

Systematic Review of the Prevalence and Incidence of Intellectual Disabilities: Current Trends and Issues

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Abstract The prevalence of intellectual disabilities is often quoted at 1 %. A meta-analysis of articles published between 1980 and 2009 confirmed this prevalence. Changes in diagnostic practices, population characteristics, and exposure to known risk factors in recent years place this estimate in question and make it imperative to examine more recent studies of prevalence and incidence. Twenty relevant articles were obtained from five databases (PubMed, Embase, PsycInfo, Cochrane, and MEDLINE), published between 2010 and 2015. Most studies ($n=17$) only reported prevalence estimates, while two provided incidence estimates. Various methodologies were applied, with the majority of studies ($n=16$) using administrative data. Heterogeneity in study settings, methodologies, age groups, and case definitions contributed to a range of prevalence estimates (0.05 to 1.55 %). Future research should include reproducible and consistent

definitions of intellectual disabilities, provide age-specific estimates, and monitor changes in prevalence over time.

Keywords Prevalence · Incidence · Intellectual disability · Developmental disability · Meta-analysis · Review

Introduction

Intellectual disabilities are lifelong conditions that manifest during the developmental years and are characterized by below-average general intellectual function and limitations in adaptive functioning [1]. In the 1970s, when diagnostic criteria focused on standardized intelligence quotient tests (IQ) cut-offs, it was estimated that 3 % of annual births could be expected to “acquire” such disabilities at some point in their lives (incidence) [2]. This proportion corresponded to a cut-off of approximately 70 on a Gaussian curve for the distribution of intelligence scores. Using this cut-off, the proportion of a given population affected (prevalence) would also be 3 %. The recognition that IQ alone is not sufficient to diagnose intellectual disabilities, that intellectual disabilities manifest at different ages and under different conditions, and that there are identified causes of the disabilities has led to a reconsideration of both incidence and prevalence.

As incidence reflects risk in a population, recent focus has been on incidence of intellectual disabilities from specific known causes, such as genetic abnormalities, prenatal exposure to alcohol or infection, trauma during birth, early childhood infections, exposure to heavy metals, and severe malnutrition. Trend analyses, including those obtained through systematic reviews of the literature, contribute to the identification of changes in risk factors. In 2011, Maulik et al. published a systematic review and meta-analysis that evaluated studies of the prevalence of intellectual disabilities published between

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1980 and 2009 [3••]. The authors highlighted the variability of prevalence estimates across countries, age groups, and study design. Prevalence estimates were highest in low- and middle-income countries, in children/adolescents populations, and when psychological assessments were used to identify cases [3••]. They concluded that the best estimate of prevalence for that time period was 1 %.

Knowing the distribution of intellectual disabilities as a whole in the population (prevalence) informs service planning across multiple sectors from child and youth services, education, health, social services, and aging services. However, to understand variations in the occurrence of intellectual disabilities over time or place requires an appreciation of the shifts and differences in diagnostic practices, population characteristics, and exposure to known risk factors.

Over the past few decades, considerable shifts have occurred in diagnostic practices. While IQ tests are no longer sufficient to identify intellectual disabilities, they are still applied in conjunction with measures of adaptive functioning. IQ tests are subject to the Flynn effect [4], which refers to the steady and substantial increase in IQ in the population over the past century. To compensate, tests are re-normed and become more difficult, resulting in more individuals falling below an IQ of 70 after the test is re-normed [5]. Similarly, measures of adaptive and intellectual functioning, which are culturally based [6, 7], must also be re-normed as societal views and expectations of individuals with intellectual disabilities evolve. The Vineland Adaptive Behaviour Scales II, a commonly used measure of adaptive behavior, includes updated content about social expectations of tasks and living skills [8], which may alter diagnostic rates.

Changes in diagnostic criteria are often held responsible for the fluctuating prevalence estimates of intellectual disabilities, and in particular prevalence estimates of autism spectrum disorder—a condition associated with intellectual disabilities. Multiple revisions to two international classification systems, the *Diagnostic and Statistical Manual* (DSM) [9, 10] and the *International Classification of Diseases* (ICD) [11], have resulted in broadening and tightening of diagnostic criteria for intellectual disabilities, including the addition of adaptive functioning criteria to case identification [12], as well as for autism spectrum disorders [13, 14]. One influential change to the diagnostic criteria for autism spectrum disorder is the allowable age of diagnosis: the specific age of onset at 3 years of age was removed in the most recent DSM (DSM-5) [15]. Furthermore, a proportion of the documented increases in the administrative prevalence of autism spectrum disorder corresponds to a drop in the administrative prevalence of other disabilities, most notably intellectual disabilities—a phenomenon known as diagnostic substitution [16, 17].

