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What do we know about the health and healthcare of people with intellectual disabilities from minority ethnic groups in the United Kingdom? A systematic review

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Declaration of Interest

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Abstract

Background. People with from minority ethnic communities face inequalities in health and healthcare. This systematic review considers the question of what we know about the health and healthcare of children and adults with intellectual disabilities from ethnic minority communities in the UK.

Method. Studies published from 1990 to 2018 were identified via electronic literature databases, email requests, and cross-citations. Studies were reviewed narratively in relation to identified themes.

Results. 23 studies were identified, most commonly focusing on South Asian communities. Very little information was identified on physical health or physical healthcare, with the identified evidence tending to focus on mental health care, access to specialist intellectual disability services, and inpatient services.

Conclusion. Little is known about the health status of people with intellectual disabilities from minority ethnic groups in the UK. It is clear that they may experience barriers to accessing specialist intellectual disability services and other forms of healthcare.

What do we know about the health and healthcare of people with intellectual disabilities from minority ethnic communities in the United Kingdom? A systematic review

Introduction

The 2011 Census for England and Wales found that 86.0% of the population was White (falling from 94.1% in 1991 (Public Health England, 2018)), with 7.5% of the population coming from Asian minority ethnic groups, 3.3% from Black ethnic minority groups, 2.2% from Mixed/Multiple ethnic minority groups, and 1.0% from Other ethnic minority groups (Office for National Statistics, 2018). The prevalence of intellectual disabilities in non-White groups is likely to be at least as high as that in White groups (McGrother et al., 2002) and, indeed, higher rates of more severe intellectual disability have been reported among some South Asian groups in the UK (Emerson et al., 1997, Emerson and Hatton, 2004, Emerson, 2012). An early prediction, that by 2021 one in 10 of all people with intellectual disabilities in the United Kingdom (UK) will belong to a non-White minority ethnic group (Emerson and Hatton, 1999), may indeed have been an underestimate in light of the 2011 Census figures. More recent population projections for 2012 to 2030 predict that 25% of new entrants to adult social care for people with intellectual disabilities will belong to minority ethnic communities (Emerson et al., 2012). In areas with substantial populations belonging to minority ethnic communities, the proportion of people with intellectual disability will also be substantial. For example, 43% of young adults with intellectual disabilities in Birmingham in 2001 belonged to a minority ethnic group and this figure was predicted to rise to 56% by the year 2011 (Emerson and Robertson, 2002).

Differences in health across ethnic groups have been repeatedly documented in the UK (Nazroo, 2014, Smith et al., 2000, Wohland et al., 2015). For example, minority ethnic groups in England consistently have higher than expected levels of poor health with significantly higher levels in the Pakistani and Bangladeshi group (Darlington et al., 2015). Overall, generally poorer health has been found among non-White minorities, with Bangladeshi people having the poorest health, followed by Pakistani, Black Caribbean, Indian and Chinese people (Nazroo, 2014). However, ethnic inequalities in health have been neglected in policy discussions, most notably being absent from the Marmot Review (Nazroo, 2014).

These disparities in health are not thought to be related to biological differences or inherent features of distinct ethnic groups, but to socioeconomic factors in relation to social determinants of health and the additional disadvantages of discrimination, marginalisation and racial harassment (Darlington-Pollock and Norman, 2017). A great number of potential barriers exist in relation to the use of health services by minority ethnic communities. These include barriers such as low education and a lack of appropriate translated materials (Scheppers et al., 2006), with evidence of ethnic differences in the treatment of mental health problems being indicative of institutional racism (McKenzie and Bhui, 2007). These issues occur across the range of minority ethnic communities, for example Chinese people are underrepresented in mental health service uptake on account of poor access (Cowan, 2001).

Health inequalities are also experienced by children and young people with intellectual disabilities in the UK (Allerton et al., 2011) and the population of people with intellectual disabilities generally (Emerson and Hatton, 2013). People with intellectual disabilities from

minority ethnic communities and newly arrived communities may thus be doubly disadvantaged in relation to health. These families often face "double discrimination" (Department of Health, 2009), experiencing discrimination on the basis of both intellectual disabilities and minority ethnic status. Consequences of this double discrimination include a lack of culturally appropriate services, limited friendships and closer relationships, and a lack of meaningful leisure activities (Azmi et al., 1997). In view of the double disadvantage they may face, people with intellectual disabilities and their families from minority ethnic communities have been highlighted as priority groups for better access to health and social care support (Foundation for People with Learning Disabilities, 2012, Department of Health, 2009).

People with intellectual disabilities from minority ethnic communities may experience a wide range of barriers to service access and uptake. Insufficient and inappropriate services may be experienced due to policy and services which are not always culturally sensitive, incorrect assumptions about what certain ethnic groups value, language barriers, and discrimination (Department of Health, 2009). A formal investigation into physical health inequalities experienced by people with intellectual disabilities and/or mental health problems found that those from minority ethnic communities faced complex barriers (Disability Rights Commission, 2006, Nocon et al., 2008). These range from practical issues such as a lack of health information available in community languages where people can access it (places of worship, community centres, refugee centres) to attitudinal issues. For example, among professionals, it is often wrongly assumed that people from minority ethnic communities prefer help and support from their extended families which may result in wrongly denying them a right to choose what is on offer (Arshad and O'Hara, 2011).

However, the pervasive assumption and stereotype that South Asian people live in self-supporting extended families, and therefore, that the support of social services is largely unnecessary, is not supported by research findings (Katbamna et al., 2004). People with intellectual disabilities from new migrant communities also face these barriers, as well as specific attitudinal barriers around their culture and country of origin (Wightman, 2012). Such experiences may represent cultural patterning of fairly common experiences across ethnic groups, which are under-investigated (and hence less visible in the research literature) within majority ethnic groups (Hatton, 2004). Many of these barriers are also likely to reflect the disadvantaged social and economic circumstances that many people with intellectual disabilities across all ethnic communities find themselves in (Hatton, 2004, Wightman, 2012).

As a result, people with intellectual disabilities from some minority ethnic communities may be under-represented as users of some services. Individuals with intellectual disabilities from minority ethnic communities are largely under-represented as users of specialist intellectual disability services, with carers from minority ethnic communities being largely unaware of specialist intellectual disability services (Royal College of Psychiatrists, 2011). A systematic review of ethnic variation in mental health service utilisation by people with intellectual disabilities in high income countries found that South Asian people with intellectual disabilities in the UK had lower use of mental health services than White British comparison groups (Dura-Vila and Hodes, 2012). Conversely, those from some minority ethnic communities may be over-represented in particular services, for example admission rates to intellectual disability inpatient services are higher than average among Black and

White/Black Mixed groups (Care Quality Commission and National Mental Health Development Unit, 2011).

Whilst it is clear that people with intellectual disabilities from minority ethnic communities in the UK may face inequalities in health and healthcare, to date there has been no attempt to systematically summarise and appraise the evidence-base on this topic. In this paper, we present the first systematic review to consider what is known about the health and healthcare of people with intellectual disabilities from ethnic minority communities in the UK. The review considers evidence regarding both children and adults in view of the potential for early-life experiences to influence health across the lifetime (Braveman and Barclay, 2009) and also the need to consider possible inequalities in access to both child and adult services.   Our aims are twofold. Firstly, we aim to summarise what is known about the health status of those with intellectual disabilities from minority ethnic communities in order to document potential health inequalities and identify gaps in knowledge. Secondly, we aim to provide a narrative synthesis of research relating to the physical or mental healthcare of people with intellectual disability from minority ethnic communities in order to provide potential directions for future research, policy and practice.

Method

The review was conducted in accordance with PRISMA guidelines (Moher et al., 2009). Electronic database searches were conducted using Medline, PsycINFO, and Cinahl (all on EBSCO) and Web of Science. In addition, a request for information on research relevant to the review was sent to the Intellectual Disability UK Research mailing list, and the IASSIDD Health SIRG (November 2017). The reference lists of studies meeting the inclusion criteria were searched.

Four blocks of search terms were developed and combined with the Boolean operator 'and':
1. terms for ethnicity which were collated by examining terms occurring in existing systematic reviews relating to ethnicity (Bhui et al., 2015, Dawson et al., 2017, Evans et al., 2012); 2. terms for physical or mental health, or healthcare collated by examining existing reviews (Dawson et al., 2017, Balogh et al., 2016, Hergenrather et al., 2015b, Hergenrather et al., 2015a) ; 3. terms for intellectual disability which have been used in previous systematic reviews (e.g. Robertson et al., 2017); and 4. terms for the UK which were adapted from the Medline UK (Ovid) search filter (Ayiku et al., 2017).   An example of a database specific search strategy (Medline) is given in Appendix 1

Inclusion/Exclusion Criteria

Inclusion

Articles were required to meet all the following criteria:

- Peer reviewed

- English language full text

- Published from 1990 to 2018. Articles published before 1990 were excluded as they predate major changes in service provision for people with intellectual disabilities (National Health Service and Community Care Act 1990).

- Quantitative research, qualitative research, evaluation or audit

- Samples where 75% or more have intellectual disability or mixed samples where results are disaggregated for people with intellectual disability

- Samples where 5 or more participants are from minority ethnic communities

- Includes quantitative or qualitative data regarding the physical or mental health (including determinants of health), or healthcare of people with intellectual disability from minority ethnic communities in the UK.

Exclusion Criteria

- Not peer reviewed or peer review status unclear

- Any study employing any research design with a sample size of less than 5 for participants from minority ethnic communities (i.e. excluding participants in the sample who are not from an minority ethnic community) in order to exclude case studies and other very small scale studies which may not be generalizable to people from minority ethnic groups generally

- Reviews, letters, commentaries, editorials, meeting or conference abstracts

- Studies on conditions where intellectual disability cannot be assumed (e.g. cerebral palsy) where results not disaggregated for people with intellectual disability

- Studies where reported outcomes are not direct indicators of physical or mental health e.g. general morale, self-esteem, quality of life (QoL) unless a specific health related QoL domain reported, social inclusion

- Studies relating to challenging behaviour that do not include measures of psychopathology in order to differentiate challenging behaviour that functions as an indicator of mental ill health from challenging behaviour related to, for example, physical conditions and pain (de Winter et al., 2011).

- Studies relating to the physical or mental health of carers of people with intellectual disability

Initially, titles and abstracts were used to exclude studies that were obviously not within scope (first author). A random sample of 20% (339) of those excluded and 20% (15) of those retained at this stage was assessed by a second reviewer. There was one instance of disagreement and this article was not ultimately included in the final review (overall agreement 99.7%; Kappa .966).

Those retained for further screening were those for which relevance could not be assessed without accessing full text, or those that were chosen as potentially within scope. These studies were screened by the first and last author and discussed until consensus was reached on whether or not they met the inclusion criteria. All relevant studies were included in the review regardless of methodological quality.

