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Review Article

Mental health service utilisation amongst children and young people with intellectual disability in low income countries: systematic review

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Abstract. Background *Mental health service utilisation amongst children and young people with intellectual disability (ID) in low income countries has not previously been reviewed.* **Aims** *To investigate influences on uptake of mental health services in children and young people with ID in developing countries.* **Method** *A systematic review was carried out using main databases of studies that explore mental health utilisation of children and young people with ID. Methodological quality of included studies was assessed.* **Results** *Four studies provided data in low income countries offering a powerful depiction of help-seeking behaviour and access to services.* **Conclusion** *Internationally there is an extremely low level of mental health service provision for children including those with ID. There may be delays in service access even when provided and these often relate to cultural variables. Models of intervention will be needed that integrate services into existing institutions such as schools and also general health services and child mental health services in middle income counties. Greater investment in services is required in low-middle income countries.*

Keywords: culture, ethnicity, intellectual disability, mental health, service utilisation, children, adolescents.

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INTRODUCTION In global perspective mental health services for children and adolescents have been poorly developed (Omigbodun, 2008). Many low and low-middle income countries have no mental health services for young people and no plans for developing them (WHO, 2005; Lancet Global Mental Health Group, 2007), and even newly industrialised countries have variable service provision (Tan *et al*, 2008). Furthermore, the needs of children and adolescents with intellectual disability (ID) have also been neglected (WHO, 2007). Nevertheless there are signs that the situation is changing with greater attention being given to service planning and provision for children and adolescents (Omigbodun, 2008; Patel *et al*, 2008) including those with ID. It is recognised that a key issue in provision of effective services and the delivery of treatments is accessibility (Patel *et al*, 2008).

We have recently shown that ethnic and cultural factors are important influences on mental health service utilisation for people with ID in high income countries (Durà-Vilà & Hodes, 2011). This systematic review found that studies that had been carried out in the UK and the USA comparing two or more ethnic groups did identify ethnic factors in mental health service utilisation (McGrother *et al*, 2002; Bouras *et al*, 2003; Stancliffe & Lakin, 2006; Bhaumik *et al*, 2008; Anand *et al*, 2009; Durà-Vilà &

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Hodes, 2009). The most consistent finding was that South Asian children and adults with ID in the UK had lower use of mental health services than White British comparisons (McGrother *et al*, 2002; Bhaumik *et al*, 2008; Durà-Vilà & Hodes, 2009).

The aim of this paper is to extend the earlier review and ascertain the range of factors that have been shown to be important influences on utilisation of mental health services for children and young people with ID in low income countries. We carried out a systematic review to address this question and assess the quality of available evidence.

METHODS

Data sources An extensive literature search was conducted in the electronic databases Medline, EMBASE and PsycINFO (January 1950 to December 2009).

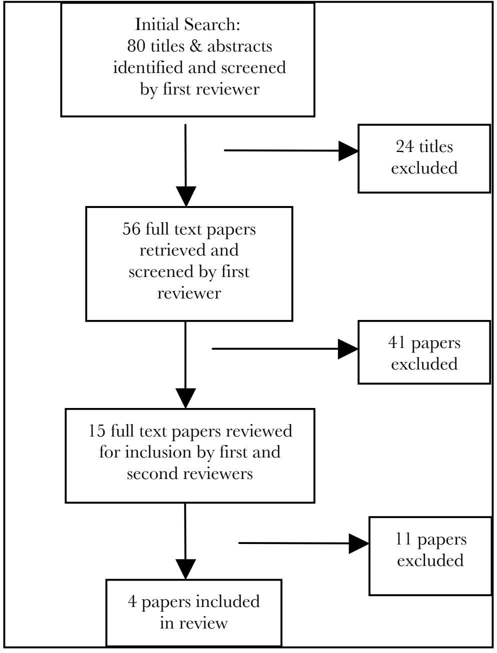
Search terms The following search terms were used: 'intellectual disability', 'learning disability', 'mental retardation', 'ethnicity', 'ethnic groups', 'culture', 'cultural characteristics', 'service utilisation', 'mental health services', 'service uptake', and 'health service accessibility'. Reference lists from papers on the topic were checked to identify additional studies. We report on the findings of studies that explored mental health service utilisation and accessibility amongst children and young people with ID in low income countries.

