122-2140.