Data Extraction and Synthesis

Study data were extracted from full text articles and entered into an Excel database with regard to: authors, year, country, main focus of study, study design, sample source, key sample features, sample size, ethnic breakdown of sample[1], sample age range (mean, SD and median), sample living situation, percentage of sample male, measures employed, and main findings. An iterative approach was taken in which a list of themes was identified via reading and re-reading the study summaries in Excel and these themes were allocated to overarching themes (Braun and Clarke, 2006). The themes and overarching themes identified were entered into the Excel database for each study. These were then checked by the last author and discussed until consensus was reached.

Quality Assessment/Risk of Bias

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[1] Where studies have used the term 'Caucasian' this is referred to as 'White' throughout this review

Study quality was assessed using the Mixed Methods Appraisal Tool (MMAT) which was designed for the appraisal stage of systematic reviews that include qualitative, quantitative and mixed method studies and allows reviewers to concomitantly appraise most common types of study methodology and design (Pluye et al., 2011). In the MMAT, primary studies (or mixed method study components) are rated in relation to four specific methodological quality criteria depending on study type: qualitative; quantitative randomized controlled (trials); quantitative non-randomized; or quantitative descriptive studies. The number of the criteria met is reported in the form of an asterix (*) for each criterion met. The MMAT is an efficient tool, but reliability needs further improvement, particularly for two items relating to qualitative studies including the sentence 'appropriate consideration' (Souto et al., 2015). MMAT scores were entered into the Excel database. All extracted data in Excel were subsequently checked for accuracy and completeness by the last author. Whilst a third reviewer was available to resolve any disagreements, none arose.

Results were collated, summarised and reported via a tabulation of key data, a descriptive numerical summary of included studies (e.g. number with particular research designs) and a descriptive narrative summary of the identified themes. Due to variation in the methodology of included studies, meta-analysis was not appropriate.

Results

Electronic database searches identified a total of 2,298 records, with 1,769 remaining following the removal of 529 duplicate records. Following screening by title and abstract, 1,694 were excluded, leaving 75 for consideration of full text, of which 24 were included in the review along with one additional article from other sources (cross-citation) giving a total of 25 articles (see Figure 1).

Two articles were clearly based on different phases of the same study of people placed in long term out-of-area hospital care from three East London boroughs, with one considering the views of family carers (Bonell et al., 2011) and one the views of the people placed out-of-area (Chinn et al., 2011). Two articles were based on the same study in one inner city area (Emerson et al., 2004, Emerson et al., 2005). In the absence of clear statements to the contrary, the remaining articles are considered here as separate studies. However, four articles were based on new referrals to a specialist mental health service for adults with intellectual disabilities in South East London (Bouras et al., 2003, Cowley et al., 2004, Maitland et al., 2006, Tsakanikos et al., 2010). Four studies were based on analysis of data from the Leicestershire Intellectual Disability Register (LIDR) (Kiani et al., 2013, McGrother et al., 2002, Tyrer et al., 2007, Devapriam et al., 2008), with a further four studies being conducted in Leicestershire whilst not being based on LIDR data in their entirety (Bhaumik et al., 2008, Bhaumik et al., 2011, Chaplin et al., 1996, Dunkley et al., 2017). The LIDR was established in 1987 and contains all adults with intellectual disabilities known to specialist health or social services in Leicestershire (McGrother et al., 2002). It does not contain a representative sample of adults with mild intellectual disabilities because these adults are less likely to access specialist support.

Studies are summarised in Table 1 and described narratively below in relation to identified themes: health status (physical health, mental health); characteristics of people with intellectual disabilities; source of referral; service use; awareness of services; unmet service needs; barriers to service access; experiences of services; and improving service access. Overall study quality was good, with one qualitative, one quantitative descriptive, and six

quantitative non-randomized studies obtaining the maximum rating on the MMAT. No study obtained a MMAT rating of less than **.

Health Status

Physical Health Status

In a screening study of people with intellectual disabilities conducted in Leicestershire, participants of non-White ethnicity were almost four times more likely to have abnormal glucose levels compared with white European participants (OR 3.93; 95% CI 2.10, 7.33) (Dunkley et al., 2017).   Secondary analysis of UK data found that obesity in 11 year old children with mainly mild to moderate intellectual disabilities was associated with maternal education (only having overseas qualifications, reference category NVQ Level 3 to 5) (OR 4.31 (95% CI 1.47, 12.65)), mixed ethnicity (reference category White, OR 2.13 (95% CI 0.69, 6.64, ns) and being Black/Black British (reference category White, OR 2.33 (95% CI 0.99, 5.51, ns)) (Emerson et al., 2016). Finally, analysis of LIDR data found that ethnicity was not a predictor of mortality (Tyrer et al., 2007).

Mental Health Status

In a study of South Asian and White patients seen by the Department of Psychiatry of Learning Disabilities at one Leicestershire hospital, South Asian people were significantly more likely than White people to receive a psychiatric diagnosis (South Asian 36 (95%), White 59 (78%)), in particular psychosis (South Asian 16 (42%), White 17 (22%)) (Chaplin et al., 1996). Amongst new referrals to a specialist mental health service in London, White participants were less likely to be diagnosed with schizophrenia spectrum disorder than other ethnic groups, but more likely to be diagnosed with personality disorder (Cowley et

al., 2004). A later study of new referrals also found that schizophrenia disorder was less likely in White participants than other ethnic groups (OR 0.46; 95% CI 0.31, 0.77), and compared to other ethnic groups was more likely in the Black group (OR 1.70; 95% CI 1.01, 2.76) and 'Other non-White' group (OR 2.21; 95% CI 1.22, 4.01) (Tsakanikos et al., 2010). Dementia was more common in the White (4.2%) than the Black (0.8%) or Other non-White (0%) groups, probably due to the age structure of the population with both the Black (OR 0.95; 95% CI 0.93, 0.97) and Other Non-White (OR 0.95; 95% CI 0.95, 0.92) groups being more likely to be younger than other ethnic groups. However, for adults on the LIDR, those from ethnic minority communities (mainly South Asian) were less likely to have a clinical diagnosis of mental illness based on a psychiatric assessment from the specialist intellectual disability service than those in the White population (21.4% vs. 35.4%) (Kiani et al., 2013). This may be because they are less likely to access psychiatric services in the first place.

South Asian 16-19 year olds with intellectual disabilities in Leicestershire were less likely to be identified by family carers as having mental health problems and/or challenging behaviours (29%) than White people (63%) whilst the prevalence of other reported health problems was similar (Bhaumik et al., 2011). For adults with intellectual disabilities on the LIDR living with family members, South Asian carers were less likely to report that the person they were caring for showed psychological symptoms of irrational fears or anxiousness (South Asian 9% v White 16% p<.001) (Devapriam et al., 2008) but there was no significant difference for any other psychological symptoms. For all adults on the LIDR, there was no difference in the extent of psychological symptoms between South Asian people and White people in comparisons adjusted for age, sex, city/county dwelling, level of intellectual disability and year of interview, with only lethargy remaining significantly higher

(adjusted OR 1.63; 95% CI 1.17, 2.27, p=0.004) (McGrother et al., 2002). For children with intellectual disabilities in one inner city area (74% White, 14% South Asian, 7% Black and 5% Other), caseness on the Developmental Behaviour Checklist – primary family carer version (DBC-P), which assesses behavioural and emotional disturbances in children and adolescents with intellectual disability, was associated with White ethnicity (corrected OR 2.2; 95% CI not given, p=.005), as were subscale scores for 'self-absorbed' on the DBC-P (OR 2.15; 95% CI not given, p=.006); subscale scores for 'disruptive/antisocial' on the Developmental Behaviour Checklist – teacher version (DBC-T) were associated with not being South Asian (OR 3.49, 95% CI not given, p = .02) (Emerson et al., 2005).

Healthcare

Characteristics of Service Users

A retrospective analysis of referrals to a specialist mental health service from 1983 to 2001 found that there was a marked increase in the proportion of individuals of African/Caribbean origin referred to a specialist mental health service and a slight increase in the proportion of Asian people (whether or not this includes only South Asian people is not specified) reflecting the demographics of the area (Bouras et al., 2003). For low secure units in South London, Kent, Surrey and Sussex, patients in low secure units for people with intellectual disabilities were more likely to be Black Caribbean or African than those in mental health low secure units where most patients do not have intellectual disabilities (Beer et al., 2005).

Source of Referral

For South Asian and White patients seen by the Department of Psychiatry of Learning Disabilities at one Leicestershire hospital in 1991, no significant differences were found in routes of referral or number of contacts (Chaplin et al., 1996). For new referrals to a specialist mental health service in South East London, the other non-White group (predominantly Asian) were more likely to be referred from generic mental health services (GMHS) than White or Black ethnic groups (OR 1.76; 95% CI 1.01, 3.06) (Maitland et al., 2006). Similarly, a subsequent study of new referrals to the service found a significantly lower proportion of White participants being referred from mainstream mental health services (Tsakanikos et al., 2010).

Service Use

In an inner city area, South Asian carers of children with intellectual disability did not differ from other carers in relation to total number of services received but their child was more likely to have received audiology, a community nurse, and a health visitor; and they were less likely to have accessed a behavioural support team (Emerson et al., 2004). Of carers of adolescents or adults with intellectual disabilities from South Asian communities in two metropolitan boroughs in North West England, (Hatton et al., 1998) the following services were used by less than 10% of people in the last 3 months: chiropodist (5; 8%), home help (4; 7%), hospital day-patient (3; 5%), physiotherapist (3; 5%), educational psychologist (3; 5%), community intellectual disability nurse (2; 3%), psychiatrist (1; 2%), and occupational therapist (1; 2%). No families had used: audiologist, speech therapist, community psychiatric nurse, clinical psychologist, advocate, and additional support team. Service receipt was higher if the person with intellectual disabilities was difficult to supervise,

household income was higher, and if carers had lived in the UK for longer (Hatton et al., 1998).

For children with mild or moderate intellectual disabilities attending special schools in London, access to speech and language therapy varied across six ethnic minority groups, being highest for the Middle East/Arab group (72.7% of 33), followed by White Europeans (68.2% of 22), mixed ethnic group/other ethnic groups (55.5% of 27), and lowest for Black groups (36.7% of 49) (Durà-Vila and Hodes, 2009).

