Prevalence of intellectual disability: A meta-analysis of population-based studies

Colin Mathers

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Review article

Prevalence of intellectual disability: A meta-analysis of population-based studies

Pallab K. Maulik [a,b,*], Maya N. Mascarenhas [c,1], Colin D. Mathers [c,2], Tarun Dua [d,3], Shekhar Saxena [e,4]

[a] The George Institute for Global Health, Plot 839C, Road 44A, Jubilee Hills, Hyderabad 500033, India
[b] Department of Mental Health, Johns Hopkins School of Public Health, 624 N Broadway Street, Baltimore, MD 21205, USA
[c] Department of Health Statistics and Informatics, World Health Organization, Geneva, Switzerland
[d] Programme for Neurological Diseases and Neuroscience, Evidence, Research and Action on Mental and Brain Disorders (MER), Department of Mental Health and Substance Abuse, World Health Organization, Geneva, Switzerland
[e] Department of Mental Health and Substance Abuse, World Health Organization, Geneva, Switzerland

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ABSTRACT

Intellectual disability is an extremely stigmatizing condition and involves utilization of large public health resources, but most data about its burden is based on studies conducted in developed countries. The aim of this meta-analysis was to collate data from published literature and estimate the prevalence of intellectual disability across all such studies. The review includes studies published between 1980 and 2009, and includes data from populations that provided an overall estimate of the prevalence of intellectual disability. Meta-analysis was done using random effects to account for heterogeneity. Subgroup analyses were also done. The prevalence of intellectual disability across all 52 studies included in the meta-analysis was 10.37/1000 population. The estimates varied according to income group of the country of origin, the age-group of the study population, and study design. The highest rates were seen in countries from low- and middle income countries. Studies based on identification of cases by using psychological assessments or scales showed higher prevalence compared to those using standard diagnostic systems and disability instruments. Prevalence was higher among studies based on children/adolescents, compared to those on adults. Higher prevalence in low and middle income group countries is of concern given the limitations in available resources in such countries to manage intellectual disability. The importance of using standardized diagnostic systems to correctly estimate the burden is underlined. The public health and research implications of this meta-analysis have been discussed.

Contents

* Corresponding author at: Head, Research and Development, The George Institute for Global Health, Plot 839C, Road 44A, Jubilee Hills, Hyderabad 500033, India. Tel.: +91 4023558091; fax: +91 4023541980.
E-mail addresses: pmaulik@georgeinstitute.org.in, pallabmaulik@gmail.com (P.K. Maulik), mascarenhasm@who.int (M.N. Mascarenhas), mathersc@who.int (C.D. Mathers), duat@who.int (T. Dua), saxenas@who.int (S. Saxena).
[1] Tel.: +41 22 7911855; fax: +41 22 7914328.
[2] Tel.: +41 22 7914529; fax: +41 22 7914328.
[3] Tel.: +41 22 7913059; fax: +41 22 7914160.
[4] Tel.: +41 22 7913625; fax: +41 22 7914160.

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1. Introduction

Intellectual disability (ID) or mental retardation is defined as "a condition of arrested or incomplete development of the mind, which is especially characterized by impairment of skills manifested during the developmental period, which contribute to the overall level of intelligence, i.e., cognitive, language, motor, and social abilities" (World Health Organization, 1992). The International Classification of Functioning, Disability and Health (ICF) (World Health Organization, 2001) complements the definition of the International Classification of Diseases, Version 10 (ICD10) (World Health Organization, 1992) and incorporates the concept of disability and functional adaptation to disability. The American Association on Intellectual and Developmental Disabilities (AAIDD) defines it as "limitations both in intellectual functioning and adaptive behavior" (American Association on Intellectual and Developmental Disabilities, 2010). Adaptive behavior assesses conceptual skills (e.g., language, money and time concepts), social skills (e.g., interpersonal skills and social problem solving) and practical skills (e.g., activities of daily living, occupation). Throughout this paper, the term intellectual disability has been used in most areas. Mental retardation has been used in some places only where it is related to other sources, but has been used with the same meaning as intellectual disability.

Harris (2006) reported the prevalence of ID to vary between 1% and 3%, globally. Among those with ID, mild, moderate, severe, and profound mental retardation affects about 85%, 10%, 4%, and 2% of the population, respectively (King, Toth, Hodapp, & Dykens, 2009). There are few incidence studies. Katusic et al. (1996) and Heikura et al. (2003) reported incidence of 9.1 and 12.6 per 1000 population, in their studies from the U.S. and Finland, respectively. While the initial study reported a cumulative incidence of a 5-year birth cohort, the latter was based on two birth cohorts. Similarly large population-based mortality studies on people with intellectual disabilities are also few, and a 35-year cohort study (Patja, Iivanainen, Vesala, Oksanen, & Ruoppila, 2000) reported no differences in mortality rates between people with intellectual disability and the general population. However, mortality rates are much higher among those with more severe forms of intellectual disability. Given the paucity of research in areas of incidence and mortality, studies reporting on prevalence assume greater significance as sources of critical data for estimating the burden of intellectual disability. However, to the best of our knowledge there are no studies that report any global prevalence estimates, or have reported on data collated through systematic reviews of different studies. Most currently reported estimates are based on extrapolated figures from studies conducted in the U.S., or some other developed country.

This meta-analysis is part of a larger study that reviewed research in the area of incidence, prevalence, mortality and etiology of intellectual disability in community-based population, as part of the Global Burden of Disease estimates. The current paper uses a sub-group of those studies. The primary aim of this paper is to report on the findings of the meta-analysis of population-based studies reporting prevalence estimates for intellectual disability. The focus was not on any particular disorder associated with intellectual disability or intellectual disability among a sub-population. For example, studies that reported on prevalence of comorbid mental disorders among people with intellectual disability were not

included. Similarly, intellectual disabilities examined only among populations with Down's syndrome, autism, lead toxicity, or population within correctional facilities were excluded.

2. Method

The initial search was conducted with the larger review in perspective, which included studies on incidence, prevalence, mortality and etiology. The current review uses a sub-group of those studies that reported on prevalence estimates.

2.1. Literature search

PubMed, Embase, CINAHL, PsycInfo were searched using specific search strategy that combined keywords, MeSH terms or Thesaurus words, and text words. Cochrane, WHOLIS, and LILAC were also searched using key words. The search strategy is outlined below. The important terms were organized into three groups:

1. Terms to characterize the outcome – intellectual disability, mental retardation, mental subnormality, mental insufficiency
2. Terms related to study design – cross-sectional studies, longitudinal studies, panel studies, cohort studies, case–control studies
3. Terms related to outcome – epidemiology, prevalence, incidence, mortality, etiology

2.2. Study inclusion criteria

The inclusion criteria included the following:

2.2.1. Types of participants

The participants included participants from all age-groups who had been assessed for intellectual disability using large population-based administrative registries, or through community-based, or hospital-based studies.

2.2.2. Type of outcome measure

This meta-analysis focused on one outcome – prevalence of intellectual disability. For the purpose of this meta-analysis, the studies that were representative of the overall population – i.e., included data from all categories of mental retardation, mild, moderate, and severe; were not only from special schools or psychiatric institutions; and did not report intellectual disability only in people with medical illnesses like down's syndrome, autism or lead toxicity – were selected. This helped to reduce the bias in estimates as special populations may increase or decrease the estimates.

2.2.3. Types of studies

The three different types of studies included in the search were cohort, case control and cross-sectional studies.

2.2.4. Search period and language

The search was limited between the years 1980–2009 and to human subjects when that limit was available. Studies from all languages were included to the extent that translation was available or data was understandable.