Another change related to diagnostic practices is the advent of prenatal diagnosis for some intellectual disabilities, namely, Down Syndrome (Trisomy 21), Edwards Syndrome (Trisomy

13), and Patau Syndrome (Trisomy 18) initially recommended for women over 35 years of age but now offered to all women [18–21]. Such technological advances may contribute to a decrease in the occurrence of intellectual disabilities in the population due to a high number of elected terminations of pregnancy. In a systematic review of termination rates following a definitive prenatal diagnosis of Down Syndrome, Natoli et al. (2012) reported a weighted mean termination rate of 67 % among seven US-based population studies [22].

Changes or differences in population characteristics, including the average parental age, socioeconomic status, and sex ratios, can influence the prevalence and incidence of intellectual disabilities. Increasing maternal age has been identified as a risk factor for intellectual disabilities including Down Syndrome [23–25] and autism spectrum disorder [26]. Increasing paternal age is also identified as a risk factor for autism spectrum disorder [27]. Reviews demonstrating a doubling in the prevalence of intellectual disabilities in low- and middle-income countries compared to high-income countries suggest a role for socioeconomic status in the risk of intellectual disabilities [1, 3••, 28]. In addition, a decreasing male-to-female ratio seen in autism spectrum disorder, likely due to increased rates of diagnosis in females, may be indicative of an overall increase in prevalence of the disorder [29, 30]. Given that between 40 and 61 % of individuals with autism spectrum disorder are estimated to have intellectual disabilities [31, 32], this increasing prevalence may have associated implications for intellectual disabilities more broadly.

Finally, changes in exposure to risk factors associated with brain development can attenuate or increase the overall risk of intellectual disabilities in a population. These changes may be related to the application of risk reduction strategies such as education concerning consumption of alcohol during pregnancy, failure of preventive measures such as the recent lead contamination of drinking water in Flint, Michigan [33], or changes in the spread and/or virulence of infectious agents. The latter is exemplified by the recent spread of the Zika virus across northeastern Brazil and other nations, which has raised concerns about the risk of microcephaly and other congenital malformations in infants born to infected mothers and the subsequent intellectual disabilities associated with these malformations [34]. Such concerns are reminiscent of epidemics of rubella throughout the twentieth century, where congenital rubella syndrome increased the risk of a diagnosis of intellectual disabilities [35]. An understanding of such epidemics may explain some variation in the occurrence of intellectual disabilities prior to the introduction of rubella vaccines.

Considering the extensive collection of epidemiological factors that can influence the occurrence of intellectual disabilities, it is necessary to continue to systematically monitor trends and carefully review contemporary estimates. The

purpose of the current review was to extend Maulik et al.'s work [3••] beyond 2009.

Methods

The systematic review included the period 2010 to 2015. It involved searching PubMed, Embase, PsycInfo, Cochrane, and MEDLINE using both keywords and MeSH terms or Thesaurus words. The searches specified two elements: the population of interest (intellectual disability) and the outcome (prevalence and/or incidence) (Table 1). Articles known to the authors were also included as gray literature.

Articles were included if they represented original research on prevalence or incidence of intellectual disabilities in the underlying population. All age groups were included. To reduce the risk of under- or over-estimating prevalence or incidence, studies were excluded if (1) the estimates did not reflect all individuals with intellectual disabilities (e.g., focusing on individuals born prematurely, with chromosomal abnormalities, with autism), (2) the researchers only sampled from specific populations (e.g., individuals living in correctional facilities, visiting pediatric hospitals, or attending special schools), or (3) there was no report of prevalence for all levels of intellectual disabilities combined (e.g., only mild, moderate, or severe cases).

Articles were limited to those in English or French, and full-text articles. Study inclusion was not limited by study design (e.g., cross-sectional, cohort); however, studies that did not provide a case definition or that did not provide an adequate explanation of the methodology used to calculate prevalence or incidence were excluded.

