

RESEARCH DEPARTMENT OF CLINICAL,
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**Knowledge, inclusion attitudes, stigma and
beliefs regarding intellectual disability and
schizophrenia among the UK public:
The role of ethnicity, religion and contact**

Katrina Scior

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University College London

Declaration of authorship

I, Katrina Scior, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signature:

Date:

Abstract

Lay people's understanding about a health condition and their perceptions of the condition can have far reaching consequences. Where ignorance, and misinformed beliefs about the condition or its causes prevail this may lead to stigma, prejudice and discrimination, and can have negative consequences for help seeking. These processes have been extensively studied in relation to mental illness, particularly schizophrenia and depression. In contrast, in the intellectual disability field empirical investigations have largely concentrated on the study of explicit attitudes. While the primary aim of this thesis was to increase our understanding of lay conceptualisations of intellectual disability and their consequences for stigma associated with intellectual disability, throughout comparisons are drawn with lay responses to schizophrenia to identify generic and disorder specific processes and to relate the findings to a larger body of evidence.

A new measure, the Intellectual Disability Literacy Scale (IDLS), was developed. This assesses knowledge, beliefs about causes of, suitable interventions for, and social distance towards an individual presenting with symptoms of intellectual disability. It allows comparison with lay conceptualisations of schizophrenia, using diagnostically unlabelled vignettes. A large scale UK general population survey was conducted using the IDLS and the Community Living Attitude Scale-Intellectual Disability version (Henry, Keys, Balcazar & Jopp, 1996a). Responses by 1002 lay people of working age were examined to assess the relationships between awareness, inclusion attitudes and social distance. Causal and intervention beliefs of 1752 lay people and the association between causal beliefs and social distance were investigated. The sample was ethnically and religiously diverse and close attention was paid throughout to participants' socio-demographic characteristics, with a particular focus on the role of contact, ethnicity and religion.

The findings indicate that awareness of intellectual disability and schizophrenia among the UK public is relatively low. When presented with an unlabelled vignette 28% of lay people recognised intellectual disability. Recognition of schizophrenia was at a similar level, with 24% identifying the condition in an unlabelled vignette and a further 44% making reference to mental illness in general or to another psychiatric diagnosis. Awareness of both conditions was lower among participants from ethnic minorities. Contact with people with intellectual disability/mental health problems was the strongest predictor of lay people's ability to recognise the two conditions. There was support for the view that people with intellectual disabilities have similar life goals as people without disabilities and should not be segregated from society, but support for empowerment, i.e. choice and self-advocacy, was weaker. Correlations between inclusion attitudes and social distance were significant but modest. Social distance was lower for intellectual disability than for schizophrenia, but views on social contact with an individual with mild intellectual disability were no more than ambivalent.

Lay people were most likely to endorse environmental causes for the intellectual disability vignette and biomedical and adversity causes for the schizophrenia one. Recognition of the condition was associated with reduced social distance, increased endorsement of biomedical causes and reduced endorsement of supernatural causes for both intellectual disability and schizophrenia. Belief in supernatural causes, which were associated with increased social distance, was low overall but more common among specific sections of the public, including people with low educational attainments, those who viewed religion as important in their lives, and Muslims.

Expert help was much less likely to be recommended for intellectual disability than for schizophrenia. Beliefs about suitable sources of help showed fairly close

correspondence with participants' causal beliefs. Lay people who recognised the symptoms were more likely to favour expert help, and less likely to endorse lifestyle or religious/ spiritual help. Familiarity with someone with intellectual disability or mental illness did not influence causal beliefs, but was associated with endorsement of expert help.

Overall the findings suggest that many of the relationships between awareness, causal beliefs, social distance, contact and socio-demographic factors are common to intellectual disability and schizophrenia, but vary in strength, while some are disorder specific. The findings indicate that people with intellectual disability or mental illness from ethnic minority backgrounds not only face racial discrimination and poorer access to appropriate assessment and treatment, but the additional challenge of increased stigma and lack of understanding among their own cultural communities. Raising awareness and tackling stigmatising attitudes and beliefs at general population level should go hand in hand. Public education and anti-stigma interventions that target certain sections of society in particular seem indicated.

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Chapter 1: Introduction

Intellectual disabilities affect around two per cent of the population worldwide. They are defined as a significant impairment in intellectual functioning together with significant impairments in social (adaptive) functioning, which have an onset before adulthood (ICD-10, World Health Organisation, 1990). There are around 1.2 million people with intellectual disabilities in England (Emerson et al., 2012) and an estimated further 230.000 in other parts of the UK. Thus this population is not an insignificant minority, even if often rather invisible.

1.1 People with intellectual disabilities and the social context

Societal views of people with intellectual disabilities and policies have changed dramatically over the last hundred years. In the 1920s and 1930s the eugenics movement had a powerful voice in claiming that people with intellectual disabilities were a danger to the moral fabric of society and should be eliminated from the gene pool. As a result thousands were forcibly sterilised and many more segregated from society in institutions. In Nazi Germany this was taken one step further and, alongside enforced sterilisation on an unprecedented scale, people with intellectual disabilities were used for human experimentation or exterminated as one of the many groups deemed 'undesirable'. While the atrocities of the Nazi government contributed to the loss in influence of the eugenics movement, across Europe and in the UK people with intellectual disabilities continued to be mostly segregated in large institutions distributed across the British countryside. Concern about the negative consequences of institutionalisation slowly grew following the publication of Goffman's *Asylums* (1961) and in the UK scandals about abuses perpetrated by staff against very vulnerable patients in a number of institutions gained widespread attention.

These developments, alongside an increased emphasis on individual and civil rights in the 1960s, contributed to the growing influence of *normalisation*, which

paved the way for current policies that have the social inclusion and rights of people with intellectual disabilities at their heart. Early proponents of normalisation argued that increased community inclusion was the best way to improve the attitudes and beliefs of the general population towards people with intellectual disabilities (Bank-Mikkelsen, 1969; Wolfensberger, 1972). However, Wolfensberger (1983) later argued that the mere presence of people with intellectual disabilities in the community was not sufficient, and that in order to change the public's negative attitudes and achieve greater acceptance by society at large, they must also play an active part in society and occupy socially valued roles. Such claims are loosely in line with intergroup contact theory, according to which contact between two groups is most likely to reduce intergroup prejudice when the groups are of equal status, pursue common goals, cooperate and have official support (Allport, 1954). Pettigrew and Tropp (2006) concluded on the basis of a meta-analysis that intergroup contact typically reduces intergroup prejudice and that Allport's conditions are not essential for prejudice reduction, a conclusion that could be seen to offer promise for attempts to reduce negative attitudes towards people with intellectual disabilities.

Deinstitutionalisation began in the UK in the 1970s and the last large institutions for people with intellectual disabilities were eventually closed in the 1990s, notwithstanding the continued existence of mini institutions for persons deemed "hard to place" in the community. Since the early days of normalisation the disability agenda has greatly moved on, and self-advocacy has become a powerful voice in the demand for change. In the US and Northern European countries self-determination, independence and the right to full citizenship are very much at the heart of policy discourse. Current policies governing services for people with intellectual disabilities in Western countries aim to maximise their social inclusion, independence and empowerment (for example, UK Department of Health, 2001,

2009). However, as Kock et al. (2012) noted, one consequence of increased independence and integration is that people with intellectual disabilities may find themselves more exposed to negative perceptions held by the general population regarding people with disabilities. Furthermore, there are continued indicators that large numbers of people with intellectual disabilities find themselves excluded from society and not treated as "equal citizens". Only around 6.5% are in some form of paid employment (Emerson et al., 2012), and few have meaningful relationships with people who do not have intellectual disabilities, are not relatives or paid to offer support (Robertson et al., 2001; Emerson & McVilly, 2004).

Such evidence lends support to Cummins and Lau's (2003) argument that the physical inclusion of people with intellectual disabilities has largely been achieved, but that we are far from achieving genuine social inclusion. Others have warned that definitions of social inclusion that focus on productivity and participation in community-based activities are too narrow and inappropriate for people with more severe disabilities (Cobigo, Ouellette-Kuntz, Lysaght & Martin, 2012). Regardless what perspective on social inclusion one adopts, whether society at large is welcoming and comfortable with physical proximity and social interaction, or conversely tries to keep individuals with intellectual disabilities at a distance is important. It affects the likelihood of equitable access to all areas of public life and the experiences of people with intellectual disabilities and those close to them.

This PhD thesis focuses on the broader social context to examine what at general population level may stand in the way of people with intellectual disabilities achieving social inclusion and equal rights, including within different cultural and religious communities. While public attitudes towards people with intellectual disabilities have been studied fairly extensively, our understanding of aspects beyond lay people's self-reported attitudes is surprisingly limited. In particular, evidence on

lay people's understanding of the concept of 'intellectual disability' and various synonyms used to denote the condition is very limited, as is evidence on lay beliefs about likely causes of intellectual disability and suitable sources of help, and on stigma associated with intellectual disability. This stands in stark contrast to both the physical and mental health fields where stigma has been a key focus for understanding negative societal responses and discrimination against members of stigmatised groups. In the physical health arena researchers have tried, for example, to understand lay responses that can help explain and ultimately point to ways of tackling the prejudice and discrimination that people with HIV/ AIDS have to contend with (Parker & Aggleton, 2003). Public beliefs and the stigma attached to different forms of mental illness¹ have also been the subject of a great deal of investigation and serve as an evidence base for efforts to reduce the stigma attached to these conditions (e.g. Jorm, 2000; Angermeyer & Dietrich, 2006; Jorm & Oh, 2009; Thornicroft, 2006).

Corrigan (2004) argued that mental illness "strikes with a two-edged sword"; on one side are the symptoms and consequences of the underlying illness that prevent people from enjoying a good quality life, on the other, the public's reaction: "a plethora of prejudicial beliefs, emotions and behaviours that cause the public to discriminate against those labelled mentally ill" (p.404). A very similar argument can be made in relation to intellectual disability, and in fact recognition of this "two-edged sword" is implicit in major developments in theory and policies concerning people with intellectual disabilities in Western countries. Since the 1970s there has been a dramatic shift away from a medical model that focuses on the individual and

¹ The term 'mental illness' is used throughout this thesis for simplicity's sake. It is recognised that many people find this term and its positioning of distress and psychological disturbance within a medical model contentious. Hence in asking lay people about personal contact, the term 'mental health problems' was used and has been retained when reporting the respective findings.

their impairments towards a social model, which emphasises barriers erected by society and holds that these are key to the negative effects of disability. It is surprising that despite this emphasis on social barriers there has been only limited interest in understanding perceptions and responses to intellectual disability at general population level. Caution is called for in speculating why, but perhaps there is less investment in understanding and removing social barriers than policies would have us believe. Alternatively, an emphasis on improving the physical conditions of the lives of people with intellectual disabilities and a focus on ensuring they receive good social and health care may be viewed as more important in the face of limited resources.

1.2 Intellectual disability in the context of a multi-cultural society

The UK is highly culturally diverse, with around 7.9% of the population according to the 2001 census belonging to a Black or ethnic minority (BME) group (Office for National Statistics, 2001). Although 2011 census figures have not been formally published yet, it is estimated that this figure has risen to 9.5%. Hence there are likely to be at least 120,000 people with intellectual disabilities from BME communities in the UK. This figure most probably is an underestimate though due to the concentration of people from BME communities in younger age cohorts and suggestions of a possible increased prevalence of intellectual disability among some BME communities (Emerson, Azmi, Hatton, Caine, Parrott & Wolstenholme, 1997; Emerson & Robertson, 2002; McGrother, Bhaumik, Thorp, Watson & Taub, 2002).

Over half of the BME population is of Asian origin, with the largest numbers of South Asian origin. Among the 2.8% of the population recorded as 'black', the black African population has shown the fastest growth and is now larger than the much longer established black Caribbean population (Office for National Statistics, 2011). While there has been some research regarding intellectual disability in the

context of the South Asian community, very little is known about intellectual disability in the context of the black African and Caribbean communities.

The risk of a double disadvantage for families from ethnic minorities who have a member with intellectual disabilities, due to racial discrimination and culturally inappropriate care and service provision is now well recognised (Department of Health, 2009; Mencap, 2009; Mir, Nocon, Ahmad & Jones, 2001; National Autistic Society, 2007; O'Hara, 2003). There has been rather little attention though to potential prejudice and discrimination which people with intellectual disabilities and their families may face within their cultural communities and which may create additional stresses. Drawing on research with South Asian families of children with intellectual disabilities, it has been suggested that they have a poorer understanding of the causes of intellectual disability (Fatimilehin & Nadirshaw, 1994). One possible reason is that the concept of intellectual disability is less developed in South Asian cultures and often there is no distinct term to denote the condition (Miles, 1995).

Furthermore it has been suggested that potentially stigmatising lay beliefs about the causes of intellectual disability may be common, such as a belief that the condition results from possession by spirits (Hatton, Akram, Robertson, Shah & Emerson, 2003) or punishment for past sins (Hubert, 2006). There have been some reports that South Asian parents may be reluctant to disclose their child's diagnosis in view of prejudices amongst their own communities, particularly fearing that this might negatively impact on the marriage prospects of siblings (Hughes, 1983). It has also been suggested that in some cases parents may avoid services altogether to keep the disability hidden from the community (McGrother, Bhaumik, Thorp, Watson & 2002), and that the taboo attached to intellectual disability in some Asian communities can result in parents becoming socially isolated (Fulton & Richardson, 2010).

It must be stressed though that the evidence cited is almost entirely extrapolated from research with parents of children and adults with intellectual disabilities; the extent to which intellectual disability is stigmatised within different cultural and religious communities has not been tested at general population level. The tentative tone of Allison and Strydom's (2009) observation that "the degree to which individuals with intellectual disabilities are stigmatized *may* differ between cultures depending on prevailing beliefs regarding undesirable attributes" (p.356; my emphasis) reflects our current very limited understanding of societal responses to intellectual disability, and the potential role of culture.

The UK is not only culturally but also religiously very diverse. After the 78% of the population who described themselves as Christian in the 2001 census (Office of National Statistics, 2006), Islam was the second largest religion with 3% of the population and Hinduism the third with 1%; 16% described themselves as non-religious. Given higher population increases among sections of the population that follow Islam and Hinduism, these figures are likely to be substantially higher by now. It has been suggested that religion may play a major role in shaping attitudes to intellectual disability (Fatimilehin & Nadirshaw, 1994). To date our understanding of its influence on lay attitudes and beliefs regarding intellectual disabilities and of the interplay between religion and culture is extremely limited though. It has been suggested that Islam holds a fairly benevolent view of disability, as a test from Allah and thus an opportunity to prove one's strength of faith (Miles, 1992; 1995). Within Hinduism, beliefs such as Karma, the cycle of rebirth whereby previous actions affect later incarnations, imply that Hindus generally are likely to view disabilities as punishment for past misdeeds (Gabel, 2004; Miles, 1995). While this may imply that disability is something to be feared (Miles, 1995), conversely it may also be perceived as an opportunity to redeem oneself and fulfil one's duties (Gabel, 2004).

Nevertheless to date few of these assertions have been tested among lay people in the context of ethnically and religiously diverse Western societies such as the UK.

1.3 Aims of this thesis

This thesis seeks to increase our understanding of perceptions of, and responses to, intellectual disability at general population level. While acceptance of people with intellectual disabilities by the general population is important for the potential success of policies aimed at their social inclusion and equal rights, as noted above, to date empirical evidence in this area is woefully thin. This applies even more when considering perceptions and responses towards intellectual disability among lay people from non-Western backgrounds. This thesis aims to address the following main questions: what level of 'intellectual disability literacy' prevails among lay people in the UK; and what is the association between its components and social distance? In particular, answers are sought to the following questions: a) how able are lay people in the UK to recognise intellectual disability; b) what attitudes to the community inclusion of people with intellectual disabilities prevail; c) what beliefs about causes and suitable interventions prevail; and d) what is the relationship between these components of intellectual disability literacy and social distance as measure of external stigma? Furthermore the influence of ethnicity, religion and contact on these aspects will be examined, alongside other socio-demographic characteristics.

These questions are addressed through a large scale general population survey led by the author over the period mid-2009 to late 2011. In translating the concept of 'mental health literacy' (Jorm, Korten, Jacomb, Christensen, Rogers & Pollitt, 1997; Jorm, 2000) to an intellectual disability context, the central premise of this thesis is that a better understanding of public knowledge and beliefs about intellectual disability can help us to understand not only *where* but ideally also *how*

attempts to “improve” these should be targeted. Improvement here refers to reaching an understanding that is conducive to the social inclusion of people with intellectual disabilities and to the reduction of discrimination against people with intellectual disabilities. Throughout this thesis lay responses to intellectual disability are compared to responses to schizophrenia, in order to allow drawing on the much larger evidence base in the mental health field and to place the findings in a broader context. Furthermore such a comparison makes it possible to address the question whether the relationship between knowledge, stigma and beliefs about causes is disorder specific or generic to very different forms of mental and developmental disorders.

1.4 Thesis structure

This thesis is organised into eight chapters. Chapter 2 sets the scene by providing a review of the literature on lay awareness, attitudes and beliefs regarding intellectual disability. Based on gaps identified in the literature, chapter 3 describes the development of a new tool, the Intellectual Disability Literacy Scale (IDLS), designed to allow empirical investigation of awareness of typical symptoms, social distance and beliefs about causes and suitable sources of help regarding intellectual disability and schizophrenia as comparison case.

Chapters 4 to 7 present results from a series of four empirical studies that used the IDLS to address this thesis’ main questions. Chapter 4 reports findings on inclusion attitudes to people with intellectual disabilities, awareness of the condition and social distance among different ethnic groups. Chapter 5 presents findings on the relationship between awareness of intellectual disability and schizophrenia and social distance. Data on causal beliefs about intellectual disability and schizophrenia and their relationship with awareness of the condition and social distance are presented in chapter 6. Chapter 7 presents findings on lay beliefs about suitable

interventions for intellectual disability and schizophrenia and their fit with causal beliefs.

Chapter 8 closes the thesis by providing a synopsis of the main results and discussing these, considering key methodological issues, and outlining implications for future research and public education work.

1.5 Overview of datasets

An overview of the datasets used in empirical work presented in chapters 4 to 7 is shown in Table 1. As noted above, data was collected over the period mid-2009 to late 2011, both by the author and by undergraduate students who completed their final year projects under the author's supervision and are named in the Acknowledgements section. All analyses and interpretation of the results presented in this thesis are entirely the author's work.

Table 1. *Overview of datasets used in this PhD*

Empirical Chapter	Dataset used and N
Ch 3: Development and validation of the Intellectual Disability Literacy Scale	Pilot: N=114 Main study: N=1375 33.8% white UK residents 9.4% South Asian UK residents 7.1% Black African UK residents 31.5% East Asians residing in Hong Kong or Singapore* 7.8% Indian citizens* 10.3% other ethnic backgrounds *participants not included in any other chapter
Ch 4: Social distance, public awareness about intellectual disability and attitudes to inclusion among different ethnic groups	N=1002 UK residents of working age 41.2% white British 12.6% South Asians 12% Asians from other backgrounds 18.7% Black Africans Subset of larger dataset presented in chapters 5 to 7 with different ethnic groups matched on gender, age & education
Ch 5: Awareness of intellectual disability and schizophrenia and its relationship with social distance across ethnic groups in the UK	N=1752 UK residents of working age Sample larger than chapter 4 due to continuing data collection; also main focus not differences between ethnic groups, hence ethnic groups not matched
Ch 6: Public causal beliefs about intellectual disability and schizophrenia and their relationship with knowledge and social distance	N=1752 Same dataset as chapter 5
Ch 7: Public beliefs about suitable interventions for intellectual disability and schizophrenia and their match with causal beliefs	N=1752 Same dataset as chapter 5

**Chapter 2: Public awareness, attitudes and beliefs
regarding intellectual disability: a systematic review**

Abstract

Background: The general public's responses to people with intellectual disabilities influence the likely success or failure of policies aimed at increasing their social inclusion. The present paper provides a review of general population based research into awareness, attitudes and beliefs regarding intellectual disability published in English between 1990 and mid-2011.

Method: An electronic search using PsycINFO and Web of Science plus a hand search of the literature was completed.

Results: Most of the 75 studies identified consisted of descriptive surveys of attitudes. They tend to conclude that age, educational attainment and prior contact with someone with an intellectual disability predict attitudes, while the effect of gender is inconsistent. Eight studies examined lay knowledge about intellectual disability and beliefs about its causation in a range of cultural contexts. The impact of interventions designed to improve attitudes or awareness was examined by 12 studies. The evidence is limited by the fact that it is mostly based on relatively small unrepresentative samples and cross-sectional designs.

Conclusions: Overall, high quality research into general population attitudes to intellectual disability is limited. Public knowledge of intellectual disability and causal beliefs are particularly under-researched areas. There is a notable absence of well designed evaluations of efforts to reduce misconceptions about intellectual disability and tackle negative attitudes. Areas for future research are noted, including the need for well designed studies that consider awareness, attitudes and beliefs in relation to stigma theory.

Public awareness, attitudes and beliefs regarding intellectual disability: a systematic review

Lay conceptualisations of intellectual disability have an important influence on the likely success or failure of policies aimed at the social inclusion and equal rights of people with intellectual disabilities. This chapter sets out the background to this thesis by reviewing general population based research into awareness², attitudes and beliefs regarding intellectual disability published in English between 1990 and mid-2011. After setting out the background, the method of the review is detailed and the evidence is presented on lay knowledge, attitudes and beliefs regarding intellectual disability; the effects of socio-demographic characteristics and prior contact on beliefs and attitudes; cross-cultural comparisons; and outcomes of interventions aimed at increasing the public's understanding and social acceptance of people with intellectual disabilities. Gaps in the literature are discussed and areas for further research are identified.

2.1 Introduction

Current policies governing services for people with intellectual disabilities in Western countries aim to maximise their social inclusion, independence and empowerment. Around the globe policies and services for this population are being put in place to assert their equal rights and tackle barriers to their inclusion, exemplified by initiatives such as the *Montreal Declaration on Intellectual Disabilities* (Lecompt & Mercier, 2007), or *Better Health, Better Lives*, the European declaration on the health of children and young people with intellectual disabilities and their families (World Health Organisation, 2010). Furthermore the rights of people with disabilities to equal enjoyment of all human rights were formally ratified by the UN in its 2006 *Convention on the Rights of Persons with Disabilities*. However, where poor

² The term 'awareness' is used in this thesis to refer to "knowledge or understanding of a subject" and is used interchangeably with the terms 'knowledge' and 'understanding'.

lay knowledge of the condition, negative community attitudes and stigmatising beliefs prevail, attempts at equality and greater community integration may well be met with resistance. Thus understanding public responses to intellectual disability has important implications for the likely success of inclusion policies.

A recent large scale survey in the UK concluded that lay people's understanding of intellectual disability is still limited (Mencap, 2008). This is of concern as lack of awareness about individuals with intellectual disabilities has been linked to negative attitudes (Myers et al., 1998) and to stigmatising beliefs more prevalent in some cultures, such as that intellectual disability is due to possession by spirits (Hatton et al., 2003; Hughes, 1983) or punishment for past sins (Hubert, 2006). To date though, as noted in the introductory chapter, concerns about stigma associated with intellectual disability are largely derived from research with the families of individuals with intellectual disabilities, not from general population based research.

There are some suggestions that attitudes have become more positive over time (Rees, Spreen & Harnadek, 1991). Nevertheless, bullying and harassment continue to be frequently reported by both children and adults with intellectual disabilities (Mencap, 2000) and disability hate crime has been recognised in some countries as a matter of serious concern (e.g. UK Crown Prosecution Service, 2010). This raises the question to what extent discriminatory attitudes and behaviour arise from general low levels of awareness and more widely held negative attitudes, or rather from extreme prejudices and hostility among a small minority.

Public awareness, beliefs about causes and their effect on stigma have been the subject of intense enquiry in the mental health field (Angermeyer & Matschinger, 2005; Corrigan et al., 2000; Jorm et al., 1997). These factors have found less attention though in relation to intellectual disability and no systematic review of

knowledge, attitudes and beliefs in the general adult population is currently available. The literature on children's attitudes towards peers with intellectual disabilities was reviewed by Nowicki and Sandieson (2002) and Siperstein, Norins and Mohler (2007). For these reasons a systematic review of the literature on awareness, attitudes and beliefs regarding intellectual disability among the general population of working age seemed timely.

2.1.1 Aims

This review addressed the following questions:

1. To what extent does the general public hold adequate knowledge about intellectual disability?
2. What attitudes towards people with intellectual disabilities prevail among the public? What beliefs about the causes of intellectual disability are prevalent among the public? Have there been any changes in attitudes and beliefs over the years?
3. What is the influence of socio-demographic characteristics, such as age, gender, educational attainment and prior contact with someone with intellectual disabilities, on these factors?
4. What are the results of cross-cultural comparisons of attitudes and beliefs towards intellectual disability?
5. Are there any studies evaluating the effects of interventions aimed at improving the public's understanding and attitudes? If so, what are their results?

It was hoped that these questions would advance our understanding and provide an evidence base for evaluations of future efforts at improving public awareness and attitudes and at promoting beliefs that might lead to greater social acceptance.

2.2 Method

2.2.1 Search Strategy

The electronic databases PsycINFO and Web of Science were searched for studies covering the period from January 1990 to May 2011, by entering the keywords intellectual disabilit*/mental retardation/learning disabilit* in combination with general public; attitude*; knowledge; recognition; belief*; lay belief*; stigma; social distance; discrimination; prejudice in each of these databases. The references of all included studies were searched to identify any further relevant studies. Finally the indices of relevant journals were searched to identify any studies covering the period under investigation that had not yet been picked up by electronic databases.

2.2.2 Review Process

The initial search produced over 9000 potential references. Once papers which were clearly irrelevant and duplicates had been omitted, approximately 700 remained. To refine the search the following inclusion criteria were applied: 1) the paper was written in English; 2) only articles published in full (not solely as conference abstracts) in peer reviewed journals were considered to ensure some form of quality control, although it is recognised that some significant reports failed to meet this criterion (e.g. Special Olympics, 2003); 3) the focus of the study was on the general public of working age, including late adolescents (aged 16+). On this basis, studies that focused on high school students either in their early to mid teens (e.g. Hastings, Sjöström & Stevenage, 1998) or of unspecified age (e.g. Karnilowicz, Sparrow & Shinkfield, 1994; Krajewski, Hyde & O'Keefe, 2002) were excluded. Research focused on children or professionals providing services to them, such as teachers, was excluded (e.g. Balboni & Pedrabissi, 2000; Lifschitz & Glaubman, 2002). Studies investigating attitudes and beliefs among particular subgroups, such as staff members or relatives of individuals with intellectual disabilities, were

excluded (e.g. Henry, Duvdevany, Keys & Balcazar, 2004; Nursey, Rhode & Farmer, 1990). Finally, studies that focused on future service providers, such as medical students and trainee teachers, were excluded (e.g. Hall & Hollins, 1996; Hampton & Xiao, 2009; Miller, Chen, Glover-Graf & Kranz, 2009). The evidence on service providers' attitudes and beliefs would merit a separate systematic review.

2.3 Results

2.3.1 Overview of studies

Seventy-five articles met the inclusion criteria, reporting findings pertaining to 68 studies. This literature was published at a very steady rate, with 17 to 18 papers published during every 5-year period up to 2004 and 23 papers published since 2005, generating an average 3.5 papers annually. With regard to locality, 32 articles reported research carried out in North America, 15 in Asia, 13 in Europe, 8 in Australasia, 6 in the Middle East, 3 in Africa and 1 in Central America; all of these were local or regional studies, none national surveys. Only three studies used stratified random samples (Burge, Ouellette-Kuntz & Lysaght, 2007; Ouellette-Kuntz, Burge, Brown & Arsenault, 2010; Pace, Shin & Rasmussen, 2010), all others recruited convenience samples. Of the 68 study samples, 33 consisted of community members of various designations, 29 of student samples and 6 studies sampled both students and members of the public. Twenty-four articles stated the response rate, ranging from 23% to a surprising 100% (Rice, 2009). Questionnaires were the favoured data collection method, while a few studies employed personal interviews (Gabel, 2004; Hudson-Allez & Barrett, 1996; Kisanji, 1995; Sinson & Stainton, 1990) or telephone interviews (Burge et al., 2007; Lau & Cheung, 1999; Ouelette-Kuntz et al., 2010). Studies focused on lay people's understanding of intellectual disability (U), attitudes (A), stigma, in terms of social distance and comfort during interactions (S),

and beliefs (B). A few studies evaluated interventions aimed at increasing awareness or improving attitudes among lay people (E), see table 2.

Table 2. *Overview of studies included in the review*

Study	Location	Focus	Sample	N	Method	Results
Ahlborn, Panek & Jungers (2008)	USA, Midwest	A, B	Psychology students, mean age= 19.7 years	320	12-item Semantic differential scale	Attitudes did not differ on basis of factors intrinsic to person with intellectual disabilities (ID), e.g. age or gender
Akrami, Ekehammer, Claesson & Sonnander (2006)	Uppsala, Sweden	A	Students, mean age = 23.9 years	235	1) Classical & modern attitudes scale toward people with ID, developed by authors 2) Social Dominance Orientation Scale (Pratto et al., 1994)	-Males more likely to show prejudicial attitudes -Modern prejudice scale had better discriminant validity than classical prejudice scale
Alem, Jacobsson, Araya, Kebede & Kullgren (1999)	Ethiopia	B, U	Lay people, aged 30-83 years & key informants in a rural district	100	Key Informant Questionnaire (Wig et al., 1980)	Of seven common neuropsychiatric disorders, ID regarded as 2 nd most serious condition after schizophrenia
Aminidav & Weller (1995)	Israel	U	Israeli Jews from Western, Iraqi and Yemenite backgrounds	120	1) Open-ended question, "What is mental retardation?" 2) 10-item Information questionnaire (Efron & Efron, 1967)	Israelis of Western origin showed more accurate and greater breadth of knowledge about ID than those of Eastern origin
Antonak (1994)	USA	U Development of new measure	Students, aged 18-56 years	251	40-item Test of Knowledge About Mental Retardation, developed by author	Results largely about measure's psychometric properties
Antonak, Fiedler & Mulick (1993)	USA	A Development of attitude scale	Students (+109 professionals)	139	32-item Attitudes towards Mental Retardation and Eugenics scale (AMRE), developed by authors	Results largely about measure's psychometric properties
Antonak & Harth (1994)	USA	A	Students and professionals Students mean age=30 years	230	Mental Retardation Attitude Inventory-Revised (MRAI-R)	Best demographic predictors of attitudes: familiarity followed by education
Antonak, Mulick, Kobe & Fiedler (1995)	USA	A	Students in health/ human services (n=259), other subjects (n=192); 129 professionals	572	1) AMRE (Antonak et al., 1993) 2) MRAI-R (Antonak & Harth, 1994)	-Students less likely to endorse eugenic principles re. people with mild to moderate ID, than severe to profound -Educational attainment and familiarity with people with ID inversely related to endorsement of eugenic principles for all four levels of ID
Beckwith & Matthews (1994)	Australia	A, S Comfort in interacting with people with ID	Students, of these 135 enrolled on ID degree course	468	1) Interaction with Disabled Persons (IDP) scale (Gething, 1991), adapted 2) Social Desirability Scale (MCSDS) (Crowne & Marlowe, 1960)	-Contact, frequency of contact and age predicted comfort in interacting with hypothetical individuals with ID -IDP and SDS scores not correlated -Completing ID programme associated with more positive attitudes

Study	Location	Focus	Sample	N	Method	Results
Beh-Pajooch (1991)	Northern England, UK	A, E Impact of link programme between college & school for kids with severe ID; compared high, low & no contact	College students, aged 16-19 years	132	54-item questionnaire adapted from McConkey et al. (1983), assessing emotional reactions and attitudes	-Contact with students with ID in college associated with more positive attitudes and emotional reactions -Most marked differences between contact and no contact groups: when asked about meeting hypothetical student with severe ID: -11% of former vs 71% of latter said they would feel embarrassed. 11% of former vs 81% of latter said they would feel scared -63% of former said find it a good experience, but only 8% of latter
Brown, Ouellette-Kuntz, Lysaght & Burge (2011)	Ontario, Canada	A Behavioural intentions towards peers with ID or physical disabilities	Secondary school pupils, aged 14 (n=189) and 17 (n=130) years	319	1) Behavioural Intentions Questionnaire, developed by authors 2) Open-ended questions re. comfort during interactions	-Respondents more willing to engage in more distant roles with peers with ID than social/personal roles -Behavioural intentions towards peers with ID more negative than towards peers with physical disabilities
Bryant, Green & Hewison (2006)	Yorkshire, UK	B Beliefs about Down's Syndrome (DS)	Mixed	76	Q Sort	-People's views about disability multi-layered -Consensus among participants about rights of people with DS to be included in society
Burge, Ouellette-Kuntz & Lysaght (2007)	Ontario, Canada	A, S	Stratified random community sample	680	Telephone poll: 1) Mod. version of survey used in Multinational study of attitudes towards individuals with ID (Special Olympics, 2003) 2) Social distance sub-scale of MRAI-R (Antonak & Harth, 1994)	-<1% believed adults with ID should not work -65% felt jobs in integrated work places most suitable employment for people with ID -Being male, older, less educated and unemployed associated with more pro-segregation views
Choi & Lam (2001)	Korea & USA	A	Korean & Korean-American students	359	Scale of Attitudes toward Disabled Persons (Antonak, 1982)	-Contact associated with more positive attitudes -No differences between Korean American and Korean students on attitudes to physical disability, but Koreans more negative re. ID -Graduate students held more favourable attitudes than undergraduate students
Cuskelly & Bryde (2004)	Australia	A Sexuality	Community sample (n=63), parents (n=43) and staff (n=62) 33% of community sample psychology students	63	Attitudes to Sexuality Questionnaire (ID version), developed by authors	-Community attitudes to sexuality of people with ID generally positive -Age (aged 60+) associated with more conservative attitudes to sexuality of this group -No differences in attitudes between community sample, parents and staff once age accounted for

Study	Location	Focus	Sample	N	Method	Results
Cuskelly & Gilmore (2007)	Australia	A Sexuality	Community sample	261	Attitudes to Sexuality Questionnaire-ID (Cuskelly & Bryde, 2004) and parallel general population version, developed by authors	-Being male and older associated with more negative attitudes to sexuality of people with ID -Views about parenting by this group more cautious than for other aspects of sexuality
Dhillon & Chaudhuri (1990)	India	A,B	Six groups of n=20, incl. parents of typically developing children, professionals and parents of children with ID	120	Semantic differential scale consisting of 21 bipolar adjective scales measuring 3 factors: evaluation, potency, activity	-Image of ID is mainly a negative one -Parents of typically developing children held slightly more negative views of ID
Eayrs, Ellis & Jones (1993)	UK	A, B, S Responses to three different ID labels	Community sample	111	1) 12-item social distance scale 2) 24-item semantic differential scale to ascertain a stereotype of the labelled group 3) 24-item scale to assess beliefs about abilities of labelled individuals 4) 10-item scale to assess views on rights of these individuals 5) Open ended items re. perceptions of different ID labels All developed by authors	-No effect of label on social distance -Public perception of term 'learning difficulties' more favourable than terms 'mentally subnormal' and 'mentally handicapped'; former seen as more able but also as less deserving of special support
Eggert & Berry (1992)	Germany	A	Grammar school pupils, aged 15 to 20 years	119	Attitudes questionnaire (McConkey et al., 1983)	-German students more confident about meeting someone with ID and more positive attitudes than previous Irish and Australian adolescent samples (but also older than comparison samples) -Evidence of lots of more negative attitudes, e.g. only 15% agreed that people with ID experience similar problems as them, only 25% felt they should use cafes more often and 15% felt should not be allowed to vote
Esterle, Muñoz Sastre & Mullet (2008)	Toulouse, France	A Sexuality	Lay people recruited in public places	367	Measure designed for study: 64 cards each with brief vignette, question and 10-point Likert scale judging acceptability of sexual intercourse	-Lay people's judgements about acceptability of sexual intercourse involving a person with ID depend on 4 interacting factors: 1) use of contraception; 2) person's level of autonomy; 3) whether partner of a similar age; 4) whether partner of similar level of disability -Younger people more accepting of sexuality of people with ID
Gabel (2004)	USA, Midwest	B How do Indian immigrants think and talk about ID?	Hindi Indian 1 st generation immigrants to US	20	In-depth interviews	-In India people with ID are mostly kept at home as seen to bring shame on family; mothers' role to care for them -Religious beliefs have marked influence on views and beliefs about ID

Study	Location	Focus	Sample	N	Method	Results
Gilmore, Campbell & Cuskelly (2003)	Australia	A, U Knowledge about DS and attitudes towards educational inclusion of children with DS	Community members	2053	Questionnaire to assess knowledge & attitudes re. DS, adapted from Wishart & Manning (1996)	-Life expectancy of people with DS significantly underestimated -Expectations of adult attainments of people with DS quite optimistic -Both community members and teachers held stereotype of people with DS as exceptionally happy and affectionate -Only 20% saw inclusive education as best option, though most saw benefits of inclusion for both children with DS and peers
Gordon, Feldman, Tantillo & Perrone (2004)	USA, Midwest	A, U	Psychology students	218	1) Knowledge scale; 2) 7-item social distance scale Both developed by authors	-Understanding of concept of ID frequently poor -Out of 13 disabilities, ID rated lowest as likely friend, and as least desirable for social interactions
Hall & Minnes (1999)	Canada	A, E Attitudes to DS; impact of 3 different television portrayals of young adult male with DS on attitudes	Students	92	1) Attitudes towards Disabled Persons Scale (Yuker et al., 1960); 2) Comfort Scale (Marcotte & Minnes, 1989); 3) Volunteering Intentions Scale, developed by authors 4) Social Desirability Subscale of Personality Research Form (Jackson, 1974); 5) Contact Questionnaire, developed by authors	-Predictors of attitudes: prior media exposure to people with DS, quality of contact and social desirability, accounting for 20%, 10% and 7% of variance respectively -Documentary associated with more positive affect than drama -Predictors of intention to volunteer: type of media presentation (17%) and quality of previous contact (6%): those who watched documentary and had previous positive contact experiences more willing to volunteer
Henry, Keys, Balcazar & Jopp (1996a)	USA	A	Community members (+340 staff members)	152	1) CLAS-ID (Henry et al., 1996a) 2) Demographics Questionnaire	-Community members are opposed to exclusion of people with ID; agree that people with ID are similar to themselves; ambiguous about need for sheltering/ protection of people with ID; only somewhat agree with empowerment
Henry, Keys, Jopp & Balcazar (1996b)	USA	A	104 students & 283 community members	387	1) CLAS-ID, developed by authors; 2) Community Attitudes towards Mental Illness Scale (Taylor & Dear, 1981); 3) Scale of Attitudes toward Disabled Persons (Antonak, 1982); 4) Balanced Inventory of Social Desirability (Paulhus, 1984)	-No significant correlations between CLAS-ID subscales and subscales on Social Desirability measure
Horner-Johnson et al. (2002)	Japan	A	Students	286	1) CLAS-ID (Henry et al., 1996a); 2) MRAI-R (Antonak & Harth, 1994) 3) AMRE (Antonak et al., 1993) 4) MCSDS short form (Strahan & Gerbasi, 1972)	-Those with friend or relative with ID more likely to endorse rights of people with ID -No correlation between social desirability and other measures

Study	Location	Focus	Sample	N	Method	Results
Hudson-Allez & Barrett (1996)	UK	A, E Neighbours' attitudes to people with ID moving into ordinary houses	Neighbours of ID community homes	150	Interview	-Positive attitude change not evident immediately, but at 6 to 12 months follow-up; conclude when newcomers arrive fears are reduced and attitudes slowly improve; even though majority may hold positive attitudes, negative minority can generate fears in majority and block new developments -Attitudes at baseline neutral, not negative as predicted -Older interviewees more concerned about new neighbours, no effect of gender and contact -Attitudes and social distance correlated
Karellou (2003)	Greece	A Sexuality	Public, no details	301	Greek Sexuality Attitudes Questionnaire-ID version, developed by author	-Age & education affect attitudes to sexuality of people with ID, but not gender, contact or social class -Older, unemployed respondents discriminated most against people with ID
Katz, Shemesh & Bizman (2000)	Israel	A Sexuality	Students, aged 18-35 years	135	1) 30-item attitudes to sexuality scale, 2 versions: ID & paraplegia, developed for study 2) California F scale (Adorno et al., 1950) to measure levels of authoritarianism	-Attitudes to people with ID more negative than to people with paraplegia on: 1) emotional issues; 2) responsibility & control; 3) right to personal choice -Attitudes to both groups similar on sexual needs -Those high on authoritarianism expressed more negative attitudes to sexuality of both groups
Kisanji (1995)	Tanzania	A, B	44 Tribal elders, 7 executives & government officials (+10 headteachers, 45 teachers)	51 (excl. teachers)	Interviews	Tribal elders named God's will and witchcraft (44% and 39%) as most likely causes of ID. In contrast, teachers saw disease as the most likely cause, and only 13.3% named God's will and 6.6% witchcraft as likely causes
ten Klooster, Dannenberg, Taal, Burger & Rasker (2009)	Netherlands	A	Peers of nursing students as controls (+ 78 nursing students)	43	1) Attitudes towards Disabled Persons Scale (Yuker et al., 1960) 2) Scale of Attitudes toward Disabled Persons (Antonak, 1982) 3) CLAS-ID short form (Henry et al., 1996a)	-Controls less likely than nursing students to endorse empowerment and similarity of people with ID -Having a relative or friend with a physical disability predicted positive attitudes to physical disability across whole sample, but same not case for ID
Kobe & Mulick (1995)	USA, Midwest	A, E Effects of 10-week course on psychology of ID	Students	37	AMRE (Antonak et al., 1993)	Following 9x2 hour lectures + minimum of 20 hours of direct contact with person with ID found: -No change in attitudes -Increase in self-rated knowledge of ID

Study	Location	Focus	Sample	N	Method	Results
Lau & Cheung (1999)	Hong Kong	A, S	Community Members	822	Telephone interviews, 9 items designed to tap into control, rejection & keeping away	-Discrimination higher towards people with mental illness (MI) than ID -Contact in past 6 months associated with less discrimination for both conditions -Education predicted discrimination towards people with ID, not age or gender -Social distance much lower for ID than MI: only 8.3% would mind person with ID as neighbour (34.7% for MI), and 6.1% as colleague (23.9% for MI)
MacDonald & MacIntyre (1999)	Canada	A, E Effects of label change and positive information on attitudes	College students, mean age=21.8 years, split into 4 groups	168	1) MRAI-R (Antonak & Harth, 1994) 2) Vignette emphasising skills and activities of person with ID or ADHD	-Even very brief information emphasising capabilities of persons with ID can result in more positive attitudes -Label in itself did not affect attitudes -Females held more positive attitudes
Madhavan, Menon, Kumari & Kalyan (1990)	Rural Hyderabad, India	A, U	246 parents & 43 community health volunteers (+67 teachers and 37 midwife trainees)	289	Case vignette of boy with severe ID followed by 5 open ended questions	Only approx. half of parents and community health workers able to recognise ID in vignette
McCaughey & Strohmer (2005)	USA	A, B Prototypes of 6 disability groups	Students	122	Participants asked to list 10 phrases that define/describe person	Identified 2 core prototypes for ID: 1) needs help/ dependent; 2) slow learner/ comprehension problems
Morales, Ramirez, Esterle, Sastre & Mullet (2010)	Mexico	A Sexuality	Convenience sample, few details	120	Measure designed by Esterle et al. (2008): 64 cards each with brief vignette, question and 10-point Likert scale judging acceptability of sexual intercourse	Three factors had effect on judgment of acceptability of sexual intercourse involving person with ID: 1) use of contraception; 2) person's level of autonomy; 3) whether partner of a similar age. Contrary to Esterle et al. (2008), partner's level of disability had no effect
Mulatu (1999)	Ethiopia	A, B, S Comparison of responses to 9 different conditions	Community Sample, aged 17-70 years	450 n=50 per group	Interviews: vignette of 9 conditions (incl. ID, mental & physical illnesses), followed by questions on: 1) attitudes; 2) causal beliefs; 3) treatment beliefs	-ID seen as less likely to be caused by psychosocial stress than MI and more likely by supernatural retribution than depression, alcoholism and tuberculosis -Attributing ID to supernatural retribution associated with increased belief in prayer and negative attitudes -Age and education most important predictors of causal beliefs

Study	Location	Focus	Sample	N	Method	Results
Nagata (2007)	Lebanon	A	Students	94	47-item survey (Equal Opp. Commission, Hong Kong, 2000) comparing attitudes to 5 categories: ID, former MI, physical disability, deaf, blind	-Attitudes very negative towards people with ID and people with MI -No effect of gender on attitudes
Narukawa & Maekawa (2004)	Japan	A	Students & lay people	682	Construction of Causal Model based on data from Narukawa (1995) and Narukawa & Nasu (2002)	Can have high level of goodwill towards people with ID without affirming their abilities
Narukawa, Maekawa & Umetami (2005)	Tokai, Japan	A	Students, aged 18-22 years (reanalysis of data from Narukawa, 1995 and Narukawa & Nasu, 2002)	415	28-item attitude survey, based on Narukawa (1995)	Experiences of contact during school years influence attitudes to integration, affirmation of abilities and positive behavioural intentions
Nosse & Gavin (1991)	USA, Midwest	A, E Impact of contact on attitudes	Students	31 & 23 controls	1) Adjective generation technique (Allen & Potkay, 1983) 2) Semantic differential scale Questionnaire developed by NIMH, India	Direct contact experience improved attitudes and reduced use of anxiety related adjectives
Ojha, Gupta, Dhingra & Menon (1993)	New Delhi, India	B, U, E Effects of integrated education programme consisting of films, slides & vignette on public awareness of ID	Slum dwellers	43 (unclear)		-Increased awareness of ID post-intervention -Pre: parents' fault most common cause cited (32.65), post: pre-natal problems (32.6%) -Beliefs re. support: pre: 86% viewed medical services as most appropriate, post: special education seen as most appropriate by majority -Idea in marriage as cure evident pre- but not post
Oliver, Anthony, Leimkuhl & Skillman (2002)	USA, Midwest	A Sexuality	Students & older adults recruited from 2 daycentres	149 students, 42 older adults	18-item scale of attitudes to sexuality of individuals with ID (Lunsky & Konstantareas, 1998)	-Differences in attitudes towards sexuality of person with ID and typically functioning adult mainly related to marriage and parenthood -With increased age attitudes to sexuality more conservative, regardless of disability or not
Ouellette-Kuntz, Burge, Brown & Arsenault (2010)	Ontario, Canada	S	Stratified random community sample (mean age=50 years)	625	Telephone survey: 8-item social distance subscale of MRAI-R (Antonak & Harth, 1994)	-Being older and less educated associated with greater social distance to people with ID, no effect of gender -Having family member with ID and perceiving average level of ID as mild associated with lower social distance -Overall limited variability in social distance; authors question whether views expressed overly favourable
Ouimet & De Man (1998)	Canada	S	Community sample, aged 19-74 years	85	1) AMRE (Antonak, Fielder & Mulick, 1993) 2) State-Trait Anxiety Inventory (Spielberger et al., 1970) 3) Self-Esteem Scale (Rosenberg, 1965) 4) Locus of Control Scale (Levenson, 1981)	Factors associated with eugenic attitudes: being male, less educated and higher on trait anxiety with external locus of control