2.3. Study exclusion criteria

The exclusion criteria were; (1) Non original articles like letters, reviews, editorials and book chapters reporting on previously published studies; (2) Studies that failed to provide either raw numbers of the effect measures or appropriate prevalence estimates. (3) Studies describing intellectual disability in specific population subgroups, such as Down's Syndrome, specific genetic disorders, low birth-weight; (4) Studies involving only special schools or psychiatric or rehabilitation facilities or correctional facilities. (5) Studies that failed to report on all subtypes of intellectual disability: mild, moderate or severe; (6) Studies that failed to provide corroboration of diagnosis either based on standardized diagnostic systems or clinical judgement.

2.4. Data extraction

The articles were downloaded into a bibliographic data manager and duplicates were removed. The title and abstracts of each article were screened to identify relevant articles. Hardcopies of the screened articles were obtained and reviewed in detail to identify studies that fulfilled review criteria independently by two reviewers (PM & MM). References of the selected studies were hand searched and included if eligible. At times authors were contacted to clarify some data. Quality of the studies was assessed prior to including them in the final dataset. Though no score was assigned during quality assessment of the studies the final decision was based on the study criteria and overall representativeness of the study population, as outlined earlier. Any disagreement about the eligibility of studies was resolved by discussion among the reviewers and if needed, by a third reviewer (CM).

2.4.1. Qualitative and quantitative data abstraction

Qualitative and quantitative data was entered in an electronic database. The qualitative data included assessment for study design, sampling method, information about target population and study period, selection bias (representativeness of the data), case ascertainment, assessment instruments and diagnostic systems used, age and gender distribution, and etiological factors. When multiple articles from the same study were identified, only the most relevant articles (based on the information available) from each unique study were included. The quantitative data included estimates about sample size and number of individuals with diagnosis of intellectual disability. Prevalence was estimated from the quantitative data. For the purpose of this analysis, data from each country, of any multi-country study, was considered as a separate observation.

2.5. Analysis

Initially descriptive analysis of the studies was done. Given that this was a meta-analysis of observational studies, heterogeneity was anticipated. Random effects model accounted for the heterogeneity of studies. The analysis was also done by different subgroups based on a priori decisions, to disaggregate the effect of some factors:

1. Economic group to which the country belonged – the groups are based on World Bank (2010) gross national income/capita estimates and are low income (≤$975), lower-middle income ($976–$3855), upper-middle income ($3856–$11,905), and high income (≥$11,906). For the purpose of this meta-analysis the two middle income group countries have been combined into one group – middle-income group.
2. Type of population targeted – rural; urban slum/mixed rural-urban; regional/provincial; national
3. Age-group of study population – adult; child/adolescent; both adult and child/adolescent
4. Type of study – cross-sectional; cohort; case control.
5. Sampling strategy used to gather data – random household survey; hospital data or administrative registry; key informant report; school based study.
6. Measure used for diagnosis – Diagnostic Statistical Manual of Mental Disorders (DSM)/International Classification of Diseases (ICD); American Association on Intellectual and Developmental Disabilities (AAIDD)/The International Classification of Functioning, Disability and Health (ICF)/some disability criteria; psychological assessment that includes administering psychological instruments and using clinical judgement.

Reporting on *I*-squared statistics was found to be irrelevant for this review as the sample sizes for some of the individual studies were as large as the national population, hence making the *I*-square statistics highly inaccurate. Prior research has

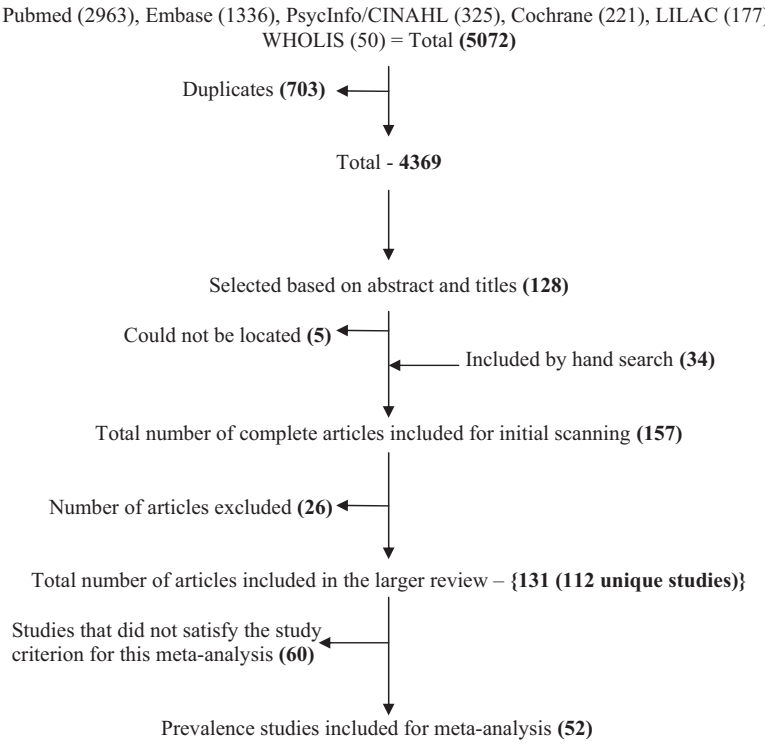

Fig. 1. Flowchart of search algorithm.

also raised some concerns about the extent to which one should rely on *I*-square statistics (Higgins, 2008; Higgins, Thompson, Deeks, & Altman, 2003; Rücker, Schwarzer, Carpenter, & Schumacher, 2008). Post hoc cross tabulation using Fischer's exact test was also done between some study characteristics especially for those factors that may be associated with the economic affluence and development of the country, and could be a cause for heterogeneity. Cumulative meta-analyses were done to identify the year of publication of study around which the estimates became reasonably consistent. Egger's test was done to check for bias due to small study effects. All analyses were done using STATA 11 (STATA, 2009).

3. Results

Electronic database search resulted in 4369 articles of which 128 were initially screened based on abstracts and titles. Hardcopies of these were reviewed in detail and this list was supplemented by articles identified by hand searching of their references. Finally 112 unique studies were selected that reported on prevalence, incidence, mortality and etiology (Fig. 1). The meta-analysis was done using 52 studies that satisfied the study criteria and provided data on prevalence (Table 1).

More than half of the studies were from high income countries and almost half were from either rural or a rural-urban slum population, which represents a more impoverished community. Two thirds of the studies were conducted on child or adolescent population. Almost 80% of studies were cross-sectional, and research based on clinical or administrative data accounted for almost 58% of the studies. No case–control study fulfilled the selection criteria for the meta-analysis. Almost 60% of the studies were based on psychological and clinical assessments by a medical expert and did not specify use of any standard diagnostic system (Table 2).

3.1. Meta-analyses

The overall prevalence of intellectual disability across all the studies was 10.37/1000 population (95%CI 9.55–11.18 per 1000 population). The prevalence was higher in males in both adult and children/adolescent populations. Among adults the male-to-female ratio varied between 0.7 and 0.9, while in children/adolescents it varied between 0.4 and 1.0. Across studies which reported on causal factors, the majority reported that the causal factor was unknown in almost half of the cases. Antenatal, perinatal, and postnatal causes were almost equally responsible for the remaining half of the population, although the estimates varied a lot across the studies. Genetic causes, including Down's Syndrome, was a common antenatal factor. Birth injury, birth asphyxia, and intra-uterine growth retardation were common perinatal causes, and infections and developmental disorders were the common postnatal causes.

There was heterogeneity in the overall prevalence rates across the studies. Sub-group analyses were done to estimate how population or study characteristics affected prevalence rates. The meta-analyses by sub-group are outlined in Table 2.