Four studies report findings regarding the use of mental health services specifically. South Asian people on the LIDR were less likely to use specialist intellectual disability psychiatric services than White people (62.1% versus 76.8%, adjusted OR 0.532; 95% CI 0.379, 0.746) (McGrother et al., 2002). A later study in Leicestershire also found that South Asian people were less likely to access specialist intellectual disability psychiatric services (31.9% of 348) than White people (47.5% of 2278) and the Other/unknown group (61.5% of 83) (Bhaumik et al., 2008). For children with mild or moderate intellectual disabilities attending special schools in London, child and adolescent mental health service (CAMHS) use was significantly lower for South Asian children (5.6% of 36) than the White British group (22.7% of 75) and there was a trend for lower CAMHS use for South Asian children than the Black group (22.4% of 49) (Durà-Vila and Hodes, 2009). In a study of young South Asian people with intellectual disabilities in Bradford, despite all participants screening positive for mental health problems, only 8 (22.9%) were using mental health services, and few families were accessing professionals such as psychiatrists (5 (14.2%)), clinical psychologists (2 (5.7%)) or behaviour nurse specialists (2 (5.7%)) (Raghavan and Waseem, 2007). Most families were

using mainstream children's services (health) (19 (54.3%)) and their GP (25 (71.4%)) for general healthcare needs of the young person.

Awareness of services

Amongst carers of adolescents or adults with intellectual disabilities from South Asian communities in two metropolitan boroughs in North West England, awareness of general community health and social services was high but awareness of specialist services for people with intellectual disabilities was much lower (Hatton et al., 1998). Carers were more likely to be aware of services if they both spoke and wrote English. Similarly, a qualitative study on experiences of health services, including White British, White Other and South Asian participants, found that South Asian people were particularly likely to experience inequalities in accessing healthcare, with five carers (all South Asian) having no knowledge of community intellectual disability services or only being referred recently (Ali et al., 2013).

Unmet Service Needs

In Leicestershire, South Asian carers of 16-19 year olds with intellectual disabilities perceived greater unmet needs in all areas of healthcare compared with that of the White population, including needs for paediatrics, neurology, clinical psychology, speech and language therapy, occupational therapy, physiotherapy, and dietetics (Bhaumik et al., 2011). For adults on the LIDR, South Asian family carers felt considerably more unmet need for community services than White family carers, particularly for social services rather than health services (McGrother et al., 2002). For adults with intellectual disabilities on the LIDR living with family members, South Asian carers reported greater unmet needs for any service than White carers (76% v 59% p<.001) (Devapriam et al., 2008). South Asian carers

reported significantly higher rates of unmet need than White carers for GP advice (17% v 7%, p<.001) and Occupational Therapy (13% v 7%, p<.05).

Barriers to service access

Possible barriers to service uptake reported by 54 South Asian carers of adolescents or adults with intellectual disabilities were: a lack of awareness of services (94%); a lack of staff who could speak the same language as the carer (81%); the cultural inappropriateness of existing services in terms of diet, activities and staff provision (35%); and racial discrimination within services (22%) (Hatton et al., 1998). In a study of South Asian young people with intellectual disabilities in Bradford who screened positive for mental health problems, barriers to service use included: lack of knowledge and awareness of services; language barriers; lack of a single point of contact with services; and inappropriateness of services to meet the needs of the young people and their families, lacking cultural and religious sensitivity (Raghavan and Waseem, 2007). In a qualitative study, several South Asian carers who did not speak English as their first language reported that language was a significant barrier to accessing help, with many health services failing to provide carers with an interpreter (Ali et al., 2013).

Language was identified as a primary barrier to therapeutic engagement by service providers/professionals working with South Asian people with intellectual disabilities, and whilst interpreters were frequently used, serious problems were noted with regards to their use (Heer et al., 2016). This included a failure of interpreting services to recognize the distinctions between different South Asian languages, interpreters claiming to be proficient in more than one language when they are not, feeling powerless and out of control in being unable to assess the quality of the interpretation, interpreters lacking familiarity with

health-related concepts, altering the nature of the therapeutic relationship by introducing a greater potential for misinterpretations, and a lack of emotional sensitivity during consultations (Heer et al., 2016). Service providers further perceived that caregiving was contained within the family environment, meaning that often service providers were unaware of the needs of South Asian families, with families delaying making contact with services until situations reached crisis point (Heer et al., 2016). However, it is not clear to what extent the views expressed by the service providers are in themselves influenced by stereotyping or discrimination.

Experiences of Services

Family carers of people with intellectual disabilities placed in out-of-area inpatient services reported many examples of cultural needs being met, for example with regard to dietary needs (Bonell et al., 2011). However, there was some concern expressed that people would become alienated from their culture, for example due to staff not speaking the service user's first language, or due to the culture of staff, with some families from minority ethnic communities feeling that the service users' progress was being hampered by language and cultural issues (Bonell et al., 2011). In a related qualitative study on the views of the people placed out-of-area, there appeared to be limited opportunities for individuals to practice, explore and develop their cultural and religious identities, for example, having nobody with whom they could speak in their first language (Chinn et al., 2011).

A Delphi study looking at user experiences of specialist community-based mental health services found slightly less positive views about services (on three items) and a broader spread of opinions in the Black than the White group, with the Black group reporting the only negative experiences (Bonell et al., 2012).

Improving Service Access

Family carers of adolescents or adults with intellectual disabilities from South Asian communities reported suggestions for improving services (Hatton et al., 1998): receiving information about services in appropriate languages and formats (43 carers; 80%), increasing the number of South Asian staff throughout mainstream services for people with learning disabilities (35 carers; 65%); improving cultural appropriateness of services in terms of diet, culturally appropriate activities, and same-sex carers for women (26 carers; 48%); and 13 carers (24%) stated that a support network for carers from South Asian communities would be helpful.

One study considered the effectiveness of a specialist liaison service for increasing access to and uptake of services for young people with intellectual disability with challenging behaviour and mental health needs from Pakistani and Bangladeshi communities in Bradford (Raghavan et al., 2009). Participants in the treatment group had more frequent contact with more services, and with better outcomes than a comparison group despite a relatively modest input (Raghavan et al., 2009).

Discussion

Peer-reviewed evidence regarding the health status of people with intellectual disabilities from minority ethnic communities in the UK is very limited. Evidence regarding access to healthcare is predominately focused on mental health care and specialist intellectual disability services. Obtaining good epidemiological evidence about the health status and access to health services of people with intellectual disabilities from minority ethnic communities is problematic. This is principally due to difficulties in getting sufficient

numbers of people with intellectual disabilities from specific ethnic minority communities for meaningful comparisons to be made. For example, cohort studies (e.g. the Millennium Cohort Study) do not have enough people with intellectual disabilities from minority ethnic communities for secondary analyses to address this topic, with studies using samples of GP data (e.g. using the Clinical Practice Research Datalink) also having insufficient people for comparisons across ethnic minority communities. As such, studies have tended to be conducted in areas with relatively high proportions of people from minority ethnic communities, although these areas may not be representative of all areas in the UK.

This issue is made worse by certain minority ethnic communities (and particularly people with intellectual disabilities) being under-represented in accessing health services. For example, the confidential inquiry into premature deaths of people with intellectual disabilities (CIPOLD) was unable to conduct any analysis by ethnic minority community as there was a significant underrepresentation of people of non-white UK ethnicity (Heslop et al., 2013).

Despite these difficulties, this review identified a number of peer-reviewed studies with data regarding the health and healthcare of people with intellectual disabilities from minority ethnic communities. A key limitation of the evidence base is a lack of information relating to physical health, which is limited to evidence of an increased prevalence of screen detected abnormal glucose regulation (Dunkley et al., 2017) and obesity in children (Emerson et al., 2016).   More evidence was identified in relation to mental health. People with intellectual disabilities from ethnic minority communities (mainly South Asian) have been found to have a lower prevalence of mental illness (Kiani et al., 2013) and South Asians have been found to be less likely to use psychiatric services (McGrother et al., 2002).

However of those attending as psychiatric outpatients, South Asians have been found to be significantly more likely to receive a psychiatric diagnoses (Chaplin et al., 1996) and this may be an artefact of their overall lower use of such services (McGrother et al., 2002). For referrals to a specialist intellectual disability mental health service in South East London, schizophrenia spectrum disorder was more likely to be diagnosed in those from Black communities, and also more likely in other non-White communities (Tsakanikos et al., 2010), and less likely in the White group compared to other minority ethnic communities as a whole (Cowley et al., 2004). Overall, further research in required regarding the prevalence of mental health problems in South Asian (Chaplin et al., 1996) and other minority ethnic communities.

Lower reporting of mental health problems or challenging behaviour by South Asian family carers (Bhaumik et al., 2011) may in part explain their lower mental health service use. Possible explanations for lower reporting by South Asian carers include cultural differences in the understanding of the nature of these problems, differing perceptions of stigma, and the willingness to discuss such problems with strangers (Bhaumik et al., 2011), and a general effect of socio-economic deprivation.

There is evidence that, in accordance with changing population demographics, the proportion of people with intellectual disabilities from minority ethnic communities being referred e.g. to specialist mental health services, had been increasing (Bouras et al., 2003) although the situation in the UK may have changed since that time. However, access to such specialist services has been found to be lower for those from South Asian communities. For South Asian communities, use of specialist intellectual disability services is low (Hatton et al., 1998), as is use of specialist psychiatric services (McGrother et al., 2002, Bhaumik et

al., 2008), CAMHS (Durà-Vila and Hodes, 2009) and mental health services (Raghavan and Waseem, 2007). Further, awareness of specialist services for people with intellectual disabilities is low among South Asian carers (Hatton et al., 1998, Ali et al., 2013). South Asian carers also report higher levels of unmet needs (Bhaumik et al., 2011, McGrother et al., 2002, Devapriam et al., 2008). These findings are also supported by a further study (which did not meet the criteria for inclusion in the review) of 136 South Asian families from five local authority areas in England which found that the range of unmet needs reported by parents was extremely high, whilst uptake and awareness of specialist services was low (Hatton et al., 2004). It has been suggested that inequalities in accessing healthcare may partly reflect inadequate transition from child to adult services, and a failure of GPs to refer people to specialist services (Ali et al., 2013).

Language has consistently been reported to be one of the barriers underlying low service use by carers from South Asian communities (Hatton et al., 1998, Raghavan and Waseem, 2007, Ali et al., 2013) and has also been highlighted as a barrier to therapeutic engagement by professionals working with South Asians (Heer et al., 2016). For the non-UK born population, 2011 Census figures indicate that recent arrivals are less likely to be proficient in English (84%) than those who have been in the UK for longer (5-10 years, 90%; 11-30 years, 90%; more than 30 years, 93%) (Office for National Statistics, 2014). In some cases where family carers cannot speak English, their child with intellectual disabilities may be able to speak English. However, this cannot be assumed as among people identifying as Bangladeshi, Pakistani, or Indian who were born in the UK, a respective 30%, 23% and 14% report not speaking English well or at all (Brodie et al., 2016). As such, health services should provide interpreters in order to reduce inequalities caused by the language barrier

(Ali et al., 2013), although serious problems have been noted with regards to their use (Heer et al., 2016).