Inclusion criteria We included all studies that reported quantitative or qualitative data for mental health utilisation of children and young people with ID in low income countries. These inclusion criteria were developed following a pilot search to ensure inclusion of relevant studies. Studies whose participants had other developmental, psychiatric or physical abnormalities - besides ID - were included in the review, although only the findings concerning those with ID have been reported here.

Exclusion criteria Case studies, letters, commentaries, and review papers were excluded, although relevant studies identified from the references cited within them were included. Studies not published in English and those undertaken in high income countries were excluded, as were studies investigating mental health services among people with ID not including children or adolescents.

Selected studies and data extraction The above search strategy was carried out by the first author identifying 80 titles (see **Figure 1**).

Figure 1 Flow diagram showing review process



The relevance of the studies was initially ascertained from the titles and abstracts, and 56 full text papers were retrieved and screened by the first author. Further analysis of the full articles revealed that over half of them did not meet the inclusion criteria and they were then excluded. The resulting 15 studies were read and the inclusion conditions applied by both reviewers, selecting 4 papers to be finally included in the review. Uncertainties about whether individual studies met the inclusion criteria were resolved by discussion between the authors. The following key study data was extracted from all selected studies by one reviewer and checked for accuracy by the second: country of origin of participants, research design, study population, age of participants, sample size (only counting those participants with ID), outcome measures and findings (referring to mental health service utilisation).

Analysis The heterogeneity and small number of included studies meant that meta-analysis was inappropriate. Findings are presented as a narrative synthesis of results from individual studies in the results section (and summarised in **Table 2**).

Assessment of methodological quality In order to ensure consistent assessment of the quality of the studies both authors agreed on the criteria on which to base the assessment after careful reading of the selected literature (Centre for Reviews and Dissemination, 2009). For each study, a quality score was generated with one point for each of the following, up to a maximum of 6 points:

(a) Adequate sample size;
(b) Appropriate sample selection procedures;
(c) Use of semi-structured interviews to inform quantitative data;
(d) Validated outcome measures;
(e) Reliable outcome measures;
(f) Quality of data analysis.

Studies were quality assessed and rated by one reviewer and checked for accuracy by the second. Complete consensus was reached on appropriate ratings for each study. Details on the methodological quality for the selected studies are presented in tabular form (see **Table 1**).

RESULTS The research design, country of origin, study population, outcome measure and results are summarised in Table 2.

Two cross-sectional surveys were undertaken in *Pakistan* (Tareen *et al*, 2008; Mirza *et al*, 2009). The first study obtained information from consecutive attendees at an advertised mental health consultation day in a remote rural area aiming to describe types of treatment and families' perceptions of the effectiveness of those treatments for child and adolescent neuropsychiatric conditions (Tareen *et al*, 2008). Almost 42% (38/91) had a clinical diagnosis of ID and the most common treatments received were tablets and syrup by primary care physicians, and prayers and amulets by religious healers. In families who consulted a general practitioner, those with epilepsy reported greater effectiveness than those with ID. The authors emphasised that relatives often look for a cure for ID and, in the absence of a pathway of care after diagnosis, they often consult multiple practitioners. The second study used quantitative and qualitative instruments to look at community management of ID in Pakistan in primary care (rural setting) and secondary and tertiary care (urban setting) (Mirza *et al*, 2009). The study sample consisted of 100 carers of children and young people with ID (from 1 to 28 years old) and 10 key primary health providers (physicians, community health workers, hakeems – practitioners of ancient Greek medicine using herbs, spices and poultices – , homeopaths and faith healers). Significant delay in detection of ID – especially in a rural setting – was found as well as delay of 2.92 to 4.17 years between detection and seeking of care from any health care provider. Barriers to access mental health services were identified: difficulties in accessing services as they are located in major cities (financial and time costs), limited information about services available, stigma and beliefs that ID could be a reversible condition (some participants provided a supernatural explanation to their relative's ID, consequently seeking for divine help rather than medical advice).