3.1.1. Income group of countries

There was a large difference in prevalence across studies from different income countries. The highest prevalence was seen in low-income countries where the prevalence/1000 population was 16.41 (95%CI 11.14–21.68). A decreasing trend in prevalence was seen with increasing affluence of countries. The prevalence per 1000 population for middle-income and high-income countries were 15.94 (95%CI 13.56–18.32) and 9.21 (95%CI 8.46–9.96), respectively (Fig. 2).

3.1.2. Population type

Data was collected from different types of population. Rural, urban, urban slums/mixed rural-urban, regional/provincial, and national. The highest prevalence of cases per 1000 population was seen in studies from urban slums/mixed rural-urban settings (21.23, 95%CI 16.34–26.11) followed by studies from rural settings. Studies based on national level data showed the least prevalence of 6.23/1000 population (95%CI 5.48–6.98) (Table 2).

3.1.3. Age-group of study population

Studies were conducted on three different age-groups – child/adolescent, adults, mixed child/adolescent and adults. Studies on child/adolescent population showed the highest prevalence of 18.30/1000 (95%CI 15.17–21.43). Studies on only adults showed the lowest prevalence of 4.94/1000 (95%CI 3.66–6.22). Studies which reported on data on both child/adolescent and adult population had prevalence of 5.04/1000 population (95%CI 4.07–6.01) (Table 2).

3.1.4. Study design

Only two types of study designs were identified. Prevalence estimates per 1000 population from cross-sectional studies was 9.69 (95%CI 8.76–10.63), and the prevalence/1000 population from cohort studies was 13.21 (95%CI 10.70–15.72) (Table 2).

3.1.5. Sampling strategy

Most studies were done using either hospital data/administrative registry or community based household sampling. The prevalence/1000 population in studies based on the former data source was 9.35 (95%CI 8.60–10.10), and the rates from studies conducted through household sampling was 15.78 (95%CI 13.73–17.86). Only one study had data collected from key

Table 1
Studies included in meta-analysis ($N = 52$).

Study	Country	Economy	Population type	Age-group of population	Study design	Distribution by sex available	Distribution by age available	Target population well defined	Observation period well defined
Andersen, Fledelius, Fons, and Haugsted (1990)	Denmark	High	Regional/provincial	Child/adolescent	Cross-sectional	No	No	Yes	Yes
Arvio and Sillanpää (2003)	Finland	High	Regional/provincial	Adult and child/adolescent	Cross-sectional	No	No	Yes	Yes
Baird and Sadovnick (1985)	Canada	High	Regional/provincial	Adult and child/adolescent	Cohort	Yes	Yes	Yes	Yes
Beange and Taplin (1996)	Australia	High	Regional/provincial	Adult	Cross-sectional	Yes	Yes	Yes	Yes
Blomquist, Gustavson, and Holmgren (1981)	Sweden	High	Regional/provincial	Child/adolescent	Cohort	No	Yes	Yes	Yes
Bradley, Thompson, and Bryson (2002)	Canada	High	Regional/provincial	Child/adolescent	Cross-sectional	Yes	Yes	Yes	Yes
Camp, Broman, Nichols, and Leff (1998)	USA	High	Urban slum/mixed rural-urban	Child/adolescent	Cohort	No	No	Yes	Yes
Christianson et al. (2002)	South Africa	Higher-middle	Rural	Child/adolescent	Cross-sectional	Yes	Yes	Yes	Yes
Cooper (1990)	Germany	High	Urban	Child/adolescent	Cross-sectional	Yes	No	Yes	Yes
Dave et al. (2005)	India	Lower-middle	Urban slum/mixed rural-urban	Child/adolescent	Cross-sectional	No	No	Yes	No
Delgado Rodriguez et al. (1989)	Spain	High	Regional/provincial	Adult	Cross-sectional	Yes	Yes	Yes	Yes
Diaz-Fernandez (1988)	Spain	High	Regional/provincial	Adult and child/adolescent	Cross-sectional	Yes	Yes	Yes	Yes
Durkin, Hasan, and Hasan (1998)	Pakistan	Lower-middle	Urban slum/mixed rural-urban	Child/adolescent	Cross-sectional	Yes	Yes	Yes	Yes
Fishbach and Hull (1982)	Canada	High	Regional/provincial	Adult and child/adolescent	Cross-sectional	Yes	Yes	Yes	No
Fitaw and Boersma (2006)	Ethiopia	Low	Urban slum/mixed rural-urban	Adult and child/adolescent	Cross-sectional	No	No	No	No
Gustavson (2005)	Pakistan	Lower-middle	Urban slum/mixed rural-urban	Child/adolescent	Cohort	No	No	Yes	Yes
Hagberg, Lewerth, Olsson, and Westerberg (1987)	Sweden	High	Regional/provincial	Child/adolescent	Cohort	No	No	Yes	Yes
Heikura et al. (2003)	Finland	High	Regional/provincial	Child/adolescent	Cohort	Yes	No	Yes	Yes
Hou, Wang, and Chuang (1998)	Taiwan	High	Urban slum/mixed rural-urban	Child/adolescent	Cross-sectional	No	Yes	Yes	No
Hosain et al. (2007)	Bangladesh	Low	Rural	Adult	Cross-sectional	Yes	No	Yes	Yes
Islam, Durkin, and Zaman (1993)	Bangladesh	Low	Urban slum/mixed rural-urban	Child/adolescent	Cross-sectional	Yes	Yes	Yes	Yes
Israel Lopez, Valdespino Pineda, and Botell (2007)	Cuba	Higher-middle	Regional/provincial	Adult and child/adolescent	Cross-sectional	No	Yes	Yes	Yes
Kääriäinen (1987)	Finland	High	Regional/provincial	Child/adolescent	Cohort	Yes	No	Yes	Yes
Leonard, Petterson, Bower, and Sanders (2003)	Australia	High	Regional/provincial	Child/adolescent	Cross-sectional	Yes	Yes	Yes	Yes

Table 1 (*Continued*)