Other possible reasons for lower service use include a lack of knowledge of intellectual disabilities and the services available, religious and cultural attitudes and beliefs, more social support being available in some extended families, lack of culturally appropriate services, and institutionalized racism (Bhaumik et al., 2011). Further, it has been suggested that as more South Asian children live in two-parent families than any of the other ethnic groups, this may help them to be better able to provide care, and therefore have less need of services (Durà-Vila and Hodes, 2009). However, the extent of unmet need reported by carers and the fact that a modest input by a liaison worker significantly improved contact with services and outcomes from contacts (Raghavan et al., 2009), indicates that being able to contain care within the family does not underlie low service access. Indeed, two thirds of South Asian carers of people with intellectual disabilities in Birmingham received no help at all with care from either their own or their spouse's family (Emerson and Robertson, 2002).

Out-of-area hospitals that accept people from a wide variety of areas and ethnic backgrounds face significant challenges in developing culturally competent services (Bonell et al., 2011). Whilst the mix of service users placed may, for example, reflect the population in inner London, with about half from Black and other minority ethnic communities, this may contrast with the population in the areas where the hospital placements are sited (Chinn et al., 2011). Such placements can sever individuals from environments which reinforce and support their cultural, religious and ethnic identities and practices (Chinn et al., 2011).

Some of the findings regarding the health and healthcare of people with intellectual disabilities from minority ethnic communities mirror those for people from minority ethnic communities generally. A recent resource from Public Health England summarises the evidence base on ethnic inequalities in health (Public Health England, 2018). Whilst there is a complex picture of ethnic differences in health across different health indicators, low levels of health literacy are a concern among some ethnic minority communities, particularly those with limited educational attainment and poor English language skills given the limited provision of interpretation services within healthcare settings (Public Health England, 2018). It is also noted that social stigma regarding mental health issues may undermine mental health service access among minority ethnic communities (Public Health England, 2018).

The question of how to improve service access for people with intellectual disabilities from minority ethnic communities has received little attention. The PHE resource provides examples of local action aimed at addressing ethnic inequalities in health and healthcare for people from minority ethnic communities generally (Public Health England, 2018) but such examples may require adapting for those with intellectual disabilities from ethnic minority communities. Suggestions for improvement made by South Asian carers of people with intellectual disabilities include receiving information about services in appropriate languages and formats, increasing the number of South Asian staff throughout mainstream services for people with intellectual disabilities, and improving the cultural appropriateness of services (Hatton et al., 1998).

One suggestion for addressing barriers to service access and uptake, including barriers relating to cultural attitudes and beliefs, is that employment of liaison workers from similar

ethnic or cultural backgrounds could help families seek assistance and services (Guzmán, 2014) and use of a specialist liaison worker has been found to have significant benefits for families of a South Asian background (Raghavan et al., 2009). In a discussion of how attitudes of, and toward, people from South Asian minority ethnic communities may affect their use of intellectual disability services, Guzmán gives further examples of interventions such as a Bangladeshi Parent Adviser Service (Guzmán, 2014).

The need for all staff to develop cultural competence to ensure that services are able to meet the diverse needs of individuals with intellectual disabilities and their families and carers has been highlighted (Raghavan, 2009). However, minority ethnic groups may be heterogeneous, and the utility of the concept of cultural competence may be limited where it depends on concepts of ethnic groups as relatively fixed cultural groups with clearly defined sets of health beliefs and behaviours (Croot, 2012). It has been argued that it is perhaps more important for hospitals and health service provider institutions to develop and operate systems that ensure access, use and quality of care are the same at the point of delivery regardless of patient ethnicity (Croot, 2012).

Future Research Directions

As discussed above, obtaining good epidemiological evidence about the health status and access to health services of people with intellectual disabilities from minority ethnic communities is problematic. At present National datasets (for example Department for England statistics on children with Special Educational Needs) do produce data on ethnicity which has been reported (Hatton et al., 2017). Emerging national datasets relevant to the health of people with intellectual disabilities in England, in particular the General Practice Extraction Service (General Practice Extraction Service (GPES), 2016/17) could be

systematically investigated for their potential to yield meaningful data on minority ethnic communities.

To date, research has tended to focus on the views of family carers, with only a small number of studies including the views of people with intellectual disabilities themselves (Ali et al., 2013, Bonell et al., 2012, Chinn et al., 2011). Recent research has considered the experiences of South Asian women with intellectual disabilities in relation to general social care (Malik et al., 2017) and future research could extend such approaches to healthcare and other minority ethnic communities.

People from South Asian communities were most frequently the subject of the studies included in this review. This focus is understandable in the context of the localities that the research has taken place in, but other ethnic groups have received less attention. A number of minority ethnic communities are not represented in the evidence base. For example, whilst higher rates of identification of less severe forms of intellectual disability have been found among Gypsy/Romany and Traveller children of Irish heritage than among other ethnic groups (Emerson, 2012), no evidence was identified in relation to the health or healthcare of people with intellectual disabilities from this group. There is also little research regarding Black communities which is surprising given higher identification rates of Black Caribbean children with moderate learning disabilities (Hatton et al., 2017). Future research could consider the health and healthcare of people with intellectual disabilities from a wider range of minority ethnic communities to reflect the changing demography of the UK, and also emerging communities, such as Eastern European communities. Finally, further research should consider interventions to overcome the barriers to service access

and uptake experienced by people with intellectual disabilities from ethnic minority communities.

Limitations

There are a number of limitations to this review. First, whilst a reasonable number of studies were identified, the studies tend to be clustered around two main geographical areas (Leicestershire and London) thus limiting the generalisability of findings to the UK as a whole. Second, studies date back as far as 1996 and improvements may have been made in relation to the healthcare of people with intellectual disabilities from minority ethnic communities since that time that have not been captured by peer reviewed research. More timely research is required to keep track of changing service responses. Third, all data was extracted by one reviewer and checked for accuracy and completeness by a second reviewer. Whilst this is an accepted minimum (Centre for Reviews and Dissemination, 2009), extraction of data by two reviewers independently would have reduced the possibility of errors.

Conclusion

Very little is known about the health status of people with intellectual disabilities from minority ethnic communities in the UK, although the limited existing evidence points to health inequalities. There is no evidence to suggest that the well established link between belonging to minority ethnic communities and poor health in the general population does not apply to people with intellectual disabilities. People with intellectual disabilities from minority ethnic communities in the UK also experience significant inequalities in access to healthcare. These issues are not restricted to the UK. In the United States, Latino and non-

Latino black people with intellectual and developmental disabilities have markedly worse health than both White adults with intellectual and developmental disabilities and non-disabled Latino and Black adults (Magana et al., 2016) and people with intellectual and developmental disabilities belonging to a minority racial or ethnic group experience less access to healthcare services (Scott and Havercamp, 2014). Future research should explore further the health of people with intellectual disabilities from the full range of minority ethnic communities in the UK and consider ways in which healthcare providers can increase their competence to ensure access to good quality, culturally appropriate healthcare to people with intellectual disabilities from all ethnic groups.

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Appendix 1

Example of Database Specific Search Terms (Medline)

AB (africa* OR afro* OR asia* OR "asylum seeker" OR Bangladesh* OR black OR BME OR BAME OR Caribbean OR Chinese OR China OR cultur* OR divers* OR ethnic* OR faith* OR belie* OR religio* OR Irish OR Roma* OR Gypsy OR Gypsies OR India* OR Islam* OR Hindu* OR Sikh* OR buddhis* OR muslim* OR Jew* OR Christian* OR Catholic* OR migrant* OR immigrant* OR minorit* OR multirac* OR multi-rac* OR Pakistan* OR Poland OR Polish OR race OR racial OR refugee OR transient OR traveller OR "east* Europe*" OR Somalia* OR "non-white" or nonwhite) OR TI (africa* OR afro* OR asia* OR "asylum seeker" OR Bangladesh* OR black OR BME OR BAME OR Caribbean OR Chinese OR China OR cultur* OR divers* OR ethnic* OR faith* OR belie* OR religio* OR Irish OR Roma* OR Gypsy OR Gypsies OR India* OR Islam* OR Hindu* OR Sikh* OR buddhis* OR muslim* OR Jew* OR Christian* OR Catholic* OR migrant* OR immigrant* OR minorit* OR multirac* OR multi-rac* OR Pakistan* OR Poland OR Polish OR race OR racial OR refugee OR transient OR traveller OR "east* Europe*" OR Somalia*) OR (MH "Culture+") OR (MH "Continental Population Groups+") OR (MH "Ethnic Groups+") OR (MH "Refugees") OR (MH "Religion+") OR (MH "Emigrants and Immigrants+") OR (MH "Transients and Migrants") OR (MH "Europe, Eastern+" OR Somalia OR "non-white" OR nonwhite)

AND

AB ("Accident and Emergency" OR A&E OR "Acute Healthcare" OR "Affective disorder*" OR Anxiety OR "Care home*" OR "case manag*" OR "Community care" OR "Community service*" OR "Days in bed" OR Dental OR dentist* OR "oral health*" OR Depress* OR

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Disease* OR Doctor OR "Domiciliary care" OR "Emotional disorder*" OR "emotional problem*" OR "End of life care" OR Eyecare OR Optician OR "Family Physician*" OR "Family practice*" OR "General physician*" OR "General Practitioner*" OR GP OR "Health care" OR "Health centre*" OR "Health service*" OR Healthcare OR "Home care" OR Hospital* OR ill-health OR illness OR "interdisciplinary team*" OR "inter-disciplinary team*" OR "Learning disab* team*" OR "Medical care" OR "Medical centre*" OR "Medical diagnos*" OR Medication* OR "Mental disorder*" OR "Mental health" OR "Mental illness*" OR "Mood disorder*" OR Mortality OR "Multidisciplinary team*" OR "Multi-disciplinary team*" OR "National Health Service" OR "Nervous complaint*" OR "nervous symptom*" OR neuroses OR Neurosis OR "neurotic disorder*" OR NHS OR Nursing OR Outreach OR "Palliative care" OR "Pharmacy service*" OR "Physical limitation*" OR "Physician visit*" OR Physiotherap* OR "Primary care" OR Psychiatr* OR Psycholog* OR "Psychological* distress*" OR "Psychological symptoms" OR "Risk of death" OR "Secondary care" OR Sickness OR "Somatic symptoms" OR Stress OR "Surgical care" OR "Tertiary care" OR "Tertiary healthcare") OR TI ("Accident and Emergency" OR A&E OR "Acute Healthcare" OR "Affective disorder*" OR Anxiety OR "Care home*" OR "case manag*" OR "Community care" OR "Community service*" OR "Days in bed" OR Dental OR dentist* OR "oral health*" OR Depress* OR Disease* OR Doctor OR "Domiciliary care" OR "Emotional disorder*" OR "emotional problem*" OR "End of life care" OR Eyecare OR Optician OR "Family Physician*" OR "Family practice*" OR "General physician*" OR "General Practitioner*" OR GP OR "Health care" OR "Health centre*" OR "Health service*" OR Healthcare OR "Home care" OR Hospital* OR ill-health OR illness OR "interdisciplinary team*" OR "inter-disciplinary team*" OR "Learning disab* team*" OR "Medical care" OR "Medical centre*" OR "Medical diagnos*" OR Medication* OR "Mental disorder*" OR "Mental health" OR "Mental illness*"