Table 1 Example of search strategy

Elements	Search terms
Population	intellectual impairment intellectual disabilit* intellectual dysfunction developmental disability* intellectual developmental disorder mental deficiency mental* retard* mental* handicap* mental* disab* mental insufficiency mental* impair* mental* subnormality learning disability*
Outcome	Prevalence Incidence

All articles retrieved through the databases were placed in a bibliographic data manager, where duplicates were removed. Titles and abstracts were reviewed by three reviewers (KM, GS, MM) to identify relevant articles. Full-text articles were retrieved, if available, and each article was reviewed by two reviewers. Two reviewers (KM, GS, MM, HOK) independently recorded inclusion and exclusion criteria. If reviewers disagreed, the eligibility of the study was discussed and a third reviewer made the final decision to include or exclude. References of the chosen studies were searched and included in the review if eligible.

Descriptive information was abstracted from each included article independently by two reviewers (KM, GS, MM, HOK). If reviewers disagreed, the variable was discussed and consensus obtained before the data was entered into Microsoft Access 2013. Data included country, region, rurality, age group, age range, study type, data sources, diagnosis system or assessment instruments used, observation period, target population, survey/population size, and case definition. Reviewers also indicated if the observation period and target population were well defined. If studies provided a clear and operational case definition, cases were deemed reproducible (e.g., provided exact survey questions to identify cases, listed ICD codes). Prevalence or incidence estimates were recorded, by age, sex, and year, as applicable. Estimates obtained across studies are presented in figures to reflect differences by country, age, year, and method of data collection.

Results

A total of 3767 citations were identified across the five databases representing 2313 separate references. Three additional articles were identified by the authors, resulting in 2316 distinct citations. Articles were excluded upon abstract review ($n=2230$) and once the full text was accessed ($n=63$). As shown in Table 2, the most common reasons for exclusion were that the article was not about intellectual disabilities (often about developmental delay or disabilities in general), focused on developmental outcomes after a given exposure, or reported no estimate of occurrence in the population.

Data were extracted from 23 articles that met our inclusion criteria. During data extraction, it was determined that three articles did not provide a clear case definition [36–38]. Additionally, one article [39] reported on the same survey and provided the same prevalence estimates as another [40]. As a result, 20 articles are included in the review; one provides incidence estimates, one includes both prevalence and incidence estimates, and 17 provide prevalence estimates only (Fig. 1).

Table 3 provides a summary of the two articles reporting on incidence. The studies came from Sweden [41] and Denmark [42]. One study [41] was limited to the childhood period while

Table 2 Reasons for article exclusion

Exclusion criteria (in hierarchical order)	Abstract	Articles
Not about intellectual disabilities	1176	18
No prevalence or incidence estimates	909	10
Not in English	0	1
Not all levels of intellectual disability	11	4
Specific population (e.g., special school, premature birth)	49	8
Specific sub-group of IDD ^a	82	3
Fragile X syndrome	3	–
Down syndrome	4	–
Autism spectrum disorder	50	–
Attention deficit hyperactivity disorder	6	–
Cerebral palsy	5	–
Other	16	–
Not an original article	23	3

^a Abstracts could be excluded for including multiple sub-groups

the other extended to adulthood [39]. Both studies used administrative data although only one provided a comprehensive list of ICD codes used to identify individuals with intellectual

disabilities [42]. The cumulative incidence reported for Denmark to age 50 was higher (1.58 % for males and 0.96 % for females) [42] than that reported for Sweden overall (0.62 %) where individuals were followed to a median of 14 years [41]. The Swedish study also provided an incidence rate of 4.6 per 10,000 person-years (where person-years is the sum of the number of years each individual contributed to the study).

Table 4 provides a summary of the 18 articles that report prevalence. Three of these articles reported on multiple methodologies; as such, they are counted as distinct studies: Bielska et al. (2012) provide estimates derived from two different national household surveys [46], Lin et al. (2013) used three different case definitions [45•], and Westerinen et al. (2014) provided prevalence estimates for three age groups based on distinct definitions for each [47].