Study	Country	Economy	Population type	Age-group of population	Study design	Distribution by sex available	Distribution by age available	Target population well defined	Observation period well defined
Massey and McDermott (1996)	USA	High	Regional/provincial	Adult and child/adolescent	Cross-sectional	No	Yes	Yes	Yes
McConkey, Mulvany, and Barron (2006)	Ireland	High	National	Adult	Cross-sectional	Yes	Yes	Yes	Yes
McConkey et al. (2006)	UK (Northern Ireland)	High	Regional/provincial	Adult	Cross-sectional	Yes	Yes	Yes	Yes
Murphy, Yeargin-Allsopp, Decoufle, and Drews (1995)	USA	High	Regional/provincial	Child/adolescent	Cohort	Yes	Yes	Yes	Yes
Patja et al. (2000)	Finland	High	National	Adult and child/adolescent	Cohort	Yes	Yes	Yes	Yes
Petterson, Bourke, Leonard, Jacoby, and Bower (2007)	Australia	High	Regional/provincial	Child/adolescent	Cohort	No	No	Yes	Yes
Pongprapai, Tayakkanonta, Chongsuvivatwong, and Underwood (1996)	Thailand	Lower-middle	Rural	Child/adolescent	Cross-sectional	Yes	No	Yes	Yes
Rantakallio and von Wendt (1985)	Finland	High	Regional/provincial	Child/adolescent	Cohort	No	No	Yes	Yes
Shiotsuki et al. (1984)	Japan	High	Regional/provincial	Child/adolescent	Cross-sectional	Yes	Yes	Yes	Yes
Stein et al. (1987)	Bangladesh	Low	Rural	Child/adolescent	Cross-sectional	No	No	No	No
Stein et al. (1987)	Brazil	Higher-middle	Urban slum/mixed rural-urban	Child/adolescent	Cross-sectional	No	No	No	No
Stein et al. (1987)	India	Lower-middle	Urban slum/mixed rural-urban	Child/adolescent	Cross-sectional	No	No	No	No
Stein et al. (1987)	Malaysia	Higher-middle	Urban slum/mixed rural-urban	Child/adolescent	Cross-sectional	No	No	No	No
Stein et al. (1987)	Pakistan	Lower-middle	Urban slum/mixed rural-urban	Child/adolescent	Cross-sectional	No	No	No	No
Stein et al. (1987)	Philippines	Lower-middle	Rural	Child/adolescent	Cross-sectional	No	No	No	No
Stein et al. (1987)	Sri Lanka	Lower-middle	Rural	Child/adolescent	Cross-sectional	No	No	No	No
Stein et al. (1987)	Zambia	Low	Rural	Child/adolescent	Cross-sectional	No	No	No	No
Stromme and Valvatne (1998)	Norway	High	Urban slum/mixed rural-urban	Child/adolescent	Cross-sectional	Yes	No	Yes	Yes
Tao et al. (1982)	China	Lower-middle	Urban slum/mixed rural-urban	Adult and child/adolescent	Cross-sectional				
Tekle-Haimanot et al. (1990)	Ethiopia	Low	Rural	Adult and child/adolescent	Cross-sectional	Yes	Yes	Yes	Yes
Temtamy et al. (1994)	Egypt	Lower-middle	Urban slum/mixed rural-urban	Child/adolescent	Cross-sectional	Yes	No	Yes	Yes
Tomas Vila, Paricio Talayero, Colomer Revuelta, Andres Celma, and Moratal (1991)	Spain	High	Regional/provincial	Child/adolescent	Cross-sectional	Yes	Yes	Yes	Yes
van Schrojenstein Lantman-de Valk et al. (2006)	Netherlands	High	Regional/provincial	Adult and child/adolescent	Cross-sectional	Yes	Yes	Yes	Yes
Wellesley, Hockey, and Stanley (1991)	Australia	High	Regional/provincial	Adult and child/adolescent	Cross-sectional	No	No	Yes	Yes

Table 1 (*Continued*)

Study	Country	Economy	Population type	Age-group of population	Study design	Distribution by sex available	Distribution by age available	Target population well defined	Observation period well defined
Westerinen, Kaski, Virta, Almqvist, and Iivanainen (2007)	Finland	High	National	Adult and child/adolescent	Cross-sectional	Yes	Yes	Yes	Yes
Xie et al. (2008)	China	Lower-middle	Urban slum/mixed rural-urban	Child/adolescent	Cross-sectional	Yes	Yes	Yes	Yes
Zuo et al. (1986)	China	Lower-middle	Urban slum/mixed rural-urban	Child/adolescent	Cross-sectional	Yes	Yes	Yes	Yes
Zuo, Lei, & Zhang (1994)	China	Lower-middle	Urban slum/mixed rural-urban	Child/adolescent	Cross-sectional				

Study	Sampling strategy	Case ascertainment	Diagnostic system used	Basis of case definition	Sampled population (N)	Number of ID cases	Prevalence/ 1000 population	SE/1000 population
Andersen, Fledelius, Fons, and Haugsted (1990)	Hospital data or administrative registry	Mental health expert or pediatrician confirmed	Psychological assessment	Clinical judgement	4138	18	4.35	1.02
Arvio and Sillanpää (2003)	Hospital data or administrative registry	Mental health expert or pediatrician confirmed	Psychological assessment	Clinical judgement and medical records	341,227	1484	4.35	0.11
Baird and Sadovnick (1985)	Hospital data or administrative registry	Mental health expert or pediatrician confirmed	ICD9	ICD	739,785	4166	5.63	0.09
Beange and Taplin (1996)	Hospital data or administrative registry	Mental health expert or pediatrician confirmed	AAMR Classification	AAMR	104,584	346	3.31	0.18
Blomquist, Gustavson, and Holmgren (1981)	Hospital data or administrative registry	Mental health expert or pediatrician confirmed	Psychological assessment	Standardized tests	40,871	309	7.56	0.43
Bradley, Thompson, and Bryson (2002)	Hospital data or administrative registry	Mental health expert or pediatrician confirmed	ICD10	ICD	35,485	255	7.19	0.45
Camp, Broman, Nichols, and Leff (1998)	Hospital data or administrative registry	Mental health expert or pediatrician confirmed	Psychological assessment	Clinical judgement	35,704	1312	36.75	1.00
Christianson et al. (2002)	Random households	Mental health expert or pediatrician confirmed	Psychological assessment	Based on questionnaire	6692	238	35.56	2.26
Cooper (1990)	School-based	Mental health expert or pediatrician confirmed	ICD8	ICD8	35,026	245	6.99	0.44
Dave et al. (2005)	Random households	Mental health expert or pediatrician confirmed	Psychological assessment	IQ < 70	550,000	511	0.93	0.04
Delgado Rodriguez et al. (1989)	Hospital data or administrative registry	Mental health expert or pediatrician confirmed	Psychological assessment	IQ < 70	650,653	2705	4.16	0.08
Diaz-Fernandez (1988)	Hospital data or administrative registry	Mental health expert or pediatrician confirmed	Psychological assessment	Based on registry and assessments	2,754,747	13,636	4.95	0.04

Table 1 (*Continued*)

Study	Sampling strategy	Case ascertainment	Diagnostic system used	Basis of case definition	Sampled population (N)	Number of ID cases	Prevalence/ 1000 population	SE/1000 population
Durkin, Hasan, and Hasan (1998)	Random households	Mental health expert or pediatrician confirmed	Psychological assessment	Clinical judgement	6365	230	36.14	2.34
Fishbach and Hull (1982)	Hospital data or administrative registry	Unspecified	AAMR classification	IQ < 70	1,021,481	3642	3.57	0.06
Fitaw and Boersma (2006)	Random households	Field worker	ICF	ICF	24,453	97	3.97	0.40
Gustavson (2005)	Hospital data or administrative registry	Mental health expert or pediatrician confirmed	Psychological assessment	Clinical judgement	1476	54	36.59	4.89
Hagberg, Lewerth, Olsson, and Westerberg (1987)	Hospital data or administrative registry	Mental health expert or pediatrician confirmed	Psychological assessment	Clinical judgement	23,544	170	7.22	0.55
Heikura et al. (2003)	Hospital data or administrative registry	Mental health expert or pediatrician confirmed	ICD9	Clinical judgement and medical records	9432	105	11.13	1.08
Hou, Wang, and Chuang (1998)	Hospital data or administrative registry	Mental health expert or pediatrician confirmed	Psychological assessment	Clinical records	423,000	11,892	28.11	0.25
Hosain et al. (2007)	Key informant	Mental health expert or pediatrician confirmed	Psychological assessment	Clinical judgement	766	2	2.61	1.84
Islam, Durkin, and Zaman (1993)	Random households	Mental health expert or pediatrician confirmed	Psychological assessment	Clinical judgement	10,299	209	20.29	1.39
Israel Lopez, Valdespino Pineda, and Botell (2007)	Hospital data or administrative registry	Mental health expert or pediatrician confirmed	Psychological assessment	Clinical judgement	183,871	1140	6.20	0.18
Kääriäinen (1987)	Hospital data or administrative registry	Mental health expert or pediatrician confirmed	Psychological assessment	IQ < 70	12,882	178	13.82	1.03
Leonard, Petterson, Bower, and Sanders (2003)	Hospital data or administrative registry	Mental health expert or pediatrician confirmed	DSMIV	DSM	240,358	3426	14.25	0.24
Massey and McDermott (1996)	Hospital data or administrative registry	Unspecified	Dept of Education and Social Security Administration definitions	Subaverage IQ with adaptive behavior problems	197,368,421	1,500,000	7.60	0.01
McConkey, Mulvany, and Barron (2006)	Hospital data or administrative registry	Mental health expert or pediatrician confirmed	ICD10	ICD	2,776,587	16,794	6.05	0.05
McConkey et al. (2006)	Hospital data or administrative registry	Mental health expert or pediatrician confirmed	ICD10	ICD	1,185,114	8340	7.04	0.08
Murphy, Yeargin-Allsopp, Decoufle, and Drews (1995)	Hospital data or administrative registry	Mental health expert or pediatrician confirmed	DSMIII	DSM	89,534	1074	12.00	0.36