OR "Mood disorder*" OR Mortality OR "Multidisciplinary team*" OR "Multi-disciplinary team*" OR "National Health Service" OR "Nervous complaint*" OR "nervous symptom*" OR neuroses OR Neurosis OR "neurotic disorder*" OR NHS OR Nursing OR Outreach OR "Palliative care" OR "Pharmacy service*" OR "Physical limitation*" OR "Physician visit*" OR Physiotherap* OR "Primary care" OR Psychiatr* OR Psycholog* OR "Psychological* distress*" OR "Psychological symptoms" OR "Risk of death" OR "Secondary care" OR Sickness OR "Somatic symptoms" OR Stress OR "Surgical care" OR "Tertiary care" OR "Tertiary healthcare") OR (MH "Health Services+") OR (MH "Health Services Administration+") OR (MH "Therapeutics+") OR (MH "Health Care Quality, Access, and Evaluation+") OR (MH "Mental Health Services+") OR (MH "Health Status+") OR (MH "Health+") OR (MH "Morbidity+") OR (MH "Mortality+") OR (MH "Mental Disorders+") OR (MH "Disease+") OR (MH "Behavioral Symptoms+")

AND

(TI (learning N1 (disab* or difficult* or handicap*)) OR TI (mental* N1 (retard* or disab* or deficien* or handicap*)) OR TI (intellectual* N1 (disab* or impair* or handicap*)) OR TI development* N1 disab* OR TI (multipl* N1 (handicap* or disab*)) OR TI "Down* syndrome" OR (MH "Developmental Disabilities") OR (MH "Intellectual Disability+") OR (MH "mentally disabled persons")) OR (AB (learning N1 (disab* or difficult* or handicap*)) OR AB (mental* N1 (retard* or disab* or deficien* or handicap*)) OR AB (intellectual* N1 (disab* or impair* or handicap*)) OR AB development* N1 disab* OR AB (multipl* N1 (handicap* or disab*)) OR AB"Down* syndrome")

AND

(Medline UK Filter adapted for EBSCO)

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(MH "United Kingdom+")

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TI ("national health service*" or NHS*) OR AB ("national health service*" or NHS*) OR AF

("national health service*" or NHS*)

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TI (english not ((published or publication* or translat* or written or language* or speak* or

literature or citation*) N5 english)) OR AB (english not ((published or publication* or

translat* or written or language* or speak* or literature or citation*) N5 english))

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TI (gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united

kingdom* or (england* not "new england") or northern ireland* or northern irish* or

scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*) OR AB

(gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united

kingdom* or (england* not "new england") or northern ireland* or northern irish* or

scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*) OR SO

(gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united

kingdom* or (england* not "new england") or northern ireland* or northern irish* or

scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*)

(Note - SO is publication name)

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TI (bath or "bath's" or ((birmingham not alabama*) or ("birmingham's" not alabama*) or bradford or "bradford's" or brighton or "brighton's" or bristol or "bristol's" or carlisle* or "carlisle's" or (cambridge not (massachusetts* or boston* or harvard*)) or ("cambridge's" not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or ("canterbury's" not zealand*) or chelmsford or "chelmsford's" or chester or "chester's" or chichester or "chichester's" or coventry or "coventry's" or derby or "derby's" or (durham not (carolina* or nc)) or ("durham's" not (carolina* or nc)) or ely or "ely's" or exeter or "exeter's" or gloucester or "gloucester's" or hereford or "hereford's" or hull or "hull's" or lancaster or "lancaster's" or leeds* or leicester or "leicester's" or (lincoln not nebraska*) or ("lincoln's" not nebraska*) or (liverpool not (new south wales* or nsw)) or ("liverpool's" not (new south wales* or nsw)) or ((london not (ontario* or ont or toronto*)) or ("london's" not (ontario* or ont or toronto*)) or manchester or "manchester's" or (newcastle not (new south wales* or nsw)) or ("newcastle's" not (new south wales* or nsw)) or norwich or "norwich's" or nottingham or "nottingham's" or oxford or "oxford's" or peterborough or "peterborough's" or plymouth or "plymouth's" or portsmouth or "portsmouth's" or preston or "preston's" or ripon or "ripon's" or salford or "salford's" or salisbury or "salisbury's" or sheffield or "sheffield's" or southampton or "southampton's" or st albans or stoke or "stoke's" or sunderland or "sunderland's" or truro or "truro's" or wakefield or "wakefield's" or wells or westminster or "westminster's" or winchester or "winchester's" or wolverhampton or "wolverhampton's" or (worcester not (massachusetts* or boston* or harvard*)) or ("worcester's" not (massachusetts* or boston* or harvard*)) or (york not

("new york*" or ny or ontario* or ont or toronto*)) or ("york's" not ("new york*" or ny or

ontario* or ont or toronto*))))) OR AB (bath or "bath's" or ((birmingham not alabama*) or

("birmingham's" not alabama*) or bradford or "bradford's" or brighton or "brighton's" or

bristol or "bristol's" or carlisle* or "carlisle's" or (cambridge not (massachusetts* or boston*

or harvard*)) or ("cambridge's" not (massachusetts* or boston* or harvard*)) or

(canterbury not zealand*) or ("canterbury's" not zealand*) or chelmsford or "chelmsford's"

or chester or "chester's" or chichester or "chichester's" or coventry or "coventry's" or derby

or "derby's" or (durham not (carolina* or nc)) or ("durham's" not (carolina* or nc)) or ely or

"ely's" or exeter or "exeter's" or gloucester or "gloucester's" or hereford or "hereford's" or

hull or "hull's" or lancaster or "lancaster's" or leeds* or leicester or "leicester's" or (lincoln

not nebraska*) or ("lincoln's" not nebraska*) or (liverpool not (new south wales* or nsw)) or

("liverpool's" not (new south wales* or nsw)) or ((london not (ontario* or ont or toronto*))

or ("london's" not (ontario* or ont or toronto*)) or manchester or "manchester's" or

(newcastle not (new south wales* or nsw)) or ("newcastle's" not (new south wales* or nsw))

or norwich or "norwich's" or nottingham or "nottingham's" or oxford or "oxford's" or

peterborough or "peterborough's" or plymouth or "plymouth's" or portsmouth or

"portsmouth's" or preston or "preston's" or ripon or "ripon's" or salford or "salford's" or

salisbury or "salisbury's" or sheffield or "sheffield's" or southampton or "southampton's" or

st albans or stoke or "stoke's" or sunderland or "sunderland's" or truro or "truro's" or

wakefield or "wakefield's" or wells or westminster or "westminster's" or winchester or

"winchester's" or wolverhampton or "wolverhampton's" or (worcester not (massachusetts*

or boston* or harvard*)) or ("worcester's" not (massachusetts* or boston* or harvard*)) or

(york not ("new york*" or ny or ontario* or ont or toronto*)) or ("york's" not ("new york*"

or ny or ontario* or ont or toronto*))))) OR AF (bath or "bath's" or ((birmingham not

alabama*) or ("birmingham's" not alabama*) or bradford or "bradford's" or brighton or

"brighton's" or bristol or "bristol's" or carlisle* or "carlisle's" or (cambridge not

(massachusetts* or boston* or harvard*)) or ("cambridge's" not (massachusetts* or

boston* or harvard*)) or (canterbury not zealand*) or ("canterbury's" not zealand*) or

chelmsford or "chelmsford's" or chester or "chester's" or chichester or "chichester's" or

coventry or "coventry's" or derby or "derby's" or (durham not (carolina* or nc)) or

("durham's" not (carolina* or nc)) or ely or "ely's" or exeter or "exeter's" or gloucester or

"gloucester's" or hereford or "hereford's" or hull or "hull's" or lancaster or "lancaster's" or

leeds* or leicester or "leicester's" or (lincoln not nebraska*) or ("lincoln's" not nebraska*) or

(liverpool not (new south wales* or nsw)) or ("liverpool's" not (new south wales* or nsw))

or ((london not (ontario* or ont or toronto*)) or ("london's" not (ontario* or ont or

toronto*)) or manchester or "manchester's" or (newcastle not (new south wales* or nsw))

or ("newcastle's" not (new south wales* or nsw)) or norwich or "norwich's" or nottingham

or "nottingham's" or oxford or "oxford's" or peterborough or "peterborough's" or plymouth

or "plymouth's" or portsmouth or "portsmouth's" or preston or "preston's" or ripon or

"ripon's" or salford or "salford's" or salisbury or "salisbury's" or sheffield or "sheffield's" or

southampton or "southampton's" or st albans or stoke or "stoke's" or sunderland or

"sunderland's" or truro or "truro's" or wakefield or "wakefield's" or wells or westminster or

"westminster's" or winchester or "winchester's" or wolverhampton or "wolverhampton's"

or (worcester not (massachusetts* or boston* or harvard*)) or ("worcester's" not

(massachusetts* or boston* or harvard*)) or (york not ("new york*" or ny or ontario* or ont

or toronto*)) or ("york's" not ("new york*" or ny or ontario* or ont or toronto*)))))

(Note – AF is author address)

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TI (bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or st asaph or "st asaph's" or st davids or swansea or "swansea's") OR AB (bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or st asaph or "st asaph's" or st davids or swansea or "swansea's") OR AF (bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or st asaph or "st asaph's" or st davids or swansea or "swansea's")

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TI (aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's") OR AB (aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's") OR AF (aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's")

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TI (armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's") OR AB (armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's") OR AF (armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's")

9 = 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8

10 ((MH "Africa+") OR (MH "Americas+") OR (MH "antarctic regions") OR MH ("arctic

regions") OR (MH "asia+") OR (MH "oceania+")) NOT ((MH "United Kingdom+") OR (MH

"Europe+"))

11 9 NOT 10

Figure 1

Flowchart of Study Identification. Initial total 2298.