Study	Location	Focus	Sample	N	Method	Results
Pace, Shin & Rasmussen (2010)	USA	A Attitudes to people with DS	Stratified random community sample	5399	Questions part of US Health Styles survey	-65.7% agreed that most adults with DS should be able to work -28.9% agreed that including people with DS in ordinary classes is distracting, 25.3% that students with DS should go to special schools -Factors associated with more positive attitudes: female, contact, higher education, not age
Panek & Jungers (2008)	USA, Midwest	B	Psychology students, mean age=19.5 years	116	Semantic differential scale with 3 factors: activity, evaluation, potency	-Perceptions differed according to causality: ID due to genetics evaluated most positively, 'self-inflicted ID' (drinking cleaning fluid aged 6) most negatively -Females rated people with ID more positively
Rees, Spreen & Harnadek (1991)	Canada	A, E Evaluation of historic changes & impact of contact & info as part of 2-year ID course	106 students enrolled on ID course, 83 student controls	189	Semantic differential scale *Replication of study by Spreen (1977)	-Positive shift in attitudes from 1977 to 1991 -Attitudes in both ID students and controls became more positive over course of study
Rice (2009)	USA	A	Students	295	MRAI-R (Antonak & Harth, 1994)	-Gender had effect on 21 of 29 items, but not on subtle derogatory beliefs
Rillotta & Nettelbeck (2007)	Adelaide, Australia	A, E Effects of awareness of disability (ADP) programme	2ndary school pupils & ex-pupils, mean age=20.9 years	259	Attitudes toward persons with ID questionnaire, adapted from Down (unpubl.)	-Pupils who completed ADP programme showed more positive attitudes than non-completer -Contact and ADP programme accounted for 5% and 4% respectively of variance in attitude change scores, being older and female jointly for a further 7%
Roper (1990a)	USA	A, B, E Beliefs about competence of people with ID; effect of volunteering at Sp. Olympics on social distance & perception of individuals with ID	Special Olympics volunteers, aged 12-70 years	369	1) Semantic differential scale 2) Questionnaire on beliefs about people with ID and Special Olympics, designed for study	-Contact provided through volunteering at Special Olympics did not have significant positive effects on attitudes or perceptions of their competence -Minimal (as opposed to no or ample contact) had strongest association with increasingly positive attitudes
Roper (1990b)	USA	B, S, E	Special Olympics volunteers, aged 12-70 years	369, same as Roper, 1990a	1) Semantic differential scale 2) 13-item social distance scale, developed for study	See Roper, 1990a
Saetermore, Scatone & Kim (2001)	California, USA	A, S Stigma towards 19 disabilities among 4 different ethnic groups	469 students & 102 community members, mean age= 32.3 years	571	5-item social distance scale re. 19 disabilities, adopted from Westbrook et al. (1993)	-MI more stigmatised than ID or DS by three ethnic groups, while Asian-Americans rated both similarly negatively -Severe physical and mental disability more stigmatised by Asian-Americans than by other ethnic groups-Asian-Americans born in Asia showed higher stigma than those born in USA

Study	Location	Focus	Sample	N	Method	Results
Scattone & Lee (1999)	California, USA	A Development of new measure	Students from 4 different ethnics groups	572	Scale rating social desirability of 19 disabilities, adopted from Westbrook et al. (1993)	Results largely about measure's psychometric properties
Schwartz & Armony-Sivan (2001)	Israel	A	Students	149	CLAS-ID (Henry et al., 1996a): 2 equivalent versions: ID & MHPs	-Empowerment and Similarity subscales endorsed more than Exclusion -More likely to endorse exclusion for people with MI than for those with ID -Results of US study (Henry et al., 1996a, 1996b) more positive than present Israeli sample -No effect of prior contact on attitudes
Schwartz & Rabinovitz (2001)	Israel	A, E Impact of visiting facility for residents with ID	Neighbours of residential facilities	208	Questionnaire designed for study re views of residential facilities for people with ID in neighbourhood	-None of facility or neighbourhood variables had significant effect on facility's perceived negative impact by themselves, but only in interaction -Visiting the facility did not have positive effect on attitudes by itself, but interaction between visiting and respondent factors did (e.g. positive effects on attitudes of neighbours who had young children and visited facility)
Scior, Kan, McLoughlin & Sheridan (2010)	UK & Hong Kong	A	Lay people: 149 Hong Kong residents (mean age=37.17 years) & 135 white British (mean age=33.92 years)	284	CLAS-ID (Henry et al., 1996a)	-HK Chinese adults higher on Exclusion and Sheltering and lower on Similarity than white British adults -Age had modest effect on attitudes, older respondents more in favour of Sheltering -Gender had only small effect, females more in favour of empowerment, other gender differences disappeared when other socio-demographics accounted for
Scior & Furnham (2011)	UK, Hong Kong, Singapore, India	U Development of new measure	Lay people from 6 different ethnic groups	1376	Intellectual Disability Literacy Scale: 1) knowledge of ID; 2) causal beliefs; 3) treatment beliefs; 4) social distance, developed by authors	-Results largely about measure's psychometric properties -Across entire mixed-ethnicity sample only 24% could recognise mild ID in vignette
Scotti, Slack, Bowman & Morris (1996)	West Virginia, USA	A Sexuality	Psychology students	135	1) Perceptions of Sexuality Scale, developed by authors 2) Global Perceptions Scale, adapted from Aging Semantic Differential (Rosencranz & McNevin, 1969)	-Females showed more positive attitudes -Sexual behaviour of people with ID rated as less acceptable than in students -Global perceptions of students more positive than of people with ID

Study	Location	Focus	Sample	N	Method	Results
Sigelman (1991)	USA	A, S	Lay people	102	Social distance scale re. 10 stigmatised groups	-Social distance 5 th highest for ID (higher for sexual herpes, gay people, MI and ex-convicts) -Participants portrayed themselves as more accepting than 'most people' and overestimated social distance most people would prefer to stigmatised groups
Sinson & Stainton (1990)	USA	A	Lay people from urban & rural areas, aged 18-68 years. 254 of 720 Stage 1 participants included in Stage 2	720	Stage 1: Questionnaire re. knowledge, awareness & integration Stage 2: Information pack followed by interviews	-Media coverage on ID had negligible effect, only noted when person had particular interest. Only exception BBC's QED programme that presented highly gifted autistic individuals in a positive light and as on equal terms (mentioned by name by 7%)
Tachibana (2005)	Japan	A	Parents recruited through 11 primary schools	2381	Questionnaire: open ended questions re past experience with individuals with ID and attitudes towards this group	-Negative contact experiences with individuals with ID, especially in childhood, strongly associated with negative attitudes -Most respondents judged self as holding more positive attitudes than average person and ascribed overly negative attitudes to the latter
Tachibana (2006)	Japan	U	Parents recruited through 11 primary schools *same sample as Tachibana (2005)	2381	Questionnaire: prevalence estimates of: ID, severe ID, associated difficulties, genetic causes	-Prevalence of ID underestimated at 0.5% -ID due to hereditary causes estimated at 10% -Markedly overestimated proportion of people with ID whose disability is severe
Tachibana & Watanabe (2003)	Japan	A, U	Parents recruited through 2 primary schools	375	25-item scale: attitudes, knowledge and beliefs re. intellectual disability, developed by authors	-Prevalence of ID underestimated at 0.5% -ID due to hereditary causes estimated at 10% -No clear association between prevalence estimates & attitudes
Tachibana & Watanabe (2004a)	Japan	A Results compared to Japanese surveys completed 20 & 40 years earlier	Parents recruited through 11 primary schools *same sample as Tachibana (2005)	2381	16-item scale: attitudes to integration of people with ID, developed by authors	-Community living not well accepted, only 30% strongly agreed -Over time attitudes in Japan have become more positive
Tachibana & Watanabe (2004b)	Japan	A	Parents recruited through 11 primary schools *same sample as Tachibana (2005)	2381	16-item scale: attitudes to integration of people with ID, developed by authors	-Being younger and having friend who has family member with ID associated with more positive attitudes -Those with family member with ID showed less positive attitudes than expected

Study	Location	Focus	Sample	N	Method	Results
Townsend & Hassall (2007)	Auckland, NZ	A Attitudes to unified sports	2ndary school pupils, aged 16-17 years	107	Questionnaire: 9 items re attitudes to integrated sports; 5 items re knowledge of Special Olympics	-Attitudes to unified sports positive overall -Adolescents less positive about unified sports than younger children -Girls more positive about unified sports than boys
Varughese & Luty (2010)	UK	A	Lay people, mean age=47.9 years	186	5 item Attitude to Mental Illness Questionnaire (AMIQ, Luty et al., 2006)	-Looking at picture of man with DS while completing measure associated with more positive attitudes than completing measure alone
Weller & Aminidav (1992)	Israel	A	Lay people from 3 ethnic groups	360	Family Relations Test, used to assess emotional reactions to individuals with ID	-Country of origin, gender, socio-economic status and religiosity associated with attitudes -Attitudes to people with mild ID less favourable than to those with physical disabilities, severe ID least favourable
Westbrook, Legge & Pennay (1993)	Australia	A	Health practitioners from Chinese, Italian, German, Greek, Arabic & English Australian communities	655	Social distance scales to rate attitudes of people in respondents' communities toward 20 disability groups	-Attitudes towards 19 of 20 disabilities differed by ethnic group -Relative degree of stigma attached to different disabilities very similar across communities, people with ID among least accepted groups
Yazbeck, McVilly & Parmenter (2004)	Australia	A	Students (n=163); community members (n=127); (+disability services professionals	290	1) CLAS-ID (Henry et al., 1996a); 2) MRAI-R (Antonak & Harth, 1994) 3) AMRE (Antonak et al., 1993) 4) MCSDS short form (Strahan & Gerbasi, 1972)	-Younger people & more educated showed more positive attitudes, no effect of gender -Prior contact associated with more positive attitudes on MRAI-R, but not on other scales -No clear association between social desirability and attitudes scores
Zaleski, Eysenck & Eysenck (1995)	Poland	A Focus on many marginal groups, incl. people with ID	Adults	249	1) Scale re. attitudes to 12 marginal groups 2) Eysenck Personality Questionnaire (Eysenck & Eysenck, 1975)	-Respondent's personality and characteristics of marginal groups, including people with ID, interact in determining attitudes
Zsombok, Hammer & Rojahn (1999)	Ohio, USA	A	Lay people	206	1) Scale of Attitudes toward Disabled People (SADP) (Antonak, 1992); 2) Behavioural measure (petition for/ against residential facility for people with ID in neighbourhood)	-Direct (survey) and indirect (mock petition drive) attitude measures only moderately correlated (.40) -Positive responses to indirect measure outweighed negative responses by 20%

2.3.2 Lay knowledge about intellectual disability

Studies presented under this heading have addressed the question to what extent the general public has an “adequate” understanding of intellectual disability. Only eight articles either explicitly focused on lay people’s knowledge about intellectual disability, or included this in their enquiries. Their findings suggest that members of the public frequently show a limited understanding of the concept of intellectual disability (Gordon et al., 2004), and synonymous terms, and that awareness of intellectual disability varies considerably between different cultures. On this note, Israelis of Western origin showed more accurate as well as a greater breadth of knowledge about intellectual disability than those of Eastern origin (Aminidav & Weller, 1995). When Ethiopians were asked to estimate the relative prevalence of intellectual disabilities, they erroneously estimated conditions such as schizophrenia to be more common (Alem et al., 1999). Lay people in Japan were found to underestimate the prevalence of intellectual disability at 0.5% and to markedly overestimate the proportion of people with intellectual disabilities whose disability is severe, leading the authors to suggest that many lay people may not regard ‘mild’ intellectual disability as such (Tachibana & Watanabe, 2003; Tachibana, 2006).

Three studies used case vignettes to assess lay knowledge. Presented with a vignette of someone with symptoms of a severe intellectual disability, only around half of parents and community health workers in India were able to recognise the condition (Madhavan et al., 1990). Ojha et al. (1993), in reporting the results of a public awareness programme with slum dwellers in New Delhi, reported that recognition of intellectual disability increased from one of 34 respondents at baseline to 19 of 30 at the end of the programme. As the vignette used is not included in their report, it is not possible to judge the severity of the disability depicted though;

arguably more severe symptoms should elicit higher recognition rates. Finally, in a study that presented lay people from six different ethnic groups in the UK and Asia with a vignette depicting someone with a mild intellectual disability, across the entire sample only 24% could recognise intellectual disability (Scior & Furnham, 2011). Respondents from Asian and African backgrounds were less likely to recognise intellectual disability than white British people.

2.3.3 Public attitudes towards and beliefs about intellectual disability

The concept of 'attitude' has been defined in many ways, including as "a psychological tendency that is expressed by evaluating a particular entity with some degree of favour or disfavour" (Eagly & Chaiken, 1993, p.1). All definitions of the construct include the notion that reporting an attitude involves an evaluative judgement about an object (Maio & Haddock, 2009). Attitude surveys made up the largest proportion by far of the studies reviewed, with 66 of the 75 papers reporting data on lay attitudes. Evidence from some studies conducted in Western countries suggests that attitudes are generally pro-inclusion (Henry et al., 1996a; Scior et al., 2010). Several studies have examined the extent to which lay people view individuals with intellectual disabilities as experiencing similar concerns, emotions and life goals as themselves, with varying results. In a German study, only 15% of adolescents agreed that people with intellectual disabilities experience similar problems as them (Eggert & Berry, 1992). In contrast, students and community members in the US, Israel, Japan, the UK and Hong Kong agreed that they were similar, albeit in Israel, Japan and Hong Kong agreement was very modest (Henry et al., 1996a; Horner-Johnson et al., 2002; Schwartz & Armony-Sivan, 2001; Scior et al., 2010).

In comparative studies of attitudes to social interactions with members of different groups, people with intellectual disabilities consistently emerge as one of

the least desirable groups (Gordon et al., 2004; Nagata, 2007; Westbrook et al., 1993). Further, behavioural intentions towards them are more negative than towards people with physical disabilities (Brown et al., 2011; Katz et al., 2000). The public appear to want greater social distance though from people with severe mental illness, such as schizophrenia, than from people with intellectual disabilities (Lau & Cheung, 1999; Saetermore et al., 2001; Sigelman, 1991). Finally, lay people appear to hold more negative attitudes towards individuals with severe rather than mild intellectual disabilities (Antonak et al., 1995; Weller & Aminidav, 1992).

Negative attitudes have been linked in part to misconceptions about the capabilities of people with intellectual disabilities, such as that most have severe disabilities (McCaughey & Strohmer, 2005). Lay people who recognise that most intellectual disabilities are *mild* show lower social distance towards this population (Ouellette-Kuntz et al., 2010). It has been suggested that providing even brief information that emphasises the capabilities of individuals with intellectual disabilities can result in more positive attitudes (MacDonald & MacIntyre, 1999). Furthermore it has been suggested that media portrayals that present individuals with disabilities in a positive light and on equal terms may have particular salience for lay people, who are otherwise used to media coverage that is designed to elicit pity (Sinson & Stainton, 1990).

Although at least in highly developed societies there appears to be broad consensus about the right of people with intellectual disabilities to be included in society (Bryant et al., 2006; Henry et al., 1996a; Scior et al., 2010), a small but significant minority still believe that they should be educated, live and work in segregated environments (Burge et al., 2007; Gilmore et al., 2003; Pace et al., 2010; Tachibana & Watanabe, 2004a). One should be cautious though not to assume that such views necessarily arise from hostile attitudes, as some may genuinely believe

that integration, for example in schools, is not always in the individual's best interests. Nonetheless in some studies a wish for segregation clearly arose from fears about the consequences of educational integration for the majority (Pace et al., 2010).

Lay attitudes to the sexuality of individuals with intellectual disabilities in Australia were found to be generally positive (Cuskelly & Bryde, 2004). Sexual intercourse was deemed less acceptable though once possible pregnancy and parenthood were considered (Cuskelly & Gilmore, 2007; Esterle et al., 2008; Morales et al., 2010; Oliver et al., 2002).

Beliefs are loosely defined as ideas in which some confidence is placed, or as the acceptance of a fact, opinion, or assertion as real or true, without immediate personal knowledge (Webster's Online Dictionary). They have attracted much less attention in psychological research than attitudes. Only five studies over the review period looked at lay people's beliefs about the causes of intellectual disabilities. Studies in both India and Tanzania identified a belief in 'god's will' as the most likely cause of severe intellectual disability. A significant proportion also attributed the disability to parents' actions in India, and to witchcraft in Tanzania (Kisanji, 1995; Madhavan et al., 1990). In contrast, in India only 4% of lay people saw prenatal complications or heredity as likely causes. Based on a large scale survey, Gilmore et al. (2003) concluded that the Australian public held some significant misconceptions about the causes of Down's Syndrome, despite showing reasonably accurate knowledge about the condition. Twenty-six per cent of their respondents believed Down's Syndrome to be caused by parental lifestyle or problems during birth. One area that has found little empirical attention to date is the link between causal beliefs, attitudes and stigma. In Ethiopia, supernatural retribution was deemed one likely cause that was in turn associated with more negative attitudes (Mulatu, 1999).

In a US-based study, intellectual disability due to genetics was perceived most positively, while “self-inflicted” disability, due to drinking cleaning fluid in childhood, was viewed most negatively (Panek & Jungers, 2008).

There is a notable absence of longitudinal studies that could inform us about the effects of changes in policies and service provision on public attitudes over the study period. Only two studies made any attempt to examine attitudinal changes over time. A Canadian study concluded that there was a positive shift in attitudes from 1977 to 1991 (Rees et al., 1991). However, these results should be viewed with caution as they are based on very small cross-sectional samples. In 1991 both a group of students enrolled on a 2-year course on intellectual disability and student controls showed a shift to more positive attitudes over the 1-year study period. Tachibana and Watanabe (2004a) concluded that, over time, attitudes in Japan have become more positive, but their analyses were based on comparison with data collected 25 and 40 years earlier using different measures and samples.

By far most of the studies in this section used direct attitude measures. The only study that used an indirect measure (a mock petition drive), found only a moderate correlation of 0.4 with a direct attitude measure and concluded that indirect measures may be more useful than explicit attitude measures, particularly in gauging real-life behavioural responses (Zsombok et al., 1999). Several studies assessed the risk of a social desirability bias in using direct attitude measures (Beckwith & Matthews, 1994; Hall & Minnes, 1999; Henry et al., 1996b; Horner-Johnson et al., 2002; Yazbeck et al., 2004). Hall and Minnes found scores on the Jackson Social Desirability Inventory (Jackson, 1974) predicted a modest 7% of the variance in scores on the Attitudes towards Disabled Persons Scale (Yuker et al., 1960). All other studies found no significant correlations between measures of social desirability and attitude scales (CLAS-ID, Henry et al., 1996b; MRAI-R, Antonak &

Harth, 1994; AMRE, Antonak et al., 1993). Thus it would seem that social desirability has at best only a modest effect on measures of attitudes towards people with intellectual disabilities, perhaps because lay people have no clear conception what socially desirable responses towards this group consist of.

2.3.4 Analyses of the effects of socio-demographic characteristics and prior contact on beliefs and attitudes

This area attracted considerable attention in the literature reviewed. Gender, age and education have been shown in several studies to be associated with attitudes towards individuals with intellectual disabilities. Females, younger people and those with higher educational attainments tend to express more positive attitudes (Akrami et al., 2006; Antonak et al., 1995; Burge et al., 2007; Esterle et al., 2008; MacDonald & MacIntyre, 1999; Ouimet & De Man, 1998). However, the effect of gender in particular appears inconsistent and was not confirmed in other studies (Hudson-Allez & Barrett, 1996; Karellou, 2003; Lau & Cheung, 1999; Nagata, 2007; Ouellette-Kuntz et al., 2010; Yazbeck et al., 2004). Scior et al. (2010) reported that most initial apparent gender differences disappeared once other socio-demographics were accounted for, which hints at reasons for the lack of consistent findings. Finally, two studies found no correlation between age and discriminatory attitudes (Lau & Cheung, 1999; Pace et al., 2010).

One variable that has almost invariably been shown to be linked to more positive attitudes is prior contact with someone with intellectual disabilities (Antonak & Harth, 1994; Antonak et al., 1995; Beckwith & Matthews, 1994; Beh-Pajooh, 1991; Choi & Lam, 2001; Horner-Johnson et al., 2002; Lau & Cheung, 1999; Yazbeck et al., 2004). It should be stressed though that most studies that report positive effects of contact used cross-sectional designs, comparing those with and without prior contact and assuming the two groups to be similar otherwise, which is questionable

at best. Studies that have directly measured the effects of contact on lay people are reviewed in section 2.3.6 below.

2.3.5 Cross-cultural comparisons of attitudes and beliefs

The majority of research in this area was carried out in developed, Western countries. A few studies have examined attitudes and causal beliefs in ethnic minority communities residing in Western developed countries (Gabel, 2004) or in developing countries (Madhavan et al., 1990; Mulatu, 1999; Ojha et al., 1993), using in-depth, qualitative methodologies. Only five studies examined cross-cultural differences in attitudes and beliefs at general population level over the period studied. A study that assessed attitudes in six different ethnic communities in Australia concluded that while attitudes differ between communities, the relative degree of stigma attached to different disability groups is very similar across communities, with intellectual disability among the most stigmatised categories (Westbrook et al., 1993).

In a comparison of attitudes among North American and Japanese students, the latter were found to be less inclusion-friendly (Horner-Johnson et al., 2002). Korean and Korean American students were found to show similar attitudes to individuals with physical disabilities, but Koreans were more negative about people with intellectual disabilities (Choi & Lam, 2001). Asian-American students showed higher social distance than African- or Latin-American students (Saetermore et al., 2001). Among Asian-Americans in this study, those born in Asia showed higher levels of stigma than their US-born peers. Finally, white British adults were more in favour of the social inclusion of people with intellectual disabilities and were more likely to view them as similar to themselves than Hong Kong residents (Scior et al., 2010).

2.3.6 Outcomes of interventions aimed at increasing the public's understanding and social acceptance of people with intellectual disabilities

Twelve studies attempted to evaluate the outcomes of contact-based interventions at general population level, of these seven only sampled students. Nosse and Gavin (1991) examined the effects of direct contact on student volunteers and concluded that contact improves attitudes and reduces anxieties. In their study, 31 volunteers in groups of ten to 12 housed and entertained individuals with intellectual disabilities and their supports over 2.5 days. Their experimental group was relatively small (n=31) and potentially biased as students opted into the contact group, rather than being randomly assigned. The effects on students of a 10-week course on intellectual disability that combined lectures with a minimum of 20 hours of contact were assessed by Kobe and Mullick (1995). While they found an increase in self-rated knowledge, attitudes remained unchanged. The authors acknowledged that this might have been due to limited variability in scores and to the attitudes of several participants becoming markedly more negative over the course of the intervention.

A study by Rillotta and Nettelbeck (2007) assessed the effects of contact on secondary school pupils as part of a 3 to 10 session disability awareness programme. While attitudes improved among pupils who completed the programme, the results should be viewed with caution as the data were entirely collected retrospectively. The effects of contact on volunteers at the Special Olympics were examined by Roper (1990a, 1990b). He concluded that minimal, as opposed to no or ample, contact had the strongest association with more positive attitudes and reduced social distance. He suggested that the perception of individuals with intellectual disabilities as competent may be key to attitude change. While he succeeded in recruiting

61.5% of all volunteers to the study, the effects of contact were again only assessed retrospectively.

A study of neighbours' views of residential facilities for people with intellectual disabilities found that visiting the facility did not have a positive effect on attitudes by itself, but only in interaction with other factors, such that positive effects were observed, for example, on neighbours who had young children and visited the facility (Schwartz & Rabinovitz, 2001). As in most other studies reviewed, the design was cross-sectional, and as Rillotta and Nettelbeck (2007) and Roper (1990a, 1990b), no baseline data were collected in trying to evaluate the outcomes of an intervention.

It has been suggested that contact may have its positive effect on attitudes by reducing anxieties and fears lay people may have about interacting with individuals with intellectual disabilities (Beh-Pajoo, 1991; Hudson-Allez & Barrett, 1996), but that this may take time. A note of caution about the effect of contact has been sounded by the finding that it is *positive* contact that may lead to a greater willingness for social contact (Hall & Minnes, 1999), whereas negative contact experiences, especially in childhood, may in fact increase social distance (Narukawa et al., 2005; Tachibana, 2005).

Of note, most studies that have evaluated such interventions base their conclusions on small, unrepresentative samples. Studies that have directly measured the effects of an intervention, either based on providing contact with individuals with intellectual disabilities, and/or through education, are few and mostly rather poorly designed. Most used cross-sectional designs, and arrived at their conclusions typically by comparing those with prior contact to those without, or by retrospectively comparing those who completed an education/contact based programme to controls. This ignores confounding factors, most notably that

individuals with more positive attitudes are more likely to seek contact or enter an educational programme in the first place.

Well designed evaluations using repeated measures designs *and* representative general population samples, rather than student samples, were not identified during the study period. Only five studies used a repeated measures design (Hudson-Allez & Barrett, 1996; Kobe & Mulick, 1995; MacDonald & MacIntyre, 1999; Nosse & Gavin, 1991; Ojha et al., 1993); of these two used non-student samples that were not representative of the general population though (Hudson-Allez & Barrett, 1996; Ojha et al., 1993). The most rigorous of these studies targeted all neighbours within the micro-neighbourhood of nine new homes, interviewed them at three time points, and had a high response rate (78%), but the authors acknowledged that the information provided to neighbours may not have been representative of other areas (Hudson-Allez & Barrett, 1996).

2.4 Discussion

This systematic review identified 75 peer reviewed studies into knowledge, attitudes and beliefs about intellectual disability among the general public of working age. The majority of the evidence reviewed (66 of the 75 articles) consisted of descriptive studies of attitudes among lay people and students using direct attitude measures. These identified a number of socio-demographic factors that appear to predict attitudes, namely age, educational attainment and prior contact with someone with an intellectual disability. While in highly developed societies most lay people seem to broadly agree with the *right* of people with intellectual disabilities to be included in society, the latter continue to be viewed as highly undesirable partners for social interactions.

There is a surprising lack of evidence about possible changes in attitudes across time. While attitudes differ across cultures, there seems to be little variation

in the relative degree of stigma associated with intellectual disability. Lay people want greater social distance from people with intellectual disabilities than those with physical disabilities, but individuals with severe mental illness appear to be even more stigmatised. Of note, social desirability appears to be only weakly correlated, if at all, with attitudes, as measured on direct attitude scales. A few of the studies reviewed suggest that lay people's reluctance to interact with people with intellectual disabilities may be due, at least partly, to discomfort and anxiety. If this finding were confirmed, it suggests that, in line with Pettigrew and Tropp (2006), reducing anxiety concerning interactions with individuals with intellectual disabilities should be a key target.

Research has examined the effects of label changes on attitudes, but the question how well lay people understand different labels has largely remained unanswered. Only eight studies explicitly examined public knowledge about intellectual disability. They suggest that the public generally has a limited understanding of the concept of 'intellectual disability', is confused about different terminology used and that awareness varies considerably across cultures, but is generally low. These conclusions should be treated with caution though as they are based on a small number of studies that used unrepresentative samples. To date there is little solid evidence whether a positive relationship exists between awareness of intellectual disabilities and stigma, although it has been suggested that reducing misconceptions and emphasising the capabilities of people with intellectual disabilities can lead to improvements in attitudes.

Research into the public's causal beliefs about intellectual disability and their effects on stigma is limited to date. Only five studies examined lay people's causal attributions; of these only two considered the link with stigma. A study by Mulatu (1999) is the most informative of these, as he compared causal beliefs about nine

different health conditions and evaluated the relationship between such beliefs and stigma. The sample was a convenience sample though and the numbers responding to each condition were small (n=50). A much better understanding is needed in this area, not least as research in the area of mental health suggests such an understanding can not only highlight targets for public awareness campaigns, but also what messages to avoid (Angermeyer & Matschinger, 2005; Corrigan et al., 2000; Jorm & Griffiths, 2008).

The current review suggests a dearth of evaluations of efforts aimed at tackling low awareness and negative attitudes at general population level. While contact has consistently been shown to be associated with more positive attitudes, high quality evaluations of contact-based interventions with lay people of working age could not be identified. The main route commonly employed to tackling negative attitudes to people with intellectual disabilities is through interventions within schools aimed at providing (positive) contact experiences between typically functioning children and peers with disabilities and through inclusive education generally. Admittedly, interventions targeting adults in the general population lack a comparable ready made environment. Of the twelve studies that evaluated such interventions, most relied on retrospective data and small samples, and participants mostly opted into the programme, rendering the findings very biased. Only two studies evaluated an intervention using non-student samples and a repeated measures design (Hudson-Allez & Barrett, 1996; Ojha et al., 1993). The limited conclusions that can be drawn from this body of research indicate that interventions may have their effects not by themselves, but through an interaction between intervention and respondent factors. Further, it is important to control the quality of contact, as *positive* contact seems to reduce social distance, yet negative contact experiences may have the opposite effect. In designing future evaluations,

researchers should bear in mind that only studies that use repeated measures designs and, ideally, randomly assign participants to groups can provide reliable evidence about the effects of contact. Furthermore, a dichotomous view of contact as either absent or present is likely to mask complex aspects of contact that may influence its impact, such as whether contact occurred on a voluntary basis, its frequency and the perceived quality of the relationship or contact experience (Alexander & Link, 2003).

The research reviewed has a number of other important methodological limitations. As noted, the evidence is dominated by attitude surveys using (mostly local) convenience samples and 43% of the literature reviewed is based on student samples, rendering the findings unrepresentative. The only attitude surveys to use large stratified random samples still have marked limitations. Two collected data via telephone, which arguably increases the risk of socially desirable responses (Burge et al., 2007; Ouellette-Kuntz et al., 2010). The third study presented an analysis of secondary data and acknowledged a number of selection biases (Pace et al., 2010). While there is evidence to support the notion that explicit attitudes predict future behaviour, this relationship is strongest with non-student samples, and where self-report measures of behaviour are used (Kraus, 1995), factors that were not addressed in most of the studies reviewed. Furthermore, responses were mostly measured to a hypothetical individual, while responses to individuals with whom the respondent has had naturalistic contact were less frequently assessed. Other than the general tenets of intergroup contact theory (Allport, 1954; Pettigrew, 1998), very little of the research has tested any theoretical model. In studying attitudes, researchers on some occasions included social distance and comfort as measures of external stigma. None considered the results, for example, in relation to stigma theories, which seems a marked omission.

2.4.1 Conclusions

Future research should go beyond descriptive accounts of public attitudes and beliefs. There is a need for research that considers the complex processes involved in the formation of stigma, prejudices and discrimination that can negatively affect the opportunities available to people with intellectual disabilities and their social inclusion. Studies in the mental health field indicate that a more comprehensive understanding of the stigma process needs to consider not only lay people's attitudes, but also their emotional responses, causal attributions and familiarity with the respective condition. As yet, intellectual disability research has not tested the relationship between different variables implicated in stigmatisation. Nor has an attempt been made to link findings to the potential functions of stigma, which is likely to highlight some complex and important issues.

**Chapter 3: Development and validation of the Intellectual
Disability Literacy Scale for assessment of knowledge,
social distance and beliefs regarding intellectual disability**

Abstract

Background: Research into the general public's responses to individuals with intellectual disabilities has been dominated by attitudinal research. This approach ignores important aspects, such as lay knowledge, causal beliefs and perceptions of suitable interventions that can produce a multi-faceted understanding of public responses. This paper describes the development of a measure designed to assess respondents' intellectual disability literacy.

Method: Following a pilot with 114 participants, the IDLS was revised and then completed by 1376 members of the public (aged 18-78 years) belonging to five main ethnic groups.

Results: The measure was able to distinguish respondents who showed good intellectual disability literacy. Factor analyses revealed four causal belief factors (adversity, biomedical, environment and supernatural) that accounted for 55% of the variance in beliefs about causes and three intervention beliefs factors (expert help, lifestyle, religion/spiritual) that explained 52% of the variance in beliefs about suitable sources of help. Test-retest reliability for these factors was good for all ethnic groups. The 4-item social distance scale had good internal consistency for all ethnic groups and acceptable concurrent validity.

Conclusions: The IDLS is a useful tool to evaluate knowledge, beliefs and social distance to intellectual disability in lay people and is suitable for cross-cultural research.

**Development and validation of the Intellectual Disability Literacy Scale
for assessment of knowledge, social distance and beliefs
regarding intellectual disability**

The literature review identified a need for research that goes beyond purely descriptive accounts of public attitudes and beliefs and considers the complex processes involved in the formation of stigma, prejudices and discrimination directed at people with intellectual disabilities. At present research in this area is limited though by a lack of good quality tools that would allow us to develop a more comprehensive understanding of the stigma process pertaining to intellectual disability. This chapter describes the development of a new measure designed to test the relationships between lay knowledge, beliefs and attitudes regarding intellectual disability and to be suitable in the context of multi-cultural societies where additional challenges may arise for attempts to achieve equality and increase the social inclusion of people with intellectual disabilities.

3.1 Background

Understanding the relationship between public knowledge, attitudes and beliefs regarding intellectual disability can help identify potential barriers to social inclusion and potential targets for public education work. Such evidence can also highlight the negative influence public perceptions can have on the lives of the individuals concerned (*self-stigma*) (Ali, Strydom, Hassiotis, Williams & King, 2008), on their families and others offering them support (*affiliate stigma*) (Mak & Cheung, 2008) and on help-seeking (Wrigley, Jackson, Judd & Komiti, 2005). To date though, most research in this area has either focussed solely on attitudes or has examined beliefs and stigma in those affected (Ali et al., 2008; Jahoda & Markova, 2004) or their families (Mak & Cheung, 2008), but not among the public. Factors such as lay knowledge, causal beliefs and perceptions of suitable sources of help can provide a

much richer understanding but have rarely been the subject of empirical investigation.

This stands in stark contrast to the mental health field where a large body of empirical work has examined attitudes, causal and intervention beliefs, and, more recently, emotional responses to mental illness on the part of lay people. The concept of 'mental health literacy' was introduced by Jorm et al. (1997) in tying these strands together. Some of the findings generated in the mental health field pose important questions for public education work. For example, the assumption that knowledge about a disorder and a belief in the biological causation of mental illness will result in reduced stigma has for some time underpinned public awareness campaigns. Large scale public education campaigns have resulted in an increased public understanding of depression and schizophrenia, earlier diagnosis and treatment (Jorm, Christensen & Griffiths, 2005). They also appear to reduce the stigma associated with depression, but fail to do so consistently for schizophrenia (Angermeyer & Matschinger, 2005; Dietrich, Matschinger & Angermeyer, 2006; Jorm & Oh, 2009). Hence studies have tried to understand the link between causal beliefs and stigma and have identified what beliefs should be the target of anti-stigma campaigns (Dietrich, Beck, Bujantugs, Kenzine, Matschinger & Angermeyer, 2004; Jorm & Griffiths, 2008; Ozmen, Ogel, Aker, Sagduyu, Tamar & Boratav, 2004).

The beliefs individuals hold about likely causes and potential sources of help for a disorder are influenced by their demographic characteristics and cultural background. Age, education, prior contact and, less consistently gender, have been shown to affect knowledge, attitudes and beliefs (Horner-Johnson et al., 2002; Jorm & Oh, 2009; Lauber, Nordt, Falcato & Roessler, 2003). A number of studies have found that white Westerners tend to believe in the biological or social causation of schizophrenia (Angermeyer & Dietrich, 2006). In contrast, people of African and

Asian origin are more likely than Westerners to subscribe to supernatural explanations for schizophrenia or mental illness more generally (Adewuya & Makanjuola, 2008; McCabe & Priebe, 2004; Razali, Khan & Hasanah, 1996). It has been suggested that potentially stigmatising lay beliefs about the causes of intellectual disability may be common amongst some cultural communities, such as a belief among South Asians that the condition results from possession by spirits (Hatton et al., 2003) or punishment for past sins (Hubert, 2006). Such findings are entirely derived from small scale studies with the parents of children with intellectual disabilities though and in the absence of general population research need to be treated with caution.

With regard to beliefs, one might reasonably expect that causal beliefs individuals hold about a condition match their beliefs about suitable sources of help. Someone who holds a biomedical explanatory model of intellectual disability, for example, would likely favour medically based treatments. Conversely someone who believes that intellectual disability is caused by supernatural forces might be more likely to seek spiritual interventions and reject medical or psychosocial interventions. An enhanced understanding in this area has obvious implications for service delivery. The low uptake of disability services by some cultural communities has been explained with reference to institutional racism, health professionals' unhelpful assumptions and attitudes, language barriers, mistrust of services and clashes in values (Atkin & Ahmed, 2000; Fulton & Richardson, 2010; Hatton, Azmi, Emerson & Caine, 1997; Mir et al., 2001), but a potential clash in beliefs about causes and interventions has found little empirical attention.

3.1.1 The Case for a New Measure

A number of measures have been developed to assess public attitudes towards people with intellectual disabilities (Akrami et al., 2006; Antonak et al.,

1993; Antonak & Harth, 1994; Harth, 1974; Henry et al., 1996a; McConkey, McCormack & McNaughton, 1983; Tachibana & Watanabe, 2003). By far the most common method to assess attitudes to intellectual disability are self-report attitudinal scales. One of the most widely used measures is the Mental Retardation Attitude Inventory (Antonak & Harth, 1994), a 29 item revision of Harth's (1974) original 50 item rating inventory. The measure uses a 4-point Likert scale to assess attitudes on four subscales: integration-segregation; social distance; private rights; and subtle derogatory beliefs. While the authors suggested that the measure has good psychometric properties, a recent Canadian study by Ouellette-Kuntz et al. (2010) found surprisingly positive attitudes to intellectual disability using Antonak & Harth's (1994) eight item social desirability subscale and questioned its overall validity. Of the eight items, two concern what the respondent would allow their child to do; such items may be problematic for two reasons: their validity for both a young adult population and for cross-cultural research is questionable as young adults may have little realistic concept of parenthood and child rearing practices vary enormously across cultures.

Another widely used measure, the Community Living Attitudes Scale - Intellectual Disability version (CLAS-ID) was developed by Henry et al. (1996a) to assess attitudes to the social inclusion of people with intellectual disabilities. The 40 item measure uses a 6-point Likert scale to assess attitudes on four subscales: empowerment, exclusion, sheltering and similarity. The measure has been used in a range of cultural contexts and has been shown to have good psychometric properties (Henry et al., 1996b; Horner-Johnson et al., 2002; Schwartz & Armony-Sivan, 2001; Yazbeck et al., 2004).

Other measures were designed to assess attitudes to people with both physical and intellectual disabilities, such as Gething's (1991) Interaction with

Disabled Persons scale. All these measures have in common a focus on explicit attitudes but neglect other aspects that are likely to be important in understanding lay responses to intellectual disability, such as knowledge and beliefs about the condition and implicit attitudes (Greenwald, McGhee & Schwartz, 1998). To date no measure allows a more comprehensive understanding that links attitudes, knowledge and beliefs about causes and interventions regarding intellectual disability. In contrast, in the area of mental health the questions asked and corresponding methods and measures have become increasingly sophisticated and are allowing researchers to examine the complex interplay between knowledge, beliefs, stigma and help seeking. In order to make similar advances in our understanding of the social context to intellectual disability, there is a clear need for the development of tools designed for this purpose. This paper reports on the development and psychometric properties of the Intellectual Disability Literacy Scale (IDLS), a measure designed to provide a more comprehensive understanding of lay responses to intellectual disability.

3.1.2 Study aims

The central aim of this study was to develop a measure that would allow assessment of the relationship between different aspects of intellectual disability literacy, namely 1) the ability to recognise symptoms of intellectual disability and distinguish them from other mental 'disorders', including specific learning difficulties and mental health problems; 2) beliefs about causes of intellectual disabilities; 3) beliefs about effective sources of help/ interventions; and 4) desire for social distance from individuals with intellectual disabilities as a measure of external stigma (Link & Phelan, 2001).

The Intellectual Disability Literacy Scale (IDLS) incorporates these different aspects and also examines the significance of socio-demographic factors, thus

allowing us to develop a much more comprehensive understanding that can serve as evidence for efforts to reduce stigma and counter discrimination against people with intellectual disabilities. The measure can be used in a format that investigates the same variables in relation to schizophrenia in order to allow comparisons, namely whether beliefs about intellectual disability and mental illness are closely linked, or whether they may be influenced by different processes and factors. The reasons for choosing schizophrenia as comparison case are severalfold. Research regarding mental health literacy has mainly focused on schizophrenia and depression. Of these two conditions schizophrenia was deemed a more suitable comparison as both schizophrenia and intellectual disability often have a long lasting and pervasive impact on the person's life. Compared to other disorders both have relatively low lifetime prevalence rates, estimated at around 1.5% to 2.3% for intellectual disability (Allison & Strydom, 2009; Emerson et al., 2012; Larson, Lakin, Anderson, Lee, Lee & Anderson, 2001) and 0.4% to 1.4% for schizophrenia (Cannon & Jones, 1996; Saha, Chant, Welham & McGrath, 2005), in contrast to much higher estimates of the lifetime prevalence of depression of 15% to 30% (Blazer, Kessler, McGonagle & Swartz, 1994; Kruijshaar, Barendregt, Vos, deGraaf, Spijker & Andrews, 2005). Thus one might expect, based on numbers alone, public awareness of intellectual disability and schizophrenia to be similar.

Another key aim of this study was to develop a measure that would be appropriate for the study of intellectual disability literacy in different cultural and religious contexts. Although there are clear advantages in examining the psychometric properties of a new measure with a homogenous sample, in view of evidence of differences between ethnic groups in terms of knowledge, beliefs, stigma and service uptake, a measure with established validity and reliability in very different cultural contexts offers some real advantages.

3.2 Method

3.2.1 Development of the IDLS

A literature search was conducted using the electronic databases PsycINFO and MedLine to identify common lay beliefs about intellectual disability and schizophrenia in a range of cultural contexts. The search terms used included beliefs*, attitude*, stigma and social distance AND (intellectual disability OR learning disability OR mental retardation OR schizophrenia OR psychosis OR mental illness). On the basis of relevant studies identified, 30 items were generated regarding possible causes and 30 items referring to possible sources of help. These lists were not intended to be exhaustive but rather to tap into a range of belief systems regarding possible causes and effective interventions.

The initial scale was piloted with 114 UK residents (16-79 years old). White British participants made up 29.8% of the pilot sample, 27.2 % were of South Asian origin, 20.2% of Black African or Caribbean origin and the remainder from other ethnic groups. The scale was revised substantially in response to the pilot results. For example, the causal items "overly spoilt as a child" and "parents too lenient" were added, as many participants spontaneously cited these as likely causes for the symptoms presented in the vignettes, see Figures 1 and 2 below, in response to the question "what would you say is going with X?".

3.2.2 Participants

Of the 1375 participants in the main study, 53.1% were female (M age= 28.32, SD=11.72). 33.8% were white UK residents, 9.4% UK residents of South Asian background, 7.1% UK residents of Black African background, 31.5% East Asians residing in Hong Kong or Singapore, 7.8% were Indian citizens and 10.3% were UK residents of other ethnic backgrounds. 7.2% (n=99) had completed the legal national minimum of education, 53.4% (n=734) had been educated to age 18

(A-levels, International Baccalaureate or equivalent), 33.9% (n=466) were graduates and 5.5% (n=76) declined to provide this information. Of those educated to age 18, 71% (n=521) were currently studying for a degree, hence overall the sample was highly educated. Prior contact with someone with mental health problems was reported by 47.8% (n=657); contact with someone with intellectual disabilities was reported by 48% (n=412) of those who responded to this question, but it should be noted that there were a large number of missing responses to the latter question, possibly because it came at the very end of the survey (completed responses n=858).

3.2.3 Procedure

Convenience sampling was used to recruit participants for the study. Between July 2009 and January 2010 responses from a large mixed ethnicity sample (N=1376) were collected in the UK, India, Hong Kong and Singapore. Data was collected through distribution of the printed measure and e-recruitment. Participants recruited in Hong Kong were able to choose whether to complete an English or Mandarin version of the measure, others completed the measure in English. As an incentive to aid recruitment all participants had the option of entering a prize draw to win £100 (or the national equivalent) in retail vouchers. The response rate, that is the proportion of individuals who accepted the invitation to take part and subsequently completed the survey, was 51.5%. Due to the sampling procedure, namely mainly through electronic sampling and snowballing, it was not possible to determine the number who received an invitation to take part. A subset of 300 participants completed the measure a second time two to three weeks after initial administration to allow examination of test-retest reliability. The study was approved by the UCL Research Ethics Committee.

3.2.4 Measures

The following measures were completed by participants.

3.2.4.1 Intellectual Disability Literacy Scale (IDLS). The IDLS is in line with numerous other studies that have used a vignette methodology to assess knowledge and beliefs about a range of mental health problems amongst diverse cultural groups (Angermeyer & Dietrich, 2006; Furnham & Chan, 2004; Jorm et al., 2006). The measure presents two vignettes (see Figures 1 and 2) containing diagnostically unlabelled case stories, one depicting an individual who meets diagnostic criteria for a (mild) intellectual disability, the other for schizophrenia (American Psychiatric Association, 1994). The schizophrenia vignette closely followed research by Jorm et al. (1997). Both vignettes were reviewed by five experts (consultant psychiatrists and clinical psychologists) to ensure they met diagnostic criteria and were deemed 'typical' of someone presenting with the target disorder.

James is 22 and lives at home with his parents and younger brother. He found school a struggle and left without any qualifications. He has had occasional casual jobs since. When his parents try to encourage him to make plans for his future, James has few ideas or expresses ambitions that are well out of his reach. Rather than having him at home doing nothing, his mum has been trying to teach James new skills, such as cooking a meal, but James has struggled to follow her instructions. He opened up a bank account with his parents' help, but has little idea of budgeting and, unless his parents stop him, will spend all his benefits on comics and DVDs as soon as he receives his money.

Figure 1. *Vignette depicting individual presenting symptoms of mild intellectual disability*

Adam is 24 and lives at home with his parents. He did fine at school, but has only had a few casual jobs since. Over recent months he has spent lots of time alone, locked in his bedroom and frequently refuses to eat with his parents or have a bath. He sometimes gets very agitated for little apparent reason and his parents have heard him talking loudly even when he's alone in his bedroom. At times they find his speech disorganised and hard to follow. When his parents encourage him to make plans for his future he says this is too dangerous. They are certain he is not taking drugs because he never sees anyone or goes anywhere.

Figure 2. *Vignette depicting individual presenting symptoms of schizophrenia*

After being presented with each vignette, respondents were asked a series of questions to assess their recognition of the condition depicted in the vignette, their beliefs about causes and suitable interventions, stigmatising attitudes, contact with people with intellectual disabilities and mental health problems, and socio-demographic characteristics.

3.2.4.1.1 Recognition: Following presentation of each vignette, to assess labelling of the symptoms depicted in the vignette respondents were asked "what would you say is going on with X?".

3.2.4.1.2 Causal and Intervention Beliefs: Respondents were asked to rate their agreement with 22 statements about possible causes of the behaviours depicted in the vignette and the extent to which they believed that 22 possible sources of help were likely to be effective, using a 7-point Likert scale (1=strongly disagree to 7=strongly agree), see Appendix 1.

3.2.4.1.3 Social Distance: Respondents rated their willingness to have social contact with the person in the vignette on four statements, representing varying degrees of intimacy, using the same 7-point Likert scale as the previous sections. The items replicate items used by Link, Phelan, Bresnahan, Stueve and Pescosolido (1999). A social distance score was calculated as the mean of the four items and reversed to aid interpretation, with higher scores indicating greater social distance.

3.2.4.1.4 Socio-demographic characteristics: The last section of the IDLS was designed to elicit detailed socio-demographic information, including respondents' ethnicity, gender, age, educational attainments, and religious faith and adherence. Participants were also asked whether they knew anyone with an intellectual disability/mental health problem, and, if so, the nature and closeness of this relationship and frequency of contact.

3.2.4.2 Attitudes to Intellectual Disability. Participants also completed the Community Living Attitude Scale- Intellectual Disability (CLAS-ID) short version (Henry et al., 1996a). As noted earlier, the CLAS-ID was designed to assess attitudes to the social inclusion of people with intellectual disabilities on four subscales: empowerment, exclusion, sheltering and similarity. Participants indicated their agreement with 17 items (or 40 items on the full version) on a 6-point Likert scale ranging from 'strongly disagree' to 'strongly agree'. The aim of including this questionnaire was to explore the relationship between social distance and attitudes to the inclusion of people with intellectual disabilities. It was hypothesised that respondents who showed a higher desire for social distance would also score higher on exclusion and sheltering, attitudes that do not favour the social inclusion of people with intellectual disabilities, and lower on empowerment and similarity, which indicate attitudes in favour of inclusion. In the absence of available measures to assess beliefs about intellectual disability, it is recognised that this examines only one aspect of the concurrent validity of the IDLS.

3.2.5 Statistical Analysis

The data were analysed using the Statistical Package for Social Sciences (SPSS) version 14. To answer the question whether the IDLS can distinguish individuals who can recognise symptoms of intellectual disability and schizophrenia from those who attribute typical symptoms of the respective condition to other causes, responses to the open question "what would you say is going on with X?" were examined. Coding categories were created on the basis of the most common spontaneous responses or close approximations. If participants suggested multiple causes, only the label closest to the correct diagnosis was registered. The inter-rater reliability for coding into these categories was calculated by having two raters (the author and another clinical psychologist working with adults with intellectual

disabilities) code 120 participants' responses independently of one another and using the Kappa statistic. Exploratory factor analyses of causal and intervention belief items were carried out. Cronbach's alpha was calculated to examine the internal consistency of the causal and intervention scales and their constituent subscales and of the social distance items. Correlation coefficients between subscales were calculated. Test-retest reliability was examined by calculating the intraclass correlation coefficient. The concurrent validity of the measure's attitudinal component was determined by calculating Pearson correlation coefficients between social distance scores and CLAS-ID subscale scores.