Table 1 (*Continued*)

Study	Sampling strategy	Case ascertainment	Diagnostic system used	Basis of case definition	Sampled population (N)	Number of ID cases	Prevalence/ 1000 population	SE/1000 population
Patja et al. (2000)	Hospital data or administrative registry	Mental health expert or pediatrician confirmed	Psychological assessment	IQ < 70 and a standardized classification system	416,973	2366	5.67	0.17
Petterson, Bourke, Leonard, Jacoby, and Bower (2007)	Hospital data or administrative registry	Mental health expert or pediatrician confirmed	AAMR Classification	IQ < 70	474,285	6106	12.87	0.16
Pongprapai, Tayakkanonta, Chongsuvivatwong, and Underwood (1996)	Random households	Mental health expert or pediatrician confirmed	WHO manual training of the Disabled in the Community	Clinical judgement	4366	7	1.60	0.61
Rantakallio and von Wendt (1985)	Hospital data or administrative registry	Mental health expert or pediatrician confirmed	ICD9	IQ < 70, borderline cases included	11,965	129	10.78	0.94
Shiotsuki et al. (1984)	School-based	Mental health expert or pediatrician confirmed	Psychological assessment	IQ < 70	21,622	154	7.12	0.57
Stein et al. (1987)	Random households	Mental health expert or pediatrician confirmed	Psychological assessment	Clinical judgement	987	154	156.03	11.55
Stein et al. (1987)	Random households	Mental health expert or pediatrician confirmed	Psychological assessment	Clinical judgement	1058	68	64.27	7.54
Stein et al. (1987)	Random households	Mental health expert or pediatrician confirmed	Psychological assessment	Clinical judgement	1439	58	40.31	5.18
Stein et al. (1987)	Random households	Mental health expert or pediatrician confirmed	Psychological assessment	Clinical judgement	959	21	21.90	4.73
Stein et al. (1987)	Random households	Mental health expert or pediatrician confirmed	Psychological assessment	Clinical judgement	995	36	36.18	5.92
Stein et al. (1987)	Random households	Mental health expert or pediatrician confirmed	Psychological assessment	Clinical judgement	1000	9	9.00	2.99
Stein et al. (1987)	Random households	Mental health expert or pediatrician confirmed	Psychological assessment	Clinical judgement	962	12	12.47	3.58
Stein et al. (1987)	Random households	Mental health expert or pediatrician confirmed	Psychological assessment	Clinical judgement	1139	35	30.73	5.11
Stromme and Valvatne (1998)	Hospital data or administrative registry	Mental health expert or pediatrician confirmed	DSMIV	DSM	30,037	185	6.16	0.45
Tao et al. (1982)	Random households	Mental health expert or pediatrician confirmed	Psychological assessment	Similar to AAMR	116,522	391	3.36	0.17
Tekle-Haimanot et al. (1990)	Random households	Mental health expert or pediatrician confirmed	Psychological assessment	Clinical judgement	60,820	103	1.69	0.17

Table 1 (*Continued*)

Study	Sampling strategy	Case ascertainment	Diagnostic system used	Basis of case definition	Sampled population (N)	Number of ID cases	Prevalence/ 1000 population	SE/1000 population
Temtamy et al. (1994)	Random households	Mental health expert or pediatrician confirmed	ICD based classification of the Egyptian Psychiatric Association	IQ < 70	3000	81	27.00	2.96
Tomas Vila, Paricio Talayero, Colomer Revuelta, Andres Celma, and Moratal (1991)	Hospital data or administrative registry	Mental health expert or pediatrician confirmed	Psychological assessment	IQ < 70	29,415	401	13.63	0.68
van Schrojenstein Lantman-de Valk et al. (2006)	Hospital data or administrative registry	Mental health expert or pediatrician confirmed	AAMR Classification	IQ < 75	1,142,679	7352	6.43	0.07
Wellesley, Hockey, and Stanley (1991)	Hospital data or administrative registry	Mental health expert or pediatrician confirmed	AAMR Classification	IQ < 70	210,789	1602	7.60	0.19
Westerinen, Kaski, Virta, Almqvist, and Iivanainen (2007)	Hospital data or administrative registry	Mental health expert or pediatrician confirmed	ICD9 and ICD10	ICD	5,184,980	36,053	6.95	0.04
Xie et al. (2008)	Random households	Mental health expert or pediatrician confirmed	Criteria for Disability based on ICF	IQ < 70	60,124	560	9.31	0.39
Zuo et al. (1986)	Hospital data or administrative registry	Mental health expert or pediatrician confirmed	AAMR Classification	IQ < 75	7150	56	7.83	1.04
Zuo, Lei, & Zhang (1994)	Random households	Mental health expert or pediatrician confirmed	Psychological assessment	WHO criteria	85,170	862	10.12	0.34

Table 2
Proportion of studies and pooled prevalence estimates per 1000 population by subgroups ($N = 52$).

	N	%[a]	Prevalence/1000 population[b]	95% CI of prevalence rate
Income group of country				
Low-income	6	11.5	16.41	11.14–21.68
Middle-income	17	32.7	15.94	13.56–18.32
High-income	29	55.8	9.21	8.46–9.96
Type of population targeted				
Rural	8	15.4	19.88	13.60–26.17
Urban	1	1.9	7.0	6.12–7.87
Urban slum/mixed rural-urban	17	32.7	21.23	16.34–26.11
Regional/provincial	23	44.2	7.85	6.98–8.71
National	3	5.8	6.23	5.48–6.98
Age-group of study population				
Adult	5	9.6	4.94	3.66–6.22
Child/adolescent	35	67.3	18.30	15.17–21.43
Both adult and child/adolescent	12	23.1	5.04	4.07–6.01
Type of study				
Cross-sectional	41	78.9	9.69	8.76–10.63
Cohort	11	21.1	13.21	10.70–15.72
Sampling strategy used to gather data				
Key informant report	1	1.9	2.61	–1.00–6.23
School based study	2	3.9	7.04	6.35–7.73
Hospital data or administrative registry	30	57.7	9.35	8.60–10.10
Random household survey	19	36.5	15.78	13.73–17.86
Measure used for diagnosis				
Psychological assessment	30	57.7	14.30	12.70–15.91
DSM/ICD	12	23.1	8.68	7.89–9.48
AAIDD/ICF/some disability criteria	10	19.2	6.41	4.89–7.93

[a] Values have been rounded so may not add up to 100%.
[b] Estimates based on meta-analysis using random effects model.

informants (Hosain, Chatterjee, Ara, and Islam (2007), and two studies were based in schools (Cooper, 1990; Shiotsuki et al., 1984). The point estimates for key informant and school-based studies were 2.61/1000 (95%CI-1.00–6.23) and 7.04/1000 (95%CI 6.35–7.73) population, respectively (Table 2).

3.1.6. Diagnostic tool used

Studies based on some psychometric scales that helped to identify people with intellectual disability had an overall estimate of 14.3/1000 population (95%CI 12.70–15.91). Studies using either World Health Organization's International Classification of Disease (ICD) or American Psychiatric Association's Diagnostic Statistical Manual (DSM) or some similar system showed an overall prevalence of 8.68/1000 population (95%CI 7.89–9.48). Studies that included a disability schedule showed the lowest prevalence of 6.41/1000 population (95%CI 4.89–7.93) (Fig. 3).