Seven studies (from six articles) used national household surveys [40, 46, 48, 54, 56, 57] and 16 studies (from 12 articles) used administrative data (health, education, social services, or national registries) [42–44, 45•, 47, 49, 50•, 51–53, 55]. Of the survey-based studies, three were from the United States [48, 54, 56], and the others were from Canada ($n=2$) [40], China ($n=1$) [40], and India ($n=1$) [57]; three reported

Fig. 1 Flow chart of articles included in review. *See Table 1 for number of articles lost to each exclusion criteria

Citations identified across databases [EMBASE (1856), MEDLINE (855), PubMed (585), PsycInfo (467), Cochrane (4)] (3767)

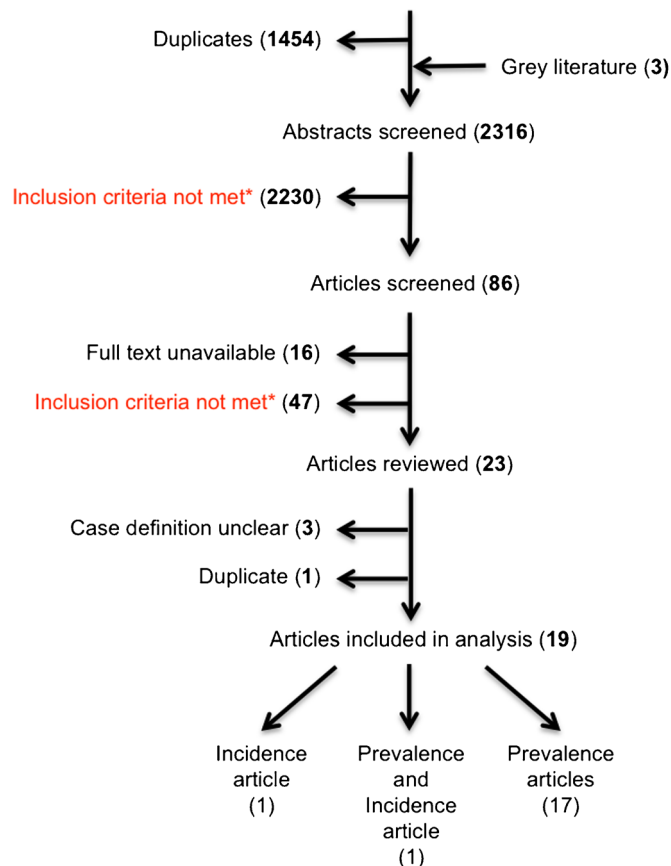


Table 3 Incidence studies included in systematic review ($N=2$)

Study	Country	Age group*	Data source	Diagnostic system	Diagnostic details	Case is reproducible?	Incidence	Observation period(s)	Population size
Sandin et al. (2013) [41]	Sweden	Child/adolescent	Admin data	ICD-9, ICD-10	Autism: ICD-9—299A; ICD-10: F84.0	No	4.6 per 10,000 person-years	1982–2009	2,541,125
Pedersen et al. (2014) [42]	Denmark	Child/adolescent and adult	Admin data (health)	ICD-8, ICD-10	ICD-8: 311.xx, 312.xx, 313.xx, 314.xx, 315.xx ICD-10: F70–F79	Yes	0.62 % 1.58 % (male) 0.96 % (female)	2000–2012	59.5 million

* Age groups were categorized using a cut-off of 18 years: < 18 indicated child/adolescent and ≥ 18 indicated adult; any overlap between these two categories was coded as children/adolescent and adult

on children/adolescents (age ranges 6–17, 0–18, 3–17) [48, 54, 56], two on adults (age ranges 18+ and 20+) [46], and two on children/adolescents and adults (age range 0+) [40, 57]. The studies relying on administrative data were from seven different countries across North America (three from USA [32, 53, 55], three from Canada [45•]), Europe (three from Finland [47], one each from Denmark [42] and Norway [49]), and the Asia-Pacific region (two from Australia [43, 44], three from Taiwan [50•, 51, 52]); these were fairly evenly spread across studies of children/adolescents ($n=6$; age ranges 0–15, 3–17, 8, 6–17) [32, 47, 50•, 51–53], adults ($n=5$; age ranges 18+, 18–64, and 65+) [43, 45•, 47], and both children/adolescents and adults ($n=5$; age ranges 6–19, 16–64, 0+, 3–21) [42, 44, 47, 49, 55].