3.3 Results

3.3.1 Recognition of symptoms

The measure was able to distinguish respondents who showed good intellectual disability literacy, that is those who were able to recognise that the person in the vignette might have an intellectual disability from those unable to do so. The inter-rater reliability for coding into the categories listed in Table 3 was $Kappa=.87, p<.001, 95\% CI (0.80, 0.94)$. Vignette 1 was correctly identified as intellectual disability by 23.8% ($n=322$) of participants. Vignette 2 was identified as depicting schizophrenia or psychosis by 24.4% ($n=307$), see Table 3.

Table 3. *Participants' beliefs about the nature of the underlying problem*

Underlying Problem Identified	Intellectual Disability Vignette %	Schizophrenia Vignette %
Intellectual Disability	23.8	0.1
Reference to other developmental disabilities, e.g. specific learning difficulty, autism spectrum disorder	4.1	2.1
General Reference to Mental Illness	3.9	31.0
Schizophrenia/ Psychosis	0.1	24.4
Depression	3.4	12.2
Anxiety	0.1	2.1
Personal Problems, including stress, family tension, difficulty growing up	14.1	11.4
Lazy/ Lacks motivation	5.8	0.2
Upbringing (e.g. "spoilt")	4.3	0.4
Spirit Possession	0	1.2
Other	37.7	12.5
Don't know	2.6	2.4
Missing	1.0	9.2

3.3.2 Beliefs about causes of intellectual disabilities and schizophrenia

The 30 items used in the main study were examined for their psychometric properties and fit with the scale's factor structure. None of the items were highly correlated, i.e. $r > .9$, suggesting that the measure assessed interrelated yet distinct concepts. The item 'black magic' showed the largest skewness and kurtosis across all cultural groups and was removed from further analyses.

3.3.3 Factor analysis of causal beliefs

To examine the factor structure of causal items, an exploratory principal components analysis of the 30 items was carried out. This together with examination

of the scree plots suggested that a four-factor solution was optimal for beliefs about the causes of intellectual disability and schizophrenia. A second analysis forcing a four-factor solution obtained through oblique rotation (Direct Oblimin) was used for development of the final scale. Oblique rotation was chosen as the factors were correlated.

The Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy value of $\geq .88$ indicated that the sample size was very good for the purposes of these analyses. After rotation, items that did not load above 0.5 for both vignettes on the same factor were not retained, these were: stress; taking illegal drugs; lack of physical exercise; drinking too much; and lack of friends. The item 'cold and uncaring parents' was omitted from further analysis as it loaded highly on two factors. Finally, the item 'mother over 40' was omitted as it showed the lowest factor loadings across both vignettes and, with hindsight, was deemed a potentially confusing item as maternal age is associated with increased risk for Down's Syndrome, which is in turn the most common genetic cause of severe intellectual disability, but not mild intellectual disability as in the vignette. Hence disagreement with this item could arise from a sophisticated understanding of intellectual disability, or conversely from a rejection of biomedical causes.

The first factor *Adversity* accounted for 24.8% of the variance for the intellectual disability but only 6.7% for the schizophrenia vignette. It contained five causal items, see Table 4 and Appendix 4. The second factor *Biomedical* contained five causal items and accounted for 17.1% of the variance for the intellectual disability and 13.1% for the schizophrenia vignette. The third factor *Supernatural* contained five causal items and accounted for 8.0% of the variance for the intellectual disability and 8.5% for the schizophrenia vignette. The final factor *Environment* contained seven causal items and accounted for only 5.5% of the

variance for the intellectual disability but 28.2% for the schizophrenia vignette. Table 4 presents factor loadings for the final 22 items for both intellectual disability (ID) and schizophrenia (Schiz.)

Table 4. *Rotated factor matrix for the final 22 causal items*

Item	Adversity ID / Schiz.	Biomedical ID / Schiz.	Supernatural ID / Schiz.	Environment ID / Schiz.
1. overly spoiled as a child				.75 / .71
2. virus/ other infection that affects the brain		.71 / .70		
3. lack of daytime occupation				.67 / .64
4. possession by spirits			.70 / .76	
5. family arguments	.74 / -.74			
6. financial worries	.68 / -.65			
7. punishment for own past wrongdoings			.72 / .73	
8. strong religious or spiritual beliefs			.71 / .66	
9. genetic factors		.72 / .73		
10. suffering abuse as a child	.73 / -.68			
11. recent traumatic incident	.71 / -.79			
12. punishment for parents' wrongdoings			.66 / .77	
13. very poor schooling				.55 / .71
14. complications at time of birth		.79 / .77		
15. being from from a single-parent family				.61 / .66
16. parents too lenient				.85 / .82
17. lack of an intimate relationship				.62 / .67
18. brain abnormality		.84 / .77		
19. a test from God/Allah			.72 / .76	
20. recent death of relative or close friend	.75 / -.81			
21. meningitis		.79 / .71		
22. isolation from extended family				.48 / .67

Note. Eigenvalues for Intellectual Disability vignette: Adversity 5.45, Biomedical 3.76, Fate 1.75, Environment 1.2; for Schizophrenia vignette: Environment 6.21, Biomedical 2.89, Fate 1.87, Adversity 1.47.

3.3.4 Correlations between causal subscales

Correlations between the four causes factors are shown in Table 5 for both intellectual disability and schizophrenia. The four factors inter-correlated in the -.12 to .48 range, indicating that they tapped into related yet distinct types of causal beliefs. The upper part of the matrix provides correlations for schizophrenia, the lower part for intellectual disability.

Table 5. *Correlations between causal subscales for both conditions*

		Schizophrenia			
		Adversity	Biomedical	Supernatural	Environment
	Adversity	–	.33**	.37**	.51**
Intellectual Disability	Biomedical	.30**	–	.22**	.12**
	Supernatural	.40**	.15**	–	.44**
	Environment	.48**	-.12**	.41**	–

** Spearman's rho significant at $p < .01$ (2-tailed), Bonferroni corrected

3.3.5 Beliefs about interventions

The 30 items used in the main study were examined for their psychometric properties and fit with the scale's factor structure. None of the items were highly correlated, i.e. $r > .9$, suggesting that the measure assessed interrelated yet distinct concepts. Two items (turn to close friends; exorcism) were removed from further analysis due to large skewness and kurtosis.

3.3.6 Factor analysis of intervention beliefs

An exploratory principal components analysis of all 30 intervention items used in the main study, together with examination of the scree plots suggested that a three-factor solution was optimal for beliefs about interventions. A second analysis forcing three factor solutions was used for development of the final scale. Again oblique rotation (Direct Oblimin) was chosen as the factors were correlated.

The KMO statistic indicated that the sample size was very good for the purposes of these analyses- all values were equal to or above .87. After rotation, six items that did not load above 0.4 for both vignettes on the same factor were not retained (learn stress management; find out about his problems from books/the internet; telephone counselling; see a homeopath/herbalist; get a tutor; take vitamins or supplements). The first factor *Lifestyle* contained 11 items and accounted for 25.3% of the variance for the intellectual disability and 33.5% for the schizophrenia vignette. The second factor *Expert Help* contained six items and accounted for 15.3% of the variance for the intellectual disability and 12.7% for the schizophrenia vignette. The third factor *Religion/ Spiritual* contained five items and accounted for 11.2% of the variance for the intellectual disability and 13.7% for the schizophrenia vignette, see Table 6.

Table 6. *Rotated factor matrix for the final 22 intervention items*

Item	Lifestyle ID / Schiz.	Expert Help ID / Schiz.	Religion/Spiritual ID / Schiz.
1. get him to take more responsibility	.69 / .78		
2. turn to close family	.43 / .61		
3. visit his GP (General Practitioner)		.54 / .60	
4. get out more	.62 / .77		
5. pray			-.85 / .87
6. see a counsellor		.70 / .63	
7. see a psychiatrist		.80 / .83	
8. see a religious person/clergy			-.84 / .89
9. get a job	.76 / .84		
10. get a good talking to from his parents	.61 / .70		
11. see a social worker		.60 / .43	
12. more physical activity	.70 / .75		
13. psychological treatment		.81 / .81	
14. get careers advice	.63 / .73		
15. attend a place of worship more often			-.90 / .92
16. see a spiritual or faith healer			-.79 / .79
17. socialise more	.72 / .83		
18. take prescribed psychiatric medication		.70 / .73	
19. make him face up to reality	.66 / .73		
20. find a girlfriend/ wife	.58 / .65		
21. go on holiday	.43 / .65		
22. be more religious			-.87 / .89

Note. Eigenvalues for Intellectual Disability vignette: Lifestyle 5.55, Expert 3.37, Religion/Spiritual 2.5; for Schizophrenia vignette: Lifestyle 7.28, Expert 2.79, Religion/Spiritual 3.0.

3.3.7 Correlations between intervention subscales

For the intellectual disability vignette the Religion/Spiritual subscale correlated with the Lifestyle subscale, $r_s=.33$, $p<.01$, and the Expert subscale, $r_s=.19$, $p<.01$. For the schizophrenia vignette only the Religion/Spiritual and the

Lifestyle subscales correlated, $r = .37$, $p < .01$. All p values reported were Bonferroni corrected. This indicates that the three factors tapped into related yet distinct belief systems.

3.3.8 Internal consistency of causal and intervention subscales

Cronbach's α for the 22 causal items of the final version was .84 for the intellectual disability and .87 for the schizophrenia vignette. The reliability of all causal items was also examined for different ethnic groups and found to be above .81 for the intellectual disability and above .86 for the schizophrenia vignette. For the 22 final intervention items the Cronbach's α values were $\alpha = .84$ for intellectual disability and $\alpha = .87$ for schizophrenia. The reliability of the 22 intervention items was above .80 for all ethnic groups for the intellectual disability and above .76 for the schizophrenia vignette. No single item deletion improved the internal reliability by more than .03. Table 7 shows the internal consistency of each subscale for the entire mixed ethnicity sample.

Table 7. *Reliability of factor solution for entire mixed ethnicity sample (N= 1368)*

Factor	ID Vignette α	Schizophrenia Vignette α
<i>Causes</i>		
Adversity (5 items)	.80	.81
Biomedical (5 items)	.84	.80
Supernatural(5 items)	.76	.79
Environment (7 items)	.79	.84
<i>Interventions</i>		
Lifestyle (11 items)	.84	.91
Expert Help (6 items)	.78	.74
Religion/Spiritual (5 items)	.90	.92

The subscales' internal consistency was also examined for the largest ethnic groups within the sample, see Tables 8 and 9.

Table 8. *Reliability of factor solution for the intellectual disability vignette by ethnic group*

Factor	White British n= 360	UK South Asian n=146	UK Black African n=100	Singaporean n=198
<i>Causes</i>				
Adversity	.83	.79	.78	.86
Biomedical	.87	.80	.76	.87
Supernatural	.70	.74	.87	.64
Environment	.82	.76	.74	.76
<i>Interventions</i>				
Lifestyle	.92	.90	.87	.90
Religion/Spiritual	.89	.92	.90	.89
Expert Help	.82	.83	.71	.77

Table 9. *Reliability of factor solution for the schizophrenia vignette by ethnic group*

Factor	White British n= 360	UK South Asian n=146	UK Black African n=100	Singaporean n=198
<i>Causes</i>				
Adversity	.83	.82	.82	.80
Biomedical	.80	.74	.72	.83
Supernatural	.72	.79	.89	.71
Environment	.85	.83	.74	.81
<i>Interventions</i>				
Lifestyle	.93	.91	.89	.91
Religion/Spiritual	.88	.90	.92	.87
Expert Help	.77	.78	.66	.72

These results indicate that the IDLS causal and intervention subscales have good internal reliability across a broad range of ethnic groups for both intellectual disability and schizophrenia.

3.3.9 Test-retest reliability for causal and intervention beliefs

Test-retest reliabilities for the causal and intervention subscales were above .6 for two and above .7 for ten of the 12 subscales. In light of the two to three week interval between administrations this suggests that the subscales are measuring relatively stable beliefs of respondents, see Table 10.

Table 10. *Test-retest reliability for causes and intervention factors: intraclass correlation coefficient (95% confidence interval)*

Subscale	Intellectual Disability <i>ICC (95% C.I.)</i>	Schizophrenia <i>ICC (95% C.I.)</i>
<i>Causes</i>		
Adversity	.72 (.61-.80)	.60 (.47-.71)
Biomedical	.74 (.65-.82)	.63 (.51-.73)
Supernatural	.64 (.52-.74)	.70 (.59-.78)
Environment	.79 (.71-.85)	.74 (.65-.82)
<i>Interventions</i>		
Lifestyle	.80 (.73-.86)	.88 (.82-.91)
Religion/Spiritual	.82 (.75-.87)	.84 (.78-.89)
Expert help	.66 (.54-.75)	.77 (.69-.84)

3.3.10 Distribution of responses

Responses to all items retained after the factor analysis were evenly distributed for at least some of the ethnic groups studied, that is the two items at either end of the scale, indicating either moderate or strong disagreement or

agreement, jointly received at least 10% affirmation for all or at least one of the samples. Thus no item was removed on this criterion.

3.3.11 Social Distance

The internal consistency of the four social distance items for the entire sample was very good for both the intellectual disability, $\alpha=.87$, and the schizophrenia vignette, $\alpha=.89$. Inter-item correlations are presented in Table 11.

Table 11. *Inter-item correlations for social distance items*

	Schizophrenia			
Intellectual Disability	Happy to move next door to someone like X	Happy to spend evening with someone like X	Happy to make friends with someone like X	Happy for someone like X to marry into my family
Happy to move next door to someone like X		.72*	.68*	.56*
Happy to spend evening with someone like X	.62*		.84*	.59*
Happy to make friends with someone like X	.58*	.80*		.62*
Happy for someone like X to marry into my family	.53*	.54*	.57*	

***r* significant at $p<.01$ (2-tailed).

The reliability of these items was also examined for different ethnic groups and found to be above .83 for all.

3.3.12 Test-retest reliability for social distance items

Test-retest reliabilities for the social distance items were above .7 for all individual items, for both conditions. For the scale's mean score test-retest reliability was .81 (95% C.I.=.73-.86) for intellectual disability and .80 (95% C.I.=.72-.86), indicating the items and scale measure relatively stable attitudes.

3.3.13 Concurrent validity

In the absence of any other measure designed to assess beliefs about intellectual disability only the concurrent validity of the social distance part of the

IDLS was assessed by comparing responses to the CLAS-ID. All correlations were in the direction predicted, though of a moderate size. Social distance scores in response to the intellectual disability vignette were positively correlated with CLAS-ID scores for *Exclusion* (broadly indicating anti-inclusion attitudes) and negatively with *Empowerment* and *Similarity* scores (broadly indicating positive, pro-inclusion attitudes), see Table 12. The correlation between Sheltering and social distance did not reach significance once the Bonferroni correction had been applied. This indicates that the attitude component of the IDLS has acceptable concurrent validity.

Table 12. *Correlations between IDLS social distance scores and CLAS-ID subscale scores*

	CLAS-ID Subscale			Social Distance
	Exclusion	Sheltering	Similarity	
Empowerment	-.40*	-.40*	.55*	-.27*
Exclusion	1.00	.22*	-.51*	.24*
Sheltering	.22*	1.00	-.33*	.10
Similarity	-.51*	-.33*	1.00	-.23*

* Spearman's rho significant at $p < .05$ (2-tailed), Bonferroni corrected

Correlations between the CLAS-ID subscales were in the same direction as in previous studies (Henry et al., 1996a; Horner-Johnson et al., 2002; Scior et al., 2010).

3.4 Discussion

The aim of this study was to develop a new tool to assess respondents' intellectual disability literacy and to examine its psychometric properties in the context of cross-cultural research. The results demonstrate that the IDLS has good psychometric properties when used with adult lay persons. The measure has an easily interpretable factor structure and all subscales have good to excellent internal

consistency. Test-retest reliability for all aspects of the scale is good. The measure is also suitable for research aiming to compare intellectual disability and mental health literacy as the measure has good psychometric properties both in the context of presentation of symptoms of mild intellectual disability and of schizophrenia.

With regard to beliefs, the four underlying causal factors depict different dimensions of beliefs about the potential origins of symptoms of intellectual disability and schizophrenia and are similar to those identified in previous studies in the area of mental health, namely including psychosocial, environmental, biomedical and religious/ spiritual dimensions (Angermeyer & Matschinger, 2003; Furnham & Chan, 2004). The causal factors *Adversity* and *Environment* explained very different amounts of the variance for intellectual disability and schizophrenia, suggesting that lay people hold rather different beliefs about the causes of typical symptoms of the two conditions depicted in an unlabelled vignette. The factors regarding beliefs about suitable sources of help refer to expert help, lifestyle and religious/spiritual interventions and thus serve as useful indicators of the types of help a respondent may deem appropriate for the respective symptomatology. Research in the area of mental health indicates that the public in Western countries prefer self-help, particularly support from family and friends and engaging in a range of activities (Jorm, 2000). Interestingly, in the current study many respondents were undecided or showed only very weak agreement with the notion that turning to close family would be helpful for either condition and this item was omitted from the final version of the measure due to its low correlation with other lifestyle and social help items.

Schomerus, Matschinger and Angermeyer (2006) discussed the differences and potential merits of the type of rating method used in the IDLS compared to an approach whereby respondents have to rank potential causes or interventions. They noted that the latter method more easily identifies respondents' preferred causal

beliefs and can thus be especially useful when seeking to identify beliefs to target in anti-stigma campaigns. In contrast, I would argue that the rating method used in the IDLS is more suitable to cross-cultural research and potential clinical use of the measure, as it highlights a range of beliefs that may co-exist and can thus facilitate a greater mutual understanding between different cultural perspectives. On this note, the initial findings presented here on the associations between different causal and intervention beliefs raise some interesting questions. For both the intellectual disability and schizophrenia vignettes, a belief in environmental causes was correlated with a belief in adversity and supernatural causes, suggesting that these are compatible in lay people's minds. In contrast, for intellectual disability a belief in biomedical causes showed only a weak association with endorsement of supernatural causes and was negatively correlated with endorsement of environmental causes. Regarding interventions, for both vignettes a belief in lifestyle interventions was positively correlated with religious/spiritual interventions, but for schizophrenia both seemed incompatible with a belief in expert help. In contrast, there was a weak association between religious/spiritual and expert help for intellectual disability. These issues may have important implications for help seeking and treatment adherence and should be the subject of further research.

The social distance items showed good concurrent validity with the CLAS-ID (Henry et al., 1996a), indicating that these brief items tap into attitudes toward the inclusion of individuals with intellectual disability in society. Stigma and discrimination continue to be important concerns for people with intellectual disabilities and individuals who experience mental illness (Mencap, 2007; Ali et al., 2008; Angermeyer, Beck, Dietrich & Holzinger, 2004). As noted earlier, research with families that have a family member with intellectual disabilities has suggested increased stigma in some cultural communities that may arise from potentially

stigmatising lay beliefs about the causes of intellectual disability (Hatton et al., 2003; Hughes, 1984; Hubert, 2006). However, these suggestions have not been tested at general population level. The IDLS allows us to examine stigma and its correlates amongst the public and is suited for cross-cultural purposes.

One of the key aims was to develop an instrument with good cross-cultural validity. For this reason items were included that refer to beliefs that are uncommon amongst white Westerners, but have been identified in studies with black and minority ethnic community members, such as a belief that disability may be a form of retribution for past sins (Hubert, 2006), or sign of spirit possession (Denham, Adongo, Freyberg & Hodgson, 2010). The measure's psychometric properties were examined for heterogeneous ethnic samples, both in a UK and East Asian context. The results indicate that the measure is well suited to examining knowledge, beliefs and social distance regarding intellectual disability and schizophrenia in a range of cultural contexts.

3.4.1 Limitations

This study has several limitations that should be noted. The data presented are derived from convenience samples from a selected number of ethnic groups. Younger, more highly educated individuals and those with internet access were over-represented in this study and the generalisability of the results is therefore questionable. The IDLS will need further validation if it is to be used in cultural contexts that differ substantially from this study or with professional and human services personnel. In some cultural contexts it is possible that validity may be increased, for example, by using culturally matched names in the vignettes. This was attempted in the pilot, but proved too unwieldy in a large, mainly internet based recruitment drive. Furthermore responses to some of the social distance items may be affected by cultural rules, for example, regarding the undesirability of social

contact between unrelated males and females, rather than necessarily being a genuine indicator of stigma.

A further limitation of the instrument concerns the use of vignettes and avoidance of labels, which was essential to allow the assessment of recognition in different groups and across conditions. As a result, respondents' agreement with causal, intervention and social distance items reflects their perception of the primary difficulty, rather than their beliefs about the diagnostic categories of intellectual disability or schizophrenia. Future research should compare responses to labelled and unlabelled vignettes to examine to what extent the responses of those who correctly identify the respective condition differ from those who interpret the depicted behaviour otherwise. Nevertheless, I would argue that in gauging public attitudes and beliefs the use of unlabelled vignettes as the primary stimulus can render useful information. In real life lay people generally form spontaneous attitudes and beliefs about others in response to observable and reported behaviour, often without access to any diagnostic labels. Nevertheless future research should examine differences in response to labelled and unlabelled vignettes.

Concurrent validity, as noted, was assessed using the CLAS-ID. It might have been more appropriate to assess this with reference to the social distance subscale of the Mental Retardation Attitude Inventory (Antonak & Harth, 1994). However, as noted in section 3.1.2 above, I had concerns about the suitability of this measure for a general adult audience. Furthermore these seem to have been borne out by Ouellette-Kuntz et al. (2010) who questioned the subscale's validity after finding very low levels of intellectual disability stigma in a Canadian general population sample.

A broader limitation concerns the question to what extent explicit measures reflect respondents' genuine attitudes and beliefs and, more importantly, how good or poor an indicator they are of actual behaviour. These issues are considered in

more depth in section 8.3 of this thesis. Notwithstanding concerns about the ecological validity of the findings, Ali et al. (2008) note that it is the perception of stigma and the associated shame on the part of stigmatised individuals and groups, rather than only discriminatory acts that influence lifestyle and well-being.

Finally, some wider issues regarding the assessment of intellectual disability or mental health literacy merit consideration. Firstly, recognition questions in response to symptoms in a case vignette could be seen to make etic assumptions, that is analysis of cultural phenomena from the perspective of an outsider, about the universality of intellectual disability and mental health problems. In some cultures, for example, there is no clearly delineated concept of 'intellectual disability', which one might argue makes such assumptions problematic (Jenkins, 1998). Secondly, different cultures may focus on different symptoms in forming beliefs about intellectual disability or schizophrenia (Pote & Orrell, 2002). Finally, where researchers aim to examine intellectual disability or mental health literacy in contexts where literacy levels in general are low, great caution is called for (Mubbashar & Farroq, 2001).

3.4.2 Future use of the IDLS

The IDLS is of potential use in a number of research and clinical contexts. It can allow us to examine the association between recognition, causal beliefs, beliefs about suitable sources of help, social distance and socio-demographics in a range of cultural contexts. Thus it can assist in the development of evidence based public education efforts aimed at promoting the greater social inclusion of people with intellectual disabilities. With regards to research in a broad range of cultural settings, the IDLS can highlight in which communities and population subgroups the stigma associated with intellectual disability may be particularly high. In such instances, targeted awareness campaigns may seem indicated that are sensitive to cultural

beliefs yet balance these with an emphasis on the well-being and need for community support of individuals with intellectual disabilities and their families.

In a clinical context a version of the measure adapted for the specific purpose could help alert clinicians to potential mismatches between beliefs underpinning policy and service delivery and beliefs held by service users regarding causes and interventions. In this way it may increase clinicians' sensitivity to a range of beliefs held by service users and promote open dialogue. This in turn could tackle barriers to service uptake and engagement.

**Chapter 4: Social distance, recognition of intellectual
disability and attitudes to inclusion among
different ethnic groups**

Abstract

Background: Attitudes to the inclusion of people with intellectual disabilities have been studied extensively, yet evidence on public knowledge of intellectual disability and stigma is limited. The relationship between attitudes, knowledge and stigma associated with intellectual disability is poorly understood. The present study examined these factors and the relationships between them in the context of a multi-cultural society.

Method: UK residents of working age (N=1002) were presented with a diagnostically unlabelled vignette of someone with a mild intellectual disability. They were asked to label the difficulties presented and to complete measures of social distance and attitudes to the inclusion of people with intellectual disabilities.

Results: While attitudes to the inclusion of people with intellectual disabilities were relatively positive overall, empowerment and social contact were viewed with ambivalence. Inclusion attitudes and social distance were only moderately correlated. Across the whole sample 27.8% recognised symptoms of mild intellectual disability as such. Recognition was associated with lower social distance and more positive attitudes than attribution of the difficulties presented to other causes. White Westerners were more likely to recognise intellectual disability, showed less social distance and favoured inclusion more than participants from ethnic minorities. Asians showed lower social distance and attitudes more in line with inclusion policies than participants from black African/Caribbean communities. Lay people who knew someone with intellectual disabilities consistently showed more positive attitudes.

Conclusions: Stigma associated with intellectual disability appears to be increased among the public from ethnic minorities. Given that contact and recognition were found to be associated with reduced social distance, they should be considered as

prime foci for efforts to tackle intellectual disability stigma. The current findings serve as baseline for attempts to increase public awareness and tackle stigma.

Social distance, recognition of intellectual disability and attitudes to inclusion among different ethnic groups

This chapter presents findings on lay people's knowledge of intellectual disability, assessed through their ability to recognise symptoms of intellectual disability presented in a diagnostically unlabelled vignette. The relationship between recognition, social distance and attitudes to the community inclusion of people with intellectual disabilities is examined. Parts of the IDLS and the CLAS-ID presented in the previous chapter are used for this purpose. Differences between ethnic groups in recognition, social distance and inclusion attitudes are examined. Given that inclusion attitudes were only assessed in relation to people with intellectual disabilities, this chapter only considers this population, unlike subsequent chapters that compare lay responses to intellectual disability and schizophrenia.

4.1 Introduction

Whether large scale deinstitutionalisation in the US and many European countries over the last few decades has indeed resulted in increased community inclusion, or perhaps only physical inclusion, but little actual *social* inclusion is a matter for debate (Cummins & Lau, 2003). Undoubtedly though, the attitudes and behaviour among the wider community affect the extent to which people with disabilities are isolated or integrated into networks and communities (Shakespeare, 2006). While many studies, detailed in chapter 2, have examined attitudes among different sections of the population, a theoretical model of public stigma and behaviour is poorly developed in intellectual disability research (Werner et al., 2012). This stands in marked contrast to the mental health field, where a rich body of research has been informed by multi-faceted conceptualisations of stigma (Corrigan, Markowitz & Watson, 2004; Jorm & Oh, 2009; Link & Phelan, 2001; Thornicroft, 2006).

In ancient Greek, a stigma referred to a mark that was branded on to the body of slaves or criminals to mark them out as undesirable. The concept was developed by Goffman (1963) who defined stigma as “the process by which the reaction of others spoils normal identity”. In current conceptualisations, stigmatisation occurs when 1) individual attributes are labelled; 2) evaluated negatively; and 3) labelled individuals experience status loss and discrimination (Link & Phelan, 2001). The current study focused on social distance as a measure of individual stigma, to denote a person’s willingness to form relationships of varying degrees of intimacy with someone with a stigmatised identity (Lauber, Nordt, Falcato & Rössler, 2004), and to ultimately gauge how far stigmatised individuals will be able, or indeed allowed, to participate in society (Jorm & Oh, 2009).

Several studies have examined self-stigma in people with intellectual disabilities (Ali et al., 2008; Finlay & Lyons, 2000; Jahoda & Markova, 2004; Kock et al., 2012). Their focus has been on understanding how those subject to being stigmatised manage this themselves, and not on how the agents, in this case members of the public, do the stigmatising. One recent exception examined social distance in a Canadian general population sample (Ouellette-Kuntz et al., 2010) and concluded that social distance was surprisingly low, yet questioned the reliability of their results.

To date the relationship between inclusion attitudes and stigma in relation to intellectual disability has not been examined, but would seem an important area for enquiry. One might expect them to be closely related. However, if we were to find, for example, that the general public are broadly in support of community living for people with intellectual disabilities, but are less keen to have social contact themselves, this would certainly give rise to concerns that inclusion is likely to remain physical integration alone, with limited prospects for genuine *social* inclusion.

Our understanding of stigma and general population attitudes to intellectual disability is even more limited in the context of culturally and religiously diverse populations, although there are several reasons why such an understanding is important. Perceptions and beliefs about (intellectual) disability can vary greatly between different cultures (Gabel, 2004; Hatton et al., 2010; Ingstad & Whyte, 1995; Katbamna et al., 2000), but to date our understanding of this area is still rather limited. Furthermore, it has been suggested that low awareness and stigmatising beliefs associated with intellectual disability are increased among black and minority ethnic (BME) communities, based on research with family members of persons with intellectual disabilities (Fatimilehin & Nadirshaw, 1996; Hatton et al., 2003; Croot, Grant, Cooper & Mathers, 2008). If this is borne out at general population level, the implications for the well-being and life chances of individuals with intellectual disabilities from BME backgrounds are negative. Moreover, increased stigma may well contribute to the low uptake of some services by BME people with intellectual disabilities and their families (Mir et al., 2001), but has found little attention in this context. In contrast, as noted in chapter 1, other potential barriers to service uptake, particularly language issues, a lack of awareness and mistrust of services, have been given more attention (Chamba, Ahmad, Hirst, Lawton & Beresford, 1998; Fatimilehin & Nadirshaw, 1994; Hatton et al., 1997).

For the reasons outlined, it seems important to further our understanding of stigma at general population level and to examine the effect of ethnicity on social distance and attitudes. It is conceivable that, due to the increased emphasis on community cohesion and collective values among Asian and African communities, family members may be more sensitive to potentially threatening attitudes within their communities, in line with the *Identity Threat Model* (Crocker, Major & Steele, 1998; Steele, Spencer & Aronson, 2002). This may leave them more sensitive to

community stigma than white Westerners, rather than necessarily reflecting increased stigma within BME communities. While this alternative explanation is unlikely in view of evidence of high levels of mental health stigma among Asian (Ng, 1997; Kramer, Kwong, Lee & Chung, 2002; Rao, Feinglass, & Corrigan, 2007) and black African cultures (Adewuja & Makanjuola, 2008; Barke, Nyarko & Klecha, 2011), it merits further investigation.

4.1.1 Study aims

The main aims of this study were (a) to examine the effect of knowledge of intellectual disability, as evidenced by the ability to recognise an unlabelled vignette as potentially depicting someone with an intellectual disability (recognition), on social distance and inclusion attitudes among the general UK population; (b) to examine the association between inclusion attitudes and social distance; (c) to examine whether recognition of intellectual disability, inclusion attitudes and social distance differ between ethnic groups; and (d) to assess the effect of recognition and socio-demographic characteristics, namely ethnicity, religion, prior contact, age, gender and educational attainments, on inclusion attitudes and social distance. It was hypothesised that inclusion attitudes would be correlated with social distance, at least for those who recognised intellectual disability, but that social distance might paint a somewhat less positive picture than inclusion attitudes because it is more a measure of behavioural intentions than general attitudes. It was also expected that age, education, prior contact and ethnicity would predict the dependent variables, while the role of gender and religion was less clear, in line with evidence of their inconclusive effects on attitudes (Scior, 2011).

4.2 Method

4.2.1 Participants

The sample was comprised of 1002 UK residents of working age who were recruited via the internet and in person in the Greater London area (see *Procedure*) between late 2009 and mid 2011. Of the participants, 29.6% were born outside of the UK; all had been resident in the UK for at least three years. The sample was purposively ethnically mixed, with the largest groups consisting of white British people (41.2), South Asians (12.6%), Asians from other backgrounds (12.0%), and Black Africans (18.7%). Particular efforts were made to recruit from these ethnic groups as South Asians and people of Black African origin are the two largest BME communities in the UK and in Greater London and are showing some of the largest percentage increases (Greater London Authority, 2011; Office for National Statistics, 2011). Despite this very little is known about lay perceptions of intellectual disability in the context of these communities, particularly for the black African and (Caribbean) community.

Participants' mean age was 27.38 years (SD 11.10); 52.5% were female, and 47.2% male. 35.2% had been educated to age 18 or less, 64.8% were either graduates or currently studying for a degree. 31.9% reported prior contact with someone with intellectual disabilities, 41.7% reported no prior contact and 26.3% of responses to this question were missing, perhaps because it was at the very end of the survey. In terms of religious affiliation, 34.5% described themselves as Christian, 16.1% as Muslim, 3.5% as Hindu, 1.8% as Jewish, the same proportion as Buddhist, 0.5% as Sikh, and 40.7% as either Agnostic or Atheist. 35% rated religion as important or very important in their life, and 45% as of little importance. 53% never or very rarely visited a place of worship, and 33% fairly or very regularly.

4.2.2 Measures

Participants were presented with a diagnostically unlabelled vignette describing a man in his 20s presenting with symptoms of mild intellectual disability (see chapter 2 for full details). Following the vignette participants were asked "*What do you think is going on with X?*", without any further prompts to assess their ability to recognise symptoms of intellectual disability and misattributions. They then indicated their agreement with four social distance items, taken from the Intellectual Disability Literacy Scale (IDLS), presented in chapter 3, using a 7-point Likert scale (1=disagree strongly to 7=agree strongly). The items reflect social contact of differing levels of intimacy, from having someone with an intellectual disability as a neighbour, acquaintance, friend and relative through marriage. The vignette and social distance items were piloted with different ethnic groups; good reliability of these items and their suitability for studying social distance in different cultural contexts was reported in chapter 3. Participants also completed the Community Living Attitudes Scale – Intellectual Disability version (CLAS-ID; Henry et al., 1996a).

The CLAS-ID assesses attitudes in line with current policy values on four subscales: Empowerment, Exclusion, Sheltering, and Similarity. *Empowerment* denotes views in support of choice and self-advocacy; *Exclusion* in support of excluding people with intellectual disabilities from society; *Sheltering* a belief that people with intellectual disabilities need help and protection; and *Similarity* a belief that persons with intellectual disabilities are similar to oneself, and have similar life goals and rights. Responses are made on a 6-point Likert scale (1=disagree strongly to 6=agree strongly). The measure has been validated in a number of studies across cultural contexts (Henry et al., 1996a; 1996b; Horner-Johnson et al., 2002; Schwartz & Armony-Sivan, 2001; Yazbeck et al., 2004; Scior et al., 2010). For the present study, two alterations were made: 1) the term '*learning disabilities*' was used instead

of the original's 'mental retardation' to reflect British terminology; 2) a paragraph was added at the beginning of the questionnaire, explaining in some detail what does and does not constitute intellectual disability, to increase the likelihood that participants would understand what they were being asked, see Appendix 1.

The CLAS-ID is available as the original 40-item version and a shorter 17-item version (Henry et al., 1996a). For this study, the short version was used, see Appendix 2 for scoring guidelines. Given that Henry et al.'s (1996a) reliability data for the short version was based on a sample of only 104 participants, it seemed important to examine the reliability of the short version with a larger data set. Data from an earlier sample of 769 respondents, collected in Greater London between 2007 and 2009 using the 40-item version, was examined to establish whether the short version is indeed a reliable and valid alternative to the long version. Descriptive data for both versions and the results of bivariate correlation analyses comparing the two versions are presented in Table 13. It was concluded that the 17-item short form is a reliable version of the CLAS-ID in showing high correlations with scores derived from the original 40-item version. Accordingly the short form was used in the study presented.

Table 13. *Descriptive data and correlations for the CLAS-ID subscales, long and short versions (N=769)*

Subscale	40-item Version M (SD)	17-item Version M (SD)	Correlation
Empowerment	4.02 (.66)	4.28 (.84)	.834*
Exclusion	1.96 (.85)	1.84 (.96)	.904*
Sheltering	3.40 (.79)	3.21 (.91)	.912*
Similarity	4.74 (.75)	5.02 (.87)	.821*

* r significant at $p < .001$ (2-tailed).

Information about participants' socio-demographic characteristics and prior contact with individuals with intellectual disabilities was collected at the end of the survey, see Appendix 1.

4.2.3 Procedure

Advertisements for the survey regarding "attitudes in the general population towards people with various types of difficulties" were placed on a number of web discussion forums targeting different ethnic groups and on social networking sites, giving a link to the survey. In addition, potential participants were approached by email and in person using social contacts of the ethnically diverse research team and asked to a) complete the survey by following the link provided and b) forward the recruitment email to others. The information sheet encouraged participants to express their "honest views, not any 'right' or 'wrong' answers". As an incentive, participants had the option of entering a prize draw upon completion of the survey. The vast majority (90.4%) completed the on-line version.

In order to assess the implications of the data collection method, social distance scores were examined. One might expect the responses to social distance items of those who completed the paper version to be potentially more affected by social desirability. However, no clear pattern was identified; among the white and black samples social distance scores were similar between those who completed the paper and e-versions, while paper respondents among the Asian sample scored lower on social distance than e-respondents. Hence differences in responses would appear to be due to genuine differences between participants rather than to data collection method, in line with Guise, Chambers, Välimäki and Makkonen (2010) who found no effect of data collection mode (web versus paper) on nurses' attitudes to mental illness.

The response rate, calculated as the proportion of respondents who completed the on-line survey after reading the information sheet, was 51.4%. Ethical approval for the study was granted by the UCL Research Ethics Committee.

4.2.4 Data Analysis

4.2.4.1 Data Screening: Exploration of the data revealed that the social distance scale met the assumptions of parametric data, but three of the four CLAS-ID subscales showed significant skewness and kurtosis. Sheltering scores were normally distributed. However, the Empowerment and Similarity subscales were negatively skewed, indicating that overall participants tended to agree with these. The Exclusion subscale was positively skewed, indicating that overall participants tended to disagree with Exclusion. These three subscales were log transformed which resolved problems with the data. Social distance and Sheltering were not transformed as comparisons between groups were only computed within each scale.

4.2.4.2 Statistical analysis: The data were analysed using SPSS version 19. To assess the influence of recognition of the vignette on social distance and inclusion attitudes, ANOVAs were computed with recognition as the independent variable. The effect of different explanations for the behaviours depicted on social distance was examined using ANOVAs and post hoc tests. To determine the association between inclusion attitudes and social distance correlation analyses were carried out. Differences in recognition, inclusion attitudes and social distance between ethnic groups were examined using chi-square tests and ANOVAs. Finally, multiple regressions were performed to examine the role of recognition and socio-demographic characteristics in predicting social distance and inclusion attitudes. Effect sizes are reported throughout as Cohen's *d*. For the Empowerment, Exclusion and Similarity subscales, all statistical analyses were performed on the log transformed data and all test results reported, including effect sizes, are based on

the transformed data. However, as the transformed means and standard deviations are difficult to interpret, the original means and standard deviations are reported.

4.3 Results

Overall participants were ambivalent about social contact with people with intellectual disabilities, with a mean score barely above the scale mid-point ($M=4.19$, $SD=1.53$). A more positive picture emerged regarding attitudes to inclusion; across the whole sample, there was agreement that people with intellectual disabilities are similar to their non-disabled peers ($M=5.09$, $SD=0.96$), and Exclusion was opposed by most participants ($M=1.88$, $SD=0.99$). Agreement with Empowerment was modest though ($M=4.27$, $SD=0.95$), and views on the need for Sheltering were undecided ($M=3.39$, $SD=0.89$).

4.3.1 Recognition of intellectual disability and social distance

Only around a quarter of participants (27.8%) recognised the description offered in the vignette as possibly representing intellectual disability. Given that the social distance items were answered in relation to the vignette, that is to whatever the respondent attributed the difficulties in the vignette, this raised the question of the impact of recognition of intellectual disability on social distance scores. Participants who failed to recognise intellectual disability attributed the difficulties presented to a host of other causes, including specific learning difficulties such as dyslexia or dyspraxia (2.4%), mental health problems (11.1% of whom 4.7% suspected depression), psychosocial stressors (3%), being overly spoilt by parents (3.6%), laziness/lack of motivation (8.5%), and a general lack of direction in life (7.6%).

A one-way ANOVA showed that type of attribution had a significant effect on social distance, $F(8,993)=10.81$, $p<.001$. Post hoc tests using Hochberg's GT2 to account for different sample sizes showed that detecting a possible underlying

intellectual disability was associated with less social distance ($M=3.62$, $SD=1.40$) than attributing the difficulties in the vignette to a mental health problem ($M=4.24$, $SD=1.68$), $p=.007$, $d=.40$; some form of personal stressor or conflict ($M=4.40$, $SD=1.42$), $p<.001$, $d=.55$; or a character defect, namely laziness/lack of motivation in the person ($M=4.95$, $SD=1.66$), $p<.001$, $d=.87$. Of note, attributing the presentation to specific learning difficulties (LD) was associated with very similar social distance as recognition of intellectual disability, $p=1.00$. Descriptive data for social distance and CLAS-ID scores for the entire sample and by recognition of the vignette are presented in Table 14.

Table 14. Means (Standard Deviations) for social distance and CLAS-ID subscales for entire sample and by recognition of intellectual disability (ID)

Subscale	Entire sample N=1002	ID recognised n=279	Specific LD n=24	ID not recognised n=699
Social Distance	4.19 (1.53)	3.62 (1.40)	3.53 (1.50)	4.44 (1.52)
CLAS-ID Subscales				
<i>Empowerment</i>	4.27 (0.95)	4.36 (0.97)	4.53 (0.71)	4.23 (0.95)
<i>Exclusion</i>	1.88 (0.99)	1.69 (0.91)	1.78 (0.87)	1.96 (1.02)
<i>Sheltering</i>	3.39 (0.89)	3.39 (0.86)	3.03 (0.74)	3.41 (0.91)
<i>Similarity</i>	5.09 (0.96)	5.29 (0.85)	5.24 (0.68)	5.01 (1.00)

4.3.2 Recognition of intellectual disability and inclusion attitudes

Responses to the CLAS-ID, which asked about views generally and could thus be viewed as independent of recognition of the preceding vignette, also showed some effects of knowledge of intellectual disability. The three groups differed on Exclusion, $F(2,995)=9.08$, $p<.001$, and Similarity scores, $F(2,995)=9.65$, $p<.001$, but not on Empowerment, $F(2,995)=2.82$, $p=.06$, or Sheltering, $F(2,995)=2.08$,

$p=.13$. Post hoc tests on Exclusion and Similarity scores using Hochberg's GT2 showed that those who recognised symptoms of intellectual disability were less likely to favour Exclusion, $p<.001$, $d=.28$, and more likely to view persons with intellectual disabilities as sharing common life goals (Similarity) than participants who failed to recognise intellectual disability, $p<.001$, $d=.30$. Of note, the differences in inclusion attitudes between those who recognised intellectual disability and those who did not were smaller than the difference between the two groups in social distance, $t(976)=7.87$, $p<.001$, $d=.56$. There were no differences in Exclusion or Similarity attitudes between those who recognised intellectual disability and those who attributed the behaviours in the vignette to specific learning difficulties. In view of the lack of any significant differences on the five dependent variables between these two groups, for subsequent analyses they were combined.

4.3.3 Association between inclusion attitudes and social distance

The second aim was to examine the association between inclusion attitudes and social distance. Across the whole sample, Spearman's rho correlations between social distance scores and three of the CLAS-ID subscales were significant if modest, namely Empowerment, $r_s=-.24$; Exclusion, $r_s=.26$; and Similarity $r_s=-.24$, all $p<.01$, Bonferroni corrected. The correlation between social distance and Sheltering scores was not significant at the 5% level once the Bonferroni correction was applied, $r_s=.07$. This suggests that participants who were more in favour of excluding people with intellectual disabilities from society also showed higher social distance, as predicted. In contrast, favouring Empowerment and Similarity were associated with reduced social distance. Social distance and Sheltering were not correlated, which supports Horner-Johnson et al.'s (2002) argument that Sheltering does not straightforwardly indicate negative attitudes, but perhaps rather a recognition that people with intellectual disabilities may well be vulnerable and in need of support,

paired with a sense that they are worthy of care and concern. In view of the effects of recognition noted above, the relationship between social distance and inclusion attitudes was examined by respondents' ability to recognise intellectual disability in the vignette. The pattern of correlations was similar to these noted for the entire sample, but correlations were higher for the recognition group, see Table 15.

Table 15. *Correlations between Social Distance and CLAS-ID scores by recognition of intellectual disability (ID)*

CLAS-ID Subscales	Social Distance	
	ID recognised n=277	ID not recognised n=699
<i>Empowerment</i>	-.28*	-.19*
<i>Exclusion</i>	.34*	.21*
<i>Sheltering</i>	.13	.03
<i>Similarity</i>	-.27*	-.20*

Spearman's rho significant at * $p < .01$, Bonferroni corrected.

4.3.4 Differences between ethnic groups

The third aim was to examine whether knowledge, inclusion attitudes and social distance differ between ethnic groups. For this purpose the sample was divided into three categories: 1) white Westerners (n=469), of whom 413 were white British, the remainder from other white, mostly European backgrounds; 2) participants from Black and minority ethnic (BME) backgrounds (n=467), 247 of whom were of Asian heritage, 208 who described themselves as black African, Caribbean or black British³, and 12 from other BME backgrounds; and 3) 'others', including participants of mixed race and Latino backgrounds (n=66). As the third category was small and very diverse, in the following the first two groups were

³ The term 'black' is used hereafter to refer to participants who described themselves as black African, Caribbean or black British.

compared. They were similar in terms of gender ratio, $\chi^2(1)=0.09$, $p=.76$; educational attainments, $\chi^2(1)=0.002$, $p=.97$; and age, $t(923)=.53$, $p=.60$. White Westerners were more likely to report prior contact with someone with an intellectual disability, $\chi^2(1)=46.04$, $p<.001$; 58% of the white sample, yet only 32% of the BME sample reported knowing someone with an intellectual disability. Finally, white participants were much less likely to rate religion as important in their lives, $t(933)=22.54$, $p<.001$, or to engage in regular worship, $t(931)=15.40$, $p<.001$.

Regarding knowledge of typical symptoms of mild intellectual disability, 38.4% of white Westerners, but only 20.5% of BME participants recognised the vignette as depicting possible intellectual disability, $\chi^2(1)=35.50$, $p<.001$. The two groups also differed markedly on social distance and on all four CLAS-ID subscales, see Table 16.

Table 16. *Social distance and CLAS-ID data for white Westerners (n=493) and participants from BME communities (n=449)*

	White M (SD)	BME M (SD)	<i>t</i>	<i>d</i>
Social Distance	3.93 (1.45)	4.41 (1.57)	-4.88*	-.32
CLAS-ID Subscales				
<i>Empowerment</i>	4.53 (0.83)	4.03 (1.02)	8.10*	.53
<i>Exclusion</i>	1.66 (0.76)	2.06 (1.12)	-5.78*	-.38
<i>Sheltering</i>	3.22 (0.77)	3.58 (0.99)	-6.25*	-.41
<i>Similarity</i>	5.43 (0.68)	4.80 (1.06)	10.94*	.72

* $p<.001$

White Westerners showed lower social distance, were more opposed to Exclusion and Sheltering, and more in favour of Empowerment and Similarity, with the biggest difference found on Similarity. To understand these differences further,

responses were examined within the BME sample by comparing participants from Asian backgrounds (n=247) to black participants (n=208). The proportions within each sample who recognised intellectual disability were very similar, $\chi^2(1)=0.4$, $p=.91$. The two groups differed though on social distance and three of the four CLAS-ID subscales, with Asians expressing less social distance and more inclusion friendly attitudes, see Table 17.

Table 17. *Social distance and CLAS-ID data for participants of Asian (n=247) and black African/ Caribbean backgrounds (n=208)*

	Asian Mean (SD)	Black Mean (SD)	<i>t</i>	<i>d</i>
Social Distance	4.28 (1.57)	4.58 (1.56)	-2.03*	-.19
CLAS-ID Subscales				
<i>Empowerment</i>	4.20 (0.96)	3.79 (1.05)	4.37***	.41
<i>Exclusion</i>	2.12 (1.14)	2.03 (1.12)	0.89	.08
<i>Sheltering</i>	3.47 (0.89)	3.73 (1.09)	-2.80**	-.26
<i>Similarity</i>	4.92 (0.94)	4.63 (1.18)	2.36*	.22

* $p<.05$, ** $p<.01$, *** $p<.001$

These differences are unlikely to be due solely to socio-demographic differences as the Asian and black samples were similar in terms of gender, $\chi^2(1)=2.33$, $p=.13$, and educational attainments, $\chi^2(1)=3.36$, $p=.08$. The black sample was older though, $t(444)=-7.12$, $p<.001$, but also more likely to report prior contact with someone with intellectual disabilities, $\chi^2(1)=13.91$, $p<.001$. Prior contact was reported by 41% of the black sample, yet only 22.2% of the Asian sample. Being younger and contact have been shown to be associated with more positive attitudes towards people with intellectual disabilities (Scior, 2011), hence these differences between the Asian and black samples might be expected to

balance each other out in terms of their effects on social distance and inclusion attitudes.