3.1.7. Cumulative meta-analyses

Cumulative meta-analysis showed that the estimates have stabilized around 11/1000 population in the studies published during the last decade (Fig. 4).

3.2. Publication bias and cross-tabulations

Publication bias may not be a problem in this meta-analysis as the outcome measure is prevalence and there are no significant levels that may have biased publications. The reasons for non-publication are more likely small studies with poor methods. However, Egger's test failed to find any bias due to small study effect ($p = 0.43$). Cross-tabulations were run using Fischer's Exact Test to ascertain if the income group of the country was significantly associated with the type of diagnostic tool being used and the age-distribution of the study population. While economy was significantly associated with the type of diagnostic tool used ($p = 0.04$), it was not associated with the age group of the study population ($p = 0.16$).

4. Discussion

Intellectual disability affects a large number of individuals. It affects the individual, his/her immediate family, and the community where they live. A number of mental and physical disorders are often associated with intellectual disability and they add their own complexities to management of people with intellectual disability (Maulik & Harbour, 2010). In addition, it is associated with a stigma and discrimination (Jeevanandam, 2009; Mercadante, Evans-Lacko, & Paula, 2009; Njenga, 2009). These factors, when seen against the background of the limited available resources (World Health Organization,

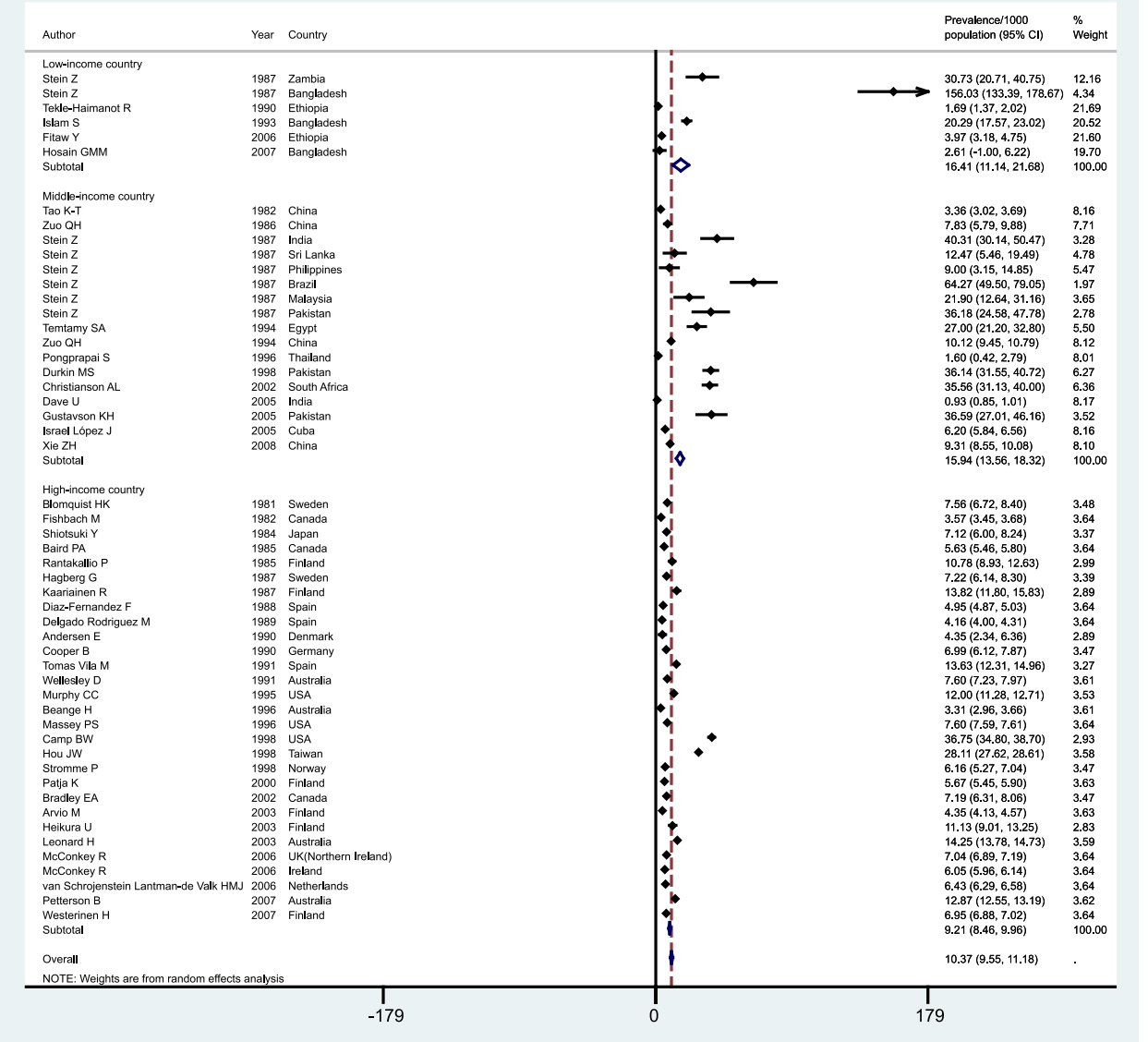

Fig. 2. Forest plot of prevalence rate/1000 population by income group of the country ($N = 52$).

2007), highlights the impact that intellectual disability has on the whole society, and underlines the importance of measuring its burden (Üstün et al., 1999).

4.1. Factors affecting prevalence

This meta-analysis estimated the prevalence to be 10.37/1000 population. This is similar to the 1% rate based on studies conducted primarily in the U.S. and other developed countries (Harris, 2006; King et al., 2009). One multi-country study (Stein, Belmont, & Durkin, 1987) reported very large prevalence rates, but random effects models adjusted for their effects by using weights. One reason for the high prevalence in those studies was the use of instruments that were not standardized or specific to intellectual disability, and which did not include level of functioning.

The rates varied according to the income group of the country. The highest prevalence was seen in low- and middle-income countries, where the rates were almost twice that in high income countries. This is understandable as in low resource countries there may be more births with proportionately higher hereditary illnesses, due to lack of adequate antenatal screening methods (Dave, Shetty, & Mehta, 2005). Some other contributing factors are iodine deficiency, birth related infections and injuries due to poor maternal and child health care facilities, and intra-uterine growth retardation (Tao, 1988).

There are some methodological issues related to the studies that may have affected the results. One reason for higher prevalence in the low-income countries is that all the six studies barring one (Fitaw & Boersma, 2006) used psychological