The seven studies that relied on surveys all used slightly different questions to ascertain the presence of intellectual disabilities. Only three specifically asked if a medical professional had made the diagnosis [46, 48, 56]. In five instances, the questions listed examples of diagnoses [46, 48, 54, 56]. Eleven studies used a recognized classification system (ICD-8, 9, or 10; DSM-IV; AAMR) to identify the presence of intellectual disabilities in administrative data [32, 42, 44, 47, 49, 52]; some provided an extensive list of codes included [45•, 47]. Finally, five studies defined having intellectual disabilities as those who scored positive on psychological assessments [50•, 51], those who sought services for persons with intellectual disabilities [43], those who met a legal definition of intellectual disabilities [55], or those who received special education because of an intellectual disability [53].

As shown in Fig. 2, prevalence was highly variable across studies. Child/adolescent estimates ranged from 0.22 % in 2007–2008 (USA) [54] to 1.55 % in 1996 (USA) [32]. Adult estimates ranged from 0.05 % in 2009 (Australia) [43] to 0.8 % in 2009 (Canada) [45•]. Estimates that included both children/adolescents and adults ranged from 0.10 % in 2000 (Denmark) [42] to 1.30 % in 2005 (Australia) [44]. The earliest prevalence estimate reported was 1.2 % for children/adolescents and adults in China in 1987 [40] and the most recent was 0.66 % for children/adolescents in the United States in 2012 [53]. There were no time trends observed when all estimates were considered. Seven studies provided prevalence estimates across multiple years [32, 40, 48, 51, 53–55]. Of these studies, one revealed an increase over time [51], three reported decreasing prevalence [40, 53, 55], while three identified no time trend [32, 48, 54].

Six studies provided a breakdown of prevalence by sex [32, 46–48, 50•] (Fig. 3). All but one study [46] reported a higher prevalence in males. This anomaly was an estimate for adults based on a national

Table 4 Prevalence articles included in systematic review (*N* = 18)

Study	Country	Age group ^a	Data source	Diagnostic system	Diagnostic details	Case is reproducible?	Prevalence by sex available?	Prevalence by age available?	Observation period(s)	Survey/population Size
Haider et al. (2013) [43]	Australia	Adult	Admin data (social services)	Seeking services	Not specified	No	No	No	2009	Unknown
Leonard et al. (2011) [44]	Australia	Child/adolescent and adult	Admin data (health, education, social services)	AAMR classification	Physician diagnosed	Yes	Yes	No	2005	382,287
Lin et al. (2013) ^b [45•]	Canada	Adult	Admin data (health, social services)	ICD-9, ICD-10, and DSM-IV	ICD-9: MR, ASD, and chromosomal abnormality codes; ICD-10: F70–F79, F84, chromosomal abnormality codes; DSM-IV: MR, ASD codes	Yes	No	Yes	2009	Unknown
Bielska, Ouellette-Kuntz, and Hunter (2012) ^d [46]	Canada	Adult	National household survey	Survey question	“Do you have autism or any other developmental disorder such as Down’s syndrome, Asperger’s syndrome, or Rett syndrome?”	Yes	Yes	Yes	2005	130,000
Zheng et al. (2011) [40]	China	Child/adolescent and adult	National household survey	Survey question; unspecified physician screening and diagnosis	“Has a doctor, psychologist or other health professional ever said that you had a developmental disability or disorder?” (examples provided)	Yes	Yes	Yes	2006	47,500
Pedersen et al. (2014) [42]	Denmark	Child/adolescent and adult	Admin data (health)	ICD-8, ICD-10	ICD-8: 311.xx, 312.xx, 313.xx, 314.xx, 315.xx; ICD-10: F70–F79	No	No	No	1987 and 2006	1,579,316 and 2,526,145
Westerinen et al. (2014) ^c [47]	Finland	A—child/adolescent B—child/adolescent and adult C—adult	Admin data	ICD-9 and ICD-10	ICD-9: MR, chromosomal abnormality, and metabolic disorder codes; ICD-10: F70–F79, F84, G11, chromosomal abnormality codes, metabolic disorder codes	Yes	No	Yes	2000	Unknown
Lakhan, Ekundayo, and Shahbazi (2015) [48]	India	Child/adolescent and adult	National household survey	Survey question	Survey question based on ICD-10 criteria for ID diagnosis	No	No	Yes	2002	70,302
Sondana, Rasmussen, Nottestad, and Lauvrud (2010) [49]	Norway	Child/adolescent and adult	Admin data	ICD-10	ICD-10: F70–79	Yes	No	No	2008	4.77 million
Lai, Tseng, and Guo (2012) [50•]	Taiwan	Child/adolescent	Admin data (national registry)	Psychological assessment	Wechsler Primary and Pre-school Scale of Intelligence, the Wechsler Intelligence Scale for Children, Wechsler Adult Intelligence Scale, the Stanford-Binet Intelligence Scale (IQ < 70)	Yes	Yes	Yes	2004, 2005, 2006, 2007, 2008, 2009, 2010	4.0–4.7 million/year
Lai, Tseng, and Guo (2013) [51]	Taiwan	Child/adolescent	Admin data (national registry)	Psychological assessment	Wechsler Primary and Pre-school Scale of Intelligence, the Wechsler Intelligence Scale for Children, Wechsler Adult Intelligence Scale, the Stanford-Binet Intelligence Scale (IQ < 70)	Yes	No	No	2000, 2001, 2002, 2003, 2004, 2005, 2006, 2007, 2008, 2009, 2010, 2011	3.9–5.0 million/year