Table 1 Assessment of methodological quality of studies for children and young people with intellectual disability access to mental health services

First Author/ Date	**Sample**		**Validity and Reliability of Measures**	**Analysis**	**Quality score[2]**
	Size[1]	**Selection**			
Pillay & Lockhat, 1997	31	Complicated cases, initially seen by the community psychiatric nurse, were seen by clinical psychologists who travelled to distant areas from their metropolitan hospital in Pietermaritzburg (South Africa). These cases were included in the study	Psychological consultation with a clinical psychologist who were often not fluent in African languages. Community nurses often acted as translators	Descriptive statistics	*
Jones *et al*, 2003	59	Systematic data collection of patients attending a child and adolescent psychiatric service. Attending patients and their families completed data collection sheet. Sample was largely restricted to the Albanian population of Kosovo (due to security concerns among non-Albanian citizens)	Socio-demographic data, source of referral and referring problem (completed by patients and their families). ICD-10 diagnosis, mode of treatment and number of sessions attended (completed by researchers). This is a report of clinical work under difficult conditions (Kosovo, in the immediate aftermath of war): data were not collected or not completed on every patient and some of the final diagnoses at the end of the second year were not included	Descriptive statistics	**
Tareen *et al*, 2008	38	Consecutive attendees and their families at an advertised mental health consultation day in a remote rural area of Punjab, Pakistan	Semi-structured questionnaires on health problems, healthcare providers consulted, type of treatment received and family views about effectiveness. Questionnaires were devised at a meeting by senior psychiatrists, senior psychologists and primary care physicians. In a majority of cases (81.2%) family members rather than the patient responded to the questionnaire. Effectiveness was measured on a 4-point Likert scale (complete cure, partial cure, cure but relapse and ineffective). Authors did not use a standardized or validated questionnaire of treatment satisfaction or effectiveness. Possibility of selection bias (study based on consecutive attendees) and response bias (participants were recruited from a medical clinic). ICD-10 diagnosis. Child and adolescent diagnoses such as pervasive developmental disorders or attention deficit hyperactivity disorder were not made, as these were not diagnoses that an adult psychiatrist of registrar level would be confident in diagnosing; therefore some of them may have been erroneously subsumed under mental retardation	Descriptive statistics	***
Mirza *et al*, 2009	170 (carers) +10 (primary health provider)	Purposive sample of rural primary care attendees, consecutive attendees to urban secondary and tertiary care	The following measurements were used: questionnaires on socio-demographic characteristics and sources of care; Self-reporting Questionnaire (SRQ-20) (measure validated in Pakistan); Short Explanatory Interview (SEMI) (Urdu adaptation developed for Pakistani population); focus groups and in-depth tape-recorded interviews (transcribed after forward and back translation, findings regularly discussed between authors and also discussed with local community leaders). Triangulation of data	Fisher's Exact Test, Chi-squared Test, Rank Sum Test and t-test. Content analysis using Non-numerical Unstructured Data Indexing Searching and Theorizing. Boolean and proximity searches to identify themes	****

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[1] Sample size only includes those with ID.

[2] See "Assessment of methodological quality" for details of how the quality is rated (quality score was agreed by first and second reviewers)

Pillay & Lockhat (1997) provided a description of the development of a 12 month mental health community intervention programme for children and adolescents in outlying areas of *South Africa* which did not have near access to a psychiatric hospital. The most common presenting problem amongst the children referred was ID (31/204, 15.2%). The authors explained that the referrals came mostly from school teachers, in the context of the deficient education system which provided virtually no educational psychological services in the outlying areas.

Systematic data collection of patients attending a CAMHS carried out in *Kosovo* in the immediate aftermath of the war (1999-2001) revealed that although stress-related disorders were the most common diagnosis in the first year, ID was one of the two most common diagnoses in the second year (Jones *et al*, 2003). Behavioural problems were commonly found to be a marker for mild ID. The authors clarified that the service was largely restricted to the Albanian population of Kosovo because of the security concerns among non-Albanian citizens.