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┌──────────────────┐  ┌──────────────────┐  ┌──────────────────┐  ┌──────────────────┐
│     Medline      │  │      Cinahl      │  │     PsycINFO     │  │  Web of Science  │
│                  │  │                  │  │                  │  │                  │
│ 1 Jan 1990-7 Feb │  │ 1 Jan 1990-7 Feb │  │ 1 Jan 1990-7 Feb │  │ 1 Jan 1990-7 Feb │
│       2018       │  │       2018       │  │       2018       │  │       2018       │
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451 duplicates deleted (auto) (1,847 left) 78 deleted by hand

Inclusion/exclusion criteria applied to 1,769 non-duplicate citations

1,694 excluded after title/abstract

75 selected based on title/abstract screen

51 excluded based on full text for the following reasons: Does not specifically relate to health/healthcare (23); no results by ethnicity (11); not primary research (10); sample does not necessarily have ID (2); sample size <5 (3); challenging behaviour in absence of measure of psychopathology (2).

24 articles assessed as eligible for inclusion

1 article included from other sources

25 articles (23 studies) included in tabulation

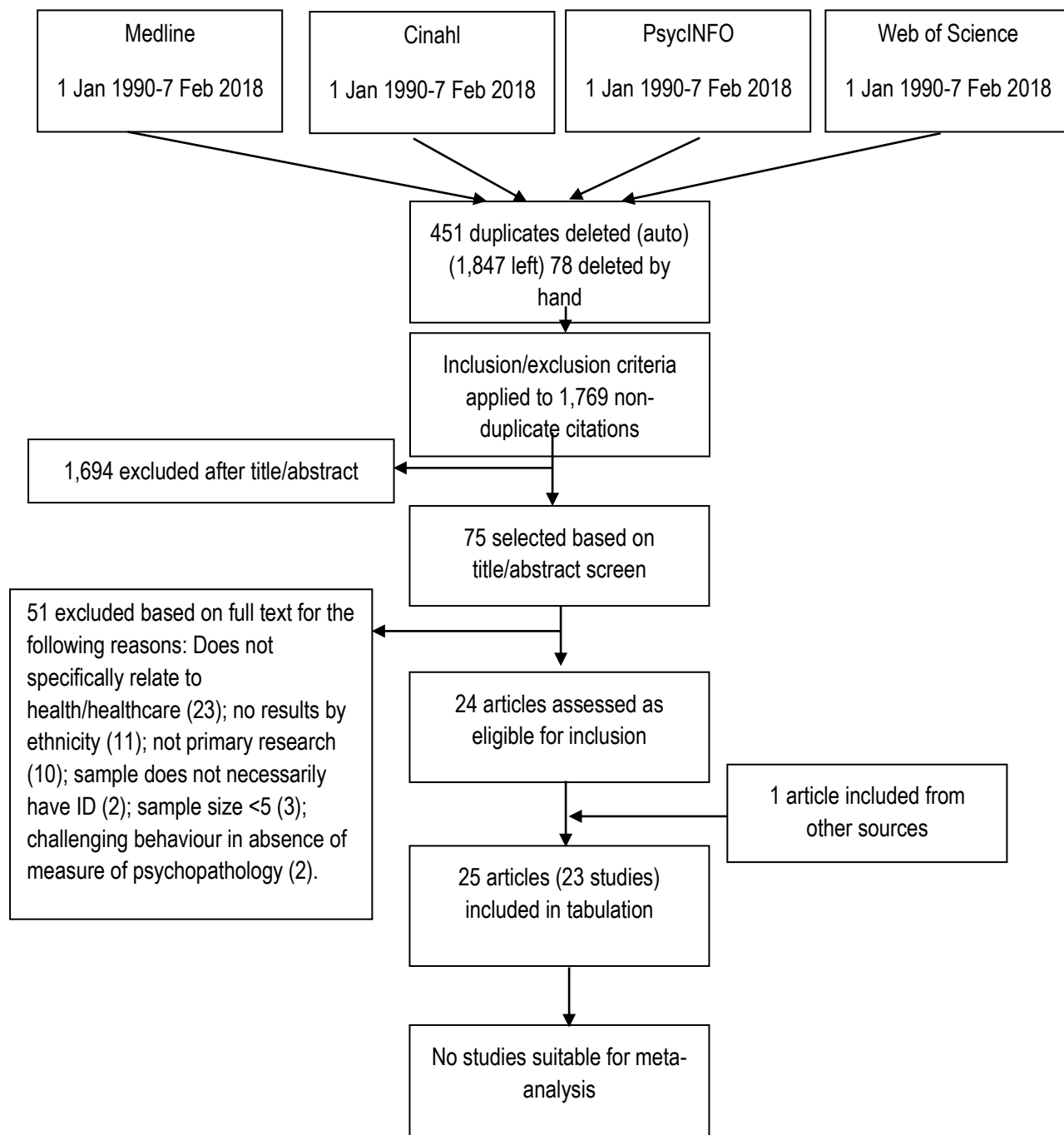No studies suitable for meta-analysis

Table One: Summary of studies regarding ethnicity & the health or health care of people with intellectual disabilities

MMAT Type & Rating	First Author & Year	Location	Focus	Design	Key sample features	Sample size	Ethnicity of sample	Age range (mean (SD); median)	% male	Relevant Outcome measures	Results
Q ****	Ali 2013	London (12 dyads), Somerset (one dyad), Lincolnshire (one dyad)	Experiences of health services	Thematic analysis of semi-structured interviews	Dyads of people with mild or moderate ID & a family carer (mostly mothers), most living in family home	29 14 ID, 15 carers	Of participants with ID: White 64.3% Asian Pakistani 21.4% Asian Indian 14.3%	ID 23-57 (ns (ns); ns) Carers 28-72 (ns (ns); ns)	50% (ID)	Themes identified in analysis of semi-structured interviews	5 family carers, all South Asian, reported having no knowledge of community ID services or only being referred recently. Several carers who did not speak English as their first language reported that language was a significant barrier to accessing help. They were ignored at consultations, little consideration was given to their views & information about the patient was frequently not shared with them. Many health services failed to provide an interpreter. "I have been to many meetings with the doctors but because my English isn't good, I couldn't say what I wanted to say. They never had a translator there at the meetings for me"
QNR ***	Beer 2005	South London, Kent, Surrey & Sussex	Characteristics of patients in low secure units	Audit survey using case notes & interviews with clinician who knew the person well	Adults living in low secure units for people with ID or mental health units where most patients do not have ID	200 61 in LD units; 139 mental health units	White 71.4% Black Caribbean & African 20.7% Other 8.0%	19-74 (39 (ns); ns)	77.0%	Number of patients who were Black Caribbean or African	Of 139 mental health unit patients, 24 were Black Caribbean or African (17.3%), 10 'other' (7.2%). Of 61 LD unit patients, 20 were Black Caribbean or African (32.8%), 7 'other' (11.5%). Patients in learning disabilities units more likely to be Black Caribbean or African (32.8%) than those in mental health units (17.3%) (chi square 5.95, p <.05)
QNR ***	Bhaumik 2008	Leicester-shire & Rutland	Specialist psychiatric service attendance	Cross-sectional retrospective analysis of records of adults seen by specialist ID psychiatric services 2001 to 2006. Measure of underlying population based on LIDR	Adult inpatients & outpatients seen by specialist ID psychiatric services & underlying population on LIDR; any living situation (mainly family home or residential home)	2,711	White 84.1% South Asian 12.8% Other or unknown 3.1%	19-60+ (ns (ns); ns)	56.3%	Accessed specialist ID psychiatric services at least once during study period	45.9% accessed specialist ID psychiatric services & these individuals were more likely to be older & to live in residential settings; they were less likely to be South Asian or to have mild/moderate ID. 31.9% (111 of 348) of South Asians had accessed specialist psychiatric service, compared to 47.5% (1082 of 2278) of Whites & 61.5% (51 of 83) of other/unknown
QNR **	Bhaumik 2011	Leicester-shire & Rutland	Unmet service needs	Postal survey completed by carers	16-19 year olds with moderate to profound ID, most living in family home	79	White 70.9% South Asian 21.5% African heritage 5.1% Mixed 1.3% Other 1.3%	16-19 (ns (ns); ns)	60.8%	Reported service use & unmet needs	29% of South Asians identified by carers as having mental health problems and/or challenging behaviours compared with 63% of the White group (the prevalence of other reported health problems was similar). South Asian carers perceived greater unmet needs (numbers not given) in all areas of

MMAT Type & Rating	First Author & Year	Location	Focus	Design	Key sample features	Sample size	Ethnicity of sample	Age range (mean (SD); median)	% male	Relevant Outcome measures	Results
											healthcare than White carers, including pediatrics, neurology, clinical psychology, speech & language therapy, occupational therapy, physiotherapy, & dietetics. Almost 50% of both groups perceived unmet need in relation to accessing adult ID services
Q ***	Bonell 2011 (see also Chinn 2011)	London (3 East London boroughs)	Family views on long term out-of-area hospital care with focus on cultural aspects of care	Thematic analysis of qualitative semi-structured interviews with carers	Carers (mainly parents) of people with ID (69% mild or borderline ID) receiving long-term out-of-area specialist inpatient services	16	White British 43.8% Bangladeshi 25% Black Caribbean 12.5% Other white 6.3% Mixed White/Black Caribbean 6.3% Pakistani 6.3% Irish 0%	ns (35 (11); ns)	87.5%	Themes identified in analysis of semi-structured interviews	Theme 'choice & culture' identified. Many examples of cultural needs being met e.g. dietary needs, fasting & opportunity to attend religious services. Sometimes this did not happen, e.g. not being able to have Indian food. Some concern expressed that people would become alienated from their culture e.g. no staff speaking their first language, & concern about learning the culture of staff. Where there was good communication this was appreciated e.g. a Turkish staff speaking staff member. Some of the families from minority ethnic backgrounds felt that the service users' progress was being hampered by language & cultural issues.
QNR **	Bonell 2012	London (3 South East London Boroughs: Lambeth, Lewisham, Southwark)	Experiences of mental health services	Two-round Delphi process (n=36 round 1, n=24 round 2) using questionnaires administered in face-to-face interviews	People with mild ID & English as first language currently using specialist community-based mental health services, living situation ns	24	Black British, Black African or Black Caribbean 54.2% White British 45.8%	White 36–65 (48 (ns); ns), Black 21–51 (34 (ns); ns)	54.2%	Median response & level of agreement with questionnaire items	Overall lower level of agreement in the Black group reflected slightly less positive views about services (on three items) & a broader spread of opinions than the White group. There was particularly low agreement (<50%) among the Black group on whether staff offered medication when they felt worried or sad, rather than talking with them. The Black group reported the only negative experiences expressed in the study: there are not enough staff that speak English & staff can make them feel angry, upset or sad. However, neither item reached consensus.
QD ****	Bouras 2003	London (2 South East London boroughs)	Trends in referrals to a Specialist Mental Health Service	Retrospective analysis of referrals over three time periods: 1983-1988 first long-stay institution in area closed; 1989-1994 second long-stay institution closed; &	New referrals to a specialist mental health service for people with ID & psychiatric disorder, mainly living in family home or supported	752	White 77.9% Afro-Caribbean 15% Asian (ns) 4% Other non-White 3.1%	ns (ns (ns); ns) 80% age 44 or less	60.6%	Number of referrals by ethnic group	There was a significant difference in the ethnicity of referrals over the three time bands (chi square 26.40, p < .001). The most marked increase was in the proportion of individuals of African/Caribbean origin, with referrals over the three time periods being: 20 (7.7%); 32 (19.5%); 61 (18.7%). For Asian referrals over the three time periods were: 6 (2.3%) 7 (4.3%) 17 (5.2%). Other non-white 4 (1.5%), 6 (3.7%), 13 (4%).