Table 4 (continued)

Study	Country	Age group ^a	Data source	Diagnostic system	Diagnostic details	Case is reproducible?	Prevalence by sex available?	Prevalence by age available?	Observation period(s)	Survey/population Size
Lee and Chen (2012) [52]	Taiwan	Child/adolescent	Admin data	ICD-9	ICD-9: ASD, MR, chromosomal abnormality codes	Yes	No	Yes	2008–2010	195,653
Boat and Wu (2015) [53]	USA	Child/adolescent	Admin data (education)	Receipt of special education	Not specified	No	No	No	2004, 2005, 2006, 2007, 2008, 2009, 2010, 2011, 2012	Unknown
Boyle et al. (2011) [48]	USA	Child/adolescent	National household survey	Survey question	“Has a doctor or health professional ever told you that [survey child] has any of the following conditions?” (included—autism, mental retardation)	Yes	Yes	Yes	1997–1999, 2000–2002, 2003–2005, 2006–2008	119,367
Houtrow et al. (2014) [54]	USA	Child/adolescent	National household survey	Criteria for disability based on ICF; survey question	“What caused disability/limitation?” (options included mental retardation)	Yes	No	No	2001–2002, 2004–2005, 2007–2008, 2010–2011	198,888
Polyak, Kubina, and Girrajan (2015) [55]	USA	Child/adolescent and adult	Admin data (education)	Legal definition	Variable case ascertainment	No	No	No	2000, 2010	6,200,000
Schieve et al. (2012) [56]	USA	Children/adolescent	National household survey	Survey question	“Has a doctor or health professional ever told you that [survey child] has any of the following conditions?” (included—autism, intellectual disability)	Yes	Yes	Yes	2006–2010	41,244
Van Naarden Braun et al. (2015) [32]	USA	Child/adolescent	Admin data (health, education)	Special education eligibility and ICD-9 codes	Record screening for test identification of ID, must indicate IQ ≤70	Yes	Yes	N/A	1991, 1992, 1993, 1994, 1996, 2000, 2002, 2004, 2006, 2008, 2010	428,858

MR mental retardation, ASD autism spectrum disorder, IQ intelligence quotient, ICD International Classification of Disease, DSM Diagnostic and Statistical Manual of Mental Disorders, ICF the International Classification of Functioning, Disability and Health, AAMR American Association on Mental Retardation classification system

^a Age groups were categorized using a cut-off of 18 years: <18 indicated child/adolescent and ≥18 indicated adult; any overlap between these two categories was coded as children/adolescent and adult

^b Lin et al. (2013) provide three different case definitions to provide prevalence estimates

^c Westerinen et al. (2014) calculated prevalence for three different age groups

^d Bielska, Ouellette-Kuntz, and Hunter (2012) use two different National Household Surveys to calculate prevalence for different years