DISCUSSION

Interpretation of findings The four studies included in the review have provided data on mental health service utilisation using a variety of study designs, populations and outcomes in three low-income countries (South Africa, Kosovo and Pakistan). The high quality studies from Pakistan found that culturally shaped ideas about ID contributed to delays in seeking mental health service contact (Tareen *et al*, 2008; Mirza *et al*, 2009). The studies provided a powerful depiction of help-seeking behaviour and access to services in low-income countries, revealing glaring deficiencies in availability and provision of services that showed striking differences with Western countries.

The patterns of mental health service uptake revealed in the studies could have been influenced by the following factors:

(a) *Family composition and support*: the lower use of psychiatric services could be explained by having support from extended family, making help outside the family context less pressing, and by families living in two-parent families (for example, see Durà-Vilà & Hodes, 2009).

(b) *Beliefs and understanding of ID*: the attribution of meaning and conceptualisation of ID varies greatly across cultures. The perceived cause of ID could be attributed, in some cultures, to non-biological causes and therefore, not amenable to medical treatment. For example, it could be explained as due to the fallibility of parents, such as the innate inferiority of the mother, bad sexual practices, or wrongdoings during pregnancy, or to external causes, such as curses or the evil eye (O'Hara & Bouras, 2007).

A further aspect of beliefs associated with ID and psychiatric problems concerns stigma. This may also affect the family's help-seeking behaviour. Again, the lower use of mental health services found in South Asians in some studies undertaken in the UK could also be understood as an attempt to keep their relative's disability as secret as possible, especially if it was associated with mental health problems (double stigma). This was shown in a large qualitative study of carers from the four main South Asian communities in the UK (Pakistani, Gujarati, Bangladeshi and Punjabi) (Katbamna *et al*, 2000; 2002).

There may also be the expectation that ID can be cured. Studies have shown that South Asian families in UK (Fatimilehin & Nadirshaw, 1994; Katbamna *et al*, 2000) and in Pakistan (Mirza *et al*, 2009) often lived in the hope that their disabled relative would get better or be cured. This belief in the reversibility of ID could contribute to explain why families from some ethnic minority communities are not keen in accessing services that does not share this view and may provide a much more negative prognosis.

Table 2 Mental health service utilisation amongst children and young people with intellectual disabilities: characteristics and outcomes of included studies

First Author/ Date	Country	Research Design	Study Population	Outcome Measures	Results[1]
Pillay & Lockhat, 1997	South Africa (province of Kwazulu-Natal)	Description of the development of a 12 month mental health community intervention programme for children and adolescents	Referrals to a mental health community intervention programme for children and adolescents n = 31▪ Age (years): 6-16	- Psychological consultation with a clinical psychologist, community nurses acting as translators	- The most common presenting problem amongst the children referred was ID (31/204, 15.2% of all the referrals) - These children were mostly referred by school teachers, in the context of the education system which provided virtually no educational psychological services in the outlying areas
Jones *et al*, 2003	Kosovo (Albanian in its majority[2])	Systematic patient data collection and audit over 2 years	Patients attending a CAMHS in Kosovo in the immediate aftermath of war (1999 - 2001) *n* = 59▪▪ Age (years): 0-20	- Questionnaire on socio-demographic information, source of referral and presenting problem, mode of treatment, number of sessions attended - ICD-10 diagnoses	- Stress-related disorders were the most common diagnosis in the first year but ID was one of the two most common diagnoses in the second year [year 1 (n = 11, 7.1%); year 2 (n = 48, 12.8%)] - Behavioural problems were a common marker for mild ID
Tareen *et al*, 2008	Pakistan (remote rural Punjab)	Cross-sectional study	Consecutive attendees to a mental health consultation day for residents of the area *n* = 38▪▪▪ Age (years): 1-18	- Questionnaires on health problems, healthcare providers consulted, type of treatment received and family views about effectiveness - Effectiveness was measured on a 4-point Likert scale (complete cure, partial cure, cure but relapse and ineffective)	- Almost 42% (38/91) had a clinical diagnosis of ID. - The most common treatment received: primary care physicians (tablets and syrup) and religious healers (prayer and amulet) - In families who consulted a general practitioner, those with epilepsy reported greater effectiveness than those with ID - Looking for a cure for ID, families consult many different practitioners
Mirza *et al*, 2009	Pakistan (rural and urban areas of Punjab)	Cross-sectional survey	Carers and key primary health providers attending primary care (rural setting) and secondary and tertiary care (urban setting) n = 170 (carers) + 10 (primary health providers) Age (years): 1-28 (people with ID); 20-73 (carers)	- Questionnaires on socio-demographic characteristics and sources of care -*Self-reporting Questionnaire (SRQ-20)* to measure distress in the carer - *Short Explanatory Interview (SEMI)* to study health beliefs and explanatory models -Focus groups -In-depth interviews	- Significant delay in detection of ID, especially in rural setting - Delay of 2.92 to 4.17 years between detection and seeking of care from any health care provider. Mean age at first contact with secondary care (6.40 years) and tertiary care (5.10 years) - Barriers to access mental health services were: difficulties in accessing services located mainly in major cities (financial and time cost), limited information about services available, stigma and believing that ID could be reversible (supernatural explanation "Allah's will" and asking for divine help)