4.3.5 Predictors of social distance and inclusion attitudes

Finally, the role of recognition and socio-demographic characteristics in predicting social distance and inclusion attitudes was examined across the whole sample (N=1002) by computing multiple regressions. The following predictors were entered: recognition of the vignette; prior contact with someone with intellectual disabilities; gender; age; and educational attainment; ethnicity (white, Asian, black, each compared to all other participants); religion, consisting of: a) religious denomination (reflecting the largest groups among the sample: Christian, Muslim, Hindu, Non-religious, each compared to all other participants), b) importance of religion in the participant's life, and c) frequency of worship. The regressions were re-run only including predictors that emerged as significant when all variables were entered.

In the final model for social distance, recognition of intellectual disability, prior contact, age and ethnicity emerged as predictors, see Table 18. Social distance was higher among participants who failed to recognise the vignette as depicting possible intellectual disability, who reported no prior contact, and among younger and black participants. However, these factors predicted only 12% of the variance in social distance, indicating that external stigma is influenced by complex factors that go beyond those considered here.

Table 18. *Predictors of social distance: Results of multiple regression analyses*

	<i>B</i>	<i>SE B</i>	β
Constant	5.31	0.20	
Recognition of ID	-0.75	0.12	-.22***
Contact	-0.50	0.11	-.16***
Age	-0.01	0.01	-.08*
Ethnicity: Black	-0.53	0.14	-.14***

Note. $R^2=.12$ ($p<.001$).

Recognition: 0=no, 1=yes; Contact: 0=no prior contact, 1=prior contact; Ethnicity: 0=named group; 1=all others

* $p<.001$

Contact, education and age predicted scores on all four CLAS-ID subscales. Participants with prior contact, higher educational attainments, and of younger age were more likely to be in favour of Empowerment and to view people with intellectual disabilities as similar to themselves, and to be opposed to Exclusion and Sheltering. Female participants were more in agreement with Similarity and more opposed to Exclusion than men. Ethnicity predicted three of the four subscales. White participants were more likely to favour Empowerment and more opposed to Exclusion than participants from Asian, black and other ethnic backgrounds. White and to a lesser extent Asian participants were more likely to agree with Similarity than those from other backgrounds. Religion played only a very small role. Those who rated religion as important in their lives were more in favour of Sheltering. Religious denomination and frequency of worship did not predict responses on any of the subscales. The participant characteristics considered provided the best model for Similarity attitudes where they explained 25% of the variance. Predictors of inclusion attitudes are presented in Table 19.

Table 19. *Predictors of inclusion attitudes: Results of multiple regression analyses*

CLAS-ID Subscale	<i>B</i>	<i>SE B</i>	β
<i>Empowerment</i>			
Constant	0.17	0.01	
Contact	0.04	0.01	.13***
Education	0.05	0.01	.14***
Age	-0.003	0.00	-.24***
Ethnicity: White	-0.07	0.01	-.24***
<i>Exclusion</i>			
Constant	0.21	0.02	
Contact	-0.07	0.02	-.16***
Education	-0.05	0.02	-.12**
Age	0.002	0.00	.09*
Gender	0.08	0.01	.19***
Ethnicity: White	0.07	0.02	.17***
<i>Sheltering</i>			
Constant	2.99	0.11	
Contact	-0.18	0.07	-.10**
Education	-0.18	0.07	-.10**
Age	0.01	0.00	.15***
Religion: Importance	0.06	0.01	.22***
<i>Similarity</i>			
Constant	0.67	0.03	
Contact	0.07	0.01	.18***
Education	0.07	0.01	.16***
Age	-0.002	0.00	-.12***
Gender	-0.04	0.01	-.09**
Ethnicity: White	-0.16	0.02	-.39***
Ethnicity: Asian	-0.04	0.02	-.09*

Note. Empowerment $R^2=.17$ ($p<.001$); Exclusion $R^2=.13$ ($p<.001$); Sheltering $R^2=.11$ ($p<.001$); Similarity $R^2=.25$ ($p<.001$).

Contact: 0=no prior contact, 1=prior contact; Education: 0=to age 18 or less; 1=graduate; Gender: 0=female, 1=male; Ethnicity: 0=named group; 1=all others

* $p<.05$, ** $p<.01$, *** $p<.001$

4.4 Discussion

This study examined attitudes to the inclusion of people with intellectual disabilities and social distance in an ethnically and religiously diverse UK general population sample. When presented with a vignette of someone with typical symptoms of mild intellectual disability, just over a quarter of participants across the entire sample identified possible intellectual disability. Marked differences in the rate

of recognition were evident between lay people from white and BME backgrounds; the former were almost twice as likely to identify intellectual disability. This finding raises concerns about low levels of intellectual disability literacy and associated stigma in the general population, particularly among members of BME communities. Moreover, given that the present sample was highly educated and relatively young, it is likely that knowledge about intellectual disability is lower among the general population than is suggested by the present findings.

One factor that may go some way towards explaining low awareness of intellectual disability among members of BME communities is the much lower proportion who reported prior contact with someone with intellectual disabilities among the BME sample (32% overall), compared to the white sample (58%), despite their similar demographic make-up. The fact that even when ethnic groups are similar in terms of key demographic characteristics, rates of prior contact differ markedly suggests that the lower likelihood of contact with individuals with intellectual disabilities among lay people from BME communities cannot be explained simply as a product of demographic factors. The similar proportion of highly educated participants among the three main groups, yet the much lower rates of contact among the black and particularly the Asian sample suggest genuine differences in opportunities for direct social interaction or perhaps differences in the likelihood of intellectual disability being kept hidden from others where there are no clear outward markers. On the other hand, the finding that black participants were almost twice as likely as Asian participants to report knowing someone with intellectual disabilities (41% versus 22%), yet showed greater social distance, suggests that contact alone may not have the desired effect. The finding that both recognition and contact predicted social distance suggests that to tackle stigma associated with intellectual disability among BME communities, education about the

condition and increased opportunities for contact and social interaction should be prime targets and go hand in hand.

The majority of respondents misattributed the symptoms presented to a host of other causes, most notably mental health problems, laziness/lack of motivation, and difficulties in assuming adult status. Admittedly the behaviours depicted in the vignette were fairly 'subtle' and many participants attributed the young man's difficulties, or rather his parents' frustrated attempts to support him in taking on an adult role, as signs of 'typical' adolescent struggles. One might have hoped though that several indicators, including the statements that he struggled at school and left without any qualifications, and his struggling to follow instructions, would raise lay people's 'suspicion' that there might be an undetected underlying difficulty. Instead, many attributed the presentation to causes that were either blaming of the parents (e.g. describing them as 'overindulgent') or of the person (described as 'lazy' or unmotivated). Of note, believing the difficulties to be due primarily to the person's character flaws was associated with increased social distance, which is in line with research in the mental health field (Jorm & Oh, 2009).

The widespread tendency to misattribute symptoms of (mild) intellectual disability to other causes suggests that in the absence of a label denoting intellectual disability, and physical features indicative of a significant disability, there is a risk that the public misattribute a person's difficulties to more stigmatising causes. While labelling is strongly opposed by the disability rights movement and unquestionably can have many negative consequences, in some instances the ascription of a label denoting intellectual disability may reduce the risk of stigma and blame laid on the person or their parents by the wider community. An alternative explanation for the present findings could be that there are fundamental attitudinal differences between lay people who have greater knowledge of intellectual disability, evidenced in their

ability to recognise the condition themselves and thus supply a label, and those lacking such knowledge. The notion that it is not just differences in knowledge, but the effects of explicitly providing a label that counter stigmatising beliefs is supported by a recent study by Connolly, Williams and Scior (accepted for publication). In their study provision of a diagnostic label suppressed social distance further than merely recognising intellectual disability in an unlabelled vignette, presumably because the explicit label ruled out possible simultaneous, more stigmatising explanations that respondents may have entertained.

An alternative explanation for the greater tendency by participants from BME backgrounds to attribute the behaviours in the vignette to causes other than intellectual disability is that the description offered may have been less readily accessible to them. It has been suggested, for example, that people of Sub-Saharan African backgrounds tend to construct symptoms of mental disorders in somatic terms (Mulatu, 1999). Hence it is conceivable that the presentation of mild cognitive and adaptive impairments, while in line with widely accepted (Western) criteria for intellectual disability, was not construed as depicting any form of mental disorder or disability by some BME participants in the absence of physical symptoms. The fact that all participants had resided in the UK for at least three years and had good English language skills may render this explanation unlikely. It merits further investigation nevertheless and has implications for timely diagnosis of undetected intellectual disabilities, in the absence of associated physical markers.

A relationship was established between social distance and inclusion attitudes, albeit a modest one, with correlations for the entire sample around .25. One might have expected a stronger relationship between social distance and a wish for Exclusion in particular, as both are concerned with keeping people with intellectual disabilities separate from oneself or society at large. Instead participants

overall showed largely ambiguous attitudes to social contact with someone like the young man depicted, but expressed strong opposition to the exclusion of people with intellectual disabilities in society. This apparent incongruence may be due to methodological issues and the types of questions contained within the social distance scale and the CLAS-ID. Alternatively social distance items, due to an arguably increased personal salience, perhaps give a more realistic picture of public responses than direct attitude measures such as the CLAS-ID. This notion is supported by Coles and Scior (2012), who found that young people in the UK initially presented themselves as very accepting and empowering of people with intellectual disabilities both on the CLAS-ID and in interviews and focus group discussions. They expressed more disempowering and at times openly hostile attitudes though once discussion moved onto topics that might have a direct impact on participants, such as use of shared sports facilities or the right to work. As long as lay people are reluctant about, or positively opposed to, interacting with individuals with intellectual disabilities in social or work environments or to support their fundamental rights, for example, to employment, discrimination may continue to be a more likely outcome than genuine social inclusion.

Both social distance and all CLAS-ID subscales were associated with contact, age and ethnicity; educational attainment predicted inclusion attitudes but not social distance. As in most previous studies, lay people who were younger, more educated and reported prior contact held more favourable attitudes (e.g. Akrami et al., 2006; Burge et al., 2007; Esterle et al., 2008; Antonak et al., 1995; Choi & Lam, 2001; Yazbeck et al., 2004). While the evidence on the role of gender is inconsistent (Scior, 2011), in the current study women expressed more inclusion-friendly attitudes on two of the four CLAS-ID subscales.

One of the questions examined concerned the effect of ethnicity and religion on inclusion attitudes and social distance. In straightforward comparisons between the two samples, increased social distance and more opposition to inclusion were apparent among the BME sample. Once ethnicity was considered alongside other socio-demographic characteristics and awareness about intellectual disability in linear regressions, it emerged as the strongest predictor of Similarity attitudes and also predicted Empowerment and Exclusion attitudes, but did not independently predict social distance. This provides evidence that concerns by family members of people with intellectual disabilities about increased stigma among BME communities in the UK (Hatton et al., 2003; Croot et al., 2008) appear to have a basis in reality. Raised levels of stigma among lay people from ethnic minority communities may be partly linked to their reduced likelihood to know individuals with intellectual disabilities personally and their lower awareness of the condition. Future research should investigate whether interventions that include contact, raise awareness, and are sensitive to beliefs and practices that may be common among BME communities, can be effective in reducing stigma and improving attitudes to the inclusion of people with intellectual disabilities.

Regarding differences between the Asian and black samples in the current study, the effects of contact merit further consideration. As noted, black participants were far more likely than Asians to have had prior contact with individuals with intellectual disabilities. Given that contact predicted lower social distance and more inclusion-friendly attitudes, this raises the possibility that the current results present an overly positive picture and that stigma and inclusion attitudes are a major concern among the black community in the UK.

The role of religion in predicting stigma and attitudes associated with intellectual disability has found little attention in previous research. In the current

study, neither religious denomination nor regularity of religious practices were associated with social distance or inclusion attitudes. The importance of religion in the respondent's life predicted views on Sheltering. This may be due to a belief among very religious people, regardless of the teachings of any specific religion, that one has a duty to guide, care for and protect more vulnerable members of society. While the role of religion was much smaller in predicting attitudes than ethnicity, the findings suggest that future research should pay attention to the interplay of culture and religion and the complexities of religious beliefs and practices as relevant to our understanding of stigma processes.

4.4.1 Limitations

Several limitations need to be considered. Due to resource limitations the study used a convenience sample and hence caution needs to be exercised in generalising the findings. As noted, participants were highly educated overall. In view of consistent evidence that higher educational attainments are associated with more positive attitudes, it is likely that the findings are not representative of the general UK population and paint an overly positive picture of general population attitudes among different ethnic groups in the UK.

Another limitation concerns the measures used. Explicit attitude measures, such as the CLAS-ID, rely on self-report and can be affected by response biases, such as social desirability or simple faking of more positive attitudes. Social desirability was not assessed in the present study given that several studies found no effect of social desirability on attitudes to people with intellectual disabilities, as noted in the literature review, and the need to balance comprehensiveness with brevity in the design of the survey.

A further important limitation concerns the question what, if anything, the findings presented on attitudes and social distance tell us about lay people's actual

behaviour in the real world. The link between attitudes and actual behaviour has been described as "tenuous at best" (Glasman & Albarracin, 2006). According to the theory of reasoned action (Fishbein & Ajzen, 1975), the ability of attitudes to predict behaviour is affected by the correspondence between measures of attitude and behaviour in terms of the action under investigation, its target, context and time component. It could be argued that measures such as the CLAS-ID therefore are likely to be weak predictors of actual behaviour, given that attitudes are assessed in relation to a very heterogeneous group, i.e. the target is only very loosely defined. In contrast, the social distance items used in this study had a much more closely defined target. Hence they are likely to be better predictors of behaviour towards a young man like the one in the vignette, but are likely to tell us little about likely social interactions with a range of people with intellectual disabilities and in a range of contexts.

Furthermore even for the social distance items the time frame for behavioural intent was not assessed, i.e. respondents were not asked how likely they were to engage in social contact during a given period, which research suggests would increase the ability to predict behaviour (Davidson & Jaccard, 1979). Future research in the intellectual disability field should include measures of implicit attitudes (Greenwald et al., 1998), as they are better at predicting spontaneous behaviour (Davidio, Kawakami, Johnson, Johnson & Howard, 1997), which is arguably of more relevance to the day-to-day experience of people with intellectual disabilities.

While a positive aspect of the CLAS-ID is that it maps closely on to policy aims, several participants in the present study expressed frustration that the measure refers to people with intellectual disabilities as a homogenous groups. They felt that their responses would greatly depend on the person's capabilities. Trying to increase the validity of responses by specifying the severity of someone's disability

may not be appropriate for studies targeting the general population, in view of evidence of low public awareness of intellectual disability. Painting a more detailed picture of the person referred to though, for example, through the use of filmed vignettes may hold more promise.

Another important limitation of the current study is that the responses of people from markedly different cultural backgrounds were studied under the very broad label of 'black and minority ethnic', similar to the approach taken in mental health research (Corrigan & Watson, 2007). While participants from Asian and black backgrounds were distinguished, it is recognised that these broad categories still do little justice to very heterogeneous cultures subsumed under these broad categories. Similarly while 88% of the white sample were white British, this sample contained people from different white cultural backgrounds. While very mindful of the criticisms that can be levelled at lack of attention to major differences in values and practices between different cultural communities, hopefully it will be accepted that this approach made it possible to begin to address some important questions that should be explored in greater depth in future research.

4.4.2 Conclusions

The findings indicate a need to increase awareness of intellectual disability and target stigma among lay people in the UK, particularly among BME communities. Attitudes to the inclusion of people with intellectual disabilities were also less positive among BME communities. While a lack of contact may partly explain low awareness, stigma and reluctance about social inclusion, contact in itself may not be the answer.

**Chapter 5: Awareness of intellectual disability and
schizophrenia and its relationship with social distance
across ethnic groups in the UK**

Abstract

Background: Research has examined the public's mental health literacy and stigma, but there is scant evidence on intellectual disabilities. This study investigated to what extent lay people in the UK can recognise symptoms of intellectual disability and schizophrenia depicted in a vignette, and what factors predict recognition and social distance.

Method: A survey of lay people of working age was completed in the UK (N=1752). The sample was ethnically mixed, with the largest groups consisting of white UK residents, and people from Asian and black backgrounds. Regression analyses were performed to identify predictors of recognition and social distance.

Results: Across the whole sample 28% recognised intellectual disability and 23.6% schizophrenia, with large differences in the rate of recognition between ethnic groups. Prior contact and gender predicted recognition of both vignettes. Social distance was higher for schizophrenia than for intellectual disability, but overall participants were ambivalent to mildly negative about social contact with individuals with either symptomatology. Symptom recognition was associated with reduced social distance for intellectual disability, while its impact was less clear cut for the schizophrenia vignette. A close prior relationship with someone with intellectual disability/mental health problems was associated with reduced social distance for both conditions. Social distance was also associated with age for intellectual disability, and with ethnicity for schizophrenia.

Conclusions: Low levels of awareness of both intellectual disability and schizophrenia among some ethnic groups indicate a need for targeted public education efforts and further research. Increasing awareness is more likely to be effective in reducing stigma for intellectual disability than for schizophrenia.

Awareness of intellectual disability and schizophrenia and its relationship with social distance across ethnic groups in the UK

The main focus in the previous chapter was on the relationship between social distance and inclusion attitudes towards people with intellectual disabilities. Lay people's ability to identify symptoms of intellectual disability was considered briefly in terms of its association with social distance and inclusion attitudes. Given that recognition does not invariably appear to be associated with reduced stigma it is incumbent to examine the relationship between the two in greater depth and for a range of conditions to gather evidence that can inform anti-stigma interventions. The role of awareness of typical symptoms and its effects on stigma are considered in greater depth in this chapter and in relation to both intellectual disability and schizophrenia. It is hoped the reader will accept that in the process some of the issues covered in the previous chapter are addressed again, albeit with a larger sample and in relation to schizophrenia in addition to intellectual disability.

5.1 Background

It is now widely recognised that the stigma associated with mental illness and intellectual disability has very negative effects on its targets. Not only do they have to manage the symptoms of the disorder, but also the negative attitudes and reactions of society at large, which can lead to discrimination and social exclusion (Corrigan et al., 2004; Mencap, 2007), self-stigmatisation (Link et al., 2001; Ali et al., 2008), and a reluctance to seek help (Rüsch, Angermeyer & Corrigan, 2005). Public education campaigns, such as *Time to Change* in the UK or *Beyondblue* in Australia, aim to target ignorance and dispel misconceptions about mental illness as an essential aspect of efforts to reduce stigma. The few longitudinal studies that have examined public awareness of mental illness indicate that over time this has increased (Angermeyer & Matschinger, 2005; Jorm et al., 2006; Reavley & Jorm,

2012a). While awareness of mental illness appears to be associated with a reduction in the public's desire for social distance from individuals with depression, this is not necessarily the case for schizophrenia (Angermeyer & Matschinger, 2005; Corrigan et al., 2001; Reavley & Jorm, 2012b). This would appear largely due to continuing negative perceptions of individuals with schizophrenia as dangerous and unpredictable, all too frequently reinforced by sensationalist media reports.

Similar to individuals with mental illness, people with intellectual disabilities have been marginalised throughout history and face discrimination. In contrast though to the substantial attention that has been paid to stigma and recognition of mental illness, particularly depression and schizophrenia (Jorm et al., 1997; Lauber et al., 2003; Jorm et al., 2006; Reavley & Jorm, 2012b), to date we know very little about lay people's ability to recognise intellectual disability. The large majority of individuals who meet diagnostic criteria for intellectual disability, show *mild* symptoms of intellectual disability and thus are at risk of having their symptoms unrecognised or misattributed to other causes. There is also no published evidence whether a positive relationship exists between awareness of intellectual disability and stigma. If such a relationship were established, increasing intellectual disability literacy would appear one important step in countering stigma and aiming towards more inclusion friendly attitudes among the public.

Both awareness of mental illness and social distance have been shown to vary across cultures (Dietrich et al., 2004; Griffiths et al., 2006). The public in Russia and Mongolia showed a higher desire for social distance than in Germany (Dietrich et al., 2004), as did the public in Japan compared to Australians (Griffiths et al., 2006). Mental illness is highly stigmatised in Asian cultures (Ng, 1997) and in sub-Saharan Africa (Adewuja & Makanjuola, 2008; Barke et al., 2012). Such cross-cultural variation may result from different patterns of mental health care, namely

institutional versus community care, in the countries concerned (Jorm & Oh, 2009), and extreme scarcity of mental health service resources in many parts of the world (Barke et al., 2012). Cross-cultural differences in attitudes have also been attributed to differences in causal beliefs and the perceived dangerousness of people with mental illness (Angermeyer et al., 2004; Dietrich et al., 2004), which is at least partly due to levels of media attention and reporting (Angermeyer & Matschinger, 1996). Furthermore it has also been suggested that stigmatisation is more severe in cultures with a collectivist ethos that discourage open displays of emotions in order to 'save face' and preserve the good reputation of the family (Ng, 1997; Fung & Tsang, 2010). In collectivist cultures mental illness and disability in a family member are seen to reflect poorly on the family and can influence others' perceptions about the suitability of family members for marriage or employment (Kramer, Kwong, Lee & Chung, 2002).

Stigma continues to have a detrimental effect on its targets and crosses cultural boundaries, yet most evidence on stigma originates from Western countries and has paid little attention to the role of culture. Hence there is a clear need for more attention to the role of culture (and religion) in stigmatisation. As noted, to date our knowledge of public attitudes and knowledge is largely restricted to prominent forms of mental illness, while intellectual disability has scarcely been the focus of stigma research.

5.1.1 Study aims

This study set out to examine public recognition and social distance regarding intellectual disability and schizophrenia. Three key cultural communities in the UK were compared, namely white UK residents, people of Asian and black African/Caribbean backgrounds (hereafter referred to as 'black'). The primary intention was to advance our understanding of lay awareness and social distance

regarding intellectual disability in the context of multi-cultural societies. Schizophrenia was chosen as comparison case for the reasons outlined in section 3.1.2 above.

Based on two diagnostically unlabelled vignettes, one depicting a male with (mild) intellectual disability, the other with schizophrenia, the main research questions were: 1) to what extent are lay people able to recognise symptoms of intellectual disability and schizophrenia in diagnostically unlabelled vignettes?; 2) what factors influence recognition and are these consistent across both conditions?; 3) are intellectual disability and schizophrenia literacy closely related, that is are lay people similarly likely or unlikely to recognise the two conditions?; and 4) what factors predict social distance and are these the same across both conditions? In particular, is recognition of the condition associated with reduced social distance?

In view of the not dissimilar low lifetime prevalence of both conditions one might expect similar levels of familiarity with and awareness of both conditions among the public. Hence it was predicted that recognition rates for both conditions would be similar. It was hypothesised that prior contact would predict recognition of both conditions, and that younger and more highly educated lay people would be more likely to recognise the behaviours depicted as possible symptoms of intellectual disability or schizophrenia. In line with the hypothesised effect of age, education and recognition on recognition of both vignettes, it was predicted that intellectual disability and mental health literacy would be closely related. Finally, it was predicted that knowledge of the condition, evidenced by recognition of the symptoms, would be associated with reduced social distance for intellectual disability, but not necessarily for schizophrenia.

5.2 Method

5.2.1 Participants

The sample was comprised of 1752 members of the UK general public aged 16 or over. Participants' mean age was 25.4 years (range 16 to 79 years); 55.6% were female, 40.2% male (4.2% missing). 4.7% (n=82) had been educated to age 16 or less, 67.9% (n=1190) to age 18, 23.1% (n=405) were graduates and 4.3% (n=75) declined to provide this information. Of those educated to age 18, 76% (n=904) were currently studying for a degree, hence overall the sample was highly educated. Prior contact with someone with mental health problems was reported by 46.4% (n=813), no prior contact by 49.1% (n=860), and 4.5% (n=79) of responses to this question were missing. Prior contact with someone with intellectual disabilities was reported by 32.6% (n=571), no prior contact by 41.7% (n=731), and 25.7% (n=450) of responses to this question were missing, most likely because it was at the very end of the survey.

The sample was ethnically mixed and consisted of three main groups: UK residents of white Caucasian (46.4%), Asian (26.4%), and black origin (14.6%). A further 7.5% were from other ethnic groups (including mixed race, Middle Eastern and Latino) and 5.1% declined to state their ethnic background. Of the participants, 30.4% were born outside of the UK; all had been resident in the UK for at least three years. As these ethnic groups noted are very broad it is worth noting their composition. Of the white sample 86% were white British, the remainder mostly of other white European nationalities. Of the Asian sample 47% were of South Asian heritage (South Asian here referring to India, Pakistan, Bangladesh and Sri Lanka), 20% of Chinese origin and the remainder from other Asian backgrounds. The black sample was predominantly of African origin, 80% were of African heritage, 15% of Caribbean heritage and the remainder described themselves as 'black British' or

'black other'. In exploratory analyses the largest groups within each broad ethnic group were compared on all outcome variables considered in this thesis. Thus for the Asian sample, South Asians and participants of Chinese origin were compared, and for the black sample those of African and Caribbean origin. As they did not differ on any of the outcomes considered in this and the subsequent two chapters, once differences in age, education and strength of religious belief were taken into account, the three broad categories (white, Asian, black) were used for the purpose of analysis.

In terms of religious affiliation, 30.7% described themselves as Christian, 14.4% as Muslim, 4.3% as Hindu, 1.9% as Buddhist, 1.5% as Jewish, 1.2% as Sikh, and 41% as either Agnostic or Atheist. Of the white group, 63.7% described themselves as non-religious, 28.9% as Christian, 3.2% as Jewish and 3.1% as Muslim. Of the Asian group, 34% described themselves as Muslim, 26.2% as non-religious, 16% as Hindu, 13.2% as Christian, 5.6% as Buddhist and 3.7% as Sikh. Of the Black group, 86.2% described themselves as Christian, 7.5% as non-religious, and 5.9% as Muslim. Across all ethnic groups 29.5% rated religion as important or very important in their life, and 46% as of little importance. 53.5% never or very rarely visited a place of worship, and 27.9% fairly or very regularly. Black participants were most likely to rate religion as very important in their lives, followed by Asians, while white participants on average rated religion as of little importance in their lives. Looking at differences by religious denomination, 55.2% of Muslims rated religion as very important in their lives, 36.3% of Christians, 29.6% of Jews, 23.8% of Hindus, 15.2% of Buddhists, and 14.7% of Hindus. Differences were much less pronounced in the ethnic and religious groups' regularity of worship.

5.2.2 Measures

Participants were presented with two unlabelled vignettes of a male in his 20s, as described in chapter 3. Following each vignette participants were asked “what would you say is going on with X?”. They also rated their views on social contact with someone like the person in the vignette by responding to four statements about social contact in situations of increasing intimacy (live next door, spend an evening socialising, make friends, marry into family), see Appendix 1. Participants rated their agreement with each item on a 7-point Likert scale (1=disagree strongly to 7=agree strongly). A social distance score was calculated as a mean of reversed scores on the four items, with higher scores indicating a stronger desire for social distance. The internal consistency of the social distance scale was very good for both vignettes across the entire sample, $\alpha=.88$ for intellectual disability and $\alpha=.90$ for schizophrenia and inter-item correlations were between .55 and .81 for the former and .61 and .85 for the latter. The scale’s reliability was also good for the three main ethnic groups, with Cronbach’s α at .86 or higher for all.

Participants also provided detailed socio-demographic information, including their gender, age, highest educational attainment, ethnicity, and information about their religion, namely denomination, importance of religion in their life (rated on a 9-point Likert scale, where 1=of little importance, 5=somewhat important and 9=very important) and frequency of visiting a place of religious worship (1=never, 2=at most 2x/ year, 3=3-6x/year, 4=fairly regularly, 5=at least 1x/week). They provided information about prior contact with individuals with intellectual disabilities and mental health problems, for each stating whether they knew any such person, rating the closeness of the relationship using a 10-point Likert scale, where 0=no prior contact, 1=not at all close, 5=somewhat close and 9=extremely close, and frequency of contact (using a 7-point Likert scale from 1=less than 1x/year to

7=more than 1x/week). Participants who indicated that they were service providers either in the field of intellectual disability or mental health were excluded as the study's focus was on the general public.

5.2.3 Procedure

Potential participants were invited to complete a brief survey on their views of "personal difficulties in others". Recruitment was mainly done electronically. Advertisements for the survey were placed on a number of web discussion forums and on social networking sites. In addition, potential participants were approached by email and in person using social contacts of the author and students supervised by her and asked to forward the recruitment email to others. Finally, the invitation for the survey was circulated to undergraduate and postgraduate students at the author's university. A small proportion of the sample (14.2%, n=248) completed a paper version of the survey and had the option to return this anonymously to a freepost address. The responses of two subsamples of those who completed the survey either as hard copy (n=30) or electronically (n=30) were compared. The samples were similar in terms of age, gender ratio, educational attainments and ethnicity. Their responses on all dependent variables considered in this and the next two chapters did not differ significantly, hence they were analysed altogether.

Participants were invited to enter a prize draw designed as an incentive to aid recruitment; their contact details were immediately separated from their responses to ensure anonymity. The response rate, calculated as the proportion of respondents who completed the survey after reading the information sheet, was 52.1%. Ethical approval for the study was granted by the UCL Research Ethics Committee.

5.2.4 Data Analysis

The data were analysed using SPSS version 19. Responses to the question "What would you say is going on with X?" were coded into 12 broad categories, see

Appendix 3, and rates of recognition of the respective condition were examined. Where multiple labels for the problem were suggested, the response that came closest to the correct diagnosis was counted. Where the correct diagnosis was not suggested, the first suggested cause was coded. For ease of interpretation the same categories were used for both vignettes. In order to examine the ability of ethnicity, religion, gender, age, educational attainment and previous contact to predict recognition, logistic regressions were carried out. The relationship between participants' likelihood to recognise the symptoms depicted in both vignettes was examined using the phi coefficient, as measure of the degree of association between two binary variables. Exploration of the data showed that social distance scores met the assumptions of parametric data. A paired samples *t* test was used to compare social distance between the two vignettes. The effect of explanation given for the behaviours depicted in the vignette on social distance was examined using one way ANOVAs and post hoc analyses. Multiple regression analyses were performed to examine the ability of recognition, contact and socio-demographics to predict social distance. Throughout effect sizes are reported as Cohen's *d*.

5.3 Results

5.3.1 Awareness of symptoms of intellectual disability and schizophrenia

In response to the question "What do you think is going on with X?", 28% of participants recognised the intellectual disability vignette as such, see Table 20. The large 'other' category mainly included responses that reiterated behaviours noted in the vignette (e.g. "he can't budget"), noted problems with self-confidence and low self-esteem, or could not be coded readily under any meaningful category, e.g. "he has not become independent from his parents" or "he is drifting".

Table 20. *Explanation given for symptoms depicted in the vignettes (N=1752)*

Explanation Advanced	Intellectual Disability vignette %	Schizophrenia vignette %
Intellectual disability	28.0	0.1
Other developmental disorder (e.g. dyslexia, autism)	3.7	1.0
Schizophrenia/psychosis	0.1	23.6
Depression	4.9	12.2
General reference to mental illness or to other psychiatric diagnosis	5.2	31.8
Brain abnormality	0.1	0.8
Personal stressors	2.5	4.4
Problems related to adolescence	8.6	0.5
Lazy/lack of motivation	8.0	0.5
Spiritual basis	0.2	1.4
Other	34.2	9.1
Don't know	1.5	3.1
Missing	3.0	11.5

In response to the schizophrenia vignette, 67.6% of participants across the entire sample made reference to some form of mental health problem, including 23.6% who identified possible schizophrenia or psychosis. Of note, 7.9% of black participants, despite having been resident in the UK for a substantial period, attributed the schizophrenia presentation to some form of possession or spiritual problem, as did 1.4% of Asians. The admittedly small number of participants who noted such a cause ranged in age from 19 to 66 years; 24% were graduates and 44% were born in the UK; 56% were Christian, and 32% Muslim. Thus any idea one might hold that beliefs in spiritual forces as causes of mental illness are *only* held by older people, people with low educational attainments, those not brought up in Western countries or specific religious groups is not supported by the data.

To examine what factors are associated with recognition for each condition (0=attribution to other causes; 1=recognition as intellectual disability/schizophrenia), logistic regressions were run with the following predictors: prior contact: a) dichotomous (yes/no), b) closeness of the relationship, measured on the 10-point scale described above, and c) frequency of contact (reduced to a 4-point scale from the original 7 categories, whereby 0=no contact; 1=infrequent, defined as up to three times per year; 2=moderate, defined as up to monthly; and 3=frequent, defined as twice per month or more frequent); for intellectual disability contact was defined as prior contact with someone with intellectual disabilities, for schizophrenia as prior contact with someone with mental health problems; ethnicity (3 levels: white, Asian, black); religion: a) religious denomination (4 levels: Christian, Muslim, Hindu, Non-religious), b) importance of religion in the participant's life, and c) frequency of worship; gender; age; and education (2 levels: to age 16/graduates, each compared to rest of sample).

In initial analyses of the contact variables, neither the closeness of the relationship nor the frequency of contact predicted recognition of either condition; also neither age, religious denomination, the importance of religion in the participant's life nor frequency of worship predicted recognition of either condition. Hence the analyses were rerun without these variables. In the final models, gender and prior contact predicted correct identification of both conditions, see Table 21. Ethnicity was only a significant predictor for schizophrenia and education for intellectual disability, although education to age 16 only was very close to the 5% significance level, $p=.054$, for schizophrenia.

Table 21. *Effects of socio-demographic characteristics and contact on the likelihood of identifying the condition depicted: Odds ratios (and 95% confidence intervals)*

	Intellectual Disability			Schizophrenia		
	<i>B</i>	<i>SE B</i>	<i>OR</i> (95% C.I.)	<i>B</i>	<i>SE B</i>	<i>OR</i> (95% C.I.)
Constant	-1.90	0.75	NA	-2.57	0.79	NA
Ethnicity						
White	-0.40	0.25	0.67 (0.41-1.10)	-0.36	0.23	0.70 (0.44-1.10)
Asian	0.08	0.27	1.09 (0.64-1.84)	0.23	0.25	1.25 (0.77-2.05)
Black	0.35	0.30	1.41 (0.78-2.56)	0.67	0.31	1.96 (1.07-3.59)*
Gender	-0.70	0.14	0.50 (0.38-0.65)***	-0.39	0.13	0.68 (0.53-0.87)**
Education						
To age 16	0.87	0.38	2.38 (1.13-5.02)*	0.88	0.46	2.42 (0.99-5.93)
Graduate	-0.36	0.16	0.70 (0.51-0.95)*	0.01	0.17	1.01 (0.73-1.41)
Contact	0.49	0.13	1.64 (1.26-2.13)***	0.78	0.13	2.17 (1.68-2.81)***

Note. For intellectual disability $R^2=.07$ (Cox & Snell), .10 (Nagelkerke).

For schizophrenia $R^2=.08$ (Cox & Snell), .12 (Nagelkerke).

Ethnicity and Education: 0=named group; 1=all others; Gender: 0=female, 1=male; Contact: 0=no prior contact, 1=prior contact.

* $p<.05$, ** $p<.01$, *** $p<.001$

Gender and the absence or presence of prior contact, but not its frequency or the closeness of the relationship, predicted recognition of both conditions. Participants were more likely to detect that the symptoms presented in the first vignette might be due to intellectual disability if they were female, had prior contact with people with intellectual disabilities and were more highly educated. Of women, 34% correctly identified intellectual disability, yet only 22.3% of men. Of respondents who said they knew someone with intellectual disabilities, 37.1% correctly identified intellectual disability, but only 23.8% of those with no prior contact. 35.8% of graduates recognised intellectual disability, compared to only 16.3% of respondents with the lowest educational attainments.

Participants who were female, knew someone with mental health problems and were not black were more likely to identify schizophrenia. Education to age 16

was close to significant for schizophrenia, $p=.054$, indicating that people with low educational attainments were less likely to recognise both conditions. Of women, 30.9% identified schizophrenia, yet only 21.8% of men. Of respondents with prior contact with someone with mental health problems, 36.8% identified possible schizophrenia/ psychosis, but only 17.3% of those with no prior contact.

Recognition rates by ethnic group are presented in Table 22. Ethnic differences were present but less marked for intellectual disability than for schizophrenia. Of note, 34.9% of black, 30% of Asian, but only 11.3% of white participants failed to recognise any form of mental illness in the schizophrenia vignette.

Table 22. *Proportion of participants who recognised intellectual disability and schizophrenia by ethnic group*

Condition	Total N=1752	White n=813	Asian n=463	Black n=256
Intellectual Disability (%)	28.0	35.4	22.8	22.4
Schizophrenia (%)	23.6	35.4	19.9	12.5

Given that contact was the strongest predictor of recognition, brief consideration of differences in contact between the three main ethnic groups is called for. The proportions within each of the three main ethnic groups who reported prior contact differed significantly, for intellectual disability $\chi^2(2)=55.33$, $p<.001$; for schizophrenia $\chi^2(2)=147.77$, $p<.001$. Among the white sample 56% reported prior contact with someone with intellectual disability and 63.4% with someone with mental health problems. Among the Asian sample the corresponding figures were 31.9% and 33.5%; among the black sample they were 42.7% and 30.0%. Hence participants from BME communities were much less likely to report prior contact for either condition. These differences in the rate of prior contact can explain why the

rates of recognition between the three ethnic groups were very different. However, as noted, ethnicity played only a small role in predicting recognition once socio-demographic characteristics and contact were taken into account in unison in regression analyses.

Lay people who recognised one condition were 2.8 times more likely to also recognise the other condition, $\chi^2(1, N=1494)=74.55, p<.001, \phi=.22$, see Table 23. According to Kotrlik and Williams (2003), this indicates a moderate but by no means strong association between intellectual disability and schizophrenia literacy.

Table 23. *Recognition of intellectual disability x Recognition of schizophrenia*

		Schizophrenia Recognised		
		Yes	No	Total
Intellectual Disability Recognised	Yes	185	249	434
	No	220	840	1060
	Total	405	1089	1494

5.3.2 Social Distance

Asked how they would feel about social contact with someone like the person in the vignette, participants expressed higher levels of social distance towards the individual with schizophrenia than the one with intellectual disability, $t(1573)=-12.29, p<.001, d=.27$. For both conditions social distance differed between the three main ethnic groups, $F(2,1418)=22.74, p<.001$ for intellectual disability; $F(2,1417)=25.48, p<.001$ for schizophrenia, with black participants showing the highest social distance, see Table 24. Post hoc tests revealed that white participants desired less social distance than Asians, $p<.001$ for both conditions, and than black participants, $p<.001$ for both conditions. The differences between Asian and black participants were significant for schizophrenia, $p=.04$, but not for intellectual disability, $p=.38$.

Table 24. *Social distance scores for intellectual disability and schizophrenia by ethnic group: means (standard deviations)*

Condition	Total N=1752	White n=813	Asian n=463	Black n=256
Intellectual Disability	4.20 (1.50)	3.95 (1.48)	4.41 (1.43)	4.57 (1.55)
Schizophrenia	4.61 (1.50)	4.35 (1.52)	4.77 (1.37)	5.07 (1.52)

To examine the relationship between participants' explanations for the behaviours presented in the vignette and social distance in more detail, respondents' explanations for the intellectual disability vignette were combined under three categories: 1) recognition of the symptoms in the vignette as possible intellectual disability; 2) reference to other developmental disorders, mainly specific learning difficulties, such as dyslexia, or Autism Spectrum disorders; and 3) other responses. For the schizophrenia vignette, respondents' explanations were combined under four categories for the purposes of further analyses: 1) recognition of the symptoms in the vignette as possible schizophrenia/psychosis; 2) explanation in terms of depression; 3) general reference to mental illness, another psychiatric diagnosis, or some form of 'brain abnormality'; and 4) other responses. The depression group was analysed separately from the third group given that a sizeable proportion of participants attributed the vignette to depression, whereas other specific psychiatric diagnoses, mainly anxiety and eating disorders, were only mentioned by a small number and therefore combined with general references to mental illness.

The underlying causes participants attributed the behaviour in the vignette to had a significant effect on social distance for both intellectual disability, $F(2,1569)=52.32$, $p<.001$, and schizophrenia, $F(3,1511)=8.47$, $p<.001$. Post hoc analyses with Hochberg's GT2 showed that accurate identification of the vignette as intellectual disability ($M=3.72$, $SD=1.40$) was associated with reduced social distance

compared to those who failed to recognise intellectual disability ($M=4.45$, $SD=1.48$), $p<.001$, $d=.51$, but not compared to participants who made a reference to other developmental disabilities ($M=3.28$, $SD=1.48$), $p=.09$.

For the schizophrenia vignette post hoc tests showed that accurate identification of the vignette as schizophrenia/psychosis ($M=4.45$, $SD=1.48$) was associated with reduced social distance compared to those who made a general reference to mental illness ($M=4.79$, $SD=1.46$), $p=.003$, $d=.23$, but not compared to those who attributed the symptoms to depression ($M=4.28$, $SD=1.54$), $p=.66$. The comparison with participants who failed to recognise mental illness altogether ($M=4.73$, $SD=1.54$) approached significance, $p=.06$.

To examine whether recognition of the condition depicted, contact and socio-demographic characteristics predict social distance, multiple regressions were performed. In addition to the predictors specified for the logistic regressions above, recognition of the vignette was considered. For intellectual disability recognition was examined as dichotomous; recognition of intellectual disability was combined with attribution to specific LD or ASD as these two groups were found not to differ on social distance in the preceding analyses. For schizophrenia recognition was examined as three levels: 1) failure to recognise mental illness, 2) general reference to mental illness, or 3) recognition of schizophrenia or attribution to depression. The last two categories were combined as they were found not to differ on social distance in the preceding analyses. In initial analyses the following variables were not associated with social distance for either condition: 1) gender; 2) educational attainment; 3) religious denomination; 4) the importance of religion in the person's life; and 5) the frequency of worship. Therefore these variables were omitted from the final regression analyses.

The final model explained 14% of the variance in social distance towards intellectual disability but only 7% of the variance in social distance towards schizophrenia. The closeness of the relationship with someone with intellectual disability/mental health problems emerged as the only common predictor of social distance, see Table 25. For both conditions those with a closer contact relationship desired less social distance. Of note, when contact was considered purely as absent or present in exploratory analyses, it emerged as significant predictor of social distance. However, once the closeness of the contact relationship and frequency of contact were considered alongside the dichotomous contact variable it was the closeness of the contact relationship that showed the strongest association with social distance.

For intellectual disability, in addition, older participants and those who recognised the symptoms as possible intellectual disability or other form of developmental disability desired less social distance. Recognition did not emerge as a significant predictor for schizophrenia, although the increased social distance among those who attributed the symptoms to mental illness in general approached significance, $p=.07$. Ethnicity was associated with social distance for schizophrenia; black participants showed higher levels of social distance and the tendency among white participants to show lower social distance approached significance, $p=.06$.

Table 25. *Predictors of social distance towards intellectual disability and schizophrenia: results of multiple regression analyses*

	Intellectual Disability			Schizophrenia		
	<i>B</i>	<i>SE B</i>	β	<i>B</i>	<i>SE B</i>	β
Constant	5.33	0.36		5.48	0.51	
Recognition						
Vignette 1:						
ID recognised	0.70	0.10	.22***			
Vignette 2:						
Schizophrenia/ depression				-0.08	0.21	-.03
General ref. to mental illness				-0.37	0.21	-.12
Mental illness not recognised				-0.14	0.21	-.04
Ethnicity						
White	0.15	0.16	.05	0.26	0.14	.09
Asian	-0.14	0.16	-.04	-0.01	0.15	-.004
Black	-0.32	0.19	-.07	-0.34	0.17	-.08*
Age	-0.01	0.005	-.09**	-0.004	0.004	-.02
Contact:						
Yes/No	-0.18	0.17	-.06	0.10	0.16	.03
Closeness of Relationship	-0.08	0.02	-.15***	-0.05	0.02	-.11*
Frequency of Contact	-0.02	0.08	-.01	-0.13	0.07	-.10

Note. For intellectual disability $R^2=.14$ ($ps<.001$); for schizophrenia $R^2=.07$ ($ps<.001$). Recognition, Ethnicity and Education: 0=named group; 1= all others; Contact: 0=no, 1=yes. * $p<.05$, ** $p<.01$, *** $p<.001$

It was also examined whether the amount of explained variance could be increased by an interaction effect between recognition and contact, since the two were related. For both conditions including this interaction in the regression model increased the value of R^2 by less than 0.005.

5.4 Discussion

Overall the results suggest that lay people in the UK have a relatively limited awareness of typical symptoms of intellectual disability and schizophrenia. Across the entire sample only 28% recognised symptoms of intellectual disability. This finding is in line with a recent Mencap (2008) survey conducted in the UK, in which 73% of lay people, when asked for an example of a 'learning disability', the most common term

used in the UK, gave incorrect responses. When presented with the schizophrenia vignette, 68% of respondents made reference to some form of psychological or mental health problem, but only 24% identified possible schizophrenia or psychosis. In view of concerted efforts over recent years to raise public awareness of mental illness, one might have expected much higher recognition of the symptoms of schizophrenia. The schizophrenia vignette used in this study was very similar to one used by Jorm et al. (1997; 2006) and Reavley and Jorm (2012a). In their general population surveys conducted in Australia, in 1995 schizophrenia was identified in an unlabelled vignette by 26.8% of lay people. This figure rose over time to 42.5% by 2004 (Jorm et al., 2006), and 37.9% by 2011 (Reavley & Jorm, 2012b). Given that the present sample was highly educated overall, one might have expected recognition rates similar if not higher to the Australian figures. The current highest recognition rate for the schizophrenia vignette of 35.4% among the white sample is low compared to Jorm et al.'s 2004 figure, but similar to the 2011 figure. However, the fact that the current findings were based on a highly educated convenience sample suggests that recognition of schizophrenia is comparatively low in the UK. In any case, the recognition rate of 12.5% among black participants in the current study should be viewed as cause for concern.

The finding of only a moderate association between intellectual disability and schizophrenia literacy suggests that while there is some cross-over between awareness of these very different conditions, increasing public awareness needs to be largely disorder specific.

While the relationship between familiarity and social distance has been studied fairly extensively, less is known about its impact on awareness about specific conditions. Prior contact increased the likelihood of recognising both conditions in the current study, as did being female. While women have been shown to have a

greater awareness of symptoms of depression (Cotton et al., 2006; Klineberg et al., 2011; Lauber et al., 2004), the role of gender in schizophrenia literacy seems a little less clear. In contrast to the current study, Cotton et al. (2006) found no gender differences in recognition rates for a psychosis vignette.

For both conditions recognition differed greatly between ethnic groups. For intellectual disability, white lay people were around 50% more likely to recognise the condition compared to participants from Asian and black African/Caribbean backgrounds. For schizophrenia, the lowest recognition rates were found among black lay people. White participants were three times more likely to recognise schizophrenia than black participants and 50% more likely to do so compared to Asian participants. These findings are in line with past research that found mental health literacy to be poorer among ethnic minorities (Andrulis & Brach, 2007). In the field of intellectual disability, to date research has focused on awareness of services, which is lower among family members of people with intellectual disabilities from BME communities (Hatton et al., 1997), but has not examined cultural differences in awareness of intellectual disability *per se*. The finding that schizophrenia was recognised less frequently by participants from BME communities, and by black participants once factors such as contact, gender, age and education were considered alongside ethnicity in regression analyses suggests a need for increased education about this condition, particularly among the black (African) community.

An alternative interpretation of the finding of ethnic differences in recognition of the two conditions is that they may not reflect genuine differences in levels of awareness but could be due at least in part to different perceptions regarding what constitutes 'typical' symptoms. On this note, Pote and Orrell (2002) found lay people from ethnic minorities were less likely to view unusual thought content and suspiciousness as signs of mental illness. In any case, the very low rates of

recognition found among some cultural groups indicate a need for further research to allow us to gauge the need for raising awareness among different sections of the population. Furthermore, the finding that a minority of black and Asian participants attributed the symptoms of schizophrenia to supernatural causes is concerning in view of evidence of the association between such attributions and increased stigma (Adewuya & Makanjuola, 2008).