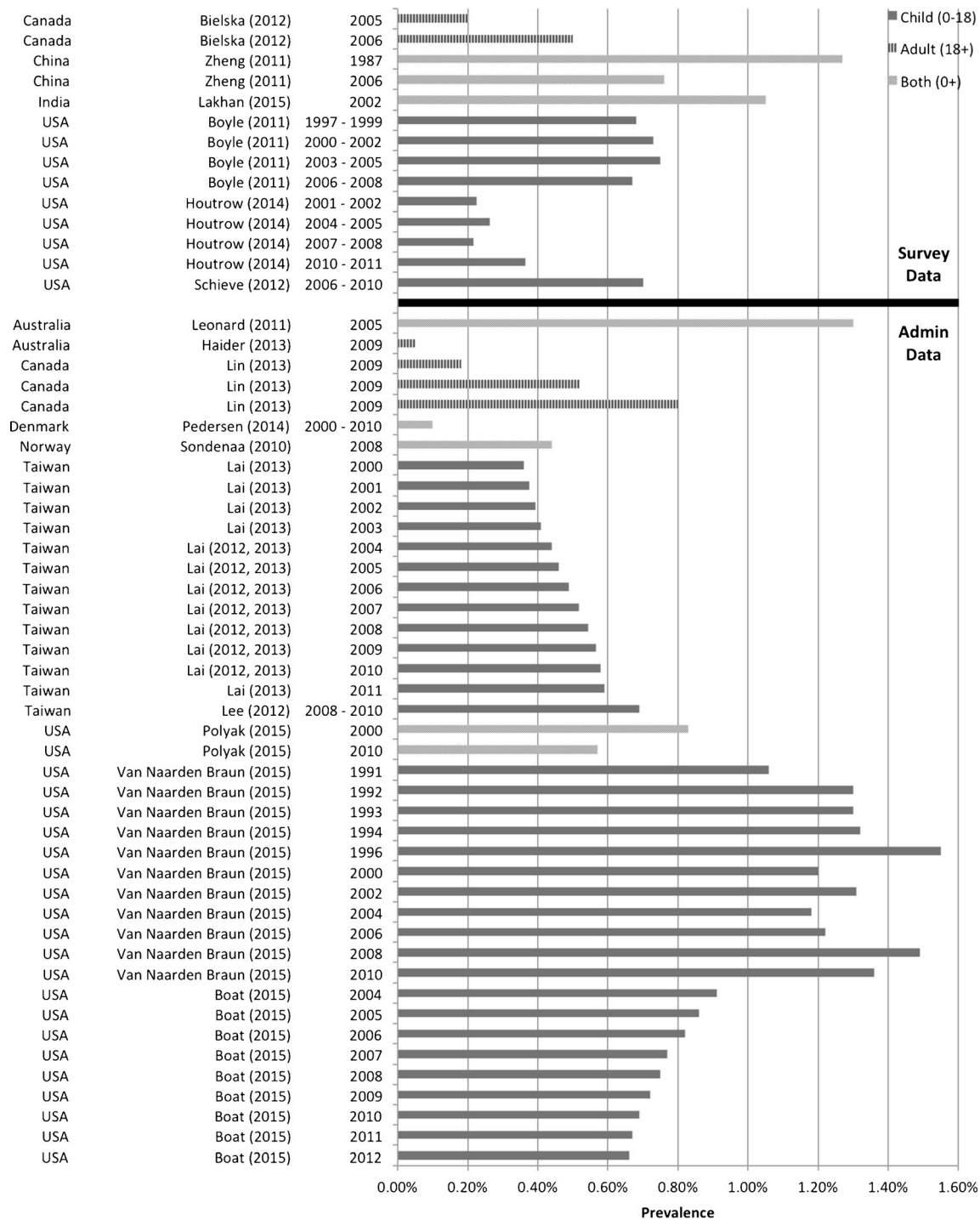


Fig. 2 Overall prevalence estimates for each of the studies

household survey in Canada. The excess prevalence in males did, however, vary considerably across the other studies. The smallest absolute difference in prevalence by sex (0.14 %) was reported in a study of children/adolescents in Taiwan in 2004 [50•]; the greatest difference (1.16 %) was reported in a study of children/adolescents in the United States in 2008 [32].