[1] Only the results referring to the outcome under study - mental health utilisation of children and young people with ID - have been presented here.

[2] The service was largely restricted to the Albanian population of Kosovo because of the security concerns among non-Albanian citizens.

▪ The study population were the children and adolescents referred to a mental health community intervention programme (n = 204), for 31 of them their primary presenting problem was ID.

▪▪ The study population were the patients attending a child and adolescent mental health service (n = 559), 59 of them had a diagnosis of ID.

▪▪▪ The study population were children and adolescents with neuropsychiatric conditions (n = 98), 38 of them were given a clinical diagnosis of intellectual disability.

(c) *Availability of sources of help*: the deficiencies in service provision due to poverty and lack of public funding (World Health Organization, 2007) and the barriers to access mental health services such as financial, time and distance obstacles will impact service use, as seen in the two studies from Pakistan reported here (Tareen *et al*, 2008; Mirza *et al*, 2009). Given this lack of service access in the mainstream health sector, families may be encouraged to seek help from accessible alternative agencies and people. This includes seeking help from religious healers that fits their religious and culturally based explanation of their relative's ID. They frequently consult many different practitioners outside the medical system, such as holy persons, homeopaths, herbalists or faith healers (Fatimilehin & Nadirshaw, 1994; Tareen *et al*, 2008; Mirza *et al*, 2009). The World Health Organisation (2006) reported many parents from South East Asian countries selling their possessions following the advice of faith healers, or giving them away to charity, in the hope that they could find a cure.

Strengths and weaknesses of the review Despite extensive searches over a 59 years period, the use of comprehensive search terms, broad inclusion criteria and identification of studies from the references cited, only 4 studies were finally included in the review. Our decision to use three databases is consistent with the approach of other researchers (Frank *et al*, 2001; Weich *et al*, 2009).

Included studies offered a depiction of mental health service use in a particular country. Given the small number of studies it is unclear how much the findings can be generalised to other countries and cultures.

The studies varied in design: systematic patient data collection, description of a mental health intervention and cross-sectional surveys. Three studies only reported descriptive statistics (Pillay & Lockhat, 1997; Jones *et al*, 2003; Tareen *et al*, 2008). The study by Mirza *et al* (2009) combined quantitative and qualitative data, offering a more comprehensive interpretation of the quantitative findings. The authors made extensive efforts to overcome language and cultural barriers.

Limitations of the review were the exclusion of studies not published in English and the small sample sizes - under 40 participants - recruited in two studies (Pillay & Lockhat, 1997; Tareen *et al*, 2008).

Implications of studies and future research While further service development is called for (Patel *et al*, 2008), models of integrated care for young people with ID in resource-poor countries are needed. Services will need to use the existing services including school systems to identify and manage the children. Expanding child and adolescent mental health services so that they can manage young people with ID is a viable way of reducing duplication and simplifying pathways to care as described by Jones *et al* (2003) for Kosovo. Further research as seen in the study by Mirza *et al* (2009) could usefully integrate qualitative and quantitative methods. Such approaches would contribute to the cultural appropriateness of models imported from other countries.

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