Public awareness campaigns and the large research effort in relation to mental health literacy, as noted earlier, are premised on the idea that increased public awareness is one important aspect of attempts to increase acceptance of people with mental illness and reduce discrimination (Lopez-Ibor, 2002; Angermeyer & Matschinger, 2005). The present findings suggest that this holds true for intellectual disability, but not for schizophrenia in line with other recent studies (Angermeyer & Matschinger, 2005; Reavley & Jorm, 2012b). Perhaps encouragingly though Lauber et al.'s (2004) finding that recognition was associated with increased stigma was not confirmed in the present study. Recognition of schizophrenia was associated with reduced social distance compared to those who made a general reference to mental illness, but curiously not compared to those who failed to recognise mental illness altogether. This is presumably due to the latter group attributing the behaviours to a broad range of explanations, some of which may have been more and others less stigmatising than schizophrenia. Overall though participants were ambivalent to positively reluctant to have social contact with the person depicted.

Contact is widely regarded as one of the most effective mechanisms for reducing stigma (Pettigrew, 1998; Alexander & Link, 2003; Jorm & Oh, 2009; Scior, 2011). In the present study contact was associated with reduced social distance for both intellectual disability and schizophrenia. When contact was considered purely as

absent or present in regression analyses, it emerged as significant predictor of social distance. However, once the closeness of the contact relationship and frequency of contact were considered alongside the dichotomous contact variable it was the closeness of the contact relationship that showed the strongest association with social distance. This lends some support to Alexander and Link's (2003) argument that a dichotomous view of contact is likely to mask complex aspects of contact that may influence its impact. Importantly the current findings regarding the effect of contact do not lend support to the suggestion that both greater awareness and contact may increase the association of schizophrenia with unpredictability and dangerousness and thus increase stigma (Corrigan, Edwards, Green, Diwan & Penn, 2001; Angermeyer & Matschinger, 2003a). Furthermore the finding that participants who applied the labels schizophrenia or psychosis to the vignette showed neither increased nor reduced social distance, compared to those who attributed the difficulties to other factors, would appear to run counter to Read et al.'s (2006) claim that illness labelling increases stigma.

The finding that there were some commonalities but also some differences in predictors of recognition and social distance for the two conditions, suggests that we can extrapolate some overarching mechanisms, such as the positive association between contact and both awareness and stigma. In parallel though what is needed is an evidence base that is specific to different conditions, cultural and socio-demographic contexts and can guide interventions aimed at increasing public awareness and reducing stigma. The possibility that the differences observed between intellectual disability and schizophrenia may be at least partly attributable to the way both vignettes were constructed and hence interpreted by participants should also be entertained.

5.4.1 Limitations

A number of limitations merit consideration. The results are specific to mild intellectual disability and schizophrenia and cannot be generalised to other conditions. It is likely that lay people would be far more likely to recognise more severe forms of intellectual disability. Furthermore it should be noted that participants were mostly recruited in cosmopolitan Greater London and were on the whole highly educated. Thus the findings are unlikely to be representative of the general UK population. Public awareness is likely to be lower in less educated samples and possibly in rural areas. A further limitation of this study is the fact that due to resource limitations sampling was opportunistic. The current findings should be confirmed with representative samples.

In evaluating differences in social distance observed in this study it is important to note that the vignettes differed in the severity of symptoms presented. The first vignette purposefully depicted someone with a milder form of intellectual disability, as it was anticipated that more severe symptoms would be easily identifiable to participants and would have made it impossible to assess the role of awareness of the condition. However, it is recognised that the differing severity of symptoms may have influenced participants' responses to the social distance items. While participants were more eager to maintain social distance from the individual presenting with symptoms of schizophrenia, it is conceivable that social distance towards intellectual disability would be increased if the person presented displayed more severe impairments, in line with evidence that severity of intellectual disability influences attitudes (Weller & Aminidav, 1992).

Regarding the effects of contact for the schizophrenia condition, the impact of prior contact with individuals with mental health problems, not schizophrenia specifically, was assessed. It is questionable whether having a relative or

acquaintance with depression, for example, is likely to increase awareness of other mental health conditions or the stigma associated with these.

Considering the relationship between recognition and social distance, one important limitation is that respondents who attributed the difficulties depicted in the vignette to a different cause, such as 'laziness' or 'spirit possession', would have related the social distance items similarly to this presumed cause. Thus one might argue that the results tell us little about the public's desire for social distance from individuals with intellectual disability or schizophrenia and that future research should use diagnostic labels. However, I would argue that the methodology employed could be seen to reflect the real world and formation of stigma, in that people mostly tend to form judgments about someone on the basis of observable behaviours and perceived characteristics of that person, rather than diagnostic labels that may well not be accessible to the observer. In any case, future research should investigate whether lay responses differ between labelled and unlabelled scenarios. Furthermore the effects of contact on stigma are poorly understood as yet. It is unclear, for example, whether as is commonly assumed contact leads to a positive shift in attitudes, or whether naturalistic contact (rather than contact generated as part of empirical studies) is mostly the product of more positive attitudes.

5.4.2 Conclusions

The findings indicate a need to increase awareness of both intellectual disability and schizophrenia among lay people in the UK. Recognition of the symptoms depicted in the vignettes was lower among members of ethnic minorities and particularly low among black (African) lay people, suggesting a need for targeted public education efforts. While recognition of the symptoms showed a strong association with reduced social distance for intellectual disability, this was not

the case for schizophrenia. Hence it would seem efforts to increase awareness are unlikely to have a positive effect on stigma by themselves, at least for schizophrenia.

Chapter 6: Causal beliefs about intellectual disability and schizophrenia and their relationship with knowledge and social distance

Abstract

Background: Public causal beliefs about mental illness and their association with social distance have been studied extensively. In contrast, the relationship between lay beliefs about the causes of intellectual disability and consequent social distance has not been examined. This study investigated what causal beliefs about intellectual disability and schizophrenia prevail among the UK public and how these relate to social distance. The role of contact and socio-demographic characteristics in influencing causal beliefs was examined.

Method: A survey of lay people of working age was conducted in the UK (N=1752). The sample was ethnically and religiously mixed, and 30.4% of participants were born outside of the UK. Participants were presented with two vignettes of someone presenting with behaviours consistent with mild intellectual disability and secondly with schizophrenia. In relation to each vignette they noted their initial explanation for the difficulties, before rating their agreement with 22 causal items and four social distance items and providing detailed socio-demographic information.

Results: Lay people were most likely to endorse environmental causes in response to the intellectual disability vignette. Biomedical factors, trauma and early disadvantage were most strongly endorsed for the schizophrenia vignette. Accurate identification of both vignettes was associated with stronger endorsement of biomedical causes, alongside weaker endorsement of adversity, environmental and supernatural causes. The relationship between causal beliefs and social distance largely differed by condition; a negative correlation between biomedical causal beliefs and social distance was found for intellectual disability, but not for schizophrenia. Causal beliefs emerged as mediators between identification and social distance for both intellectual disability and schizophrenia. While all four types of causal beliefs acted as mediators for intellectual disability though, for schizophrenia only supernatural causal beliefs

did. Recognition of the respective condition was the strongest predictor of causal beliefs, while socio-demographics had varying effects on causal beliefs.

Conclusions: This study furthers our understanding of lay beliefs about intellectual disability and schizophrenia. Educating the public about schizophrenia may have a more beneficial effect on stigma than promoting specific causal beliefs, while both strategies appear suitable for efforts to reduce the stigma associated with intellectual disability.

Causal beliefs about intellectual disability and schizophrenia and their relationship with knowledge and social distance

The previous chapter looked at the relationship between awareness of typical symptoms and social distance for both intellectual disability and schizophrenia. Research suggests that in addition to the ability to correctly identify symptoms in an unlabelled vignette, the causal attributions lay people make about such symptoms influence their desire for social distance. In the past causal attributions about schizophrenia and their effects on stigma have been studied fairly extensively, mostly in homogenous cultural and religious contexts though. This chapter presents an examination of lay causal beliefs and their relationship with knowledge and social distance for intellectual disability and schizophrenia, with attention paid to lay people's ethnicity and religious background and the role of familiarity alongside other socio-demographic factors.

6.1 Introduction

Lay causal beliefs about mental illness have found a lot of attention in the empirical literature. There has been much debate, particularly in relation to schizophrenia, how different causal beliefs or conceptualisations affect social distance (Angermeyer & Matschinger, 2005; Schomerus et al., 2006). This question has important implications for anti-stigma interventions. Causal attributions that are associated with higher levels of stigma should be discredited, whereas those that are associated with lower levels of stigma are obvious ones to reinforce. The most hotly contested question is whether promoting biological explanations has a positive effect on stigma or the reverse (Jorm & Griffiths, 2008; Jorm & Oh, 2009; Read, Haslam, Sayce & Davies, 2006). Emphasising biological factors and parallels between physical and mental illness can be expected to reduce blame from the individual and hence stigma in line with attribution theory (Weiner, 1985). Accordingly if a person's

difficulties are attributed to factors outside the individual's control people's reactions will be less negative. Conversely if causes are attributed to causes within the individual's control, one would expect others to be less willing to interact with a person.

However, the likening of mental illness to a 'brain disease' may unintentionally increase stigma by enhancing perceptions of unpredictability and dangerousness (Corrigan & Watson, 2004; Read et al., 2006) and by making the person seem 'defective' and 'almost a different species' (Phelan, 2002). Certainly some evidence suggests that biological causal explanations do not necessarily have a positive effect on levels of stigma (Dietrich et al., 2004). The authors proposed that the perception of control or a lack of it is central to the relationship between causal attributions and stigma. Thus both biological causes and those that a person can influence themselves may be associated with a perceived lack of control, such as loss of cognitive control in the case of brain damage; loss of personal control in the case of laziness attributed to a "weak character". Hence both attributions may lead the public to view the person as dangerous and unpredictable.

The evidence is mostly derived from vignette based studies, and in some cases by inviting lay people to respond directly to diagnostic labels. Based on a review of the literature, Angermeyer and Matschinger (2005) concluded that in studies using vignettes, lay beliefs about the causes of mental disorders clearly differ from empirical evidence, in that psychosocial factors, particularly psychosocial stress, predominate compared to biological factors. In contrast, when lay people respond to diagnostic labels, biological causes are at least as frequently endorsed as psychosocial stress for schizophrenia.

One important question to address in using unlabelled vignettes is whether the causal beliefs of those who identify the symptoms presented as signs of the

respective condition differ from the causal beliefs of those who interpret the behaviours presented differently. The present study attempted to do so, while also linking these processes to stigma. Understanding not only the public's awareness of intellectual disability and schizophrenia (examined in the previous chapter), but also their causal beliefs and how such beliefs relate to stigma is important for a number of reasons. Evidence on the public's causal beliefs and stigma can inform public education efforts and identify what messages are most helpful, as noted above. In addition, the integration of all three aspects in empirical inquiries allows us to identify the respective contributions of awareness and different causal beliefs to social distance and thus what targets to choose to have the greatest effect on stigma. Finally by examining the contribution of a range of socio-demographic factors, it should be possible to identify specific targets to maximise the potential benefits of such resource intensive work.

6.1.1 Lay beliefs about intellectual disability

In contrast to the burgeoning mental health literature in this area, evidence on the general public's conceptualisations about intellectual disability is thin on the ground. The literature presented in chapter 2 identified only five studies during the period 1990 to 2010 that looked at lay people's beliefs about the causes of intellectual disabilities. By way of a brief recap, studies in India and Tanzania identified a belief in 'god's will' as the most likely cause of severe intellectual disability (Kisanji, 1995; Madhavan et al., 1990). A significant proportion in India also attributed the disability to parents' actions (Madhavan et al., 1990), and in Tanzania to witchcraft (Kisanji, 1995). Only 4% of lay people in India saw prenatal complications or heredity as likely causes. Based on a large scale survey, Gilmore et al. (2003) identified significant misconceptions about the causes of Down's Syndrome among the Australian public, including 26% of the respondents who

believed the condition to be caused by parental lifestyle or problems during birth. Two studies have examined the relationship between causal beliefs about intellectual disability and stigma. In a study conducted in Ethiopia, supernatural retribution was deemed one likely cause that was in turn associated with more negative attitudes (Mulatu, 1999). In a US-based study, intellectual disability due to genetics was perceived most positively, while "self-inflicted" disability, due to drinking cleaning fluid in childhood, was viewed most negatively (Panek & Jungers, 2008). While these studies provide some useful pointers, they are mostly limited by small sample sizes. There clearly is a need for a better understanding of causal explanations of intellectual disability and their effect on stigma.

Findings derived from research with the parents of children with intellectual disabilities offer some interesting pointers. As noted earlier, it has been suggested that potentially stigmatising lay beliefs about the causes of intellectual disability may be common amongst some cultural communities, such as a belief amongst South Asians that the condition results from possession by spirits (Hatton et al., 2003) or punishment for past sins (Hubert, 2006). It needs emphasising though that such findings are entirely derived from small scale studies with the parents of children with intellectual disabilities and in the absence of general population research need to be treated with caution. In a study of Pakistani parents of children with intellectual disabilities, Croot et al. (2008) found that all parents made reference to theological explanations as to why they had a child with a disability, but most also gave biomedical or other explanations. Parents often gave theological explanations initially, but resorted to biomedical discourse when facing negative or unhelpful ideas. Their findings are in line with Hatton et al. (2003), who noted that parents who have a good understanding of the medical explanation for their child's disability appear to use this to refute unhelpful beliefs about the causes of their child's

disability among their extended family and expectations of a 'cure'. Thus the idea that biomedical explanations can lower stigma is certainly present within the intellectual disability literature, but at present is poorly articulated and not empirically tested. The study presented in this paper will aim to fill this gap by examining the relationship between a range of causal explanations for symptoms of intellectual disability and stigma in the general UK population.

6.1.2 The role of culture and religion in shaping lay beliefs

Cross-cultural studies have found differences in causal beliefs between different countries. Dietrich et al. (2004) found that the tendency to blame the affected person or their family for schizophrenia or depression was more pronounced in Russia and Mongolia than in Germany. Hong Kong Chinese lay people were less in agreement with biological explanations and were more likely to agree that social stress plays a role in the aetiology of schizophrenia than British lay people (Furnham & Chan, 2004). Finally, lay people in Nigeria were most likely to endorse supernatural factors, with 48.9% in agreement, followed by psychosocial factors, while biological factors were only endorsed by 30.4% (Adewuya & Makanjuola, 2008).

The role of religion in shaping beliefs about mental illness was considered in some depth by Hartog and Gow (2007). They noted, for example, that for fundamentalist Christians much of mental or emotional suffering is due to sin or moral failings. They found that while religious individuals were more likely to attribute mental illness to religious causes, they were also accepting of psychiatric causal explanations. In a study of lay beliefs about depression and schizophrenia among women from five religious groups, respondents felt that schizophrenia was more serious, more likely to be associated with organic problems, to be hereditary,

and that religion was less relevant as a coping strategy (Cinnirella & Loewenthal, 1999).

6.1.3 Theoretical approaches to the study of causal beliefs

Studies of causal beliefs among patients themselves, frequently referred to 'explanatory models' (Kleinmann, Eisenberg & Good, 1978), have drawn on a number of inventories developed for clinical use, including the Illness Perception Questionnaire (IPQ; Weinman, Petrie, Moss-Morris & Horne, 1996), the Short Explanatory Model Interview (SEMI; Lloyd et al., 1998) and the Explanatory Model Interview Catalogue (EMIC; Weiss, 1997). Their main purpose is to improve clinicians' understanding of their patients' beliefs. In contrast, research into lay beliefs about mental disorders mostly has used brief survey methods and pre-defined causal items to which respondents indicate their agreement. The approach used in most studies assumes that participants may hold a range of causal beliefs simultaneously. It has been proposed though that in some instances a hierarchical rating system, whereby a respondent ranks causes in terms of their presumed significance, may be more appropriate to gain a picture of the perceived relative importance of different causes (Matschinger & Angermeyer, 1996; Schomerus et al., 2006). While this method may have the advantage of rendering a clearer picture, in everyday life lay people often entertain various and at times competing beliefs simultaneously. Hence the present study adopted a rating rather than ranking approach.

6.1.4 Study aims

The present study set out to investigate the relationship between lay knowledge, causal beliefs and social distance in relation to intellectual disability and schizophrenia. The role of contact and socio-demographic factors in influencing causal beliefs and social distance were examined. The research questions were: 1)

what beliefs about the likely causes of typical symptoms of mild intellectual disability and schizophrenia (of the affective subtype) are prevalent among the UK general population?; 2) what effect does awareness of intellectual disability/schizophrenia, as evidenced by the ability to recognise symptoms of the respective condition in a diagnostically unlabelled vignette, have on causal beliefs and social distance? In particular, do people who recognise the condition attribute more importance to biomedical factors, and less to psychosocial and supernatural factors?; 3) what is the association between causal beliefs and social distance?; and 4) what is the role of contact, ethnicity, religion, gender, age and education in predicting causal beliefs? (The role of such factors in predicting knowledge and social distance was examined in the previous chapter and is not revisited in this chapter.) These processes were examined in relation to intellectual disability and schizophrenia to ascertain whether they are disorder specific or more generic.

On the basis of the evidence it was hypothesised that increased awareness of either condition would be associated with greater endorsement of biomedical causes, alongside weaker endorsement of environmental, adversity and supernatural causes. It was hypothesised that accurate identification of the second vignette as schizophrenia/psychosis, rather than more general reference to mental illness would enhance this effect, in line with such a trend observed by Schomerus et al. (2006). It was also hypothesised that agreement with biomedical causes would be associated with reduced social distance for either condition, and belief in supernatural causes with increased social distance. Furthermore it was hypothesised that the relationship between knowledge and social distance would be mediated by participants' causal beliefs. Finally it was predicted that participants from cultures that have a stronger belief in supernatural forces and those for whom religion was very important would

be more likely to endorse supernatural causes, and possibly less likely to endorse biomedical causes.

6.2 Method

6.2.1 Participants

The sample was the same as that detailed in chapter 5.

6.2.2 Measures

After being presented with the two vignettes described in previous chapters, participants indicated their agreement with 22 possible causes of the person's difficulties. The development and psychometric properties of these items was described in chapter 3. Participants also rated their willingness for social contact with someone like the person in the vignette, by responding to four statements about social contact in situations of increasing intimacy, as set out in chapter 3. Participants rated their agreement with each item on a 7-point Likert scale (1=disagree strongly, 7=agree strongly). Responses to the 22 causal items were analysed under four subscales, see Appendix 4, in line with the factor and reliability analyses presented in chapter 3: biomedical, adversity, environmental, and supernatural causes. The adversity and environment subscales encompassed a range of psychosocial explanations. For each subscale a mean score of the constituent items was calculated. Higher scores indicate stronger endorsement of the respective cause. The social distance items were reversed and a mean score was calculated, so that higher scores indicate higher social distance.

It needs emphasising that participants' causal beliefs relate to the symptoms depicted in the vignette rather than a diagnostic category. The approach adopted, namely to relate participants' causal beliefs to symptoms depicted in a vignette rather than a diagnostic category is similar to many other studies that have examined causal beliefs and stigma regarding mental illness (Angermeyer,

Buyantugs, Kenzine & Matschinger, 2004; Angermeyer & Matschinger, 2005; Jorm et al., 2005; O'Reilly, Bell & Chen, 2010; Schomerus et al., 2006). Of note though, participants who failed to recognise that the behaviours presented might be due to an underlying mental illness or intellectual disability, but instead attributed them to other factors, also rated their causal attributions and social distance in relation to this premise, an issue that was considered in the analyses and interpretation of the results.

Participants provided the socio-demographic information detailed in chapter 5.

6.2.3 Procedure

The procedure was the same as that detailed in chapter 5.

6.2.4 Data Analysis

6.2.4.1 Data Screening. Exploration of the data indicated that three of the four causal belief subscales were normally distributed. However the supernatural subscale showed large positive skewness for both intellectual disability and schizophrenia; most participants disagreed with such causes, regardless of condition. This subscale and its constituent items were log transformed which resolved problems with the data. The other subscales were not transformed as comparisons were only computed between items within each scale.

Inspection of the causal beliefs and social distance data for outliers revealed that, for intellectual disability only the supernatural causes subscale had outliers. For schizophrenia the environment and supernatural causes subscales had outliers. In order to understand these further, the data were examined for outliers by ethnic group, focusing on the four main groups (white, Asian, black, other). While dealing with outliers by recognition group rather than by ethnic group was also considered, as expected, there were large numbers of outliers, particularly for the group who

failed to recognise the condition, as they entertained a range of very different explanations. For intellectual disability there were no outliers for any of these broad ethnic groups on biomedical causes, adversity causes and social distance. However, on environmental causes four outliers were identified among the Asian sample. For supernatural causes there were nine outliers for the white sample, three for the Asian sample, and four for the black sample, all at the upper end. For schizophrenia, there were no outliers for any of these broad ethnic groups on biomedical causes and adversity causes. On environmental causes two outliers at the upper end were identified among the white sample; on supernatural causes 11 outliers at the upper end were identified among the white sample; and for social distance three outliers were identified at the lower end among the Asian sample. All outliers were replaced with the mean for the ethnic group +/- two standard deviations, as suggested by Field (2005).

6.2.4.2 Statistical analysis. The data were analysed using SPSS version 19. The internal consistency of the causal subscales was very good for both vignettes across the entire sample. Cronbach alphas for the intellectual disability vignette were biomedical $\alpha=.85$, adversity $\alpha=.81$, environment $\alpha=.79$, and supernatural $\alpha=.78$. For the schizophrenia vignette the internal reliability of the causal subscales across the entire sample was also good, with biomedical $\alpha=.80$, adversity $\alpha=.81$, environment $\alpha=.84$, and supernatural $\alpha=.81$. Inter-item correlations were between .17 and .63. Paired samples *t* tests were used to compare endorsement of the four causal beliefs between the two vignettes. The effect of explanation given for the behaviours depicted in the vignette on causal beliefs was examined using one way ANOVAs and post hoc analyses. To examine what associations exist between different causal beliefs and social distance Spearman's rho correlations were calculated. To test the hypothesis that the relationship between knowledge about the respective condition

and social distance would be mediated by participants' causal beliefs, path models were computed for both conditions using linear regressions. Finally, to assess the effect of contact and socio-demographic characteristics on participants' causal beliefs, multiple regressions were performed. Effect sizes are reported throughout as Cohen's *d*.

6.3 Results

6.3.1 Causal beliefs

Participants' agreement with the 22 causal items was examined. Paired-samples *t* tests were conducted to evaluate whether participants differed in their agreement with the potential causes when responding to the intellectual disability or schizophrenia vignettes, see Table 26.

Table 26. *Endorsement of 22 causal belief items for intellectual disability and schizophrenia: Descriptive statistics and results of within-subjects tests*

Causal Belief	ID M (SD)	Schizophrenia M (SD)	<i>t</i>	<i>d</i>
<i>Biomedical</i>				
Virus/ brain infection	3.23 (1.78)	3.87 (1.86)	-12.92*	0.35
Genetic factors	3.86 (1.78)	4.31 (1.81)	-9.22*	0.25
Complications at birth	3.49 (1.74)	3.14 (1.79)	7.10*	0.20
Brain abnormality	4.04 (1.85)	4.72 (1.78)	-12.90*	0.37
Meningitis	3.08 (1.66)	2.98 (1.71)	2.37	0.06
<i>Adversity</i>				
Family arguments	3.65 (1.69)	3.72 (1.78)	-1.38	0.04
Financial worries	3.14 (1.75)	3.30 (1.81)	-3.25*	0.09
Suffering abuse as a child	3.76 (1.75)	3.98 (1.81)	-4.81*	0.12
Recent trauma	3.65 (1.77)	4.26 (1.83)	-12.63*	0.34
Recent death of relative or close friend	3.64 (1.80)	4.16 (1.85)	-11.33*	0.28
<i>Environment</i>				
Overly spoilt as a child	3.70 (1.86)	2.20 (1.47)	30.10*	0.89
Lack of daytime occupation	4.29 (1.79)	3.60 (1.88)	13.61*	0.38
Very poor schooling	4.51 (1.67)	2.36 (1.54)	45.18*	1.34
From single-parent family	2.95 (1.76)	2.37 (1.63)	13.85*	0.34
Parents too lenient	4.20 (1.88)	2.59 (1.70)	31.79*	0.90
Lack of an intimate relationship	3.47 (1.78)	3.48 (1.90)	-0.39	0.01
Isolation from extended family	2.79 (1.63)	2.89 (1.79)	-2.37	0.06
<i>Supernatural</i>				
Punishment for own past wrongdoings	2.54 (1.71)	2.48 (1.84)	1.40	0.03
Strong religious or spiritual beliefs	1.99 (1.44)	2.26 (1.71)	-6.52*	0.17
Spirit possession	1.65 (1.34)	1.92 (1.61)	-8.10*	0.18
Punishment for parents' wrongdoings	2.46 (1.67)	2.29 (1.71)	4.75*	0.10
A test from God/ Allah	1.81 (1.56)	1.82 (1.59)	-0.36	0.01

**p* < .05 (Bonferroni corrected)

The results showed that for the intellectual disability vignette, a history of poor schooling, lack of daytime occupation, overly lenient parenting and brain abnormality received the strongest endorsement. For the schizophrenia vignette, brain abnormality, genetic factors, recent trauma or bereavement were rated as most likely causes. Of the five biomedical causes three were judged as more likely causes of the schizophrenia vignette (brain infection, genetic factors and brain abnormality), while complications at birth were seen as a more likely cause of intellectual disability. All adversity causes were deemed more likely causes of the schizophrenia presentation, while most environmental causes were judged as more likely causes of intellectual disability. Finally, spirit possession, strong religious or spiritual beliefs and retribution for parental wrongdoings were seen as less likely causes of intellectual disability, but the effect sizes were small.

6.3.2 Causal beliefs and recognition

Looking at the four causal factors presented in chapter 3, the results of paired samples t tests showed that participants were less likely to endorse biomedical causal explanations, $t(1478)=-6.18$, $p<.001$, $d=.19$, and adversity causes, $t(1478)=-9.15$, $p<.001$, $d=.18$ for intellectual disability than for schizophrenia, with small effect sizes. They were far more likely to endorse environmental explanations for intellectual disability, $t(1478)=30.21$, $p<.001$, $d=.82$. Agreement with supernatural causes did not differ between the two conditions, $t(1478)=-0.17$, $p=.86$.

As the next step, participants' causal beliefs for intellectual disability and schizophrenia were examined by explanation given for the respective vignette, see Tables 27 and 28.

Table 27. *Endorsement of causal beliefs by explanation given for intellectual disability vignette: means (standard deviations) and ANOVA results*

	Total N=1697	Intellectual Disability (n=490)	Specific LD/ ASD n (65)	Other Explanation (n=1142)	<i>F</i>
<i>Causal Beliefs</i>					
Biomedical	3.55 (1.38)	4.28 (1.19)	4.02 (1.25)	3.21 (1.36)	122.66*
Adversity	3.60 (1.32)	3.39 (1.32)	3.16 (1.17)	3.71 (1.31)	14.23*
Environment	3.71 (1.17)	3.09 (1.16)	3.03 (1.15)	4.01 (1.04)	136.68*
Supernatural	2.09 (1.11)	1.72 (0.88)	1.81(0.99)	2.26 (1.16)	50.65*

* $p < .001$

The results presented in Table 27 indicate that across the entire sample, lay people were most likely to endorse environmental causes in response to the intellectual disability vignette, with adversity and biomedical causes following closely behind. One-way ANOVAs revealed a significant effect of explanation of the vignette on all four causal belief subscales. To account for different sample sizes, post hoc tests were performed using Hochberg's GT2 for the adversity and supernatural causes subscales given that Levene's test was not significant, and the Games-Howell procedure for the biomedical and environmental causes subscales given that Levene's test was significant, $p < .001$.

Accurate identification of the vignette as intellectual disability was associated with stronger endorsement of biomedical causes, $p < .001$, $d = .84$; alongside weaker endorsement of adversity, $p < .01$, $d = .24$; environmental causes, $p < .001$, $d = .84$; and supernatural causes, $p < .001$, $d = .54$, compared to those who failed to recognise intellectual disability, with large effect sizes for endorsement of biomedical and

environmental causes. Against expectations, causal beliefs of those who identified intellectual disability did not differ significantly from participants who made a reference to other developmental disabilities, biomedical: $p=.27$; adversity: $p=.44$; environment: $p=.91$; and supernatural: $p=.94$.

For the schizophrenia vignette, adversity and biomedical causes were most strongly endorsed; participants endorsed environmental causes much less than for the intellectual disability vignette, perhaps due to a perception that this presentation seemed much more serious than the intellectual disability vignette. Participants tended to disagree with supernatural causes for both vignettes. Differences in participants' causal beliefs by explanation for the schizophrenia vignette are presented in Table 28.

Table 28. *Endorsement of different causal beliefs by explanation given for schizophrenia vignette: means (standard deviations) and ANOVA results*

	Total N=1527	Schiz./ Psychosis (n=365)	Depression (n=190)	Mental Illness (general/ other) (n=470)	Other Explanation (n=308)	<i>F</i>
<i>Causal Beliefs</i>						
Biomedical	3.81 (1.32)	4.20 (1.20)	3.38 (1.30)	3.97 (1.29)	3.35 (1.34)	34.26*
Adversity	3.85 (1.39)	3.59 (1.34)	4.25 (1.37)	3.82 (1.34)	3.97 (1.45)	10.60*
Environment	2.73 (1.22)	2.18 (1.03)	3.15 (1.18)	2.60 (1.11)	3.32 (1.24)	67.01*
Supernatural	2.13 (1.28)	1.59 (0.87)	2.30 (1.34)	1.98 (1.10)	2.91 (1.52)	66.63*

* $p<.001$

As for intellectual disability, one-way ANOVAs showed a significant effect of explanation on all four causal beliefs for the schizophrenia vignette. Post hoc tests were performed using Hochberg's GT2 for the biomedical and adversity causes subscales given that Levene's test was not significant. The Games-Howell procedure was applied for the environmental and supernatural causes subscales given that

Levene's test was significant at $p=.007$ for environment and $p<.001$ for supernatural causes.

As predicted, accurate identification of the vignette as schizophrenia/psychosis was associated with stronger endorsement of biomedical causes, $p<.001$, $d=.67$; alongside weaker endorsement of adversity, $p=.003$, $d=.27$; environmental causes, $p<.001$, $d=1.00$; and supernatural causes, $p<.001$, $d=1.07$, compared to those who failed to recognise mental illness. Furthermore, in line with the tentative hypothesis, identification of the vignette as schizophrenia/psychosis, rather than more general reference to other forms of mental illness, enhanced this effect, although only the results for environmental, $p<.001$, $d=.39$, and supernatural causes, $p<.001$, $d=.39$, reached significance.

Participants who attributed the behaviours in the second vignette to depression, compared to those who recognised schizophrenia, were less likely to endorse biomedical causes, $p<.001$, $d=.66$, and more likely to agree with the other three causes, adversity: $p<.001$, $d=.49$; environment: $p<.001$, $d=.88$; supernatural: $p<.001$, $d=.63$. They were as likely as participants who failed to recognise mental illness altogether to endorse biomedical causes, $p=1.00$; adversity, $p=.25$; or environmental causes, $p=.53$. The only difference found between these two groups was the depression group's lower endorsement of supernatural causes, $p<.001$, $d=.44$, even though this difference was much smaller than the difference in agreement with supernatural causes between the schizophrenia group and the group who failed to recognise mental illness altogether, see above.

6.3.3 Causal beliefs and social distance

In order to identify what associations exist between different causal beliefs and social distance, regardless of participants' interpretations of the symptoms in the

vignette, correlations were calculated, initially for individual causal items, see Table 29.

Table 29. *Correlations between individual causal items and social distance*

Causal Item	Social Distance	
	Intellectual Disability	Schizophrenia
<i>Biomedical</i>		
Virus/ brain infection	-.11*	.08*
Genetic factors	-.17*	-.03
Complications at time of birth	-.18*	.01
Brain abnormality	-.14*	.08*
Meningitis	-.14*	.03
<i>Adversity</i>		
Family arguments	.05	-.01
Financial worries	.00	-.04
Suffering abuse as a child	-.04	-.03
Recent traumatic incident	-.10*	-.06
Recent death of relative or close friend	-.04	-.06
<i>Environment</i>		
Overly spoiled as a child	.26*	.05
Lack of daytime occupation	.15*	.03
Very poor schooling	.07	.03
Being from a single-parent family	.13*	.02
Parents too lenient	.30*	.09*
Lack of an intimate relationship	.05	.03
Isolation from extended family	.03	-.03
<i>Supernatural</i>		
Punishment for own past wrongdoings	.08*	.10*
Strong religious or spiritual beliefs	.06	.08*
Spirit possession	.09*	.12*
Punishment for parents' wrongdoings	.13*	.10*
A test from God / Allah	.05	.09*

* Spearman's rho significant at $p < .05$ (Bonferroni corrected)

The results point to some interesting similarities and differences regarding the relationship between causal beliefs and social distance for intellectual disability and schizophrenia. Several items were associated with increased social distance for both conditions: spirit possession, punishment for own or parents' past wrongdoings, and excessive lenience on the part of parents. Of the five items constituting the supernatural scale, three were positively correlated with social distance for intellectual disability and all five for schizophrenia. There were some notable differences though for items subsumed under the biomedical subscale: virus/cerebral infection and brain abnormality were negatively correlated with social distance for intellectual disability, yet positively for schizophrenia. Genetic factors were associated with decreased social distance for intellectual disability but showed no association for schizophrenia. Notably, for schizophrenia none of the items showed a negative correlation with social distance. Overall though, the correlation coefficients for schizophrenia in particular were low (highest .12), suggesting only a weak relationship between causal beliefs and social distance.

Subsequently the relationships between causal beliefs and social distance were examined by focusing on the four subscales derived from the factor analysis described in chapter 3, see Table 30.

Table 30. *Correlations between causal beliefs and social distance for intellectual disability and schizophrenia vignettes (N=1752)*

Causal Beliefs	Social Distance	
	Intellectual Disability	Schizophrenia
Biomedical	-.19*	.05
Adversity	-.04	-.07
Environmental	.21*	.05
Supernatural	.12	.14*

*Spearman's rho significant at $*p < .01$ (Bonferroni corrected)

For intellectual disability, as predicted, belief in biomedical causes showed a negative correlation with distance, and supernatural causal beliefs were positively correlated with social distance. While the expected positive relationship between supernatural beliefs and social distance was also found for the schizophrenia condition, against expectations there was no significant correlation between biomedical beliefs and social distance. Endorsement of environmental causes was positively correlated with social distance for intellectual disability, but not for schizophrenia. Finally, endorsement of adversity causes was not significantly correlated with social distance for either condition.

6.3.4 Relationship between knowledge, causal beliefs and social distance

To test the hypothesis that the relationship between knowledge of the respective condition and social distance would be mediated by participants' causal beliefs, mediation analyses in line with Preacher & Hayes (2004) were performed. Accordingly bootstrapping analyses were conducted to estimate direct and indirect effects with multiple mediators using a script described in Preacher & Hayes (2008). Separate path models were generated for intellectual disability and schizophrenia to

ascertain whether mediation processes are disorder specific or common to both conditions considered in this study.

6.3.4.1 Intellectual Disability

For the purpose of analysis, 'intellectual disability literacy' was defined as mention of intellectual disability (or one of its synonyms) or attribution of the presentation to a specific learning disability (LD) or autism spectrum disorder (ASD), given that the responses of these two groups were similar on all outcomes. Results indicated that the total effect of recognition of intellectual disability on social distance of $-.79$, $p < .001$, became smaller when causal belief mediators were included in the model (direct effect $= -.42$, $p < .001$). The total indirect effect of recognition of intellectual disability on social distance through causal belief mediators was significant, $p < .001$, with a point estimate of $-.37$ and a 95% bias-corrected and accelerated (BCa) bootstrap confidence interval of $-.48$ to $-.27$. Therefore causal beliefs fully mediated the association between recognition and social distance for intellectual disability. The specific indirect effects of each proposed mediator showed that belief in biomedical causes, with a point estimate of $-.08$, adversity causes, with a point estimate of $.07$, environmental causes, with a point estimate of $-.29$, and supernatural causes, with a point estimate of $-.06$ were all significant mediators. Overall the model explained 11% of the variance in social distance towards the individual presenting with symptoms of schizophrenia. The model is presented in Figure 3; confidence intervals (CI) reported are 95% BCa bootstrap confidence intervals.

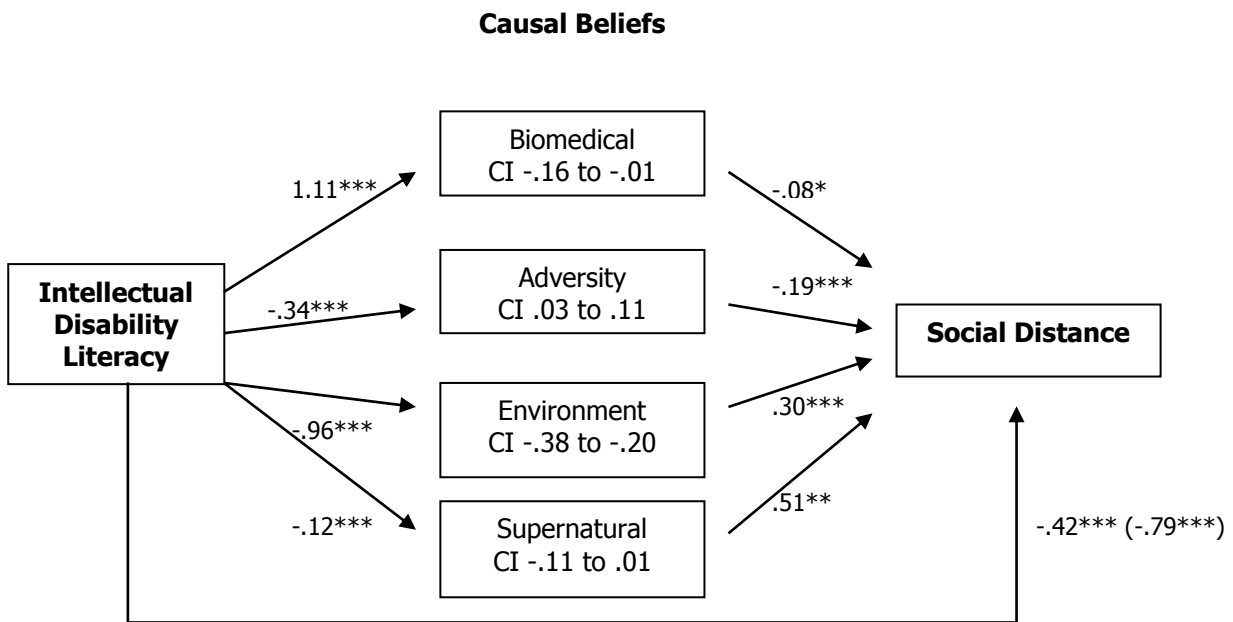


Figure 3. Associations between intellectual disability literacy, causal beliefs and social distance

Note: Path values represent unstandardised regression coefficients. The value outside the parenthesis represents the total direct effect, from bootstrapping analyses, of recognition of intellectual disability on social distance after causal belief mediators were included. The value inside the parenthesis represents the total effect of recognition on social distance, prior to the inclusion of mediating variables. * $p > .05$, ** $p < .01$, *** $p < .001$, $n = 1572$.

In sum, the bootstrap analyses indicate that all four types of causal beliefs mediated the relationship between intellectual disability literacy and social distance.

6.3.4.2 Schizophrenia

For schizophrenia, on the basis of the comparisons between the four explanation groups, 'schizophrenia literacy' was defined as recognition of schizophrenia/psychosis, and compared to those who failed to recognise mental illness altogether. Participants who made general reference to mental illness, a different psychiatric diagnosis, or depression, were excluded from the path analysis as their causal beliefs and social distance differed from the schizophrenia group, as noted above and in chapter 5. Results indicated that the total effect of recognition of schizophrenia on social distance of $-.23$, $p = .055$, became smaller when causal belief mediators were included in the model (direct effect $= .12$, $p = .42$). The total indirect

effect of recognition of schizophrenia on social distance through causal belief mediators was significant, $p=.0005$, with a point estimate of $-.35$ and a 95% bias-corrected and accelerated (BCa) bootstrap confidence interval of $-.56$ to $-.17$. Therefore causal beliefs fully mediated the association between recognition and social distance for schizophrenia. The specific indirect effects of each proposed mediator showed that supernatural causal beliefs, with a point estimate of $-.35$ were significant mediators, $p<.001$, and the role of adversity causal beliefs, with a point estimate of $.04$, approached significance, $p=.06$. Biomedical causal beliefs, with a point estimate of $.02$, and environmental causal beliefs, with a point estimate of $-.06$ did not add to the overall model. Overall the model explained only 5% of the variance in social distance towards the individual presenting with symptoms of schizophrenia. The model is presented in Figure 4.

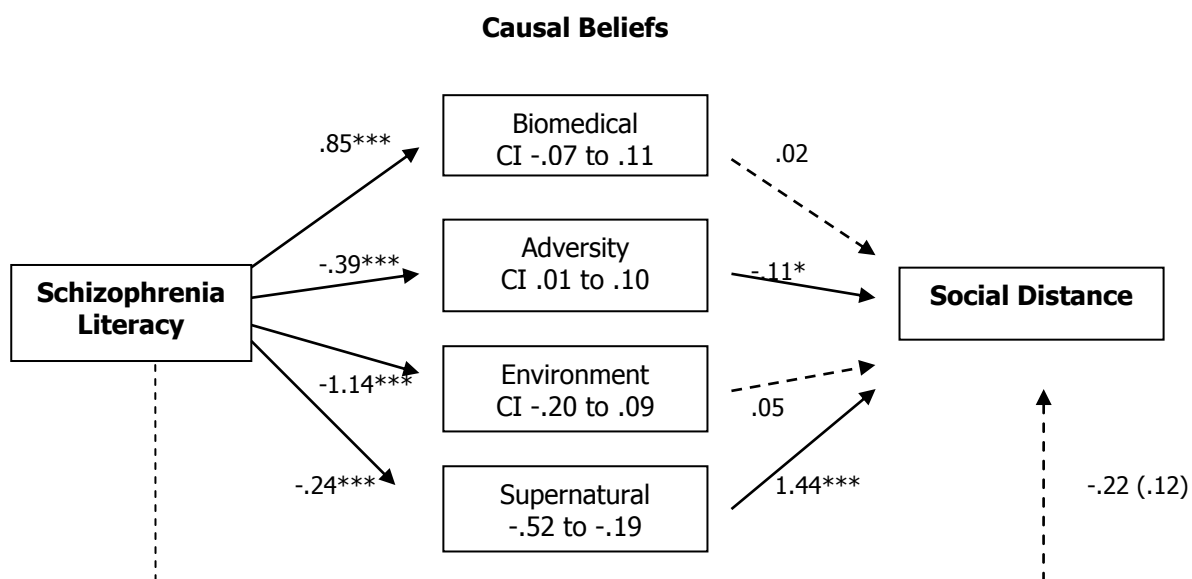


Figure 4. *Associations between schizophrenia literacy, causal beliefs and social distance*

** $p>.05$, ** $p<.01$, *** $p<.001$, $n=668$.*

In sum, the bootstrap analyses indicate that differently to intellectual disability, for schizophrenia only supernatural causal beliefs mediated the relationship

between schizophrenia literacy and social distance; the mediating role of adversity causal beliefs approached significance. Recognition of schizophrenia was associated with reduced endorsement of supernatural causes, which in turn was associated with increased social distance. As for intellectual disability, recognition was associated with reduced endorsement of adversity causes, in turn associated with reduced social distance. While one might view this effect as an undesirable bi-product of increased knowledge of the conditions, its effect on social distance was much less pronounced than the effect of supernatural causal beliefs.

6.3.5 Socio-demographic factors and causal beliefs

Given that this thesis is concerned with the role of ethnicity and religion in influencing lay perceptions, causal beliefs were examined for the main ethnic groups, see Table 31, and subsequently by religious group. The ethnic 'other' group is included in the entire sample but was excluded from the computation of ANOVAs.

Table 31. *Causal beliefs by ethnic group: Means (Standard Deviations) and results of one-way ANOVAs*

Causal Beliefs	Entire sample N=1752	White n=813	Asian n=463	Black n=255	<i>F</i>
Intellectual Disability					
<i>Biomedical</i>	3.54 (1.38)	3.63 (1.40)	3.56 (1.35)	3.29 (1.41)	4.61**
<i>Adversity</i>	3.58 (1.31)	3.55 (1.30)	3.77 (1.30)	3.13 (1.35)	14.47***
<i>Environment</i>	3.71 (1.16)	3.54 (1.16)	4.01 (1.08)	3.46 (1.20)	23.40***
<i>Supernatural</i>	2.08 (1.10)	1.76 (0.79)	2.42 (1.20)	2.35 (1.35)	41.26***
Schizophrenia					
<i>Biomedical</i>	3.81 (1.32)	3.85 (1.30)	3.83 (1.36)	3.65 (1.38)	2.10
<i>Adversity</i>	3.89 (1.38)	3.85 (1.32)	4.22 (1.40)	3.42 (1.43)	24.19***
<i>Environment</i>	2.79 (1.22)	2.59 (1.17)	3.29 (1.25)	2.59 (1.15)	44.79***
<i>Supernatural</i>	2.16 (1.28)	1.72 (0.90)	2.70 (1.38)	2.67 (1.60)	103.70***

Endorsement of causal beliefs differed for the three main ethnic groups on all subscales for intellectual disability and on three of the four subscales for schizophrenia. For intellectual disability, post hoc tests using Hochberg's GT2 showed that white participants were more likely to agree with biomedical causes than black participants, $p=.002$, $d=0.24$; the same applied for Asian compared to black participants, $p=.04$, $d=0.20$. Agreement with adversity causes was higher among Asians compared to both white, $p=.046$, $d=0.17$, and black participants, $p<.001$, $d=0.48$; white were also more likely to agree with such causes than black participants, $p<.001$, $d=0.32$. Post hoc tests using the Games Howell procedure indicated that Asians were more likely to endorse environmental causes than whites and blacks, both $p<.001$, $d=0.42$ and $d=0.48$ respectively. Finally, both Asians and black participants were more likely to agree with supernatural causes than whites, both $p<.001$, $d=0.65$ and $d=0.53$ respectively.

For schizophrenia, post hoc tests using Hochberg's GT2 showed that Asian participants were more likely to agree with adversity causes than both white and black participants, both $p<.001$, $d=0.27$ and $d=0.57$ respectively. Whites were also more likely to agree with such causes than blacks, $p<.001$, $d=0.31$. Asians were more likely to endorse environmental causes than whites and blacks, both $p<.001$, $d=0.58$. Finally, both Asian and black participants were more likely to agree with supernatural causes for the schizophrenia vignette than whites, both $p<.001$, $d=0.84$ and $d=0.73$ respectively.

Analyses of causal beliefs for the main religious groups are presented in Table 32.