MMAT Type & Rating	First Author & Year	Location	Focus	Design	Key sample features	Sample size	Ethnicity of sample	Age range (mean (SD); median)	% male	Relevant Outcome measures	Results
					1995-2001, no local long-stay institutions		housing				
QNR ****	Chaplin 1996	Leicester	Psychiatric outpatient service use & diagnoses	Retrospective case note analysis for year 1991. South Asian participants matched for age & sex with two White controls. Data collection facilitated by reference to LIDR	South Asian & White adult outpatients with ID seen by Dept of Psychiatry of LD in one hospital excluding those in NHS accommodation	114 38 S Asian, 76 White controls	White 66.7% S Asian 33.3%	S Asian ns (30.2 (7.5); ns) White ns (29.8 (7.8); ns)	63.0%	Source of referral, number of psychiatric contacts, psychiatric diagnoses	South Asians under-represented on LIDR: 17% South Asian compared to 25% in the local general population (78% LIDR White, 72% general population). Of 193 people seen, South Asians 38 (20%), White 146 (76%) & others nine (4%). No significant differences in routes of referral or number of contacts. Referred by medical practitioners: South Asian 26 (68%), White 51 (67%). Slightly more South Asians referred specifically by GP: South Asian 15 (39%), White 18 (24%). Mean number of contacts South Asian 4.0, White 3.1. South Asians significantly more likely to receive a psychiatric diagnoses (South Asian 36 (95%), White 59 (78%) (p <.05)) & in particular of psychosis (South Asian 16 (42%), White 17 (22%) (p<.05)) with further research required regarding this
Q ***	Chinn 2011 (see also Bonell 2011)	London (3 East London boroughs)	Views of people placed in out-of-area inpatient psychiatric facilities	Service user consultation exercise via thematic analysis of qualitative semi-structured interviews	People placed in out-of-area specialist inpatient psychiatric facilities for people with ID, mostly with mild ID	17	White British ≈ 50% Other ethnic minority communities ≈ 50%	ns (34 (ns); ns)	76.5%	Themes identified in analysis of semi-structured interviews	Within the theme 'group versus individualized treatment', there appeared to be limited opportunities for individuals to practice, explore & develop their cultural & religious identities e.g. "There's lots of people [at home] there they speak in my language, & it's easier to speak in my language but I haven't spoken my language for a long time now"
QNR ****	Cowley 2004	London (2 South East London boroughs)	Variables associated with presence of psychiatric diagnosis	Cross-sectional retrospective study; binary logistic regression used to predict presence of psychiatric diagnosis	New referrals to a specialist mental health service for people ID, 53% with psychiatric diagnosis, mild to severe ID, mainly living in family home or supported housing	752	White 78% Other 22%	ns (ns (ns); ns) 80% age 44 or less	61%	Presence of any psychopathology; presence of specific psychiatric diagnoses	Ethnicity was not a predictor of the presence or absence of any psychiatric diagnosis. For schizophrenia spectrum disorder, White ethnicity OR 0.46 (95% CI 0.28–0.75). For personality disorder, White ethnicity OR 2.95 (95% CI 1.27–6.88). Models for dementia, anxiety disorder & depressive disorder accounted for only a very modest or almost none of the variance & did not include ethnicity
QNR	Devapriam	Leicester &	Carer profiles,	Restrospective	Adults with ID on	742	White 63%	<35-50+	58.4%	Reported unmet	South Asian adults were more likely to have a

MMAT Type & Rating	First Author & Year	Location	Focus	Design	Key sample features	Sample size	Ethnicity of sample	Age range (mean (SD); median)	% male	Relevant Outcome measures	Results
**	2008	Rutland	stress levels & unmet service needs	cross-sectional study using LIDR data	LIDR living with family carers (mainly parents)		South Asian 37%	(ns (ns); ns) South Asian <35 69% White <35 62%		need; reported psychological symptoms	profound learning disability (44%) than White adults (20%) (p<0.001) & conversely less likely to have mild ID (9% v 23%, p<.001). South Asian carers reported greater unmet needs for any service than carers of White adults (76% v 59% p<.001). Significantly different rates of unmet need for specific health related services were: GP advice 17% v 7% (p<.001), OT 13% v 7% (p<.05). For psychological symptoms carers of South Asian adults were less likely to report that they showed irrational fears or anxiousness (9% v 16% p<.001). No significant difference for any other psychological symptoms
QNR **	Dunkley 2017	Leicester-shire	Prevalence & risk factors for screen detected Type 2 diabetes & glucose intolerance	Cross-sectional population-based screening study; logistic regression used to assess association between key biomedical & anthropometric characteristics & abnormal glucose regulation	Adults with mild to profound ID mainly living in family home or residential/nursing home, excluding those with prior diagnosis of diabetes (type I or II) or disease that could affect glycated haemoglobin measurement	675	White 80.4% South Asian 15.8% Black 1.5% Mixed 1.4% Other 0.9% (for 930 who consented)	18-74 (43 (14.2); ns) for 930 who consented	57.7% for 930 who consented	Blood test result indicating Type 2 diabetes or impaired glucose regulation	Of the 675 participants with outcome data nine participants (1.3%, 95% CI 0.6 to 2.5) had previously undiagnosed type 2 diabetes & 35 participants (5.2%, 95% CI 3.6 to 7.1) had impaired glucose regulation. Prevalence of abnormal glycaemia (combined type 2 diabetes & impaired glucose regulation) was 6.5% (95% CI 4.7, 8.4). Participants of non-White ethnicity were almost four times more likely to have abnormal glucose levels compared with White European participants (OR 3.93; 95% 2.10 to 7.33). Non-White ethnicity normal glucose 119 (85%), abnormal glucose 21 (15%).
QNR **	Durà-Vila 2009	London	Ethnic variation in service use	Service evaluation & audit, data provided by school teachers & administration staff using case files. Binary logistic regression used to identify variables which may predict service uptake (4 out of 12 special schools agreed to take part)	Children in 4 special schools with mild or moderate ID (mostly moderate ID), living with families	242	White British 31.0% Black 20.2% South Asian 14.9% Middle East/Arab 13.6% Mixed/Other 11.2% White European 9.1%	7-17 (ns (ns); ns)	67.4%	Service utilisation	CAMHS use lower for South Asians than White British (2/36, 5.6%, vs. 17/75, 22.7%) (chi square 3.886, 1 d.f., p<.05), & trend for lower CAMHS use for South Asians than Black group 11/49 (22.4%) (chi square 3.361, 1 d.f., p = 0.0668). Access to SALT varied across the six ethnic groups (chi square 18.59, 5 d.f., p = 0.002), being highest for Middle East/Arab 24/33 (72.7%), followed by White European 15/22 (68.2%) & mixed ethnic group/other ethnic groups 15/27 (55.5%). Lowest was for Black groups 18/49 (36.7%). In regression analysis family composition (two parent vs single parent/foster family) predicted CAMHS service utilisation & social

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											service community support (less likely if two parent family). For South Asians 25 (78.1%) were in two parent families, compared to 29 (39.2%) White British, & 25 (52.0%) on the Black group.
QNR ***	Emerson 2016	UK (England, Wales, Scotland, Northern Ireland)	Prevalence of & risk factors for obesity	Secondary analysis of longitudinal study (Millennium Cohort Study); multivariate logistic regression to identify predictors of obesity	11 year old children predominantly with mild to moderate ID. Living situation ns	ID 647 (n=484 for multivariate logistic regression) non-ID 14,485	Numbers not stated. Coded as: White; Mixed Ethnicity; Indian; Pakistani or Bangladeshi; Black or Black British; Other.	Analysis at age 11	61%	BMI compared to age & gender-specific overweight & obesity BMI thresholds	31.1 % of children with ID were obese at age 11 (compared to 21.2% of those without ID, OR 1.68 (95% CI 1.39–2.03)). At age 11 risk of child obesity was associated with persistent maternal obesity (OR 7.18 (95% CI 3.77–13.67)), maternal education (only having overseas qualifications, OR 4.31 (95% CI 1.47–12.65)), child ethnicity (mixed OR 2.13 (95% CI 0.69–6.64, ns) & Black/Black British OR 2.33 (95% CI 0.99–5.51, ns)) & being bullied at age 5 (95% CI 2.54 (0.74–8.77) ns)
QNR ***	Emerson 2005 (see Emerson 2004)	Inner city in England, city ns	Emotional & behavioural needs of children with ID	Cross-sectional survey via postal questionnaire or interview if English not carer's first language. Information on mental health needs of children collected from child's teacher (for a 50% random sample of children) & from family carers for full sample	Children with moderate, severe or complex learning disability recorded as primary special educational need on local education authority database	615	White 74% South Asian 14% Black 7% Other 5%	5-16 (ns (ns); ns)	65%	Developmental Behaviour Checklist (parent (DBC-P) & teacher (DBC-T) versions) total & subscale scores	Caseness on DBC-P (n=356) associated with White ethnicity (corrected OR 2.2 (95% CI ns, p=.005)) (largest OR was for Ambulant (corrected OR 26.5 (95% CI ns)). Disruptive/antisocial subscale on DBC-T (n=228) associated with not belonging to South Asian ethnic group (OR 3.49 (95% CI ns, p = .02)). Self absorbed subscale on DBC-P (n=356) associated with White ethnicity (OR 2.15 (95% CI ns, p=.006)). Ethnicity was not retained in final regression models for any other scale outcomes
QNR **	Emerson 2004 (see Emerson 2005)	Inner city in England, city ns	Service receipt	Cross-sectional survey via postal questionnaire, or interview for family carers who did not have English as their first language	Children with moderate, severe or complex learning disability recorded as primary special educational need on local education authority database	408	White 70% South Asian 18% (93% Pakistani origin) Black 7% Other 6%	5-16 (ns (ns); ns)	63.0%	Reported receipt of 35 different services over preceding 3 months	No statistically significant differences between South Asian & other carers for total number of services received, total number received on a fortnightly or more frequent basis, & total number received on a monthly or more frequent basis. South Asian carers more likely to have received (using Fisher's exact test): audiology (p<.001), community nurse (p<.05), & health visitor (p<.01) (% values not given). Less likely to have received behavioural support team (p<.05)
QNR	Hatton	Two metro-	Awareness &	Structured interviews	Carers of	54	Pakistani 63%	22-68	3.7%	Number aware of	Carer awareness of general community health &