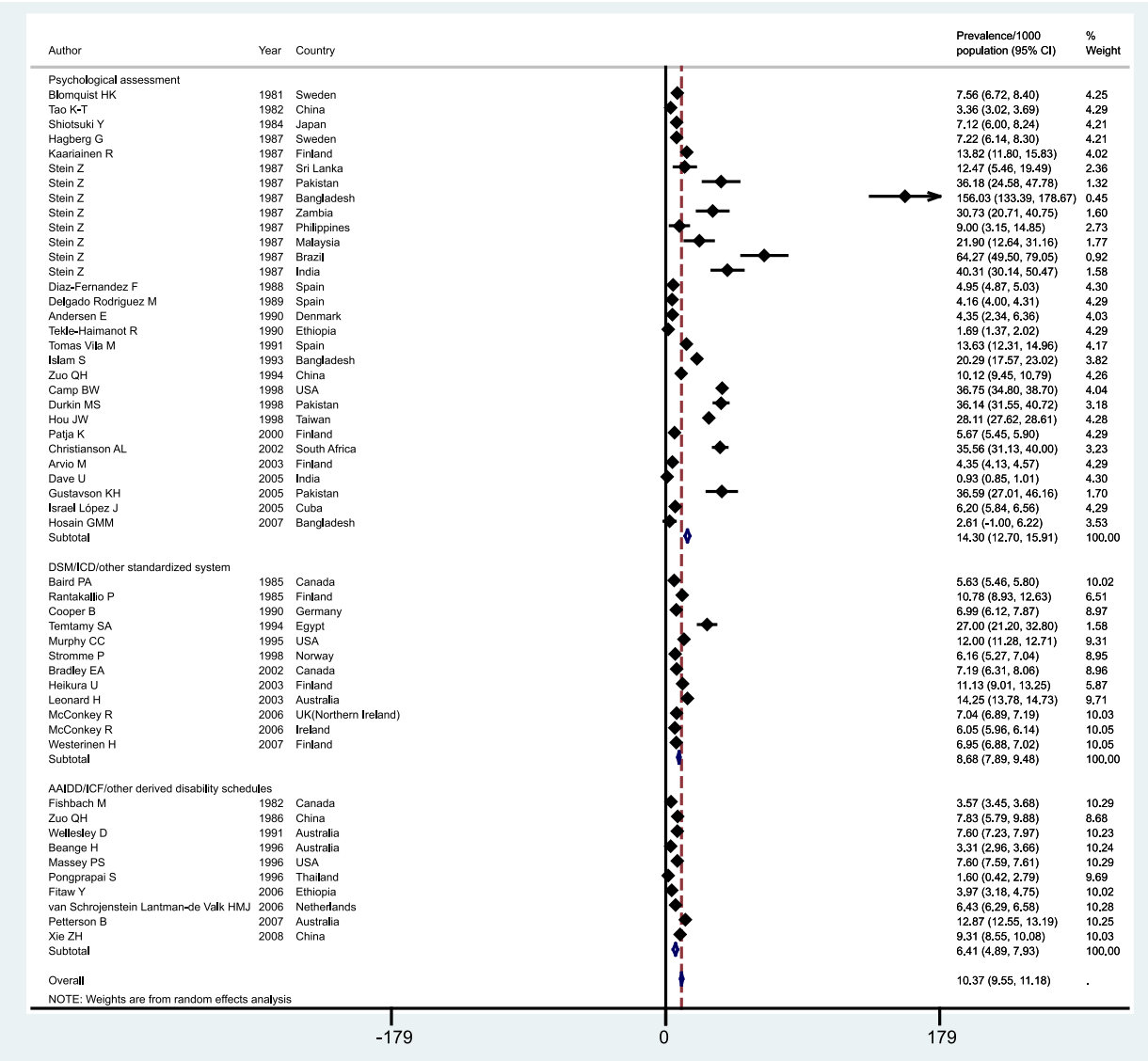

Fig. 3. Forest plot of prevalence rate/1000 population by diagnostic tool used ($N = 52$).

assessments or scales like the Ten Questions (Stein et al., 1987) or instruments developed for the specific study to identify intellectual disability and this resulted in slightly higher prevalence rates as borne out in the analysis stratified by diagnostic systems used for the studies. Ten Questions were not specific to intellectual disability assessment. Such instruments do not account for adaptive capabilities that an individual has, or his/her level of functioning. They identify intellectual disability based on assessments that determine an Intelligence Quotient (IQ) cut-off score, or are based on questions that inquire about presence or absence of intellectual disability to individuals, which in turn are based on psychological assessments. On the other hand, standardized diagnostic systems or disability schedules include adaptive skills and functioning abilities of individuals with any disability, while diagnosing cases. Thus, psychological assessment or other scales tend to identify more cases than standardized instruments which account for adaptive skills and functioning level. Additionally, borderline mental retardation with almost normal adaptive skills and functioning levels are included, thus inflating the numbers. On the other hand, the majority of studies from high income countries used standard diagnostic systems or disability measurements, and this association was statistically significant. There might also be other factors that are interlinked with the study design that may have affected the results, too.

Overall, the sampling strategy and the type of diagnostic tool used in each study, were not found to be significantly associated ($p = 0.08$). However, community-based studies using household sampling strategies used psychological assessments or some scales to identify cases, in most studies. On the other hand, administrative data used standardized diagnostic systems more frequently. Moreover, in administrative data, especially school-based ones, cases of mild

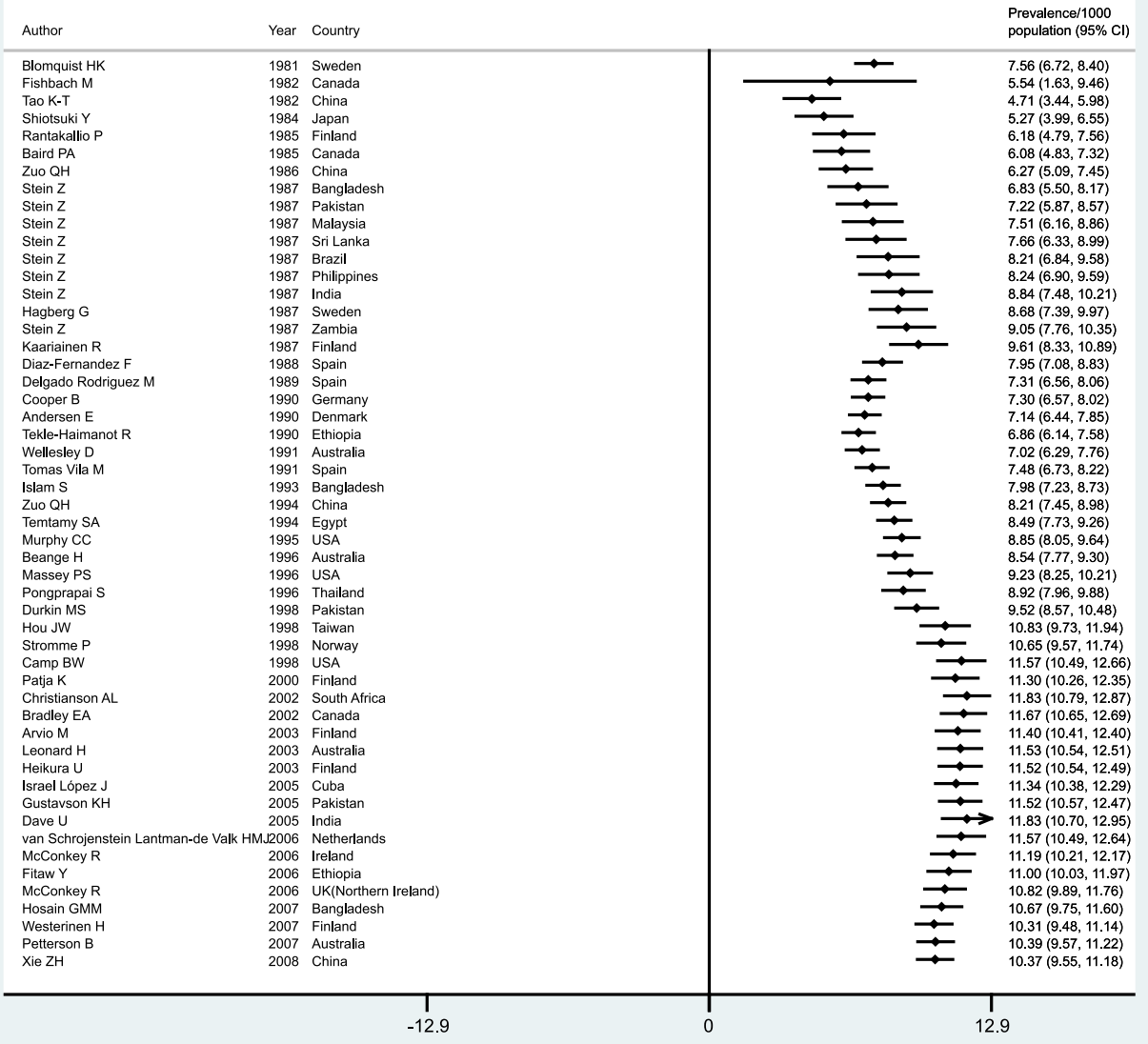

Fig. 4. Cumulative meta-analysis by year of publication of the study ($N = 52$).

intellectual disability with good functioning levels are being increasingly identified as suffering from 'learning disorders', thus lowering the prevalence of 'intellectual disability' in such databases (Harris, 2006). Higher rates observed in studies based in rural and urban slums/mixed rural-urban settings can also be partly attributed to majority of such studies using psychological assessments or scales, as tools for identification of cases. In comparison, the majority of the studies involving national or regional populations used standardized diagnostic systems that accounted for both functional ability of individuals and their psychological assessment.