Table 32. *Causal beliefs by religious group: Means (Standard Deviations) and results of one-way ANOVAs*

Causal Beliefs	Entire sample N=1672	Christian n=538	Muslim n=252	Hindu n=75	Other n=89	Non-religious/ Atheist n=718	<i>F</i>
Intellectual Disability							
<i>Biomedical</i>	3.55 (1.39)	3.51 (1.41)	3.60 (1.38)	3.59 (1.40)	3.71 (1.31)	3.52 (1.39)	0.53
<i>Adversity</i>	3.57 (1.32)	3.37 (1.36)	3.72 (1.39)	3.83 (1.35)	3.98 (1.20)	3.58 (1.25)	7.11***
<i>Environment</i>	3.69 (1.16)	3.58 (1.22)	3.97 (1.16)	3.96 (1.08)	3.96 (1.14)	3.62 (1.11)	7.86***
<i>Supernatural</i>	2.07 (1.10)	2.12 (1.15)	2.75 (1.28)	2.16 (1.06)	2.21 (1.15)	1.77 (0.84)	36.76***
Schizophrenia							
<i>Biomedical</i>	3.82 (1.32)	3.68 (1.34)	3.85 (1.31)	3.79 (1.37)	3.83 (1.40)	3.91 (1.29)	2.17
<i>Adversity</i>	3.89 (1.38)	3.73 (1.42)	4.24 (1.36)	4.24 (1.48)	4.20 (1.34)	3.83 (1.32)	7.28***
<i>Environment</i>	2.78 (1.22)	2.74 (1.17)	3.25 (1.25)	3.23 (1.33)	3.04 (1.28)	2.59 (1.18)	14.81***
<i>Supernatural</i>	2.15 (1.28)	2.29 (1.37)	3.08 (1.45)	2.41 (1.18)	2.24 (1.18)	1.72 (0.94)	49.85***

Endorsement of causal beliefs differed for the five main religious groups on all subscales, except biomedical causes, for both intellectual disability and schizophrenia. For intellectual disability, post hoc tests using the Games Howell procedure showed that Christians were less likely to agree with adversity causes compared to Muslims, $p=.006$, $d=0.25$; Hindus, $p=.04$, $d=0.34$; those of other religions, $p<.001$, $d=0.48$; and non-religious participants, $p=.03$, $d=0.16$. Those of other religions were more likely to agree with such causes than non-religious participants, $p=.03$, $d=0.33$. Post hoc tests using Hochberg's GT2 showed that agreement with environmental causes was lower among Christians compared to Muslims, $p<.001$, $d=0.33$, and those of other religions, $p=.04$, $d=0.32$. Muslims were more likely to agree with such causes than non-religious participants, $p<.001$

$d=0.31$. Finally, post hoc tests using the Games Howell procedure indicated that Muslims were more likely to endorse supernatural causes than all other groups, namely compared to Christians, $p<.001$, $d=0.52$; Hindus, $p=.004$, $d=0.59$; those of other religions, $p=.005$, $d=0.44$; and non-religious participants, $p<.001$, $d=0.91$. The latter were less likely to endorse such causes than Christians, $p<.001$, $d=0.35$; Hindus, $p=.03$, $d=0.41$; and those of other religions, $p=.003$, $d=0.44$.

For schizophrenia, post hoc tests using Hochberg's GT2 showed that Muslims were more likely to agree with adversity causes compared to Christians, $p<.001$, $d=0.37$, and non-religious participants, $p=.002$, $d=0.31$. Agreement with environmental causes was higher among Muslims and Hindus compared to Christians, $p<.001$, $d=0.42$, and $p=.04$, $d=0.39$ respectively, and compared to non-religious participants, $p<.001$, $d=0.54$ and $p=.002$, $d=0.51$ respectively. Those of other religions tended to agree more with such causes than non-religious participants, $p=.03$, $d=0.37$. Finally, post hoc tests using the Games Howell procedure indicated that Muslims were more likely to endorse supernatural causes than all other groups; compared to Christians, $p<.001$, $d=0.56$; Hindus $p=.03$, $d=0.51$; those of other religions, $p<.001$, $d=0.64$; and non-religious participants, $p<.001$, $d=1.11$. The latter were less likely to endorse such causes than Christians and Hindus, both $p<.001$, $d=0.49$ and $d=0.65$ respectively, and those of other religions, $p=.002$, $d=0.49$.

The role of recognition, contact, ethnicity, religion, gender, age and education as potential independent predictors of causal beliefs was examined by performing multiple regressions. The following predictors were entered: recognition of intellectual disability (dichotomous: 1) recognition as intellectual disability or attribution to specific LD/ASD versus 2) other explanations) and schizophrenia (four different explanations detailed above); prior contact: a) dichotomous (yes/no), b)

closeness of the relationship, measured on a 10-point scale (0=no contact, 1=not at all close and 9=extremely close); and c) frequency of contact (0=no contact; 1=infrequent, defined as up to three times per year; 2=moderate, defined as up to monthly; and 3=frequent, defined as twice per month or more frequent).

As before, for the intellectual disability condition contact was defined as prior contact with someone with intellectual disabilities, for the schizophrenia condition as prior contact with someone with mental health problems. Other predictors considered were ethnicity (3 levels: white, Asian, black); religion: a) religious denomination (4 levels: Christian, Muslim, Hindu, Non-religious); b) importance of religion in the participant's life; and c) frequency of worship; gender; age; and education (3 levels: to age 16, to age 18, graduate). The regressions were re-run only including predictors that had emerged as significant when all variables were entered. In the final models, endorsement of different causal beliefs was predicted by the variables detailed in Tables 33 and 34.

Table 33. *Predictors of causal beliefs for intellectual disability: results of multiple regression analyses*

Causal Beliefs	<i>B</i>	<i>SE B</i>	β
Biomedical (N=1625)			
Constant	3.03	0.09	
Recognition	1.05	0.07	.36***
Ethnicity: Black	0.21	0.09	.06*
Adversity (N=1608)			
Constant	3.70	0.13	
Recognition	-0.33	0.07	-.12***
Age	-0.02	0.003	-.12***
Ethnicity: Black	0.47	0.09	.13***
Environment (N=1592)			
Constant	3.48	0.14	
Recognition	-0.87	0.06	-.35***
Age	-0.01	0.003	-.08***
Gender	0.14	0.05	.06*
Ethnicity: White	0.25	0.06	.11***
Ethnicity: Black	0.53	0.09	.16***
Religion: Importance	0.03	0.01	.07**
Supernatural (N=1618)			
Constant	0.48	0.03	
Recognition	-0.09	0.01	-.20***
Education: to age 16	-0.15	0.03	-.15***
Religion: Muslim	-0.09	0.02	-.14***
Religion: Importance	0.02	0.002	.21***

Note. Biomedical $R^2=.13$; Adversity $R^2=.05$; Environment $R^2=.18$; Supernatural $R^2=.17$ ($p < .001$).

Recognition: 0=no, 1=yes; Ethnicity, Religious Denomination and Education: 0=named group; 1=all others; Gender: 0=female, 1=male; Contact: 0=no prior contact, 1=prior contact;

* $p < .05$, ** $p < .01$, *** $p < .001$

Recognition of the vignette as intellectual disability or some other form of developmental disability predicted all four causal beliefs. Those with greater intellectual disability literacy were more likely to endorse biomedical causes and less likely to endorse adversity, environmental and supernatural causes. Younger people were more likely to endorse adversity and environmental causes. Gender only affected endorsement of environmental causes with women less likely to agree with these. Ethnicity affected three of the four subscales: black participants were less likely to agree with biomedical, adversity and environmental causes; white participants were also less likely to agree with the latter. Participants of any denomination who described religion as important in their lives were more likely to endorse environmental and supernatural causes. Muslims and participants with the lowest educational attainments were more likely to agree with supernatural causes. Contact was not associated with any of the causal beliefs for intellectual disability.

Knowledge played a similar role in relation to causal beliefs for the schizophrenia vignette, see Table 34. Those who recognised the vignette as schizophrenia/psychosis were more likely to endorse biomedical causes and less likely to endorse adversity, environmental and supernatural causes. Those who explained the behaviour with reference to mental illness generally were also less likely to agree with environmental and supernatural causes but the effects were much smaller than actual recognition of schizophrenia. Failure to recognise mental illness, compared to all other explanations, was only associated with reduced endorsement of biomedical causes. Of note, explanation of the vignette as depression was also associated with reduced endorsement of biomedical causes. Women were more in agreement with adversity causes and less with environmental causes than men. Younger participants agreed more with adversity causes, as for intellectual disability. Ethnicity influenced agreement with adversity, environmental

and supernatural causes. Black participants were less likely to agree with adversity and environmental causes; white participants were less likely to endorse environmental and supernatural causes compared to all other participants. Religion was only relevant to supernatural causes in that, similar to intellectual disability, Muslims and participants of any denomination who described religion as important in their lives were more likely to agree with such causes. As for intellectual disability, prior contact played no role in predicting causal beliefs.

Table 34. *Predictors of causal beliefs for schizophrenia: results of multiple regression analyses*

Causal Beliefs	<i>B</i>	<i>SE B</i>	β
Biomedical (N=1477)			
Constant	3.05	0.17	
Recognition: Mental Illness not recognised	0.59	0.09	.18***
Recognition: Schizophrenia	-0.26	0.09	-.09**
Recognition: Depression	0.56	0.11	.14***
Adversity (N=1441)			
Constant	3.53	0.16	
Recognition: Schizophrenia	0.54	0.08	.17***
Gender	-0.20	0.07	-.07**
Age	-0.02	0.003	-.12***
Ethnicity: Black	0.54	0.10	.14***
Environment (N=1457)			
Constant	0.63	0.13	
Recognition: Schizophrenia	1.04	0.08	.37***
Recognition: General Reference to Mental Illness	0.63	0.07	.24***
Gender	0.23	0.06	.09***
Ethnicity: White	0.48	0.07	.20***
Ethnicity: Black	0.74	0.09	.22***
Supernatural (N=1452)			
Constant	0.23	0.05	
Recognition: Schizophrenia	0.14	0.02	.24***
Recognition: General Reference to Mental Illness	0.07	0.01	.13***
Education: to age 16	-0.13	0.03	-.12***
Education: Graduate	0.03	0.01	.06*
Ethnicity: White	0.09	0.01	.18***
Religion: Muslim	-0.08	0.02	-.11***
Religion: Importance	0.01	0.002	.16***

Note. Biomedical $R^2=.06$; Adversity $R^2=.06$; Environment $R^2=.19$; Supernatural $R^2=.25$ ($ps<.001$).

Recognition, Ethnicity, Religious Denomination and Education: 0=named group; 1=all others; Gender: 0=female, 1=male; Contact: 0=no prior contact, 1=prior contact

* $p<.05$, ** $p<.01$, *** $p<.001$.

6.4 Discussion

This study set out to examine the relationships between knowledge of intellectual disability and schizophrenia, causal beliefs and social distance among the UK general public. One of the central questions was whether these relationships are similar for both conditions or disorder specific. When presented with an unlabelled vignette depicting a young man displaying behaviours in line with a diagnosis of mild intellectual disability, lay people were most likely to endorse environmental causes. In contrast, when presented with the unlabelled schizophrenia vignette they were most likely to endorse biomedical and adversity causes. This difference may be due to a perception voiced by many participants that the schizophrenia presentation was “more serious”, which may reflect a belief that it is more likely to be due to organic and other complex factors over which the person has less control, or to feelings of uneasiness, and fear associated with psychotic symptoms.

Alternatively lay people may have a better understanding of the potential role of biomedical factors and adversity in the aetiology of mental illness, rather than intellectual disability, through public education campaigns and media coverage. Furthermore, had the focus in this study been on more severe, rather than mild, intellectual disability it is likely that biological causes would have figured far more prominently. Of note, studies of public perceptions of different types of mental illness have observed a tendency to perceive symptoms of schizophrenia as indicative of a more serious underlying disorder than depression (Cinnirella & Loewenthal, 1999; Furnham, 1988). Hence it would seem that schizophrenia may generally be perceived as very severe by lay people and as more likely to be caused by biomedical factors than other forms of mental illness or intellectual disability.

Increased intellectual disability and schizophrenia literacy were associated with increased endorsement of biomedical factors, and reduced endorsement of

psychosocial and supernatural factors, in line with findings on mental illness by Schomerus et al. (2006). As predicted, recognition of schizophrenia, rather than attribution to mental illness generally, enhanced this effect. The same was not found for intellectual disability though, where no significant differences were found between those who recognised intellectual disability and those who attributed the presentation to specific learning difficulties or autism spectrum disorders. Again it is likely that this is due to the fact that the vignette depicted someone with mild symptoms of intellectual disability. Were the presentation of someone with more severe intellectual disabilities one would expect an increased endorsement of biomedical causes, compared to specific learning difficulties, but perhaps not when compared to autism spectrum disorders. The differences found between those who identified schizophrenia rather than attributing the presentation to depression or mental illness generally indicate that future research should pay close attention to lay people's detailed understanding, rather than simply studying the dichotomy of recognition as mental illness or not.

The correlations between causal beliefs and social distance were only partly in the direction predicted. For intellectual disability, endorsement of biomedical causes was associated with reduced overall social distance, but no such association was found for schizophrenia (where two individual items were associated with increased social distance). Unexpectedly environmental causal beliefs had the strongest positive correlation with social distance for intellectual disability. Why this may be the case becomes clearer once individual items constituting the environmental subscale are considered. 'Lack of daytime occupation' and 'overly lenient parents' could be construed as signs of character weakness (Dietrich et al., 2004), and thus in line with attribution theory (Weiner, 1985) as more stigmatising because the person is being blamed for their difficulties. However, the distinction

between causes within or outside the person's control drawn by Dietrich et al. (2004) seemed to hold neither for intellectual disability nor for schizophrenia in the current study. Items such as 'overly lenient parents' could not be classified as within the person's control. Furthermore, if controllability was as strong a factor as suggested previously, one might have expected adversity items such as child abuse or recent death of a relative or friend to be associated with reduced social distance, which was neither the case for intellectual disability nor for schizophrenia.

The lack of a significant correlation between biomedical causal beliefs in general and social distance in the case of schizophrenia is in line with Grausgruber, Meise, Katschnig, Schöny & Fleischhacker (2007). More specifically though, endorsement of brain abnormality/infection as cause of the behaviours depicted in the vignette was associated with increased social distance for schizophrenia, yet with reduced social distance for intellectual disability. This could be seen to discredit attempts to destigmatise schizophrenia by teaching the public to recognise it as an illness of primarily biological aetiology, and as giving credence to Read et al.'s (2006) argument that such an approach in fact increases stigma.

While emotional reactions were not assessed in the current study, recent evidence suggests that they may have an important mediating role. Accordingly, when lay people perceive mental disorders to be due to 'brain pathology' they perceive the person as unpredictable and to be feared and desire greater social distance (Angermeyer, Holzinger & Matschinger, 2010). Recent research by Connolly (2011) confirmed these findings, but also concluded that the relationship between belief in brain pathology and emotional reactions is disorder specific, and likely strongly influenced by stereotypes and media portrayals pertaining to different conditions. For schizophrenia, belief in biomedical causes was associated with increased compassion and fear to a similar degree, but the positive association

between fear and social distance was twice as strong as the negative association between compassion and social distance (Connolly, 2011). In contrast, for intellectual disability endorsement of biological causes was associated with increased compassion, which in turn was associated with decreased social distance (Connolly, Williams & Scior, in press). Thus future research into the relationships between biological causes and stigma should pay attention to the public's emotional reactions.

Agreement with supernatural causes in the current study was associated with increased social distance for both intellectual disability and schizophrenia. This confirms concerns in the intellectual disability literature, for example, that beliefs about intellectual disability as due to punishment for past sins or wrongdoings (Hubert, 2006) and religious explanations for intellectual disability generally (Croot et al., 2008) are associated with increased stigma. However, it should be noted that such beliefs were rare in the current study, including among ethnic and religious minorities. Among lay people who had low educational attainments, were very religious, or followed Islam, stigmatising supernatural beliefs were far more common though. The finding that ethnicity and religion had different effects on causal beliefs indicates that future research should consider the interplay between cultural and religious beliefs.

It is important to stress that the correlations between causal beliefs and social distance were only small for schizophrenia. Furthermore the model incorporating recognition and causal beliefs explained only 6% of the variance in social distance. This suggests that awareness and causal beliefs have only a weak influence on stigma associated with schizophrenia, which is perhaps much less driven by these factors than by negative stereotypes about people with schizophrenia as dangerous and potentially violent. Furthermore the weak relationship identified between causal beliefs and social distance for schizophrenia

may again point to a mediating role for emotional reactions, which were not the subject of this study. Finally, the fact that for schizophrenia eight causal items showed weak positive correlations with social distance, and none significant negative correlations, could be taken to suggest that aiming to lower the stigma associated with schizophrenia by tackling stigmatising causal beliefs is likely to be ineffective. In contrast, this strategy may hold more promise for intellectual disability where a much clearer relationship between causal beliefs and social distance emerged.

The hypothesis that causal beliefs mediate the relationship between knowledge and social distance was confirmed for both conditions. For intellectual disability, all four types of causal beliefs acted as mediators. Knowledge of the condition had favourable strong direct and indirect effects on social distance, the latter via the mediating effects of causal beliefs. Those who showed a greater awareness of the condition were more likely to endorse biomedical causes and less likely to endorse adversity, environmental and supernatural causes. In turn, agreement with biomedical causes was associated with reduced social distance, while agreement with environmental and supernatural causes was associated with increased social distance. One undesirable effect of recognition of the condition was identified, in that it was associated with reduced endorsement of adversity causes which, in turn, were associated with reduced social distance. In identifying suitable messages to impart as part of public education efforts, the fact that developmental delay can result from severe neglect and trauma is worth emphasising; admittedly this was of little relevance in the intellectual disability vignette used in this study, which suggested a positive home environment and made no mention of any traumatic incident.

While causal beliefs also mediated the relationship between knowledge and social distance for schizophrenia, here knowledge had only a weak direct effect on

social distance, and less comprehensive indirect effects than for intellectual disability. Only supernatural beliefs had a strong mediating role; recognition of the condition was associated with reduced endorsement of supernatural causes, and endorsement of such causes had a strong positive effect on social distance. Recognition showed strong direct effects on agreement with biomedical and environmental causes, but their effects on social distance were not significant. A similar “undesirable” effect was found for adversity causes as noted for intellectual disability, again suggesting that the potential role of trauma in the aetiology of severe mental illness should be considered as a message in public education efforts.

A mixed picture emerged regarding the role of contact and participants’ socio-demographic characteristics as predictors of causal beliefs. As noted in the previous chapter, prior contact with individuals with intellectual disability/mental health problems was associated with increased awareness and reduced social distance. Contact had no role though in predicting causal beliefs for either condition. This may seem surprising as one might have expected contact to be associated with greater endorsement of the role of biomedical factors and trauma in the aetiology of psychopathology, in line with scientific evidence, not least in the field of schizophrenia (e.g. Howes, McDonald, Cannon, Arseneault, Boydell & Murray, 2004; Read, van Os, Morrison & Ross, 2005). However, the lack of association between contact and causal beliefs may suggest that contact allows lay people to appreciate the often very complex aetiology of disorders. In the case of mild intellectual disability, in about 50% of cases the cause is unknown and clearly diagnosed genetic causes have been found in only 5% of people in this category (Stromme & Diseth, 2000; The Knowledge Network, undated). Instead, organic causes, such as exposure to alcohol and other toxins prior to birth, hypoxia and other peri-natal problems, and some chromosomal abnormalities are believed important (Muir, 2000). Furthermore,

higher rates of mild intellectual disability in some social classes suggest that social inequalities, and factors such as large families, overcrowding and poverty are important (Emerson, Hatton & Robertson, 2011).

Similarly the finding of a lack of association between contact and causal beliefs may indicate that lay people who know anyone with psychotic symptoms may be aware of the very complex distal and proximal risk factors for psychosis. It is important though to note that participants were asked about prior contact with someone with mental health problems, but not specifically about contact with individuals with schizophrenia. Hence the effect of contact on causal beliefs regarding schizophrenia may have been underestimated.

Education, gender and age played fairly minor roles in predicting causal beliefs. In line with previous studies, less educated people had less well informed beliefs (Furnham & Telford, 2012). The greater likelihood among younger people to subscribe to adversity causes for both conditions, and also to environmental causes for intellectual disability can perhaps be explained with reference to a generally stronger interest in psychosocial factors among younger people, or what one might describe as an affinity with the nurture pole of the long-standing nature-nurture debate.

The associations found between ethnicity and causal beliefs were only partly as predicted. Lay people from ethnic minorities are more likely to belong to cultural communities where beliefs in supernatural forces and spiritual retribution are more common (Srinivasan & Thara, 2001), hence it was expected that Asian and black participants would be more likely to endorse supernatural causes. When the effects of ethnicity on causal beliefs were examined in isolation, large differences were noted in the likelihood among different ethnic groups to agree with supernatural and environmental causes in particular. Both Asians and blacks were far more likely to

endorse supernatural causes than whites, and Asians were more likely to endorse environmental causes than both whites and blacks. However, once recognition, educational attainment, and religion were taken into account, ethnicity emerged as independent predictor of belief in supernatural causes only for schizophrenia, but not for intellectual disability. The fact that ethnicity did not play a stronger role may be at least in part due to the sample's characteristics; on the whole participants were relatively young, highly educated and fluent in English, suggesting a high level of acculturation. It is likely that supernatural causes are more likely to be endorsed by older individuals who adhere more strongly to values and practices of their cultures of origin. Alternatively it is possible that the present findings are not untypical and that belief in supernatural causes of mental disorders is weak across different cultural groups, in line with Swami, Furnham, Kannan and Sinniah (2008).

Causal beliefs differed by religious denomination, not surprisingly differences were largest for supernatural causes. Once religion was considered jointly with other socio-demographic factors in regressions, it was only independently predictive of supernatural beliefs. Muslims, and, unsurprisingly, those who described religion as important in their lives, were more likely to endorse supernatural causes, such as the idea that both presentations could result from some form of retribution for wrongdoings, spirit possession or some other form of spiritual problem, or a divine test. While it has been noted that beliefs in possession may be more common among fundamentalist Christians (Hartog & Gow, 2007), in this study only Muslims but not Christians were more likely to agree with supernatural causes. This perhaps reflects the fact that the current Christian sample consisted of people from very different ethnic backgrounds and thus different Christian orientations, including Church of England as well as more fundamentalist beliefs found particularly among African congregations. It is also worth noting that in many instances there is a lot of

interplay between culture and religion. Practices that are influenced by traditional African cultural values and norms, for example, have been integrated into Christianity, which originates in a Western context (Kassah, 2008). Nevertheless it seems important in future research to study the influence of culture and religion on lay perceptions separately to avoid the frequent *a priori* confusion of ethnicity and religion.

6.4.1 Limitations

Several limitations of the present study are important to note. Due to resource limitations the study used convenience sampling and snowballing to recruit a large general population sample. Overall the sample was comparatively young and highly educated; hence caution should be exercised in trying to generalise the findings. Furthermore, the fact that the data were mostly gathered in English, via a web survey means that the views of less computer literate people and those with limited English skills are inevitably underrepresented. Hence caution should be exercised in generalising the findings. It is likely that particularly in examining the effects of ethnicity and religion on causal beliefs, a more representative sample may generate different findings. A further limitation concerns the choice of causal items. While these were informed by a pilot and revised in line with lay people's responses to open ended questions relating to the vignettes, see chapter 3, without question the items cited may not map closely onto lay people's beliefs. For the purposes of studying beliefs in some cultural and religious contexts the items may need augmenting with items that tap into beliefs that may be common within the context studied. Colleagues who have used the IDLS, for example, to study lay beliefs within the UK Sikh community have done so by adding causes that may find greater endorsement among this community. Thus a more accurate picture of causal beliefs

within this community was gained, without negatively affecting the measure's psychometric properties (Kaur, 2011).

Another limitation concerns the fact that the order of presentation of the vignettes was kept constant rather than randomly varied. It is conceivable that had the schizophrenia vignette been presented first, endorsement of biomedical causes might have been lower as respondents might not have experienced a sense of increased severity and greater likelihood of underlying organic factors compared to the intellectual disability vignette. Future studies that use the IDLS should vary the presentation order.

Finally, the risk of participants giving socially desirable responses merits consideration. It is conceivable that the study being conducted by a university may have discouraged participants from expressing beliefs that could be deemed 'unscientific'. Evidence on social desirability effects in different recruitment methods is limited. However, it seems reasonable to suggest that in an anonymous web based survey social desirability effects may be less pronounced than for example in studies that have used telephone interviews (e.g. Ouellette-Kuntz et al., 2010) or face to face interviews (e.g. Jorm & Griffiths, 2008). The potential bias inherent in such different methods is a question for further research though.

6.4.2 Conclusions

What conclusions can be drawn from the present findings? Knowledge of the respective condition had a much clearer role in predicting causal beliefs than socio-demographic factors. This suggests that increasing the public's awareness of a range of mental disorders through education has an important role to play. This may also have the beneficial effect of lowering stigma associated with intellectual disability, but is less likely to do so for schizophrenia, where causal beliefs, other than supernatural ones, showed only a weak association with stigma.

**Chapter 7: Beliefs about suitable interventions for
intellectual disability and schizophrenia and
their match with causal beliefs**

Abstract

Background: Public causal beliefs about different types of mental illness have found much empirical attention, while intervention beliefs are somewhat less well understood. Research into lay beliefs about suitable interventions for intellectual disability is almost non-existent, but can have important implications for help seeking and early diagnosis where developmental delay is undiagnosed.

Methods: 1752 members of the UK public of working age were presented with two diagnostically unlabelled vignettes of someone presenting behaviours indicative of intellectual disability and schizophrenia. They indicated their agreement with 22 possible causes and 22 interventions and provided detailed socio-demographic information.

Results: Intervention beliefs closely matched causal beliefs, with the closest match between environmental causes and social and environmental interventions, subsumed under a *lifestyle* factor. Lay people favoured expert help for schizophrenia, and lifestyle changes ahead of expert input for intellectual disability. Religious or spiritual interventions were generally deemed unhelpful, more so for schizophrenia, but were endorsed by a sizeable minority. Awareness of the respective condition was associated with increased endorsement of expert interventions and reduced endorsement of lifestyle and religious interventions, regardless of condition. Participants' ethnicity and religion were associated with endorsement of lifestyle and religious/spiritual interventions, while other socio-demographic characteristics played only a minor role in predicting intervention beliefs.

Conclusions: Lay beliefs about interventions for intellectual disability and schizophrenia can provide useful insights that may affect help seeking and early

diagnosis. Public endorsement of religious interventions in particular may generally be underestimated and should be the focus of further research.

Beliefs about suitable interventions for intellectual disability and schizophrenia and their match with causal beliefs

The final aspect of lay conceptualisations under investigation in this thesis concerns beliefs about suitable sources of help. This chapter presents data on lay people's beliefs about suitable interventions for someone presenting with symptoms of intellectual disability or schizophrenia. Differences in lay beliefs about both conditions are compared and the association between causal and intervention beliefs is examined. Furthermore the effect of awareness of the condition, contact and socio-demographic characteristics on intervention beliefs is examined.

7.1 Introduction

Lay conceptualisations of mental illness have been described as involving dimensions of pathologising, that is judgments about deviance and social norm violations; moralising, that is judgments about weak character and personal will; medicalising, essentially a perception that the behaviour is unintentional and distinct from the norm; and psychologising, whereby the behaviour is viewed as rooted in life events (Hinshaw & Stier, 2008). In view of these dimensions, one would expect different lay beliefs to lead to different treatment preferences and responses. Studies have examined whether there is a clear and rational relationship between lay people's causal beliefs and treatment preferences. One might expect, for example, that if problems are attributed to biological causes, some form of physiological treatment would be favoured. Conversely if the problem is attributed to supernatural factors, the help of a spiritual healer might be preferred. While a clear relationship between causal beliefs and treatment preferences has been established in some studies (Furnham & Buck, 2003, Hugo, Boshoff, Traut, Zungu-Dirwayi & Stein, 2003; Kuppin & Carpiano, 2009; Riedel-Heller, Matschinger & Angermeyer, 2005), this is not always the case. In Furnham and Bower's (1992) study, for example, lay people

favoured psychosocial causes for schizophrenia, yet perceived medication as the most suitable treatment.

Lay people's treatment preferences have been studied in relation to a wide range of psychiatric and behavioural disorders, including schizophrenia, depression, substance abuse and ADHD (Jorm et al., 2005; Kuppin & Carpiano, 2006; McLeod, Fettes, Jensen, Pescosolido & Martin, 2007; Reavley & Jorm, 2012a; Riedel-Heller et al., 2005). Psychotherapy is generally preferred over drug treatment (Angermeyer & Matschinger, 1996; Angermeyer & Dietrich, 2006; Riedel-Heller et al., 2005). Nevertheless it appears the preference for psychotherapy varies across different conditions. Comparing public perceptions of the perceived effectiveness of a range of treatments, Furnham (2009) found that while psychotherapy was the most favoured treatment for depression and obsessive compulsive disorder, for schizophrenia and bipolar disorder drug treatment was favoured over psychotherapy, although the latter was still deemed helpful. A preference for drug treatment may well be due to a perception among lay people that schizophrenia is more serious, and more likely to have an organic cause than depression, the two most widely studied conditions (Cinnirella & Loewenthal, 1999; Furnham, 2009).

Despite strong evidence of the effectiveness of psychotropic medication in treating psychosis and depression and agreement with drug treatment in some studies, numerous studies have found lay beliefs about medication to be very negative. Such perceptions have been attributed mainly to fears about side effects and a perception that medication only tackles the symptoms but not the causes of distress (Angermeyer et al., 1993; Fischer, Goerg, Zbinden & Guimon, 1999; Jorm et al., 1997; Caldwell & Jorm, 2001). Perceptions about medication may be changing over time though, as suggested by Jorm, Christensen and Griffiths (2006) and Reavley and Jorm (2012a). They found that over the period 1995 to 2011, the rate

of Australians who rated anti-depressants and anti-psychotics as helpful had doubled to 59% and 48.3% respectively in 2011. Nonetheless, treatments such as physical activity and learning about the problem were still deemed far more helpful for schizophrenia (Reavley & Jorm, 2012a). In contrast, Furnham (2009) found that British lay people thought drug treatment the most effective intervention for schizophrenia followed by psychotherapy.

Lay beliefs about treatment have been studied in a range of cultural and religious contexts. In a study of the perceptions of religious lay people in the UK, Cinnirella and Loewenthal (1999) found that, compared to depression, schizophrenia was perceived as more likely to require professional help and as less likely to benefit from religious coping strategies. Furthermore due to concerns about community stigma associated with mental illness among black Christian and Pakistani Muslim participants, lay people from these communities had a preference for private coping strategies. Studies in developing nations have concluded, for example, that Malaysians tend to believe that schizophrenia is caused by stress in interpersonal relationships, social life or childhood development and show a corresponding preference for treatment by changing societal responsibilities, while also viewing psychiatric in-patient treatment as potentially beneficial (Swami et al., 2008). In Ethiopia traditional sources of help, such as witchcraft, holy water and herbalists, were viewed as more helpful for a range of mental illnesses than medical help (Alem et al., 1999). In Pakistan lay people tended to view general practitioners, psychologists and psychiatrists as most appropriate to treat psychosis, but a sizeable proportion favoured magic or religious healers (Suhail, 2005).

One of the few studies to include intellectual disability in comparative analyses of lay perceptions, conducted in Ethiopia, concluded that intellectual disability was less likely to be attributed to psychosocial stress than mental illness,

and more likely to be attributed to supernatural retribution than depression, alcoholism and tuberculosis (Mulatu, 1999). Perceiving intellectual disability to be caused by supernatural retribution in turn was associated with increased belief in prayer and more negative attitudes.

Why is it important to understand lay beliefs about interventions for different conditions? In an era of evidence based practice, there is a danger at times that the views of the public as potential future users of services are ignored. As Jorm (2000) noted, where evidence based treatments do not accord with public views, people who develop mental disorders, or care for someone who does, may be unwilling to seek those treatments or unlikely to adhere to them. They may also delay diagnosis and appropriate treatment and may burden services by seeking inappropriate help.

In addition, studying lay beliefs by paying attention to lay knowledge of the respective condition is important. Where lay knowledge is low, and conversely the risk that symptoms are misconstrued high, this can result in delayed help seeking, and stigma. In relation to intellectual disability, for example, a failure to recognise possible symptoms of developmental delay in children can result in delayed diagnosis and delayed access to remedial interventions. Furthermore attribution of behaviours associated with mental illness or intellectual disability to, for example, bad character, laziness or poor parenting may not only result in inappropriate interventions, but also in blaming and stigmatisation of the individual and their family. Moreover, knowledge of a condition and use of appropriate terminology may facilitate communication with health professionals about possible interventions. In this context it is important to pay attention to the role of culture and religion in shaping lay beliefs about treatment. It has been suggested that mistrust of services and a clash in values contribute to the disparity in access to services and poorer health among ethnic minorities (Atkin & Ahmad, 2000; Mir et al., 2001; Sashidharan, 2003; Szczepura,

2005). However the role of intervention beliefs among lay people from ethnic and religious minorities has found little attention to date as a potential barrier to equitable access.

7.1.1 Study aims

The present study set out to advance our understanding of lay beliefs regarding suitable interventions for someone presenting with undiagnosed symptoms of intellectual disability or schizophrenia. The research questions were: 1) what interventions are deemed most helpful by the UK public for an adult presenting with undiagnosed symptoms of intellectual disability or schizophrenia?; 2) are beliefs about interventions closely in line with causal beliefs?; 3) what is the role of intellectual disability and schizophrenia literacy in informing intervention beliefs?; and 4) what is the role of contact and socio-demographics in influencing intervention beliefs? As in previous chapters these processes were examined in relation to both intellectual disability and schizophrenia.

It was hypothesised that the UK public would deem expert help delivered by medical or psychological personnel more appropriate for schizophrenia. For intellectual disability it was predicted that a more mixed picture would emerge with psychosocial interventions over which the individual has control perhaps being favoured, but with expert help also endorsed, yet with less agreement with medical treatment than for schizophrenia. It was further hypothesised that beliefs about suitable interventions would show a fairly close correspondence with causal beliefs. Hence participants who endorsed biomedical causes were expected to favour expert help, those who agreed with environmental causes to favour lifestyle solutions, and those who endorsed supernatural causes to also agree with religious/spiritual interventions. It was also predicted that increased awareness of either condition would be associated with greater endorsement of expert help and less endorsement

of religious/spiritual help. Finally, it was predicted that participants from cultures that have a stronger belief in supernatural forces and those for whom religion is important would be more likely to endorse religious/spiritual help than non-religious participants, but would entertain expert and lifestyle solutions at the same time.

7.2 Method

7.2.1 Participants

The sample was the same as that described in chapter 5.

7.2.2 Measures

Participants were presented with the same diagnostically unlabelled vignettes as described previously. Following each vignette, participants indicated their agreement with 22 possible causes of the person's difficulties, and 22 possible sources of help using a 7-point Likert scale (1=disagree strongly, 7=agree strongly), see Appendix 1. Hence participants' causal and intervention beliefs related to their understanding of the symptoms depicted in the vignette rather than a diagnostic category.

Participants also provided detailed socio-demographic information, as described in previous chapters. As in the previous studies, participants who indicated that they were service providers either in the field of intellectual disability or mental health were excluded as the study's focus was on the general public.

7.2.3 Procedure

The procedure was the same as that described in chapter 6.

7.2.4 Data Analysis

7.2.4.1 Data Screening. Exploration of the data indicated that the expert and lifestyle subscales for both intellectual disability and schizophrenia approximated normal distributions. However, the religious/spiritual subscale showed large positive skewness; most participants disagreed with such interventions, regardless of

condition. This subscale and its constituent items were log transformed which resolved problems with the data. The other subscales were not transformed as comparisons were only computed between items within each scale.

7.2.4.2 Statistical analysis: The data were analysed using SPSS version 19. As noted in chapter 6, responses to the 22 causal items were analysed under four subscales: biomedical, adversity, environment and supernatural (log transformed). Responses to the 22 interventions were analysed individually and under three subscales, in line with the factor and reliability analysis presented in chapter 3: expert, lifestyle and religious/spiritual help. For each subscale a mean score of the constituent items was calculated. Higher scores indicate stronger endorsement for both causal and intervention beliefs.

Descriptive statistics were calculated for each condition. Endorsement of expert and lifestyle items and their corresponding factors was compared between intellectual disability and schizophrenia using *t* tests. The relationships between causal and intervention beliefs were examined using Spearman's rho correlations, given that two subscales were not normally distributed: beliefs about religious/spiritual interventions and about supernatural causes. Intervention beliefs were then examined separately for intellectual disability and schizophrenia by the explanation participants advanced for the vignette using ANOVAs and post hoc tests. Finally, the role of explanation, contact and participants' socio-demographic characteristics in predicting intervention beliefs was examined using multiple regressions. Bonferroni corrections were applied to all multiple tests to control for Type I error, other than post hoc tests that employed the more stringent Games-Howell procedure, taking account of comparisons where homogeneity of variances could not be assumed. Effect sizes are stated throughout as Cohen's *d*. For the religious/spiritual items and subscales, all statistical analyses were performed on the

log transformed data and all test results reported, including effect sizes, are based on the transformed data. However, as the transformed means and standard deviations are difficult to interpret, the original means and standard deviations are reported.

7.3 Results

7.3.1 Intervention beliefs

Participants' agreement with the 22 intervention items was examined. Paired-samples t tests were conducted to evaluate whether participants differed in their agreement with the interventions when responding to the intellectual disability or schizophrenia vignettes, see Table 35.

Table 35. *Endorsement of 22 intervention items for intellectual disability and schizophrenia: Descriptive statistics and results of within-subjects tests*

Intervention	Intellectual Dis. M (SD)	Schizophrenia M (SD)	<i>t</i>	<i>d</i>
<i>Expert</i>				
General Practitioner	4.28 (1.82)	5.54 (1.74)	-25.80*	.71
Counsellor	5.10 (1.57)	5.53 (1.60)	-10.20*	.27
Psychiatrist	4.53 (1.77)	5.96 (1.46)	-30.49*	.88
Social worker	4.31 (1.77)	4.23 (1.92)	1.51	.04
Psychological treatment	4.24 (1.80)	5.62 (1.58)	-28.91*	.81
Prescribed psychiatric medication	3.20 (1.81)	5.01 (1.86)	-34.84*	.97
<i>Lifestyle</i>				
Get him to take more responsibility	5.27 (1.48)	3.40 (1.87)	36.18*	1.11
Turn to close family	4.61 (1.51)	4.54 (1.75)	1.39	.04
Get out more	4.78 (1.54)	4.47 (1.84)	6.33*	.18
Get a job	5.24 (1.61)	3.82 (1.90)	28.66*	.81
Get a good talking to from his parents	3.88 (2.03)	2.86 (2.00)	22.30*	.51
More physical activity	4.79 (1.62)	4.33 (1.83)	10.54*	.27
Careers advice	5.20 (1.66)	3.67 (1.95)	29.15*	.84
Socialise more	3.58 (2.05)	4.33 (1.85)	-13.47*	.38
Make him face up to reality	4.52 (1.99)	3.33 (1.97)	23.28*	.60
Find a partner/spouse	3.34 (1.83)	3.02 (1.88)	7.50*	.17
Go on holiday	2.85 (1.77)	3.18 (1.91)	-7.81*	.18
<i>Religious/ Spiritual</i>				
Pray	2.99 (2.09)	2.87 (2.12)	5.46*	.09
Religious person/clergy	2.72 (1.81)	2.67 (1.93)	3.46*	.06
Attend a place of worship more often	2.74 (1.91)	2.66 (1.95)	3.25*	.06
Spiritual or faith healer	3.23 (2.08)	2.18 (1.75)	20.90*	.55
Be more religious	2.40 (1.77)	2.42 (1.82)	-0.36	.00

* $p < .05$ (Bonferroni corrected)

The results showed that for the intellectual disability vignette, seeing a counsellor, getting the person to assume more responsibility, finding employment and obtaining careers advice were judged as most helpful. For the schizophrenia vignette, seeing a psychiatrist or psychologist were rated as most likely to be effective. Participants on average agreed 'somewhat' with psychiatric medication for schizophrenia, but deemed this unhelpful for intellectual disability. Overall participants felt that expert-led interventions, except social work input, were more likely to be helpful for someone presenting with symptoms of schizophrenia, with four of these comparisons showing large effect sizes. Eight of the 11 lifestyle interventions were deemed more suitable for someone presenting with symptoms of intellectual disability, five of these comparisons showing large effect sizes. The only lifestyle interventions deemed potentially of any help in the case of the schizophrenia vignette were support from close family, getting out more, increased socialising, and more physical activity. The largest difference between the conditions in lifestyle interventions concerned getting the person to take more responsibility, which participants on average agreed with somewhat for intellectual disability, but tended to disagree with for schizophrenia. Participants generally disagreed with religious/spiritual interventions, regardless of condition. The largest difference in endorsement of religious/spiritual interventions was found for 'seeing a spiritual or faith healer', which was deemed less suited to schizophrenia than to intellectual disability.

Endorsement of the three intervention factors based on the factor analysis presented in chapter 3 was then examined for both conditions. The subscales' internal reliability was very good for both conditions. For intellectual disability, Cronbach alpha values were $\alpha=.81$ for expert, $\alpha=.83$ for lifestyle, and $\alpha=.86$ for religious/spiritual interventions. For schizophrenia, Cronbach alpha values were

$\alpha=.76$ for expert, $\alpha=.92$ for lifestyle, and $\alpha=.93$ for religious/spiritual interventions. Inter-item correlations were between .16 and .82, indicating that the items measured distinct yet in some cases overlapping constructs.

As predicted, participants deemed expert help ($M=5.33$, $SD=1.09$) as most suitable for someone presenting with symptoms of schizophrenia, ahead of lifestyle ($M=3.70$, $SD=1.39$) and religious/spiritual interventions ($M=2.54$, $SD=1.70$). A more mixed picture emerged for the intellectual disability vignette, as predicted. For this vignette expert help ($M=4.30$, $SD=1.26$) and lifestyle interventions ($M=4.37$, $SD=1.03$) found similar levels of endorsement, with less agreement with religious/spiritual interventions ($M=2.82$, $SD=1.54$). Comparisons of responses to the intellectual disability and schizophrenia vignettes showed that participants were much less likely to favour expert help for intellectual disability than for schizophrenia, $t(1471)=-31.59$, $p<.01$, $d=.87$. They were less likely to deem lifestyle interventions suitable for schizophrenia than for intellectual disability, $t(1471)=21.88$, $p<.01$, $d=.55$. The same picture emerged for religious/spiritual interventions, $t(1470)=13.34$, $p<.01$, $d=.26$. As noted above, all p-values were Bonferroni corrected.

7.3.2 Association between intervention and causal beliefs

To assess whether beliefs about interventions were in line with causal beliefs, correlations were computed, see Table 36. In line with the hypotheses, beliefs about suitable interventions showed a fairly close correspondence with causal beliefs. For both conditions, participants who endorsed biomedical causes favoured expert help, those who endorsed environmental causes favoured lifestyle solutions, and endorsement of supernatural causes was associated with increased agreement with religious/spiritual interventions. No predictions had been made about beliefs in adversity causes. For intellectual disability, these showed only moderate correlations

with the three intervention factors. For schizophrenia, they showed the strongest correlation with lifestyle interventions. Of note, by far the strongest correlations were established between endorsement of environmental causes and lifestyle interventions. Furthermore, participants who endorsed environmental causes were far more likely to favour religious/ spiritual interventions than expert led ones.

Table 36. *Correlations between causal and intervention beliefs*

	Expert Interventions	Lifestyle Interventions	Religious/Spiritual Interventions
<i>Intellectual disability</i>			
Biomedical Causes	.48*	-.11*	.10*
Adversity Causes	.24*	.32*	.20*
Environmental Causes	.01	.64*	.31*
Supernatural Causes	.11*	.33*	.46*
<i>Schizophrenia</i>			
Biomedical Causes	.35*	-.04	.06
Adversity Causes	.17*	.41*	.23*
Environmental Causes	-.10*	.73*	.39*
Supernatural Causes	-.13*	.38*	.60*

*Spearman's rho significant at $p < .05$ (Bonferroni corrected)

7.3.3 Awareness of the condition and intervention beliefs

To assess the role of intellectual disability and schizophrenia literacy in informing intervention beliefs, the latter were examined by the explanation participants spontaneously advanced for the respective vignette, when asked "*what would you say is going on with X?*", see Tables 37 and 38.

Table 37. *Endorsement of interventions by explanation given for intellectual disability vignette: Means (standard deviations) and results of between-subjects tests*

Interventions	Total N=1697	Intellectual Disability (n=490)	Specific LD/ ASD n (65)	Other Explanation (n=1142)	<i>F</i>
Expert	4.29 (1.26)	4.68 (1.17)	4.80 (1.10)	4.09 (1.26)	45.23*
Lifestyle	4.37 (1.03)	3.86 (1.04)	3.76 (1.03)	4.63 (0.93)	123.63*
Religious/Spiritual	2.81 (1.54)	2.46 (1.40)	2.46 (1.47)	2.99 (1.58)	22.49*

* $p < .001$

There was a significant effect of explanation on all three intervention beliefs for intellectual disability. Post hoc tests using the Games-Howell procedure indicated that, compared to participants who gave other explanations for the vignette, those who recognised intellectual disability were more likely to endorse expert interventions, $p < .001$, $d = .49$, and less likely to agree with lifestyle, $p < .001$, $d = .78$, and religious/spiritual interventions, $p < .001$, $d = .37$. However, comparisons of the three types of interventions between those who recognised intellectual disability and those who attributed the presentation to specific learning difficulties or ASD were not statistically significant at $p < .05$.

Table 38. *Endorsement of interventions by explanation given for schizophrenia vignette: means (standard deviations) and results of between-subjects tests*

Interventions	Total N=1527	Schiz./ Psychosis (n=365)	Depression (n=190)	Mental Illness (general/ other) (n=470)	Other Explanation (n=308)	<i>F</i>
Expert	5.35 (1.09)	5.76 (0.81)	5.21 (1.02)	5.47 (1.00)	4.78 (1.27)	41.13*
Lifestyle	3.64 (1.39)	2.92 (1.18)	4.27 (1.20)	3.49 (1.31)	4.33 (1.38)	72.13*
Spiritual/religious	2.51 (1.71)	1.81 (1.22)	2.77 (1.84)	2.32 (1.60)	3.47 (1.82)	48.81*

* $p < .001$

For schizophrenia there was also a significant effect of explanation on all three intervention beliefs. Post hoc tests using the Games-Howell procedure indicated that those who recognised schizophrenia were more like to endorse expert interventions than those who attributed the presentation to depression, $p < .001$, $d = .60$; mental illness in general, $p < .001$, $d = .32$; or gave other explanations, that is failed to recognise mental illness, $p < .001$, $d = .92$. They were also less likely to endorse lifestyle interventions than the other three groups, with large differences found compared to the group who attributed the behaviours to depression, $p < .001$, $d = 1.13$, and those who gave other explanations, $p < .001$, $d = 1.10$, and a moderate difference with the group who referred to mental illness in general, $p < .001$, $d = .46$. Finally, participants who recognised schizophrenia were also less likely to endorse religious/spiritual help than the other three groups: compared to the depression group, $p < .001$, $d = .56$; and compared to the general reference to mental illness group, $p < .001$, $d = .36$. Those who gave other explanations for the vignette were most likely to endorse religious/spiritual help, $p < .001$, $d = 1.05$, compared to those who recognised schizophrenia.

7.3.4 Socio-demographic factors and intervention beliefs

In considering the role of socio-demographic factors, initially intervention beliefs were examined for the main ethnic and religious groups, see Tables 39 and 40.

Table 39. *Intervention beliefs by ethnic group: Means (Standard Deviations) and results of one-way ANOVAs*

Intervention Beliefs	Entire sample N=1742	White n=813	Asian n=463	Black n=255	<i>F</i>
Intellectual Disability					
Expert	4.28 (1.26)	4.33 (1.21)	4.24 (1.34)	4.21 (1.22)	1.26
Lifestyle	4.37 (1.03)	4.26 (1.01)	4.57 (0.96)	4.17 (1.13)	17.77***
Religious/Spiritual	2.82 (1.54)	2.14 (1.16)	3.40 (1.55)	3.77 (1.65)	190.60***
Schizophrenia					
Expert	5.33 (1.09)	5.50 (1.01)	5.20 (1.14)	5.00 (1.17)	24.00***
Lifestyle	3.70 (1.39)	3.48 (1.33)	4.22 (1.37)	3.49 (1.42)	38.26***
Religious/Spiritual	2.54 (1.70)	1.78 (1.13)	3.35 (1.75)	3.77 (1.86)	240.42***

Endorsement of intervention beliefs differed for the three main ethnic groups on the lifestyle and religious/spiritual subscales for intellectual disability and on all three subscales for schizophrenia. For intellectual disability, post hoc tests with Games Howell correction showed that Asians were more likely to agree with lifestyle interventions than both white, $p < .001$, $d = 0.31$, and black participants, $p < .001$, $d = 0.38$. Agreement with religious/spiritual interventions was higher among both Asian and black participants compared to whites, both $p < .001$, $d = 0.92$ and $d = 1.14$ respectively. The difference between Asian and black participants was also significant, $p = .02$, $d = 0.23$, all Hochberg's GT2 corrected.

For schizophrenia, white participants were more likely to agree with expert help than both Asian and black participants, both $p < .001$, $d = 0.28$ and $d = 0.46$ respectively, Games Howell corrected. The difference between Asian and black participants was not significant. Asians were more likely to endorse lifestyle interventions than whites and blacks, both $p < .001$, $d = 0.55$ and $d = 0.52$, Hochberg's GT2 corrected. Finally, agreement with religious/spiritual interventions (Games Howell corrected) was higher among both Asian and black participants compared to whites, both $p < .001$, $d = 1.07$ and $d = 1.29$ respectively. The difference between Asian and black participants was also significant, $p = .04$, $d = 0.23$.