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****	1998	politan boroughs in North West England	receipt of services	with main carer	adolescents or adults with ID from South Asian communities, mainly mothers		Bangladeshi 17% East African Asian 17% Indian 4%	(45 (ns); ns)		service, number using service	social services was high but awareness of specialist services for people with learning difficulties was, with the exception of awareness of day services, much lower. Less than 20% of carers were aware of: community ID nurse (5; 9%), community psychiatric nurse (10; 19%), clinical psychologist (7; 13%), advocate (5; 9%), & additional support team (4; 7%). The following services were used by less than 10% of carers in the last 3 months: Chiropodist (5; 8%), Home help (4; 7%), Hospital day-patient (3; 5%), Physiotherapist (3; 5%), Educational psychologist (3; 5%), Community intellectual disability nurse (2; 3%), Psychiatrist (1; 2%), Occupational therapist (1; 2%). No carers had used: Audiologist, Speech therapist, Community psychiatric nurse, Clinical psychologist, Advocate, & Additional support team. Multiple regression indicated that carers were more likely to be aware of services if they both speak & write English. Service receipt higher if the user difficult to supervise, household income higher, & carers lived in the UK for longer. Carers reported possible barriers to service uptake were: lack of awareness of services (51 carers; 94%); lack of staff who could speak the same language as the carer (44 carers; 81%); cultural inappropriateness of existing services in terms of diet, activities & staff provision (19 carers; 35%); & racial discrimination within services (12 carers; 22%). Reported suggestions for improving services were: receiving information about services in appropriate languages & formats (43 carers; 80%), increasing the number of south Asian staff throughout mainstream services for people with learning difficulties (35 carers; 65%), improving cultural appropriateness of services, in terms of diet, culturally appropriate activities, & same-sex carers for women (26 carers; 48%). Finally, 13 carers (24%) stated that a support network for carers from south Asian communities would be helpful
Q ***	Heer 2016	ns	Service provider	Focus groups; analysed using	Service providers from localities	20	White British, Scottish, or European 70%	ns	30%	IPA generated themes	Theme 'language as a primary barrier to therapeutic engagement'. Interpreters frequently utilized but

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			experiences of working with South Asian families	interpretative phenomenological analysis (IPA)	with high numbers of South Asian populations offering peripatetic & domiciliary support services to people with ID (e.g. learning disability nurse, OT, clinical psychologist)		British Indian 15% British Pakistani 10% African Caribbean 5%				overall consensus that their use posed serious problems. Theme 'understanding & managing cultural difference'. Containing caregiving within the family environment meant that often service providers were unaware of the needs of South Asian families; contact with services delayed until situations reached crisis point
QNR ***	Kiani 2013	Leicester-shire & Rutland	Rates of mental illness, ASD & behaviour disorder in people with ID living in urban versus rural areas.	Cross-sectional study using the LIDR (Chi square, no multivariate analysis)	Adults registered with intellectual disability service (LIDR)	2,713	White 84.1% South Asian 12.8% Other/unknown 3.1%	<30-50+ (ns (ns); ns)	56.3%	Clinical diagnosis of mental illness	1507 (55.5%) urban, 1206 (44.5%) rural areas. 21% of those living in urban areas were South Asian compared to 2.7% of those living in rural areas. The prevalence of mental illness was lower in the ethnic minority population than in the white population (21.4% vs. 35.4%) (statistically significant - test values not given). Urbanicity was not associated with a higher rate of psychiatric disorders in people with ID
QNR ****	Maitland 2006	London (South East, boroughs ns)	Source of referral to specialist mental health service	Retrospective study of new referrals; binary logistic regression performed with source of referral (SoR) as dependent variable	New referrals to a specialist mental health service for people with ID, mainly living in family home or supported housing.	791	White 77.0% Black 15.0% Other non-white (mainly Asian (ns)) 8.0%	16-86 (33.5 (13.5); ns)	61.0%	Source of referral	People referred from GMHS were more likely to be from the 'other-non-White' (predominantly Asian) ethnic group (11.0%) than those referred from PC/SS (6.1%) (chi square 6.19, df = 1, p = 0.01), & people referred from PC/SS were more likely to be 'White' (79.5%) than those referred from GMHS (72.9%) (chi square = 4.52, df = 1, p = 0.03). In regression model other non-White group were more likely to be referred from GMHS (OR 1.76 (1.01–3.06)).
QNR ***	McGrother 2002	Leicester-shire & Rutland	Related disabilities, psychological morbidity, service use & felt need for services	Cross-sectional analysis of LIDR data from most recent home interview between 1987 & 1998	Adults on the LIDR	2,540	White 91.9% South Asian 8.1%	South Asian 20-61 (33.7 (ns); ns) White 20-93 (41.2 (ns); ns)	M:F ratio South Asian 1.64 White 1.31	Psychological symptoms, psychiatric service use, unmet service needs	No difference in the extent of psychological symptoms between South Asians & Whites in adjusted comparisons, with only lethargy being significantly higher for South Asians (adjusted OR 1.63, 95% CI 1.17, 2.27, p=0.004). 62.1% of South Asian adults & 76.8% of White adults had been notified to the register as using psychiatric services (adjusted OR 0.532 (95% CI 0.379, 0.746). Overall,

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											South Asians felt considerably more unmet need for community services than Whites, particularly for social services rather than health services. Unmet need (some or more needed) reported by the following proportion of South Asian carers: day care 24.1%, community nurse 2.6%, speech therapist 17.3%, physiotherapist 9.6%, OT 8.6%, chiropodist 15.8%, social worker 17.1%, home help 10.3%, sitting service 12.7%, advice from GP 11.5%. Any unmet need South Asians 64.8% (adjusted OR 1.86, 95% CI 1.27–2.72 p= 0.0015)
QD **	Raghavan 2007	Bradford City	Service use	Semi-structured interviews with participants & family carers to map service access	Young people with ID who screened positive for mental illness & their family carers, mild to severe ID, mainly living with parents,	35	Pakistani 88.6% Bangladeshi 11.4%	14-25 (ns (ns); ns)	74.3%	Number using services	Majority of families were using mainstream children's services (health) (19 (54.3%)) & their GP (25 (71.4%)) for general healthcare needs of the young person. Despite all participants screening positive for mental illness, only 8 (22.9%) were using mental health services & few families were accessing professionals such as psychiatrists (5 (14.2%)), clinical psychologists (2 (5.7%)) or behaviour nurse specialists (2 (5.7%)). Many family carers were not aware of the mental health and/or behavioural needs of their son/daughter. Many carers felt that services were not culturally & religiously sensitive to the needs of young people with ID. Barriers to service use included: lack of knowledge & awareness of services; language barriers; lack of a single point of contact with services; & inappropriateness of services to meet the needs of the young people & their families
RCT ***	Raghavan 2009	Bradford City	Effectiveness of a specialist liaison service for increasing access to & uptake of services	Non-blinded RCT. Liaison worker visited &/or telephoned participants at least once every fortnight, advised on availability of services & helped participants access services. 9 month study period	Young people with ID who screened positive for mental health problems/ challenging behaviour & who were receiving services for challenging behaviour &/or	26 12 treatment, 14 control	Pakistani 88.5% Bangladeshi 11.5%	Treatment 13-25 (17 (ns); ns); Control 13-25 (19 (ns); ns)	ns	Number of services contacted, & number of outcomes from contacts	Participants in the treatment group, who had the additional help of a liaison worker, had statistically significantly more frequent contact (111 vs 40; Z = -3.620, p = 0.001), with more services (47 vs 17; Z = -3.335, p = 0.001) & with more outcomes from such contacts (33 vs 9; Z = -3.579, p = 0.001) than did controls

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					mental health problems						
QNR ****	Tsakanikos 2010	London (3 South East London boroughs: Lambeth, Lewisham & Southwark)	Role of ethnicity in the presentation of psychiatric disorders	Retrospective study of new referrals; binary logistic regression analyses with ethnicity (White, Black & other non-White) as dependant variable	New referrals to specialist mental health service for adults with ID, mostly living in family home or supported housing	806	White 76.8% Black 15.4% Other 7.8%	16-86 (33.6 (13.6); ns)	60.0%	Clinical diagnoses; care pathways	Lower proportion of White participants referred from mainstream mental health services (chi square 4.04, df = 1, p = 0.04). Between group differences for schizophrenia spectrum disorders (White: 15.5%, Black: 23.4%, other non-White: 28.6%; chi square 9.89, df = 2, p = 0.007) & dementia (White: 4.2%, Black: 0.8%, other non-White: 0.0%; chi square 6.04, df = 2, p = 0.05). Schizophrenia spectrum disorder less likely to be found in White participants in comparison to other ethnic groups (OR 0.46 (95% CI 0.31–0.77)), & more likely in the Black group than the other ethnic groups (OR 1.70 (95% CI 1.01–2.76)). Schizophrenia spectrum disorder was more likely in the 'Other non-White' group (OR 2.21 (95% CI 1.22–4.01))
QNR ****	Tyrer 2007	Leicester-shire & Rutland	Factors associated with survival	Data from LIDR analysed using Cox proportional hazards models to explore factors associated with mortality	Adults on the LIDR	2,453	White 82.9% South Asian 13.3% Other/unknown 3.8%	20+ (ns (ns); ns)	57%	Death	There were 402 (16%) deaths in the 19-year follow-up period. In multivariable model (and single variable models), ethnicity was not a predictor of mortality - White of 2034 participants, 367 died (18%; reference category), South Asian of 326 participants, 28 died (9%) hazard ratio 1.27 (0.85–1.90), & 'other/unknown' of 93 participants 7 died (8%), HR 1.28 (0.60–2.74). Physical impairment was a strong predictor of mortality (non-mobile HR 7.14 (4.99–10.21))

Abbreviations: ASD autistic spectrum disorder; CI confidence interval; GMHS generic mental health services; ID intellectual disabilities; IPA interpretative phenomenological analysis; LIDR Leicestershire Intellectual Disability Register; MMAT mixed methods appraisal tool; ns not stated; OR odds ratio; OT occupational therapist/therapy; PC primary care; Q qualitative; QD quantitative descriptive; QNR quantitative non-randomised; RCT randomised controlled trial; SoR source of referral; SS social services