Another reason for these differences could be that most studies from low and middle income countries gathered data from the community using household sampling strategy compared to hospital/administrative data based sampling strategy as seen in studies from high income countries. The meta-analysis shows that studies using hospital/administrative data had an overall lower prevalence rate compared to those done using household sampling, and the income group of the country and sampling strategy were significantly associated ($p < 0.001$). However, more research is needed in future to ascertain if this is a potential source for bias, as other factors may be associated, that have not been assessed.

Studies restricted to child/adolescent population showed the highest prevalence of intellectual disability, and those restricted to adults the lowest. Childhood, especially school-going age is the time when more cases are identified due to the increased pressures of schooling. But these rates drop in early adulthood when the pressures of school are not there, and later in life due to early death of individuals with more severe forms of disability (Harris, 2006). Out of the 35 studies involving child/adolescent population, 22 had used psychological assessments or scales to identify cases and had not used any

standardized diagnostic systems. In comparison, 2 out of the 5 studies on exclusively adult population had used psychological assessments or other scales. This is a contributing factor for higher rates seen in studies on child/adolescent population.

In this meta-analysis cohort studies show a higher prevalence of intellectual disability. A reason for such is that 9 out of the 11 cohort studies are based on child/adolescent population who have higher prevalence rates, and even the last two (Baird & Sadovnick, 1985; Patja et al., 2000) includes both adult and child/adolescent population.

4.2. Public health and research implications

While the overall prevalence of intellectual disability is about 1% and is similar to earlier reports, there is a lot of heterogeneity attributed to population and study design. These estimates will help to develop more accurate estimates of the global burden due to intellectual disability as part of the Burden of Diseases Study, based on models that take into account different factors that influence the prevalence rates. The estimates found in this study and those that would be developed for the Burden of Disease Study would also go a long way in having better population level estimates for countries. Such estimates could also be an effective tool in informing development of appropriate services for persons with intellectual disabilities keeping in mind the Convention for the Rights of Persons with Disability (United Nations, 2006).

A key finding is that studies from low- and middle-income countries and studies on children/adolescents report higher prevalence rates. From a public health perspective these observations are highly significant. Given the increasing population of child and adolescents in some large low and middle income countries like Bangladesh, China, India, Nigeria, and Pakistan, to name a few, it is of paramount importance that services are developed that facilitate appropriate genetic screening during antenatal period in such countries (Dave et al., 2005; Gustavson, 2005). While quality of maternal and child health services have generally improved over the past couple of decades across countries, special focus should be laid on reducing any kind of brain injury during child-birth, avoiding postnatal infections, and lowering perinatal growth retardation. Schemes like iodine supplementation and regular postnatal and early childhood health check-ups should also be encouraged. While this involves improving service delivery from primary to tertiary care levels, it also brings to the forefront factors like poverty and food security that can affect maternal and child health-goals and objectives that are very much a part of the Millennium Development Goals, and focus of the ongoing thrust to end poverty by 2015 (United Nations, 2010). Besides, these countries should also give more importance to improving infrastructure that helps in rehabilitation of individuals with intellectual disabilities. The focus should be to integrate such individuals in the larger community at all levels – academic, workplace and social.

The cost of intellectual disability to the society in the form of additional resources to provide adequate services is huge. This is not accounting for the burden of stigma and other associated mental and physical illnesses and their complications. Estimates from the U.S. suggest that lifetime cost of intellectual disability for persons born in the year 2000 will be USD 51.2 billion (Honeycutt, Dunlap, Chen, al Homsi, & Schendel, 2004). An earlier study from The Netherlands also predicted high health care cost for individuals with intellectual disability (Polder, Meerding, Bonneux, & van der Maas, 2002). Many of the known etiological causes of intellectual disability, on the other hand, are relatively less expensive and can be delivered without any major additional cost to existing services. Some such examples include safe delivery practices, identification and management of postnatal infections and congenital hypothyroidism, improving maternal and child health, and immunization. Screening techniques to avoid congenital problems like Down's Syndrome, Fragile X syndrome, phenylketonuria are also cost-effective when compared against the burden of such conditions to the society over time. However, few studies have done a detailed assessment of the cost of intellectual disability on the society and future research should focus on such areas.

From a research perspective, future studies should use standardized instruments that assess functional ability in addition to psychological development to correctly identify cases of intellectual disability. An important factor that affects correct categorization of severity is the distinction between mild and moderate forms of intellectual disability. In some databases, mild intellectual disability is classified as learning disability. Some uniformity of definition should be maintained based on standardized diagnostic criteria. The meta-analysis shows that psychological assessment based ascertainment fails to capture the adaptive capabilities of individuals and tend to over-estimate the burden. Adaptive skills learned during developmental period often improve the social and psychological functional capacities of individuals and need to be accounted. From an administrative view-point too, such changes in skills should be addressed by recording changes in functional ability in administrative data. Improved techniques of case identification and data gathering would allow better estimates of the actual burden and also track changes longitudinally over time. Future studies should also focus more on incidence and mortality studies for intellectual disability in the community. Currently such studies are few and are often restricted to a sub-population affected by intellectual disability.

4.3. Strengths and limitations

This study has a number of strengths. To the best of our knowledge this is the first meta-analysis on the prevalence of intellectual disability. Having identified a number of studies we were able to stratify the results by different meaningful categories and were able to identify differences in rates across such categories. However, there are also some limitations. As in any meta-analysis using observational data, the effect estimates varied a great deal and there was heterogeneity across the studies. Though we have minimized such heterogeneity by using random effects models and by analyzing data by different

categories and stratifications, there may be residual factors that affected heterogeneity and have not been accounted in the analyses. While one could criticize the rationality of conducting a meta-analysis given the heterogeneity, others have argued against not conducting a meta-analysis, and have suggested that leaving the reader to make all the decision about summative effect measures, when adequate data is available to summarize, leads to increased erroneous assumptions by the readers due to 'vote counting' (Borenstein, Hedges, Higgins, & Rothstein, 2009). It was not possible to generate accurate age categories due to the non-availability of complete age distribution for all the studies. Thus, more generic categories such as adult, child/adolescent, and mixed adult and child/adolescent, had to be used. This made it difficult to estimate rates by specific age groups. Finally, while an effort was made to make this review comprehensive, it is possible that some studies have not been included either due to publication in databases outside those included in this meta-analysis, or being published in non-scientific 'grey literature'.

5. Conclusion

In conclusion, the meta-analysis provides an estimate of the prevalence of intellectual disability from different studies conducted across different populations. It provides estimates by specific stratifications. The highest estimates were in low and middle income countries, and in child and adolescent populations. The results have also identified some lacunae in the extant literature that should be addressed in future. The public health implications of the results highlight the work that needs to be done in this area across different countries, especially the low and middle income countries.

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