Analyses of intervention beliefs for the main religious groups are presented in Table 40. Participants for whom religious information was missing were excluded from these analyses.

Table 40. *Intervention beliefs by religious group: Means (Standard Deviations) and results of one-way ANOVAs*

Intervention Beliefs	Entire sample N=1672	Christian n=538	Muslim n=252	Hindu n=75	Other n=89	Non-religious/ Atheist n=718	F
Intellectual Disability							
Expert	4.28 (1.26)	4.25 (1.23)	4.28 (1.41)	4.27 (1.37)	4.59 (1.12)	4.26 (1.23)	1.45
Lifestyle	4.35 (1.02)	4.31 (1.11)	4.54 (1.01)	4.59 (1.00)	4.61 (0.90)	4.26 (0.96)	6.14***
Religious/ Spiritual	2.82 (1.54)	3.37 (1.57)	3.95 (1.57)	2.94 (1.32)	3.15 (1.37)	1.99 (1.05)	130.22***
Schizophrenia							
Expert	5.33 (1.08)	5.25 (1.11)	5.08 (1.20)	5.18 (1.14)	5.36 (1.06)	5.50 (1.00)	7.67***
Lifestyle	3.70 (1.39)	3.69 (1.39)	4.24 (1.39)	4.13 (1.51)	4.12 (1.38)	3.44 (1.32)	17.22***
Religious/ Spiritual	2.55 (1.70)	3.18 (1.74)	3.92 (1.76)	2.68 (1.41)	2.64 (1.54)	1.58 (1.01)	153.15***

Endorsement of intervention beliefs differed for the five main religious groups on all subscales, except for expert interventions for intellectual disability, with the largest differences on religious/ spiritual interventions. For intellectual disability, post hoc tests with Games Howell correction showed that Muslims were more likely to agree with lifestyle interventions compared to Christians, $p=.04$, $d=0.22$, and non-religious participants, $p=.002$, $d=0.28$. Followers of other religions agreed more with such interventions than Christians, $p=.04$, $d=0.30$, and non-religious participants, $p=.008$, $d=0.38$; the difference between Hindus and non-religious participants approached significance, $p=.06$, $d=0.37$. Religious/spiritual interventions (Games Howell corrected) were more likely to be endorsed by Muslims compared to all other groups, with $p=.002$, $d=0.47$, compared to the 'other' group; and $p<.001$ for all others, with effects sizes of $d=0.23$ compared to Christians, $d=0.61$ compared to Hindus, and $d=1.43$ compared to non-religious participants. The latter were also far less likely to endorse such interventions compared to the other three groups, all $p<.001$; with effect sizes of $d=1.01$ compared to Christians, $d=0.78$ compared to Hindus, and $d=0.94$ compared to followers of other religions.

For schizophrenia, post hoc tests with Games Howell correction showed that non-religious participants were more likely to agree with expert interventions compared to Christians, $p=.001$, $d=0.23$, and Muslims, $p<.001$, $d=0.38$. Lifestyle interventions (Hochberg's GT2 corrected) were least likely to be endorsed by non-religious participants compared to all others, namely compared to Christians, $p=.02$, $d=0.19$; Muslims, $p<.001$, $d=0.59$; Hindus, $p=.003$, $d=0.49$; and those of other religions, $p<.001$, $d=0.51$. In addition, Muslims agreed more with such interventions than Christians, $p<.001$, $d=0.40$. As for intellectual disability, for schizophrenia religious/spiritual interventions (Games Howell corrected) were more likely to be endorsed by Muslims compared to all other groups, all $p<.001$; with effect sizes of

$d=0.42$ compared to Christians, $d=0.69$ compared to Hindus, $d=0.74$ compared to others, and $d=1.73$ compared to non-religious participants. The latter were also far less likely to endorse such interventions compared to the other three groups, all $p<.001$; with effect sizes of $d=1.19$ compared to Christians; $d=0.95$ compared to Hindus, and $d=0.87$ compared to followers of other religions.

To address the final question, namely to what extent contact and participants' socio-demographic characteristics in combination influence intervention beliefs, multiple regressions were computed. The following predictors were entered: recognition of intellectual disability (dichotomous: 1) recognition as intellectual disability or attribution to specific LD/ASD versus 2) other explanations) and schizophrenia (four different explanations detailed in Table 38); prior contact: a) dichotomous (yes/no), b) closeness of the relationship, measured on a 10-point scale where 0=no contact; 1= not at all close and 9=extremely close, and c) frequency of contact (0=no contact; 1=infrequent, defined as up to three times per year; 2= moderate, defined as up to monthly; and 3=frequent, defined as twice per month or more frequent). For the intellectual disability condition contact was defined as prior contact with someone with intellectual disabilities, for the schizophrenia condition as prior contact with someone with mental health problems.

Other predictors considered were: ethnicity (3 levels: white, Asian, black); religion: a) religious denomination (4 levels: Christian, Muslim, Hindu, Non-religious), b) importance of religion in the participant's life, and c) frequency of worship; gender; age; and education (3 levels: to age 16, to age 18, graduate). The regressions were re-run only including predictors that had emerged as significant when all variables were entered. In the final models, endorsement of different interventions was predicted by the variables detailed in Tables 41 and 42.

Table 41. *Predictors of intervention beliefs for intellectual disability: results of multiple regression analyses*

Type of Intervention	<i>B</i>	<i>SE B</i>	β
Expert (N=1686)			
Constant	4.28	0.10	
Recognition	0.60	0.07	.23***
Age	-0.01	0.004	-.07**
Contact: Closeness of Relationship	0.03	0.01	.08**
Lifestyle (N=1591)			
Constant	4.34	0.12	
Recognition	-0.77	0.05	-.35***
Age	-0.01	0.002	-.09***
Ethnicity: Black	0.38	0.07	.13***
Religion: Importance	0.04	0.01	.13***
Religious/Spiritual (N=1585)			
Constant	0.21	0.04	
Recognition	-0.04	0.01	-.09***
Education: to age 16	-0.09	0.02	-.07***
Ethnicity: White	0.06	0.01	.11***
Ethnicity: Asian	-0.05	0.01	-.08**
Religion: Hindu	0.08	0.03	.07**
Religion: Importance	0.04	0.002	.44***
Religion: Frequency of Worship	0.02	0.01	.10***

Note. Expert $R^2=.07$; Lifestyle $R^2=.16$; Religious/Spiritual $R^2=.41$ ($ps<.001$).

Recognition: 0=no, 1=yes; Ethnicity, Religious Denomination and Education: 0=named group; 1=all others; Gender: 0=female, 1=male; Contact: 0=no prior contact, 1=prior contact;

* $p<.05$, ** $p<.01$, *** $p<.001$

For intellectual disability the factors examined offered the best model for religious/spiritual help, where they explained 41% of the variance in such beliefs. In contrast, they explained only 7% of beliefs in expert help and 16% of lifestyle interventions. Recognition of the vignette as intellectual disability or attribution to

some other form of developmental disability predicted endorsement of all three intervention types, and was the strongest predictor of agreement with expert and lifestyle interventions. Those who recognised intellectual disability or attributed the behaviours to some form of developmental disability were more likely to endorse expert help and less likely to endorse lifestyle and religious/spiritual interventions. Younger people were somewhat more likely to endorse expert and lifestyle interventions. Participants with lower educational attainments were more likely to endorse religious/spiritual interventions.

Ethnicity played a role in predicting endorsement of lifestyle and religious/spiritual help. Both white and black participants were less likely than participants of other ethnicities to agree with lifestyle interventions. White participants were also less likely to endorse religious/spiritual help, while Asians were more likely to endorse these. Religious factors predicted lifestyle and religious/spiritual interventions: participants of any denomination who described religion as important in their lives favoured such help more. Furthermore, Hindus were less likely to agree with religious/spiritual interventions, while those who engaged in regular worship were more likely to favour such help. Expert help was more favoured by participants who had a close relationship with someone with intellectual disabilities, but contact had no other role in predicting intervention beliefs.

For the schizophrenia vignette, knowledge played a very similar role. Participants who recognised schizophrenia or mental illness *per se* were more likely to endorse expert help, and less likely to endorse lifestyle and religious/spiritual interventions. This effect was enhanced for those who recognised schizophrenia rather than mental illness *per se* across all three types of interventions. A failure to recognise mental illness was only associated with reduced agreement with expert

help. Those reporting more regular contact with someone with mental health problems were more likely to agree with expert help, as did women. As for intellectual disability, younger people were more likely to endorse lifestyle solutions. Graduates were less likely to endorse religious/spiritual interventions.

As for intellectual disability, black participants were less likely to agree with lifestyle interventions, but the same applied to white participants when compared to participants of all other ethnic backgrounds. This result becomes clearer when looking at actual scores; both white ($M=3.48$, $SD=1.33$) and black participants ($M=3.49$, $SD=1.42$) were less likely than Asian participants ($M=4.22$, $SD=1.37$) and those of other ethnicities ($M=4.16$, $SD=1.21$) to endorse lifestyle help. Religious factors, not surprisingly, played a strong role in predicting belief in religious/spiritual interventions. Muslims were more likely to agree with these, as were participants of any denomination who described religion as important in their lives and engaged in regular worship. Similar to the intellectual disability vignette, for the schizophrenia vignette the variables examined offered the best model for religious/spiritual help, where they explained 47% of the variance in such beliefs. They explained somewhat more of the variance in endorsement of expert help (13%) and lifestyle interventions (22%) for schizophrenia than they did for intellectual disability, see Table 42.

Table 42. *Predictors of intervention beliefs for schizophrenia: results of multiple regression analyses*

Type of Intervention	<i>B</i>	<i>SE B</i>	β
Expert (N=1452)			
Constant	5.64	0.17	
Recognition: Mental Illness not recognised	0.37	0.09	.14***
Recognition: Schizophrenia	-0.48	0.08	-.19***
Recognition: General	-0.26	0.08	-.11**
Reference to Mental Illness			
Contact: Frequency	0.13	0.02	.13***
Gender	-0.17	0.06	-.08**
Lifestyle (N=1443)			
Constant	1.56	0.18	
Recognition: Schizophrenia	1.36	0.08	.42***
Recognition: General	0.77	0.08	.26***
Reference to Mental Illness			
Age	-0.01	0.00	-.08**
Ethnicity: White	0.49	0.08	.18***
Ethnicity: Black	0.77	0.11	.20***
Religious/Spiritual (N=1444)			
Constant	0.02	0.04	
Recognition: Schizophrenia	0.13	0.01	.20***
Recognition: General	0.08	0.01	.13***
Reference to Mental Illness			
Education: Graduate	0.03	0.01	.05**
Religion: Christian	-0.04	0.02	-.06*
Religion: Muslim	-0.11	0.02	-.14***
Religion: Importance	0.04	0.00	.46***
Religion: Frequency of Worship	0.02	0.01	.11**

Note. Expert $R^2=.13$; Lifestyle $R^2=.22$; Religious/Spiritual $R^2=.47$ ($p < .001$).
 Recognition: 0=no, 1=yes; Ethnicity, Religious Denomination and Education: 0=named group; 1=all others; Gender: 0=female, 1=male.
 * $p < .05$, ** $p < .01$, *** $p < .001$.

7.4 Discussion

This study investigated beliefs about suitable interventions for someone presenting with undiagnosed symptoms of either intellectual disability or schizophrenia in a multi-ethnic and religiously diverse UK general public sample. A number of similarities and differences emerged between lay perceptions about the two conditions. The main findings can be summarised as follows: 1) expert help, in the form of psychiatric or psychological treatment, was deemed most suitable for schizophrenia. In contrast, interventions aimed at changing the individual's lifestyle, particularly finding employment and taking increased responsibility, were favoured for intellectual disability alongside expert input; 2) psychiatric medication was judged as helpful for schizophrenia; 3) religious/spiritual interventions were generally viewed as unlikely to be helpful, more so for schizophrenia, but a sizeable minority agreed that they could be helpful; 4) beliefs about suitable interventions showed a fairly close correspondence with causal beliefs, with the strongest agreement between environmental causes and lifestyle interventions; 5) awareness of the respective condition strongly influenced intervention beliefs- those who recognised the symptoms presented were more likely to endorse expert interventions and less likely to endorse lifestyle and religious/spiritual interventions, regardless of condition; 6) intervention beliefs varied markedly by participants' ethnic and religious backgrounds, while other socio-demographic characteristics played only a minor role in predicting intervention beliefs. The results are considered in turn.

Lay people's preference for expert help when presented with psychotic symptoms is in line with previous evidence of a public perception that such symptoms are indicative of a more serious underlying disorder compared to, for example, depression and more likely to require treatment strategies outside of the individual's control (Furnham & Henley, 1988; Cinnirella & Loewenthal, 1999). The

findings confirm results from Australia where the public perceived psychiatrists and psychologists as helpful for schizophrenia (Jorm et al., 1997; Reavley & Jorm, 2012a). When presented with symptoms of schizophrenia, 49.7% strongly endorsed consulting a psychiatrist and a further 20.5% moderately agreed. These figures are markedly higher than the 34.6% who clearly endorsed seeing a psychiatrist in Riedel-Heller et al.'s (2005) German study, but lower than the 88% who rated seeing a psychiatrist as helpful in Australia (Reavley & Jorm, 2012a). In all three studies lay people were presented with diagnostically unlabelled vignettes depicting a person with schizophrenia.

The higher figure in Australia may be due to participants being asked to rate whether they thought an intervention would be helpful, harmful or neither; arguably juxtaposition with the word 'harm' may have lead participants to mostly agree with the potential helpfulness of interventions. In the German study participants ranked ten different sources of help in terms of perceived usefulness, whereas in the current study they indicated their agreement with each of the 22 options offered. Given that the strongest endorsement of all 22 items was for psychiatric help though, it seems unlikely that the response mode alone can explain the much higher belief in psychiatric help. Whether the difference is due to sampling differences, such as the younger average age of participants in the current study, differences in public opinion between Germany and the UK, or perhaps changes over time is a question for further research.

There is little prior evidence regarding lay preferences for interventions addressing difficulties associated with mild intellectual disability. One would expect beliefs about suitable sources of help to vary according to the difficulties someone with intellectual disability may present at any given time. The preference for vocational targets and getting the person to assume more responsibility would

appear to be closely matched to the current presentation and hence not surprising. In view of the suggestion though of some potential undiagnosed underlying difficulties, one might have expected greater endorsement of expert help. From a health professional's viewpoint an assessment by a psychologist (or occupational therapist, an expert not included in the current study) in particular might seem indicated. Of note, the only expert intervention that found general modest agreement was seeing a counsellor, perhaps due to a sense that "talking things over" can be a helpful problem solving strategy in general. Why psychological treatment found less agreement though seems less clear- possibly participants' lack of agreement was more triggered by the word "treatment" than by a clear difference in perception regarding the respective roles of counsellors and psychologists.

In the pilot study, described in chapter 2, several participants spontaneously voiced their belief that the person needed a "good talking to from his parents" or should be made to "face up to reality". In the main study presented here these items were viewed very ambivalently though. Arguably believing that someone whose behaviour is consistent with mild intellectual disability requires a talking to and should be made to face up to reality is blaming of the person and fails to recognise that the behaviours may be due to underlying impairments over which the person has only limited control. Whether such responses are more likely to be associated with sympathetic responses or conversely negative responses, such as anger, is impossible to say based on the current results. As noted in the previous chapter, incorporating emotional reactions into future research would seem very important.

While religious/spiritual interventions were generally not favoured, a small proportion of participants felt that prayer and seeing a spiritual or faith healer could be beneficial, more so for someone presenting with symptoms of intellectual disability. Such beliefs were more common among lay people who failed to recognise

the underlying condition and were strongly associated with the importance of religion in participants' lives as well as being somewhat more common among some faiths. The findings indicate marked differences to studies conducted in other cultural contexts. While Hugo et al. (2003) found that 70% of lay people in South Africa favoured praying (70%) in response to mental illness, in the current study only around 25% agreed at least somewhat that prayer could be helpful for either presentation. A further 32% endorsed seeing a spiritual or faith healer for intellectual disability, but only 12% for schizophrenia. Nevertheless, the fact that a quarter of participants in a religiously diverse UK sample believed prayer to have a beneficial role in relation to both mental illness and disability suggests that religious beliefs should be explored as a matter of course by professionals and certainly accorded more importance than they are at present within Western healthcare systems.

The argument by Whitley (2012) that psychiatry maintains an ambivalent attitude to the incorporation of religion and spirituality into practice certainly applies equally to many other groups of service providers. While the need for cultural competence on the part of service providers has found a lot of attention over recent years (Bhui, Warfa, Edonya, McKenzie & Bhugra, 2007; Whaley & King, 2007), much less attention has been directed at religious competence. This may be due to a common and likely misplaced assumption that the two go hand in hand. Of note, 51% of Asian and black participants in the current study described religion as important or very important in their lives, but so did 12% of white lay people. However, it should also be noted that religious participants endorsed expert and social interventions alongside religious help, in line with Cinnirella and Loewenthal (1999).

The finding that lay beliefs about suitable interventions showed a fairly close correspondence with causal beliefs is in line with numerous studies cited earlier.

Considering the possible implications of the present findings for help seeking, understanding lay people's causal beliefs may give a useful indication about the interventions they are likely to consider suitable, or in turn inappropriate. This applies most strongly with regard to beliefs that a condition is due to environmental causes, which in the current study were closely linked to endorsement of social and environmental sources of help.

The fact that awareness of the respective condition strongly influenced intervention beliefs indicates the potential benefits of educating the public about a range of mental disorders. Given that those who recognised the symptoms presented were more likely to endorse expert interventions and less likely to endorse lifestyle and religious/spiritual interventions suggests that increasing public awareness might smooth the path to early access to services, where this is indicated, and avoid delays caused by lay people trying out a range of ineffective and, at times, positively harmful strategies. Young people tended to agree more with expert and lifestyle interventions. This may be due to historical changes, in that it has become somewhat more acceptable to seek help rather than trying to deal with difficulties oneself.

Contact only predicted belief in expert help, not the other types of interventions. Of note, once all contact variables were considered simultaneously, it was not contact *per se*, but in the case of intellectual disability the closeness of the contact relationship and in the case of schizophrenia the frequency of contact that played a significant role. Lay people with a closer relationship (intellectual disability) or more frequent contact (schizophrenia) favoured expert help more than others. This supports Alexander and Link's (2003) argument that researchers should examine the impact of complex aspects of contact, beyond a dichotomous view of contact as either absent or present.

The finding that intervention beliefs varied markedly by participants' ethnic and religious backgrounds merits consideration. Perhaps surprisingly, expert interventions were equally favoured by the different ethnic and religious groups; one exception was the weaker endorsement of such help among Christians and Muslims compared to non-religious participants for schizophrenia. This indicates that on the whole lay people recognise the potential value of input from service providers, such as general practitioners, psychiatrists or psychologists to a similar extent. Differences in endorsement of different types of support were most marked with regard to religious and spiritual interventions, such as prayer, or consulting faith healers or religious persons. These were more strongly favoured by Asian and black lay people, and by Muslims. This indicates that expert led interventions are welcome by members of all ethnic and religious communities, but lay people from ethnic minorities, and Muslims in particular, may be more likely to favour help from religious and spiritual sources alongside formal, expert led input. Although these findings relate to lay people's perceptions, they suggest that in order to gain a comprehensive understanding, service providers may be well advised to ask those seeking help and their families in a sensitive and non-judgemental fashion about other input they may have already tried or may be considering.

7.4.1 Limitations

A number of limitations merit consideration. Due to resource limitations sampling was of an opportunistic nature. Overall the sample was relatively young, highly educated and the proportion of people born outside of the UK was high, which reflects the make-up of the Greater London population where the study was carried out, but is not representative of the general UK population. Furthermore, as noted in the previous chapter, the data were mostly gathered through an English language web survey. Hence the views of less computer literate people and UK residents with

limited English literacy are inevitably underrepresented. Hence caution is called for in generalising the results. It is likely that particularly in examining the effects of ethnicity and religion on intervention beliefs, a more representative sample would result in different findings.

Another potential limitation concerns the items participants responded to. The item "see a counsellor" may have evoked different responses to the item "psychological treatment", without such differences necessarily relating to any perceived difference in the help offered by the two. Instead differences may have been due perhaps to the words "see" and "treatment", the latter potentially perceived as more invasive or stigmatising. Furthermore the item "be more religious" with hindsight seems rather ambiguous as it involves a quality rather than an action, unlike other items. Any future studies looking to use the IDLS should review the wording of the intervention items.

The two vignettes by nature of the conditions they referred to presented very different behaviours. Hence many of the differences in intervention preferences may arise directly from the different presentations rather than denoting any underlying differences in beliefs about sources of help for someone with undiagnosed intellectual disability or schizophrenia. Future research should examine the effects of adding a label to the presentations and of presenting an intellectual disability vignette that lay people perceive as matched in severity to a mental illness vignette.

Finally, the order of presentation of the vignettes was kept constant with the intellectual disability vignette presented first. As noted in the previous chapter, some participants spontaneously noted that the second vignette seemed to present more serious problems. A perceived differing severity of symptoms may have influenced participants' responses, not least in believing expert help to be more indicated once the perceived severity increased. It is conceivable that lay people would have

favoured expert help somewhat less for the schizophrenia vignette if it had been presented first, or indeed if the individual with intellectual disability displayed more severe impairments.

7.4.2 Conclusions

In conclusion, the present study suggests that it is important to take into account lay beliefs about causes and appropriate sources of help for both mental illness and intellectual disability, not least as these may affect help seeking, early diagnosis and treatment compliance. To date our understanding of lay beliefs about intellectual disability in particular is very limited and future research should explore this area further.

Chapter 8: Discussion and conclusions

This thesis was motivated by the lack of evidence on public conceptualisations of intellectual disability beyond simple analyses of explicit attitudes, in contrast to the vibrant research activity in the mental health field. The central aim was to explore how awareness of the condition, attitudes and causal beliefs relate to social distance from individuals with intellectual disabilities. This question was addressed through a large scale survey of lay people of working age in the UK. Throughout schizophrenia was included as a comparison case to allow evaluation of the findings in a wider context, assess whether the processes identified are disorder specific or potentially generic to disability and mental illness, and to allow drawing on evidence in the mental health field to put the findings in context. This chapter presents an overview of the key findings and discusses strengths and limitations of this thesis. Broader methodological issues and implications for practice and future research are then considered.

8.1 Synopsis of results

This section presents a brief overview of the main findings.

8.1.1 Knowledge of intellectual disability and schizophrenia

Knowledge of typical symptoms of intellectual disability and schizophrenia among the UK public appear to be at similar levels. Among relatively young and well educated lay people only around 28% recognised intellectual disability, a further 3% to 4% attributed the behaviours depicted to specific learning difficulties or an autism spectrum disorder, and around a further 10% to some form of mental illness and the remainder to a host of other causes. The behaviours depicted in the schizophrenia vignette were identified as such by approximately 24% of the sample, and a further 44% recognised them as signs of a possible mental illness. Lay people who recognised one condition were 2.8 times more likely to also recognise the other

condition. However, the association between recognition of both conditions was by no means strong. This indicates that there is some cross-over between mental health and intellectual disability literacy, but that lay people also require specific knowledge of different conditions.

Regarding intellectual disability, the findings confirm evidence presented in the literature review that the public has a limited understanding of the concept of intellectual disability. Despite indicators in the vignette of a possible underlying difficulty, almost three quarters of participants did not consider an intellectual disability as possible reason for the young man struggling at school, leaving without any qualifications, and having difficulties following instructions. While many attributed the presentation to 'typical' adolescent struggles, around 12% attributed it to causes that were either blaming of the individual or his parents. Poor lay knowledge of intellectual disability may have implications for timely detection of potential developmental disabilities and help seeking.⁴

The present findings on lay knowledge about symptoms of schizophrenia suggest that despite concerted efforts, public awareness of the condition continues to be concerningly low. Comparison to findings from Australia based on a very similar general population survey (Jorm et al., 2006; Reavley & Jorm, 2012a) suggests that schizophrenia literacy may be relatively low among the UK public. As noted in chapter 5, given that the present sample was relatively young and highly educated, one might have expected recognition rates similar if not higher to those in a representative Australian sample. Instead even the highest recognition rate in the present study for the schizophrenia vignette of 35.4% among the white sample was

⁴In my role as a clinical psychologist for a community team for people with intellectual disabilities in London's very ethnically and religiously diverse East End, it was not uncommon to receive a referral of someone in their late teens or even adulthood whose intellectual disability had not been picked up previously, despite very poor performance at school and long standing behavioural problems.

somewhat low, and, as noted, the recognition rate of 12.5% among black participants may be viewed as cause for concern. Of note, the Australian surveys collected data through telephone interviews, while the present findings were collected through anonymous electronic and paper copies. While it is conceivable that this difference might contribute to lay people in Australia expressing more positive attitudes, it would seem unlikely that it should affect recognition. The fact that recognition rates for schizophrenia fluctuated considerably over time in the Australian surveys (26.8% in 1995, 42.5% in 2003/3, and 37.9% in 2011), suggests though that one should be cautious in paying too much attention to recognition alone.

Given that the largest mental health campaign ever to run in the UK, *Time to Change*, aimed at reducing stigma and discrimination directed at people with mental illness is currently underway, one would hope to see higher levels of public awareness about schizophrenia in years to come. Alternatively it is possible that a number of high profile figures, such as actors Stephen Fry and Catherine Zeta-Jones, the boxer Frank Bruno, and the politician Alastair Campbell who have talked openly about their experiences of bipolar disorder and depression, have increased awareness and possibly acceptance of mental illness generally, but done little to increase awareness of schizophrenia.

For both conditions awareness of symptoms varied markedly between ethnic groups, once differences in contact, education and age were controlled for. Intellectual disability was recognised by 35.4% of white UK residents, but only by 22.6% of participants from BME communities, with no significant differences between Asian and black participants. Schizophrenia was recognised by 35.4% of white UK residents, 19.9% of Asian but only 12.5% of black participants. Furthermore, while only 13.9% of white lay people failed to recognise that the

behaviours presented might be indicative of an underlying mental health problem, around 32% of participants from ethnic minorities did. Given that schizophrenia is more frequently diagnosed among people from black African/Caribbean backgrounds (Fearon et al., 2006) it may seem surprising that awareness of the condition should be this low within these communities. One reason why awareness is low may be that due to high levels of mental illness stigma, those affected and their families may hide symptoms of mental illness from the community as far as possible. Of course this is not to minimise for one moment evidence about other factors that contribute to delayed help seeking among members of BME communities, not least experience of institutional racism, mistrust of services, and a perception that service values and treatment models have a poor fit (e.g. McKenzie, 2008; Sainsbury Centre for Mental Health, 2002).

Contact was the strongest predictor of lay people's ability to recognise the two conditions, once a broad range of socio-demographic factors were considered simultaneously in regression analyses. Other factors that emerged as predictors of recognition were gender and educational attainments, the latter had a stronger association with recognition of intellectual disability than of schizophrenia though. Of note though, these factor jointly predicted at best 10% of the variance in recognition. This indicates that lay people's intellectual disability and mental health literacy is influenced by factors beyond those one might expect to play a large role.

Thornicroft, Rose, Kassam and Sartorius (2007) described stigma as a problem of knowledge, attitudes and behaviour. In conclusion, the present findings suggest that the first aspect, namely knowledge among lay people, continues to be a concern both in relation to intellectual disability and schizophrenia, more so among lay people without direct exposure to persons with intellectual disabilities or mental

illness, ethnic minority communities, men, and those with lower educational attainments.

8.1.2 Attitudes to the inclusion of people with intellectual disabilities

The findings on attitudes to the inclusion of people with intellectual disabilities among lay people in the UK paint a mixed picture overall. On the whole participants felt that people with intellectual disabilities have similar life goals as people without disabilities and should not be segregated from society. However, endorsement of empowerment was modest and views on the need for protection and sheltering of people with intellectual disabilities were undecided. This suggests that the human rights based approach which lies at the heart of current policy (Department of Health, 2009) finds support among the general population, in that lay people, at least in the present study, broadly agreed with the principle that people with intellectual disabilities should have the same human rights as everyone else. Other key values enshrined in policy though, such as the objective to enable people with intellectual disabilities to have as much choice and control as possible over their lives (Department of Health, 2001, 2009) appear to clash with lay people's continuing perception that people with intellectual disabilities need more able others to plan and manage their lives for them and provide ample support and supervision.

Prior contact with someone with intellectual disabilities predicted attitudes as measured on all four CLAS-ID subscales, but did not emerge as the strongest independent predictor for any of them. Those who reported contact showed more inclusion friendly attitudes. Participants' ethnic background was a stronger predictor than contact on three of the four subscales.

With regards to the relationship between inclusion attitudes and stigma, correlations between three of the four CLAS-ID subscales and social distance were significant, but modest in size. Empowerment showed a negative correlation with

social distance and no significant correlation was established between sheltering and social distance. Thus while the public may not show support for the aims of the self-advocacy movement, we should be cautious not to assume that this implies opposition to social contact. As noted in chapter 4, particularly lay people's perception that people with intellectual disabilities require sheltering should not be taken as straightforwardly indicating negative attitudes, as noted by Horner-Johnson et al. (2002), but perhaps rather a recognition that people with intellectual disabilities may well be vulnerable and in need of support, paired with a sense that they are worthy of care and concern. Undoubtedly though even if the public is not openly hostile to the principle of close social contact with people with intellectual disabilities, the findings indicate continuing barriers to the self determination and equal status within society of individuals with intellectual disabilities.

8.1.3 Social distance

The findings presented on social distance confirm evidence that stigma is lower for intellectual disability than for schizophrenia (Lau & Cheung, 1999; Saetermore et al., 2001; Sigelman, 1991). This particularly applied where people recognised intellectual disability as such rather than attributing behaviours associated with intellectual disability to other more stigmatising factors. Nevertheless, lay views on social contact with an individual with mild intellectual disability were at best ambivalent, and in many cases negative. This suggests individuals with intellectual disabilities and their families and paid supports not only have to manage the impairments associated with the underlying condition, but also have to struggle with less than welcoming attitudes within wider society. It needs stressing that the present findings relate to mild intellectual disability. In view of evidence that the severity of intellectual disability affects lay people's attitudes (Antonak et al., 1995; Weller & Aminidav, 1992), it is likely that people with more

severe intellectual disabilities and their affiliates face greater stigma than suggested by the current findings.

It has been suggested that stigma associated with intellectual disability may be rooted more in discomfort and insecurity than in open hostility (e.g. Beh-Pajoo, 1991; Hudson-Allez & Barrett, 1996). In contrast, in relation to disability hate crime, Quarmby (2011) has argued that such crimes are made possible through collusion by a society that holds its most vulnerable members in disdain. Without doubt, for someone with an intellectual disability trying to live their life as an equal citizen, being exposed routinely to others' negative behaviour, for example, odd looks or avoidance of close proximity and interaction, is likely to be a very negative experience, whether motivated by discomfort or hostility. Having said that, whether negative attitudes and social distance are motivated by hostility or insecurity among lay people has very different implications for interventions and is an important question for further research.

In conclusion, while intellectual disability appears to be less stigmatised than schizophrenia, one of the most heavily stigmatised forms of mental illness, we seem to be some distance from seeing 'the end of stigma' (Green, 2009) associated with intellectual disability, if indeed this is attainable at all. At danger of painting overly negative a picture, it needs stressing that similar to the examples cited by Green in relation to chronic illness and other long-term conditions, there are many instances where people with intellectual disabilities refuse to be defined by their condition and are having a powerful voice. Some might argue our efforts are ultimately better placed in supporting such instances than in fighting negative attitudes and ignorance.

It is now widely recognised that individuals from BME backgrounds with intellectual disabilities or mental illness often face racial discrimination and poorer

access to appropriate assessment and treatment (Department of Health, 2005). The present results suggest that they and their families may face the additional challenge of increased stigma and lack of awareness within their own cultural communities, particularly within the black community in the UK. While this has been fairly widely recognised in relation to mental illness, to date evidence on increased stigma associated with intellectual disability among BME communities was based entirely on the accounts of family members of people with intellectual disabilities.

Increased stigma among BME communities has important implications for the well-being and life chances of individuals affected by these conditions and their families. Corrigan (2000) suggested that mental illness strikes with a double edged sword: not only do individuals have to struggle with the symptoms but also deal with stigma and discrimination. The present findings suggest that mental illness and intellectual disability can in fact strike with a triple edged sword: 1) the symptoms themselves; 2) negative attitudes and discrimination within society; and 3) increased stigma within their own cultural communities that can have further negative effects on social inclusion and increase discrimination.

Social distance regarding schizophrenia was significantly lower among lay people who correctly identified the symptoms presented compared to those who made a general reference to mental illness; the comparison with those who failed to recognise mental illness altogether approached significance. This suggests that what is needed to tackle the stigma associated with schizophrenia is not merely a general understanding of mental illness, but more specific knowledge of schizophrenia and of typical symptoms.

Overall increased awareness of the condition was associated with reduced social distance for both intellectual disability and schizophrenia. Once recognition of the symptoms was considered alongside contact and socio-demographic

characteristics though, it proved a significant predictor for intellectual disability but not for schizophrenia. Regarding contact it was the closeness of the contact relationship rather than the absence or presence of contact in itself that was associated with social distance. Those with a closer contact relationship with someone with intellectual disability or mental health problems showed lower social distance.

Of note, the present results do not lend support to the suggestion that both greater awareness and contact may increase the association of schizophrenia with unpredictability and dangerousness and thus increase stigma (Corrigan et al., 2001; Angermeyer & Matschinger, 2003a). Both awareness of schizophrenia and contact with people with any type of mental health problem appeared to have a positive effect on stigma. Of course it needs emphasising though that the study design was cross-sectional and no cause-effect relationship can be assumed. It should also be stressed that despite considering a large range of participant factors, the final regression models accounted only for 14% of the variance in social distance for intellectual disability and 7% for schizophrenia, suggesting that individual stigma is determined by a complex set of factors and processes that may be difficult to gauge in large scale survey based research.

8.1.4 Causal beliefs

Lay people were most likely to endorse environmental causes for the intellectual disability vignette and biomedical and adversity causes for the schizophrenia one. This difference may be due to a perception that the schizophrenia presentation was more serious, and thus perhaps more likely to be due to organic and other complex factors.

Increased intellectual disability and schizophrenia literacy were associated with increased endorsement of biomedical factors, and reduced endorsement of

psychosocial and supernatural factors, in line with findings on mental illness by Schomerus et al. (2006). Recognition of schizophrenia, rather than attribution to mental illness generally, enhanced this effect. This suggests that future research into the effects of increased awareness should assess knowledge regarding specific diagnostic categories rather than the broad label 'mental illness'.

Believing the behaviours depicted in the vignette to be due to brain abnormality or infection was associated with reduced social distance for intellectual disability, yet with increased social distance for schizophrenia. This would appear to lend support to those like Read et al. (2006) who warn that teaching the public to view schizophrenia as an illness of primarily biological aetiology may in fact increase stigma. The answer to the question why different causal explanations proved to have different associations with social distance for the two conditions is likely to lie with the mediating role of emotional reactions (Angermeyer, Holzinger & Matschinger, 2010), which were not assessed in the current study. To illustrate this point, belief in biomedical causes of schizophrenia has been found to elicit increased fear (Angermeyer & Matschinger, 2003a; Read et al., 2006). This is likely to be due to a perception that biomedical causes imply lack of control over the behaviour, and thus unpredictability and danger. Fear in turn is associated with increased social distance (Angermeyer & Matschinger, 2003a; Read et al., 2006).

In line with attribution theory (Weiner, 1985), causes on the environmental subscale that could be construed as signs of character weakness showed the strongest positive association with social distance in the present study. The relationship between controllability of causes and social distance observed in other studies (Dietrich et al., 2004), was not confirmed in the present study though.

Endorsement of supernatural causes was associated with increased social distance, regardless of condition. While such beliefs were relatively rare in the

current study, including among ethnic and religious minorities, they were more common among lay people who had low educational attainments, were very religious, or followed Islam. The finding that, when asked for their spontaneous opinion, 7.9% of black participants attributed the schizophrenia vignette to some form of spirit possession or spiritual problem, as did 1.4% of Asians, is concerning given the increased stigma associated with supernatural beliefs, both in this study and in previous research (Adewuya & Makanjuola, 2008).

Finally, once all factors under consideration were considered simultaneously, contact did not influence causal beliefs, not even when the closeness of the contact relationship and frequency of contact were taken into account.

8.1.5 Beliefs about suitable interventions

Expert help and lifestyle interventions were equally favoured for intellectual disability, while expert help was favoured for schizophrenia. Expert help was much less likely to be recommended for intellectual disability than for schizophrenia. The type of expert deemed helpful differed by condition. A broad range of experts were deemed helpful for schizophrenia, including psychiatrists, psychologists, general practitioners and counsellor. In contrast, for intellectual disability only a counsellor was deemed helpful; such expert input is of questionable help, particularly where the person's needs have not been identified on the basis of a formal assessment. Beliefs about suitable sources of help, as expected, showed fairly close correspondence with participants' causal beliefs.

Lay people who accurately recognised the condition were more likely to favour expert help, and less likely to endorse lifestyle or religious/spiritual help. Given the study's cross-sectional design it is impossible to say whether an increased belief in expert help is a consequence of increased awareness or is merely coincidental. However, evidence on the effects of public education efforts in the area

of mental health suggests that they bring lay people's treatment beliefs closer in line with those of health service providers (Kitchener & Jorm, 2002). Thus increasing lay people's awareness of conditions such as intellectual disability and schizophrenia might smooth the path towards early access to services where indicated and avoid delays due to lay people trying out numerous interventions, many of which may prove ineffective. In relation to intellectual disability this has not been tested but would seem highly relevant, particularly in the case of children who may be showing signs of developmental delay but who as yet have not been referred to services.

Prior contact influenced views regarding expert help, but not regarding other sources of help. For intellectual disability those with a closer contact relationship and for schizophrenia those with more frequent contact were more likely to favour expert help. Why contact should influence views on expert help in this way is not immediately evident and should be explored in further research.

While agreement with religious/spiritual interventions was generally low, as many as 25% of participants felt prayer could be beneficial in relation to both conditions. This suggests that alongside the attention frequently paid to the need for cultural competence among clinicians, the general ambivalence among the psych professions towards the incorporation of religion and spirituality into clinical practice should also be addressed. Without sensitivity to these aspects of people's lives, clinicians are at risk of missing important beliefs service users may have and that may affect engagement and treatment adherence. Of note, recognition that lay people may view religious interventions or coping strategies as helpful is also largely absent from the most prominent research studies in this area. Of the 34 interventions included in Australian longitudinal studies, the only one pertaining to religion was consulting a clergy (Jorm et al., 1997; Reavley & Jorm, 2012a). Similarly in a large scale German study, 'alternative' treatments such as visiting a spa, using

natural remedies, acupuncture and meditation/yoga were included in a catalogue of sources of help (Riedel-Heller et al., 2005). Prayer and other spiritual or religious interventions were apparently not presented as choices though, perhaps reflecting the same “blindness” to the importance of religion in many people’s lives.

8.1.6 Putting it all together

An overarching model that encapsulates the key outcomes under consideration in this thesis for both intellectual disability and schizophrenia, as well as the role of contact and ethnicity, is presented in Figure 5. This model does not include gender, age, education and religion as their effects were too mixed and specific to include in a broad overarching model. Nor are beliefs about suitable sources of help included in the model as they were primarily examined in terms of their fit with causal beliefs. The associations presented in Figure 5 are common to intellectual disability and schizophrenia, unless indicated otherwise, i.e. where a path is marked ‘ID only’ this association was only established for intellectual disability, where it is marked ‘Sch only’ it only applied to schizophrenia. Of note, the associations shown in Figure 5 in many instances vary in strength between the two conditions. In the figure red arrows denote negative associations, while green arrows denote positive associations.

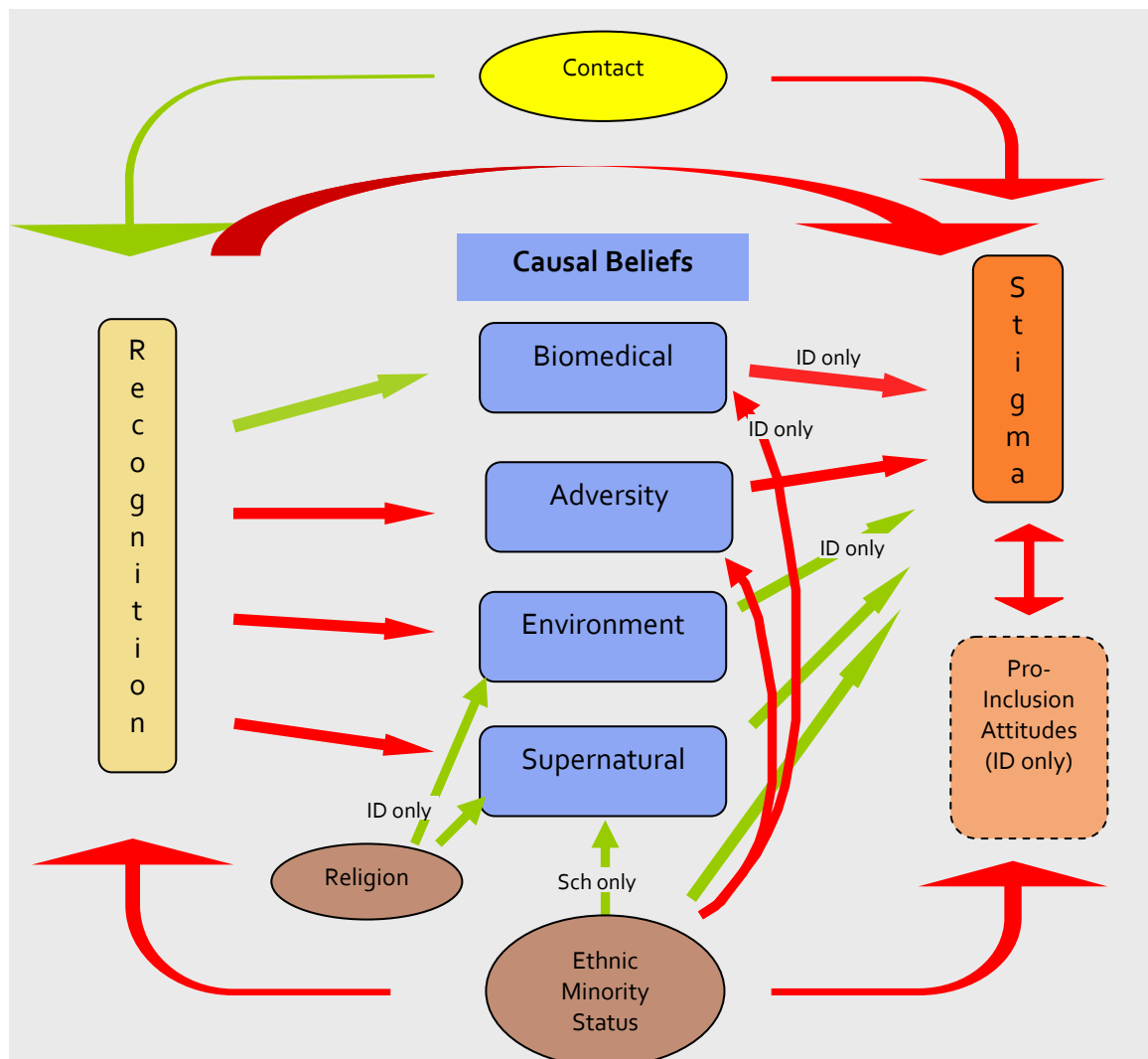


Figure 5. Associations between awareness, causal beliefs, social distance, inclusion attitudes (intellectual disability only), contact and ethnicity

This model suggests that many of the relationships between the different constructs under investigation in this thesis are common to conditions as different as intellectual disability and schizophrenia, but mostly different in strength, while some are disorder specific. For both conditions, the relationship between awareness and social distance was mediated to some extent by causal beliefs. Both the direct association between awareness and social distance, and the mediating effects of causal beliefs were stronger though for intellectual disability than for schizophrenia.

Overall the findings partly support the conclusion drawn by Jorm and Griffiths (2008) when comparing lay responses to schizophrenia and depression, that it is not

meaningful to consider stigma as applying to a generic “mental disorder”, given that the factors associated with stigma differ by condition. While much of the literature on mental illness stigma has focussed on the effects of endorsing biomedical versus psychosocial causes of mental illness, only three biomedical or psychosocial causal items (virus/brain infection, brain abnormality and overly lenient parents) were associated with increased social distance for schizophrenia, and none with reduced social distance. Many other biomedical and psychosocial items showed no significant associations with social distance in the current studies. The most consistent relationship between causal beliefs was found for supernatural causes, which were invariably associated with increased social distance for schizophrenia.

It is important to stress that altogether the factors under consideration explained only 24% of the variance in social distance for intellectual disability and 13% for schizophrenia, leaving inclusion attitudes which were only assessed in relation to intellectual disability to one side. This indicates that knowledge of the respective condition, as evidenced by correct identification of diagnostically unlabelled symptoms, causal beliefs and social distance are influenced by many factors beyond the reach of the studies presented in this thesis, even more so for schizophrenia than for intellectual disability. Research indicates an important role for emotional reactions as mediators between causal beliefs and stigma associated with mental illness (Angermeyer et al., 2010), but these were not assessed in the current study.

8.1.7 The findings and key theoretical perspectives

The role of contact as an important means to tackling prejudice and improving attitudes towards members of stigmatised groups has long been recognised, not least in Allport’s (1954) Intergroup Contact Theory and in relation to Festinger’s (1957) Theory of Cognitive Dissonance. Allport’s theory in particular has

influenced attempts to tackle negative attitudes towards people with disabilities or those with mental illness. As noted in the introductory chapter, intergroup contact theory (Allport, 1954) proposed that for contact to be successful in reducing prejudice it has to occur in conditions where members of different groups are of equal status, pursue common goals, cooperate and contact is officially sanctioned. Pettigrew and Tropp (2006) concluded that contact *per se* typically reduces prejudice and that Allport's conditions are not essential for prejudice reduction.

The present findings lend some support to this conclusion. The role of contact was assessed in relation to its absence or presence, the frequency of contact and closeness of the relationship in an attempt to address criticism that past research has taken a narrow view of contact, only as either absent or present (Alexander & Link, 2003). However the three aspects considered did not allow for a judgement whether contact met Allport's conditions; it is highly unlikely though that all contact reported did, as it will have occurred in a wide range of contexts. Contact was the strongest predictor of lay people's ability to recognise symptoms of either condition, showed a negative association with social distance for both conditions, and predicted attitudes that were more favourable towards the inclusion of people with intellectual disabilities. In the case of social distance, the closeness of the contact relationship was a stronger predictor than contact *per se*. Overall then, the findings at least partly support the notion that contact has a role to play in reducing prejudice. However, the fact that contact and socio-demographic factors jointly explained mostly only a relatively small part of the variance in attitudes suggests that contact of itself is unlikely to be sufficient in tackling the stigma associated with intellectual disability and mental illness. The finding that contact was much lower among lay people from ethnic minorities compared to white UK residents indicates though that increasing opportunities for contact is likely to have an important role to

play in increasing awareness and reducing stigma among ethnic minority communities.

With regard to future research, results in this thesis suggest that attention to the frequency of contact and the closeness of the contact relationship can provide us with a more complex understanding of the potential role of contact. This applied particularly to social distance and intervention beliefs where these aspects of contact, rather than its mere absence or presence, emerged as predictors. Future researchers would be well advised though to consider ways of formally assessing naturalistic contact against Allport's four criteria.

A further key theoretical perspective that merits brief consideration is Weiner's (1985) attribution theory, which has influenced thinking regarding the relationship between causal attributions and stigma. Attribution theory is at the root of statements such as Thornicroft's (2006) assertion that people react to difficulties of others according to their understanding of the cause of the problem. Where a behaviour is attributed to an internal cause, such as personality or a character trait, or the behaviour is seen to be within the person's control, attribution theory would predict that others respond with negative affect and behavioural intentions, such as anger and a wish to punish. Conversely where the behaviour is deemed to be outside the person's responsibility or control, one would expect a sympathetic response. As noted in chapter 6 and section 8.1.4, the present findings lend some support to attribution theory in that causes that could be construed as signs of character weakness, such as having been overly indulged by parents or being punished for past wrongdoings, showed positive associations with social distance. However, no clear relationship between the presumed controllability of a cause and social distance was observed, unlike in previous studies in the mental health field (e.g. Dietrich et al., 2004). Thus several causes one might infer a person to have no

control over, such as brain infection or abnormality, or complications at birth showed no consistent association with social distance; while they had a negative association with social distance for intellectual disability, at least some had a positive association with social distance for schizophrenia. As noted the answer is likely to lie with emotional reactions, which were not assessed in the current study.

A question for further research is whether the increased stigma associated with supernatural causes, including spirit possession, or punishment for one's own or parents' past wrongdoings, is universal and whether it can be understood in relation to attribution theory or is better understood with reference to the complex meanings given to such beliefs within the cultural and religious contexts where they occur.

8.2 Limitations of this thesis

The main strengths of this thesis are that it went beyond the focus on explicit attitudes alone in much of the intellectual disability literature, and that it crossed the usual boundaries between the fields of intellectual disability and mental health. The IDLS, while not without its limitations, offers a useful new measure that is likely to encourage further research into public awareness, beliefs and social distance elsewhere.⁵

Several key limitations of the methodology adopted in this thesis merit consideration in this concluding chapter.

⁵ Since publication of the measure (Scior & Furnham, 2011), numerous researchers internationally have shown an interest in the IDLS. As a result collaborations are underway with colleagues at universities in other European countries and in the Middle East to assess lay responses to people with intellectual disabilities in a global context. Collaborating with and supporting the efforts of colleagues in Arab countries in particular seems a very worthwhile endeavour, given a dearth of evidence on intellectual disability in an Arab context and anecdotal reports that individuals with intellectual disability and their families there experience high levels of stigma and discrimination and are a long way from experiencing social inclusion in line with the UN *Convention on the Rights of Persons with Disabilities* (United Nations, 2006).

8.2.1 Sampling considerations

Firstly, the studies relied on opportunistic sampling using advertisements on web forums and social networking sites, social contacts of the researcher and the psychology undergraduate students who contributed data to this thesis, and recruitment through student mailing lists. Given that the current findings are not derived from a representative general population sample, but rather from a convenience sample, they should be viewed above all as indicators to be tested in further research and not as conclusive evidence.

The fact that the participants were on the whole relatively young and highly educated, suggests the findings presented in this thesis may paint an overly positive picture of lay perceptions of intellectual disability and schizophrenia. The proportion of non-UK born people of 30% in the largest data set may seem large compared to the 12.6% of the population of England that is foreign born, but in fact in most London authorities foreign born people make up between 27% and 48% of the population (Office for National Statistics, 2010). Furthermore, people from BME communities, who currently make up around 34% of the Greater London population (Greater London Authority, 2011), were overrepresented in the studies presented in this thesis. However, given that a key aim of this research was to assess the contribution of ethnicity and religion to lay responses to intellectual disability and schizophrenia, rather than to present a representative picture of the Greater London or UK population, this should not be viewed as a limitation.

Data were mostly collected through the internet, although the option of a paper survey was provided. Internet mediated research offers many opportunities and facilitates data collection on a large scale and at manageable cost (Evans & Mathur, 2005; Hewson, 2003). By being more anonymous, it allows respondents to be more candid and to be less affected by social desirability (Joinson, 1999, 2001).

This notion is supported, for example, by the present finding of higher levels of social distance towards people with intellectual disabilities, noted in chapter 4, compared to a recent Canadian general population study that collected data via telephone interviews (Ouellette-Kuntz et al., 2010). A further advantage of internet mediated research is that it can redress the general bias towards women in psychological research (Hewson, 2003), evident in the more even gender split in the present studies compared to much psychological research.

Amongst the limitations of internet based research, potential sampling biases are important to consider. By 2012, 84% of the UK population had access to the internet (Office of National Statistics, 2012). Internet use is linked to various socio-economic and demographic characteristics, and use is lowest among people over the age of 75 only around a quarter of whom access the internet. In researching lay perceptions of health conditions among BME communities it is possible that electronic data collection very much under-represents the views of older and possibly more traditionally oriented members of the community. Their views may carry a lot of weight though, particularly within BME communities that traditionally assign higher social status to their elders. Having said so, accessing their views using more traditional methods is often also far from easy. In researching perceptions about intellectual disability among the Sikh community in the UK, Kaur (2012) made personal contact with older Sikhs and offered the survey measure in both English and Punjabi, but was frequently firmly referred to younger members of the family on the basis that “they know more about these matters”.

Sampling size considerations were addressed in chapter 3. While power calculations were carried out and the main analyses performed were well powered, it is a limitation of this thesis that sample size analyses for chapter 4 to 7 were not formally presented. The various regression analyses performed at most examined 11

predictors. Based on power analyses performed using G*Power 3 (Faul, Erdfelder, Lang & Buchner, 2007), specifying alpha = 5% and desired power = 80%, with 11 predictors would have required 160 participants to detect a medium effect size, and 787 participants for a small effect size. To compare means of the three main ethnic groups, assuming a small effect size of 0.2 at 80% power, would have required 82 participants per group, a number that was well exceeded. However, the analyses by religious group may have been underpowered in some instances to detect very small effects. To detect an effect size of 0.2 when comparing the six religious groups required 55 participants per sample- in fact the smallest sample had 75 participants. Small effects of a magnitude of 0.1 would have remained undetected though as they required sample sizes of $n=215$ per sample.

The risk of type 1 error was taken into account for all individual analyses reported in this thesis and the appropriate corrections applied. Nonetheless, the fact that a large number of statistical tests were performed on what was ultimately a single dataset increased the likelihood of positive findings. By testing a large number of hypotheses it was inevitable that a certain number met the criteria of statistical significance; it cannot be assumed though that the findings did not in some instance occur by chance and thus are of no clinical significance. One way of addressing this risk could have been to correct the significance level applied with reference to the number of all statistical tests conducted, rather than merely the ones pertaining to the same hypotheses. This approach was not taken as it is very conservative and markedly increases the risk of type 2 errors. In evaluating the findings across all chapters of this PhD, the risk of type 1 errors needs to be borne in mind, particularly where findings are significant at the 5% level rather than the more stringent 1% or 0.01% level, which are much less likely to occur by chance.

8.2.2 Design issues

In balancing the need for brevity in a survey designed for data collection on a large scale, it was decided not to assess social desirability based on evidence of an inconsistent effect on self-reported attitudes towards people with intellectual disabilities (see chapter 2). The studies presented in this thesis could be criticised though for not addressing the risk of impression management on the part of participants.

Inclusion attitudes were only assessed in relation to people with intellectual disabilities and not those with mental illness. This decision was driven by this thesis' primary focus on intellectual disability, and the need to balance comprehensiveness and brevity in the process of data collection. With hindsight it might have been useful to also assess inclusion attitudes towards people with mental illness to arrive at a more comprehensive model, through inclusion of the Community Attitudes Toward the Mentally Ill scale (CAMI, Taylor & Dear, 1981). This issue is less pressing though as social distance and community attitudes to people with mental illness, using the CAMI, have been evaluated jointly in previous general population studies (e.g. Ng, Martin & Romans, 1995), and are both measured in annual UK surveys on attitudes to mental illness (Health and Social Care Information Centre, 2011).

As noted repeatedly, the design of the studies reported in this thesis was cross-sectional. Thus the results can only tell us about associations between different constructs but should in no way be seen to demonstrate any cause-effect relationships. It is conceivable, for example, that lay people who hold more positive attitudes towards members of a certain group are not only more likely to have direct contact with members of the group, but also to be more aware of direct contact experiences. The individual concerned may be more likely to conceal their status as

someone with a stigmatising diagnosis when interacting with persons who they expect to show negative responses.

The decision to use a within subjects repeated measures design was informed by a number of considerations, not least the opportunity to test whether different levels of the vignette presented to the same individuals would elicit similar or different responses, thus negating the need for a much larger sample. One of the key limitations of this type of design is that presentation order may affect responses. In the studies presented here the presentation order was kept constant (intellectual disability followed by schizophrenia vignette), as was done in several similar previous studies (e.g. Furnham, Kirkby & McClelland, 2011; Furnham & Wincelous, 2012; Peris, Teachman & Nosek, 2008). The effect of presentation order of three unlabelled vignettes presented in random order was examined by Furnham, Daoud and Swami (2009) and found to have no effect on recognition or attitudes. However, these conclusions were based on a relatively small convenience sample (N=232) and no detailed analyses are presented.

With hindsight, presentation order of the vignettes should have been counterbalanced and the effects on responses assessed. As it stands, it cannot be ruled out that some of the differences in responses to the two vignettes may be a direct effect of presentation order. Thus, the increased endorsement of expert help in response to the schizophrenia vignette may at least partly have been triggered by a sense that, in comparison to the first case, the difficulties in this vignette were more serious and thus more in need of expert input. In addition, different responses may have been due to practice effects, in that participants may increasingly have guessed what the study was testing and adjusted their responses accordingly. Alternatively, or additionally, there may have been a fatigue effect in that responses became less considered over the course of completing the measures.

A final design issue meriting consideration concerns the benefits and limitations of comparing lay responses to intellectual disability and schizophrenia. As noted, the decision to draw a comparison with schizophrenia was made for several reasons, not least to place the findings in a broader context and draw on the much larger evidence base in the mental health field, and to examine whether the relationship between knowledge, stigma and beliefs about causes is disorder specific or generic to very different forms of mental and developmental disorders. Particularly in relation to the study of causal and intervention beliefs, where the evidence is almost non-existent in relation to intellectual disability, drawing on the mental health literature was of real benefit in evaluating the results. Perhaps a limitation of the decision to draw comparisons with schizophrenia lies in sacrificing breadth for depth; on this note, the question whether the relationship between knowledge, stigma and causal beliefs is similar or different for the two disorders was answered at a descriptive level. However, it was beyond the scope of this thesis to address the pertinent question *why* we may be seeing similarities and differences.

8.2.3 Ecological validity

A key issue for research such as that reported in this thesis is the question of ecological validity; that is the extent to which self-reported attitudes and social distance relate, or fail to relate, to real life behaviour. As Thornicroft (2006) noted in relation to people with mental illness, reducing discrimination, not negative attitudes, is the most important challenge. Certainly there is evidence, such as Kraus' (1995) much cited meta-analysis of the attitude-behaviour relationship, which suggests that attitudes do predict behaviour. However, the strength of the relationship depends on four key factors concerning the correspondence between measures of attitude and behaviour. These are correspondence in terms of the action under investigation, its target, context and time component (Fishbein & Ajzen, 1975). As noted in chapter 4,

measures designed to assess attitudes to the very heterogeneous population of people with intellectual disabilities show low correspondence between attitude and behaviour in terms of Fishbein and Ajzen's (1975) factors and hence are likely to be rather poor predictors of actual behaviour.

Social distance items, such as the ones used in this study, which relate to a specific individual and to different contexts are likely to be somewhat better predictors of behaviour. However while they may predict behaviour towards a young man like the one in the vignette, they are likely to tell us little about likely social interactions with a range of people with intellectual disabilities and in contexts other than the ones referred to. Furthermore even for the social distance items the time frame for behavioural intent was not assessed, i.e. respondents were not asked how likely they were to engage in social contact during a given period, which research suggests would increase the ability to predict behaviour (Davidson & Jaccard, 1979). Future research in the intellectual disability field should include measures of implicit attitudes (Greenwald et al., 1998) that are better at predicting spontaneous behaviour (Davidio et al., 1997), which is arguably of more relevance to the day-to-day experience of people with intellectual disabilities.

Furthermore in considering the relationship between attitudes and behaviour, the question whether social distance is driven by hostility or insecurity and discomfort is relevant. The theory of planned behaviour (Ajzen, 1991) paid attention to self-efficacy as an important factor beyond those specified in the original theory of reasoned action (Fishbein & Ajzen, 1975). Hence people's behaviour towards individuals with intellectual disabilities is not only influenced by their behavioural intentions, but also by their perception whether they possess the resources required to perform specific behaviours. If it is confirmed that insecurity motivates social distance from people with intellectual disabilities, then interventions should not only

aim to increase awareness and tackle prejudices, but also to increase lay people's self-efficacy.

8.3 Broader Methodological issues

A number of broader issues pertaining to the constructs under investigation require at least brief consideration.

8.3.1 Assessing intellectual disability and mental health literacy

Assessment of lay people's ability to recognise symptoms of an underlying condition in an unlabelled vignette could be criticised for the fundamental assumptions inherent in this approach and its implications. First of all this approach assumes that whether or not someone accurately recognises symptoms in an unlabelled vignette reflects their understanding of the condition more generally. While this may seem a reasonable assumption it has not actually been tested, most likely because reliably testing someone's knowledge of a condition is not without difficulties. Some studies have asked lay people to rate their own knowledge (Kobe & Mullick, 1995), but the reliability of results generated using such an approach is highly questionable. Others have asked lay people to name typical symptoms (Mencap, 2008) or have inferred knowledge from the accuracy of respondents' prevalence estimates (Alem et al., 1999; Tachibana, 2006).

Measures used to assess knowledge regarding mental health, such as the Mental Health Knowledge Survey (MAKS, Evans-Lacko et al., 2010), offer promise as they are being used across several studies, but are not without their problems either. The MAKS combines questions about respondents' views on help seeking, effectiveness of different treatments and prognosis, arguably all aspects of mental health literacy, but not straightforwardly indicators of someone's *knowledge* of mental illness, or specific conditions. Perhaps most controversial though is the attempt in the MAKS to gauge knowledge by asking respondents to what extent they

view a range of conditions as forms of 'mental illness'. While this approach has been used in other studies (e.g. Lauber et al., 2003), arguably lay people may possess a fairly sophisticated understanding of depression or drug addiction, for example, but may strongly resist their description as 'illnesses'.

On a different note, acceptance of the premise that 'ignorance' is a potential driver of stigma and investigating lay people's intellectual disability or mental health 'literacy' can be seen as problematic due to its apparent underlying stance that expert perspectives are best and that what is required is to shift public perspectives to bring them more in line with expert ones. Such a perspective could be deemed to lack sensitivity to a broad range of cultural values, and to underestimate the potential value of a broad range of practices that can lead to well-being and social connectedness.⁶

8.3.2 Researching lay conceptualisations with ethnically and religiously diverse populations

In order to study the influence of ethnicity and religion on the constructs in question, in this thesis an admittedly very broad brush approach was applied. The categorisation of participants into broad ethnic groups of white, Asian, black and other has been useful in providing a general indication as to where stigma may be of particular concern. However, this approach could be criticised for putting people whose cultural values and beliefs may show as many differences as similarities into one group. Similarly there is likely to be large variation within religious groups, not least the Christian group that contained followers of the Church of England as well as followers of African churches that are likely to be much more influenced by

⁶ In bearing these issues in mind, in this PhD I have tried to provide an overview of lay perceptions, while avoiding value judgments about these as far as possible. In instances though where certain beliefs are associated with increased stigma, treading the line between cultural and religious sensitivity and support for the rights of people with intellectual disabilities and mental illness can be very difficult and at times simply morally 'wrong'.

traditional beliefs. Future research should study conceptualisations of intellectual disability among specific cultural and religious groups to advance our understanding, similar to efforts in the mental health field (e.g. Razali et al., 1996; Swami et al., 2008)

The differences between ethnic groups reported in this thesis raise the question whether such findings reflect genuine ethnic differences or perhaps derive at least to some extent from the materials being more accessible to white participants. Attempts were made in the development of the IDLS to integrate evidence on beliefs about disability and mental illness among lay people from different cultural backgrounds.⁷ While an attempt was made to include a range of beliefs that have been reported to be more prevalent among BME communities, the necessary reduction in items after the pilot means that many participants' beliefs were not reflected in the final causal and intervention items.

Some other challenges were encountered that are relevant to future research with ethnically and religiously diverse populations. In the pilot it was attempted to use names that were at least to some extent matched to participants' own background. However this proved very unwieldy and was abandoned after the pilot. Instead the names James and Adam were used with all participants, but may well have influenced participants' responses. Furthermore, responses to the social distance items may have questionable reliability for people from cultural and religious communities where social contact between men and women is discouraged. Hence respondents' disapproval of close social contact may have been informed by views about the appropriateness of interactions between men and women, rather

⁷ However, the researcher's own position as white European and a past provider of community health services to people with intellectual disabilities and their families within the National Health Service inevitably means that Western dominant discourses about intellectual disability are likely to be more prominently reflected in the IDLS.

than necessarily reflecting stigma associated with intellectual disability or schizophrenia.

Finally some of the IDLS items may have been interpreted very differently by participants. Endorsement of the causal item 'strong religious or spiritual beliefs' in particular may have been influenced by participants' perception that either the presence or absence of such beliefs is problematic. In contrast, others' response to this item may have been influenced by their thoughts about the likely contents of such beliefs, rather than the strengths with which they are held. Future research that uses the IDLS should review the items to be used and consider the addition of items that are more likely to reflect specific beliefs among the population under investigation. This was done, for example, by Kaur (2011) who examined lay beliefs about intellectual disability among the Sikh community in the UK.

The finding that ethnicity and religion had different effects on causal and intervention beliefs indicates that future research should pay attention to the interplay between culture and religion in shaping beliefs regarding disability and illness.

8.3.3 Researching the effects of contact

This thesis illustrates problems inherent in asking about contact to a category that is often misconstrued. In order to address the risk of participants misconstruing the term 'learning disability', the term used in the survey due to its being the most widely used term in the UK, a fairly detailed definition of the term 'learning disability' was provided. This definition was placed at the beginning of the CLAS-ID (see Appendix 1) and thus shortly before the demographic information. It was added to the original measure developed in the US to a) increase the validity of responses to the CLAS-ID itself, but also b) to ensure that subsequent questions about prior contact with people with learning disabilities would not result in confusion. Despite

noting that 'learning disability' is referred to in some countries as an 'intellectual disability', that in the past the terms 'mental handicap' and 'mental retardation' have also been used to denote this condition, and stressing that "it is different from specific learning difficulties such as Dyslexia, which are not the focus of the study", confusion of the term with specific learning difficulties was evident in some responses. Following the question whether they knew someone with 'learning disabilities', participants were asked in what capacity they knew the person, leading several to note, for example, "my brother has dyslexia". While such responses were counted as indicating no prior contact with someone with intellectual disability, without doubt there will have been others who similarly misconstrued the question.

These difficulties indicate the problem inherent in attempts to study the effects of contact with people with intellectual disabilities, particularly in contexts where a number of terms may be in use and where there may be a lot of confusion about their meaning. The research community both in the US and UK has increasingly adopted the term 'intellectual disability', in the US instead of the very derogatory term 'mental retardation' (Shalock et al., 2007), in the UK instead of the confusing term 'learning disability'. Whether the term 'intellectual disability' is more widely understood and less open to misinterpretation by the public is a question for future research.

8.4 Implications for practice

The findings presented in this thesis have implications for public education and anti-stigma efforts, for policy makers and for clinical practice. Each area will be considered in turn. As anti-stigma work is already very much in evidence in relation to mental illness stigma, this discussion will focus on changing public attitudes and reducing stigma associated with intellectual disability.

The present findings of low awareness among lay people of typical symptoms of intellectual disability and general ambivalence about social interactions with people with intellectual disabilities indicate a need for interventions targeted at general population level to address barriers to equal rights and social inclusion. Evidence to date on interventions aimed at improving public attitudes towards people with intellectual disabilities is scarce, mostly poorly designed and has not tested interventions that could feasibly be implemented on a large scale. As noted in the literature review, most interventions aimed at improving attitudes have tested the effects of contact, but have usually done so over prolonged periods, using students and generally volunteers, who are likely to hold more positive attitudes to begin with. In designing future interventions aimed at the general population, a number of important issues need bearing in mind. Firstly, prejudice and discrimination against people with intellectual disabilities are likely to be motivated by a combination of factors, namely at times hostility, but perhaps more frequently insecurity and discomfort that are fuelled by a lack of familiarity, and at times perhaps a fear that social interaction might cast one into a caring role (Shakespeare, 2006). Hence interventions that fail to address all of these concerns are likely to be less successful.

In terms of the actual contents and most suitable targets for any interventions targeting the general population, the present findings give rise to the following tentative recommendations:

- In view of evidence that members of BME communities were less likely to recognise symptoms of mild intellectual disability, targeted public education efforts seem indicated. In this context it is important to note that lay people from Asian and black (mainly) African communities were much less likely to report prior contact with someone with intellectual disabilities. In line with intergroup

contact theory, creating increased opportunities for contact appears an important target. It is also conceivable that the self-reported contact rates are an underestimate. Hence where disability stigma is high and the disability not visible, the person affected and their family may well choose to conceal it. Thus many lay people may have had contact with someone with intellectual disabilities without necessarily being aware of this, and this is perhaps more likely among participants from BME communities due to raised stigma.

- The finding that social distance towards the individual presenting with symptoms of mild intellectual disability was higher among members of BME communities indicates that education about intellectual disability, increased opportunities for contact and efforts aimed at stigma reduction should go hand in hand. Furthermore, their impact may over time discourage those concerned from keeping the condition hidden, as the perceived benefits of avoiding shame and dishonour for the family may no longer outweigh the costs of missed opportunities and social isolation.
- Endorsement of supernatural causes, such as spirit possession or some form of punishment for one's own or one's parents' wrongdoings, was more common among more religious lay people and among Muslims. In order to counter the increased stigma associated with such beliefs, less stigmatising potential causes of intellectual disability, such as biomedical factors and severe trauma, should be emphasised. Furthermore attempts should be made to engage leaders of different religious faiths in encouraging more positive attitudes, similar to efforts underway in relation to reducing mental illness stigma as part of the *Time to Change* campaign (see <http://www.time-to-change.org.uk/news/faith-leaders-meet-tackle-mental-health-stigma-and-discrimination>). The two main Islamic reference texts, the Quran and the Hadith, consider disability as part of the

graded spectrum in which humans are created (Bazna & Hatab, 2005), and encourage Muslims to extend care to those in need (Morad, Nasri & Merrick, 2001). Crabtree (2007) noted that despite such teachings, within Muslim cultures the birth of a disabled child is frequently viewed as a shameful misfortune and a stain on the family's honour. In line with Crabtree, the present findings suggest that intellectual disability may be viewed negatively in some sections of the Muslim community, indicating a clear role for dialogue with and active involvement of religious leaders in countering negative attitudes and stigma.

- In the absence of visible markers of intellectual disability, it is important, if by no means easy without reverting to diagnostic labels, to rule out attribution of difficulties to more stigmatising factors that may be blaming of the person or their parents. How this can be achieved will need careful consideration in discussion with people with intellectual disabilities and their carers, who may have strong reservations about labelling.
- The development of resources designed for the purpose of recognising and managing the stigma of intellectual disability among specific ethnic and religious communities is worth considering. Such resources are likely to make interventions more feasible and more open to evaluation.
- Any interventions will need to have rigorous methods of evaluation built in from the start. Evaluation should measure both changes in knowledge and attitudes among lay people and changes in discrimination as experienced by people with intellectual disabilities and their families and carers.
- What messages are likely to be most effective in tackling negative attitudes and stigmatising lay beliefs should be developed through consensus among stakeholders with experience and expertise in the area of intellectual disability.

Engaging people with intellectual disabilities, carers and service providers from different ethnic and religious communities in this process will be very important.

With regards to the potential format of any interventions, in efforts to tackle the stigma associated with mental illness, a combination of education and contact based strategies has been suggested to result in the most durable gains (Dalky, 2012). Pinfold, Thornicroft, Huxley and Farmer (2005) concluded that the key active ingredient in stigma change interventions are the testimonies of service users about their experience of mental illness and contact with services. Evidence on lower awareness of intellectual disability and increased stigma among BME communities suggests a need for targeted interventions that are sensitive to cultural and religious beliefs and values. Furthermore, the finding of much lower rates of contact among lay people from BME communities suggests that contact, or at least personal testimonies by service users, must be a central part of any targeted intervention. While providing face to face contact may well prove difficult as part of large scale interventions targeting the general population, including testimonies from service users (and carers) in line with Pinfold et al.'s (2005) suggestion is feasible, for example through the use of film, and is conducive to tailoring interventions to different sections of the population.

Of note for policy makers, there has been large investment over recent years in tackling mental illness stigma, in the UK and other Western countries. In contrast, very little investment has gone into tackling prejudice and discrimination against people with intellectual disabilities at general population level. To the author's knowledge, the only large scale campaigns focused on intellectual disability in the UK is an annual "learning disability awareness week" run by Mencap and efforts to raise awareness of disability hate crime. The impact of such efforts at general population level will inevitably be limited though without greater resources. Recognition that

harassment, abuse and discrimination are an everyday occurrence for many people with intellectual disabilities has led to legislation on disability hate crime and an increased focus on law enforcement (see Quarmby, 2011). While such reactive steps are to be greatly welcomed, they should be matched by more proactive approaches aimed at creating a more positive climate at wider society level, and at sending clear messages about the unacceptability of disability based prejudice and discrimination.

With regard to implications for clinical practice, the findings provide an indication how cultural background and religion may influence people's perceptions of disability and their beliefs about different sources of help. Awareness of these issues can increase service providers' cultural competence, by enhancing their knowledge of the range of lay people's perceptions of intellectual disability and expectations of help (Richardson & Fulton, 2010). Such an increased understanding in turn can encourage openness about the potential influence of culture and religion on beliefs about causation and suitable help among people service providers come into contact with. Furthermore an understanding of these issues together with an awareness of power differences between themselves and service users can encourage service providers to sensitively enquire about people's perceptions and beliefs and their fit with service models. Where service providers do so, rather than wait for service users to raise concerns as is often the case in clinical practice, this is likely to have a positive impact on engagement and adherence with jointly negotiated interventions (Latif, 2010; Stewart et al., 2000).

Service providers should also be educated about the dangers of disability stigma in some cultural and religious communities and the risks these pose for the well-being of people with intellectual disabilities and their families, not least low access to opportunities and social isolation that may result from efforts to keep the disability hidden from the community.

8.5 Implications for future research

As noted above, this thesis indicates a need for effective interventions targeted at general population level to increase lay knowledge of intellectual disability (and schizophrenia) and target stigmatising beliefs. Research is needed to identify effective ways to achieving these aims in the context of a culturally and religiously diverse society.⁸

A challenge in much of intellectual disability research in this area is how to overcome the limitations of direct attitude measures and their tenuous links to real life behaviour. Future research should draw on the literature on the attitude-behaviour relationship to increase the ecological validity of research findings related to attitudes and stigma. In particular, implicit attitudes (Greenfeld et al., 1999) should be incorporated into future studies as they have implications for the likelihood of a certain behaviour occurring. To date only one study has tested implicit attitudes relevant to intellectual disability, looking at subtle stereotyping of children with trisomy 21 (Enea-Drapeau, Carlier & Huguet, 2012).⁹

This thesis set out to develop our understanding of lay causal beliefs in relation to symptoms of mild intellectual disability. Further research is needed to examine the application of attribution theory to lay responses to people with intellectual disabilities as this can aid our understanding of the messages to focus on or conversely avoid in anti-stigma interventions.

⁸ Walker (2012), under my supervision, conducted a pilot study testing a brief internet delivered intervention that contained filmed testimonies from service users with intellectual disabilities. The intervention was designed to improve attitudes and encourage lay people to take a more active stance against discrimination and harassment directed at individuals with intellectual disabilities. The findings from this pilot are fairly promising, but also indicate the need for further careful thinking to ensure that any interventions designed for the general population are effective.

⁹ Wilson (in progress), under my supervision, is currently developing an IAT designed specifically for the assessment of implicit associations towards people with intellectual disabilities. This tool should allow testing the relationship between implicit and explicit attitudes towards people with intellectual disabilities and advance our understanding of lay people's behavioural intentions, beyond what explicit attitude measures can offer.

A further area to consider in future research concerns the omission of affective responses in the current thesis. Stigma research in the area of mental health draws attention to the role of emotional reactions as mediators between attributions and stigma (Angermeyer et al., 2010). Connolly (2011) found that emotional reactions had a mediating function between causal attributions and stigma not just for schizophrenia but also for intellectual disability. Hence future research would be well advised to incorporate both measures of implicit attitudes and emotional reactions to render a more comprehensive picture.

Finally, research is needed that investigates the clinical implications of findings such as the ones presented in this thesis. In particular, in cases where intellectual disability may be undiagnosed as yet, the effects of “unhelpful” lay beliefs on help seeking and engagement should be investigated. In the mental health arena the implications of mental health literacy for help seeking have been demonstrated in a number of studies (e.g. Jorm, 2000; Wright, Jorm, Harris & McGorry, 2007). In the intellectual disability field, research with parents of children with disabilities has concluded that where parents do not have a clear causal explanation for their child’s disability, their beliefs and attributions can influence their relationships with their children (Bugental & Happaney, 2002; Nixon, 1993), lead them to blame themselves (Mickelson, Wroble & Helgeson, 1999), and influence their views on appropriate services for their child (Hassall & Rose, 2005). Such studies by definition use clinical samples though, i.e. the child is already known to disability services. It is less clear whether increasing awareness of intellectual disability at general population level and tackling beliefs that have a poor fit with seeking help from health service providers are in fact likely to result in earlier detection and more timely intervention. It is conceivable that, at least in countries with good health resources and services, awareness and beliefs among providers of services to children in particular have a

much stronger effect on early diagnosis than awareness and beliefs among parents. These questions would seem an important area for further research.

8.6 Final Conclusions

This thesis explored the relationships between lay awareness of typical symptoms of mild intellectual disability, social distance and causal beliefs. The findings provide new evidence on the association between inclusion attitudes and social distance and the fit between causal and interventions beliefs. There is already a sizeable evidence base regarding the constructs examined in this thesis as they pertain to mental illness. This thesis has provided new evidence though on some particularly contested issues, namely the relationship between lay knowledge, belief in a biomedical model of mental illness and stigma. Attention to the influence of contact, ethnicity and religion alongside other socio-demographic characteristics has increased our understanding of the potential influence of such factors on lay conceptualisations of intellectual disability and schizophrenia. Overall the broad range of participant characteristics studied explained mostly only relatively small proportions of the variance in the variables studied. This indicates that there is much beyond lay people's prominent characteristics that influences such conceptualisations.

Overall the findings should be viewed very much as starting points for further research, and not as definitive picture, as they are based on a convenience sample and do not allow conclusions about any cause and effect relationships between the aspects studied.

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Appendix 1

**Intellectual Disability Scale (IDLS) with the Community Living
Attitudes Scale- Intellectual Disability (CLAS-ID) version
as used in the studies presented**

Paper version



Attitudes towards people experiencing difficulties

We would like to invite you to participate in this important research project, conducted by University College London. Before you decide whether you want to take part, it is important that you read the following information carefully. It is up to you to decide whether or not to take part. Please ask if there is anything that is not clear or you would like more information.

Purpose of the research

We are interested in finding out more about attitudes in the general population towards people with various types of difficulties. We are also interested in finding out whether there are any differences in such attitudes between people from different cultural backgrounds.

Completing this questionnaire will take you about 15 to 20 minutes. We are very interested in your honest views, not any 'right' or 'wrong' answers.

To thank you for taking part you will be entered into a Prize Draw – you will have a chance of winning £100 in Amazon vouchers (or a shop of your choice).

All data will be collected and stored in accordance with the Data Protection Act 1998.

Principal Investigator: Dr Katrina Scior, Clinical, Educational & Health Psychology, University College London, London WC1E 6HJ; Email: k.scior@ucl.ac.uk, Tel: 0207-6791845
This study has been approved by the UCL Research Ethics Committee (Project ID Number: 0960/001)

Your completed questionnaire can be returned FREE to:

FREEPOST University College London
(Clinical, Educational & Health Psychology - Ref: Scior)
Gower Street
London, WC1E 6BT

This questionnaire is in three parts. The first part presents two case studies - we would like you to give your views of likely causes and responses. The second part is about a specific form of disability. The third part asks some information about you. Please respond to all items - if you are unsure of a response please make a best guess or leave the question blank.

James is 22 and lives at home with his parents and younger brother. He found school a struggle and left without any qualifications. He has had occasional casual jobs since. When his parents try to encourage him to make plans for his future, James has few ideas or expresses ambitions that are well out of his reach. Rather than having him at home doing nothing, his mum has been trying to teach James new skills, such as cooking a meal, but James has struggled to follow her instructions. He opened up a bank account with his parents' help, but has little idea of budgeting and, unless his parents stop him, will spend all his benefits on comics and DVDs as soon as he receives his money.

1. What would you say is going on with James?

2. How do you think James could best be helped?

3. Many people experience problems such as James'. Please indicate the extent to which you agree that the following are a likely reason for problems such as James' in *anyone*, using this scale:

1 = Disagree strongly 4 = Unsure 5 = Agree somewhat
 2 = Disagree moderately 6 = Agree moderately
 3 = Disagree somewhat 7 = Agree strongly

	1	2	3	4	5	6	7
1. overly spoilt as a child	1	2	3	4	5	6	7
2. virus / other infection that affects the brain	1	2	3	4	5	6	7
3. lack of daytime occupation	1	2	3	4	5	6	7
4. possession by spirits	1	2	3	4	5	6	7
5. family arguments	1	2	3	4	5	6	7
6. financial worries	1	2	3	4	5	6	7
7. punishment for own past wrongdoings	1	2	3	4	5	6	7
8. strong religious or spiritual beliefs	1	2	3	4	5	6	7
9. genetic factors	1	2	3	4	5	6	7
10. suffering abuse as a child	1	2	3	4	5	6	7
11. recent traumatic incident such as traffic accident	1	2	3	4	5	6	7
12. punishment for parents' wrongdoings	1	2	3	4	5	6	7
13. very poor schooling	1	2	3	4	5	6	7
14. complications at time of birth	1	2	3	4	5	6	7
15. being from a single-parent family	1	2	3	4	5	6	7
16. parents too lenient	1	2	3	4	5	6	7
17. lack of an intimate relationship	1	2	3	4	5	6	7
18. brain abnormality	1	2	3	4	5	6	7
19. a test from God / Allah	1	2	3	4	5	6	7
20. recent death of relative or close friend	1	2	3	4	5	6	7
21. meningitis	1	2	3	4	5	6	7
22. isolation from extended family	1	2	3	4	5	6	7

4. Please indicate the extent to which you agree that the following are likely to be effective in helping someone like James overcome his difficulties, using this scale:

1 = Disagree strongly
 2 = Disagree moderately
 3 = Disagree somewhat
 4 = Unsure
 5 = Agree somewhat
 6 = Agree moderately
 7 = Agree strongly

1. get him to take more responsibility	1	2	3	4	5	6	7
2. turn to close family	1	2	3	4	5	6	7
3. visit his GP (General Practitioner)	1	2	3	4	5	6	7
4. get out more	1	2	3	4	5	6	7
5. pray	1	2	3	4	5	6	7
6. see a counsellor	1	2	3	4	5	6	7
7. see a psychiatrist	1	2	3	4	5	6	7
8. see a religious person / clergy	1	2	3	4	5	6	7
9. get a job	1	2	3	4	5	6	7
10. get a good talking to from his parents	1	2	3	4	5	6	7
11. see a social worker	1	2	3	4	5	6	7
12. more physical activity	1	2	3	4	5	6	7
13. psychological treatment	1	2	3	4	5	6	7
14. get careers advice	1	2	3	4	5	6	7
15. attend a place of worship more often	1	2	3	4	5	6	7
16. see a spiritual or faith healer	1	2	3	4	5	6	7
17. socialise more	1	2	3	4	5	6	7
18. take prescribed psychiatric medication	1	2	3	4	5	6	7
19. make him face up to reality	1	2	3	4	5	6	7
20. find a girlfriend/ wife	1	2	3	4	5	6	7
21. go on holiday	1	2	3	4	5	6	7
22. be more religious	1	2	3	4	5	6	7

5. Please indicate your agreement with the following statements, using the same scale:

I would be happy to move next door to someone like James	1	2	3	4	5	6	7
I would be happy to spend an evening socialising with someone like him	1	2	3	4	5	6	7
I would be happy to make friends with someone like him	1	2	3	4	5	6	7
I would be happy for someone like James to marry into my family	1	2	3	4	5	6	7

Adam is 24 and lives at home with his parents. He did fine at school, but has only had a few casual jobs since. Over recent months he has spent lots of time alone, locked in his bedroom and frequently refuses to eat with his parents or have a bath. He sometimes gets very agitated for little apparent reason and his parents have heard him talking loudly even when he's alone in his bedroom. At times they find his speech disorganised and hard to follow. When his parents encourage him to make plans for his future he says this is too dangerous. They are certain he is not taking drugs because he never sees anyone or goes anywhere.

1. What would you say is going on with Adam?

2. How do you think Adam could best be helped?

3. Please indicate the extent to which you agree that the following are a likely reason for problems such as Adam's in *anyone*, using this scale:

1 = Disagree strongly
 2 = Disagree moderately
 3 = Disagree somewhat
 4 = Unsure
 5 = Agree somewhat
 6 = Agree moderately
 7 = Agree strongly

	1	2	3	4	5	6	7
1. overly spoilt as a child	1	2	3	4	5	6	7
2. virus / other infection that affects the brain	1	2	3	4	5	6	7
3. lack of daytime occupation	1	2	3	4	5	6	7
4. possession by spirits	1	2	3	4	5	6	7
5. family arguments	1	2	3	4	5	6	7
6. financial worries	1	2	3	4	5	6	7
7. punishment for own past wrongdoings	1	2	3	4	5	6	7
8. strong religious or spiritual beliefs	1	2	3	4	5	6	7
9. genetic factors	1	2	3	4	5	6	7
10. suffering abuse as a child	1	2	3	4	5	6	7
11. recent traumatic incident such as traffic accident	1	2	3	4	5	6	7
12. punishment for parents' wrongdoings	1	2	3	4	5	6	7
13. very poor schooling	1	2	3	4	5	6	7
14. complications at time of birth	1	2	3	4	5	6	7
15. being from a single-parent family	1	2	3	4	5	6	7
16. parents too lenient	1	2	3	4	5	6	7
17. lack of an intimate relationship	1	2	3	4	5	6	7
18. brain abnormality	1	2	3	4	5	6	7
19. a test from God / Allah	1	2	3	4	5	6	7
20. recent death of relative or close friend	1	2	3	4	5	6	7
21. meningitis	1	2	3	4	5	6	7
22. isolation from extended family	1	2	3	4	5	6	7

4. Please indicate the extent to which you agree that the following are likely to be effective in helping someone like Adam overcome their difficulties, using this scale:

1 = Disagree strongly
 2 = Disagree moderately
 3 = Disagree somewhat
 4 = Unsure
 5 = Agree somewhat
 6 = Agree moderately
 7 = Agree strongly

1. get him to take more responsibility	1	2	3	4	5	6	7
2. turn to close family	1	2	3	4	5	6	7
3. visit his GP (General Practitioner)	1	2	3	4	5	6	7
4. get out more	1	2	3	4	5	6	7
5. pray	1	2	3	4	5	6	7
6. see a counsellor	1	2	3	4	5	6	7
7. see a psychiatrist	1	2	3	4	5	6	7
8. see a religious person / clergy	1	2	3	4	5	6	7
9. get a job	1	2	3	4	5	6	7
10. get a good talking to from his parents	1	2	3	4	5	6	7
11. see a social worker	1	2	3	4	5	6	7
12. more physical activity	1	2	3	4	5	6	7
13. psychological treatment	1	2	3	4	5	6	7
14. get careers advice	1	2	3	4	5	6	7
15. attend a place of worship more often	1	2	3	4	5	6	7
16. see a spiritual or faith healer	1	2	3	4	5	6	7
17. socialise more	1	2	3	4	5	6	7
18. take prescribed psychiatric medication	1	2	3	4	5	6	7
19. make him face up to reality	1	2	3	4	5	6	7
20. find a girlfriend/ wife	1	2	3	4	5	6	7
21. go on holiday	1	2	3	4	5	6	7
22. be more religious	1	2	3	4	5	6	7

5. Please indicate your agreement with the following statements, using the same scale:

I would be happy to move next door to someone like Adam	1	2	3	4	5	6	7
I would be happy to spend an evening socialising with someone like him	1	2	3	4	5	6	7
I would be happy to make friends with someone like him	1	2	3	4	5	6	7
I would be happy for someone like Adam to marry into my family	1	2	3	4	5	6	7

What is a Learning Disability?

A '**learning disability**' is an umbrella term for a condition in which someone has an impairment in their ability to think (intellectual functioning) and to cope on their own on a day-to-day basis (social functioning) and which has been identified as having an onset before adulthood (18 years old). Learning disability is referred to in certain countries as an intellectual disability. In the past the terms '**mental handicap**' and '**mental retardation**' have also been used to denote this condition. Some specific syndromes and conditions such as Down's syndrome, Fragile X and Autism **may** in some cases be associated with having a learning disability.

Learning disabilities are different from specific learning difficulties such as Dyslexia, which are not the focus of this study.

Please indicate the extent to which you agree with the following statements according to this scale:

1 = Disagree strongly	4 = Agree somewhat
2 = Disagree moderately	5 = Agree moderately
3 = Disagree somewhat	6 = Agree strongly

- | | | | | | | |
|--|---|---|---|---|---|---|
| 1. People with learning disabilities should not be allowed to marry and have children. | 1 | 2 | 3 | 4 | 5 | 6 |
| 2. A person would be foolish to marry a person with learning disabilities. | 1 | 2 | 3 | 4 | 5 | 6 |
| 3. People with learning disabilities can plan meetings and conferences without assistance from others. | 1 | 2 | 3 | 4 | 5 | 6 |
| 4. People with learning disabilities can be trusted to handle money responsibly. | 1 | 2 | 3 | 4 | 5 | 6 |
| 5. The opinions of a person with learning disabilities should carry more weight than those of family members and professionals in decisions affecting that person. | 1 | 2 | 3 | 4 | 5 | 6 |
| 6. Sheltered workshops for people with learning disabilities are essential. | 1 | 2 | 3 | 4 | 5 | 6 |
| 7. Increased spending on programs for people with learning disabilities is a waste of money. | 1 | 2 | 3 | 4 | 5 | 6 |
| 8. Homes and services for people with learning disabilities downgrade the neighbourhoods they are in. | 1 | 2 | 3 | 4 | 5 | 6 |
| 9. People who have learning disabilities are a burden on society. | 1 | 2 | 3 | 4 | 5 | 6 |
| 10. Homes and services for people with learning disabilities should be kept out of residential neighbourhoods. | 1 | 2 | 3 | 4 | 5 | 6 |
| 11. People with learning disabilities need someone to plan their activities for them. | 1 | 2 | 3 | 4 | 5 | 6 |
| 12. People with learning disabilities do not need to make choices about the things they will do each day. | 1 | 2 | 3 | 4 | 5 | 6 |
| 13. People with learning disabilities can be productive members of society. | 1 | 2 | 3 | 4 | 5 | 6 |
| 14. People with learning disabilities have goals for their lives like other people. | 1 | 2 | 3 | 4 | 5 | 6 |
| 15. People with learning disabilities can have close personal relationships just like everyone else. | 1 | 2 | 3 | 4 | 5 | 6 |
| 16. People with learning disabilities should live in sheltered facilities because of the dangers of life in the community. | 1 | 2 | 3 | 4 | 5 | 6 |
| 17. People with learning disabilities usually should be in group homes or other facilities where they can have the help and support of staff. | 1 | 2 | 3 | 4 | 5 | 6 |

About you:

Male / Female	Age:	Occupation:
Ethnicity: White British <input type="checkbox"/> White Other, please specify Black British <input type="checkbox"/> Black African Caribbean <input type="checkbox"/> Black African <input type="checkbox"/> Black Other <input type="checkbox"/> Indian <input type="checkbox"/> Pakistani <input type="checkbox"/> Asian Other, please specify Middle Eastern <input type="checkbox"/> Other, please specify		Education: (Please tick highest) Primary School <input type="checkbox"/> to age 16 (e.g. GCSE) <input type="checkbox"/> to age 18 (e.g. A Levels) <input type="checkbox"/> University degree <input type="checkbox"/> Post-graduate <input type="checkbox"/>
Country of birth: UK / Other (please specify) If not born in UK, age of entry to UK years		Do you have children? Yes / No
Religion: Christian <input type="checkbox"/> Muslim <input type="checkbox"/> Hindu <input type="checkbox"/> Sikh <input type="checkbox"/> Buddhist <input type="checkbox"/> Non-religious <input type="checkbox"/> Other (please specify)		How important is your religion in guiding your life? (Please circle the corresponding point on the line) Of little importance Very important
How often do you visit a place of worship? Never / At most twice a year / 3 to 6 times a year / Fairly regularly / At least once a week		
Do you know anyone who experiences mental health problems? Yes / No Type of mental health problem		If yes, in what capacity to you know them? (e.g. sibling, distant cousin, fellow pupil, colleague etc)
How often do you see this person? On average times per month / year (please delete)		How close is this person to you? (Please circle the corresponding point on the line) Not at all close Extremely close
Do you know anyone with learning disabilities? Yes / No		If yes, in what capacity to you know them? (e.g. sibling, other relative, fellow pupil, colleague etc)
How often do you see this person? On average times per month / year (please delete)		How close is this person to you? (Please circle the corresponding point on the line) Not at all close Extremely close

Prize Draw

Please enter your details here if you would like to be entered into the Prize Draw – you will have a chance of winning £100 in Amazon vouchers (or a shop of your choice). On receipt your name and contact details will immediately be separated from your other responses and your responses will be kept anonymous.

Name:.....

Telephone Number:

Email address:.....

Appendix 2

Scoring Guide for the Community Living Attitude Scale-

Intellectual Disability version

Community Living Attitude Scale-ID version- Scoring Guide

Henry, D., Keys, C., & Jopp, D. (1999).

Full reference: Henry, D., Keys, C., & Jopp, D. (1999). *The community living attitudes scale, mental retardation version: Reference manual*. Chicago: Univ. of Illinois at Chicago.

Scoring of 17 item short version, as detailed in reference manual.

Subscales and item numbers (R=reverse item before calculating mean). Each subscale score is a mean of the items detailed.

Empowerment

Mean of 1R, 2R, 3, 4, 5

Exclusion

Mean of 7, 8, 9, 10

Sheltering

Mean of 6, 11, 16, 17

Similarity

Mean of 12R, 13, 14, 15

Appendix 3

Coding Frame for the Question

“What would you say is going on with x ?”

Coding Frame for the Question "What would you say is going on with x?"

1 = Intellectual Disability

2 = Reference to other developmental disorder, including specific learning disability, e.g. dyslexia, and autism spectrum disorder

3 = General reference to mental illness or to other psychiatric diagnosis, e.g. anxiety

4 = Depression

5 = Schizophrenia/ Psychosis

6 = Personal problems, including stress, family tension etc

7 = Other, including low self-esteem

8 = Don't know

9 = Upbringing, e.g. spoilt

10 = Lazy/ lack of motivation

11 = Trouble growing up/ doesn't know what he wants in life

12 = Possession by spirits/ cursed etc

Appendix 4

Scoring Guide for the Intellectual Disability Scale

Intellectual Disability Literacy Scale (IDLS) - Scoring Guide

Scior, K. & Furnham, A.F. (2011)

Full reference: Scior, K. & Furnham, A.F. (2011). Development and validation of the Intellectual Disability Literacy Scale for assessment of knowledge, beliefs and attitudes to intellectual disability, *Research in Developmental Disabilities*, 32, 1530–1541.

Subscales for final 22 item versions. Each subscale score is a mean score of the items listed.

1. Causal Beliefs

Factor 1 - Biomedical

5 items

2. virus / other infection that affects the brain
9. genetic factors
14. complications at time of birth
18. brain abnormality
21. meningitis

Factor 2 – Adversity

5 items

5. family arguments
6. financial worries
10. suffering abuse as a child
11. recent traumatic incident such as traffic accident
20. recent death of relative or close friend

Factor 3 - Environment

7 items

1. overly spoilt as a child
3. lack of daytime occupation
13. very poor schooling
15. being from a single-parent family
16. parents too lenient
17. lack of an intimate relationship
22. isolation from extended family

Factor 4 – Supernatural

5 items

4. possession by spirits
7. punishment for own past wrongdoings
8. strong religious or spiritual beliefs
12. punishment for parents' wrongdoings
19. a test from God / Allah

2. Intervention Beliefs

Factor 1 - Expert Help

6 items

3. visit GP
6. see a counsellor
7. see a psychiatrist
11. see a social worker
13. psychological treatment
18. take prescribed psychiatric medication

Factor 2 – Lifestyle/ Social

11 items

1. get him to take more responsibility
2. turn to close family
4. get out more
9. get a job
10. get a good talking to from his parents
12. more physical activity
14. get careers advice
17. socialise more
19. make him face up to reality
20. find a girlfriend/ wife
21. go on holiday

Factor 3 – Religion/ Spiritual

Final 5 items

5. pray
8. see a religious person / clergy
15. attend a place of worship more often
16. see a spiritual or faith healer
22. be more religious