Discussion

The current review highlights the paucity of studies reporting on the incidence of intellectual disabilities as a whole and provides further evidence of the variability in prevalence estimates due to methodological differences including data sources, case definitions, and included age ranges. Finding

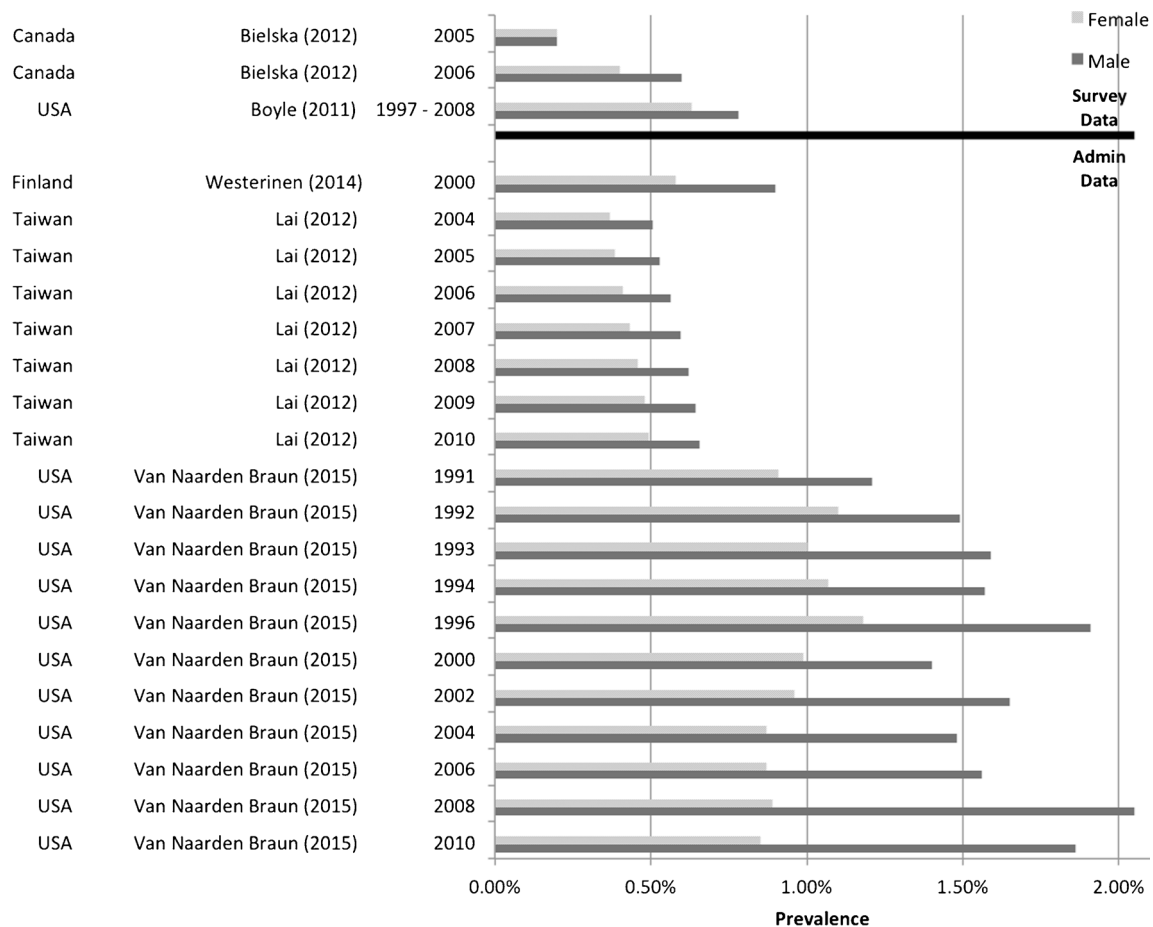


Fig. 3 Prevalence estimates by sex

only two studies reporting incidence is not a surprise as incidence rates (in person-years) may be more indicative of access to diagnosis than actual risk of intellectual disabilities, and the lifelong nature of intellectual disabilities essentially makes the reported cumulative incidence estimates (0.62 to 1.58 %) proxy measures of prevalence. While a reasonable number of high quality prevalence studies have been published in the 6 years following Maulik et al.'s (2011) review [30], the lack of comparability across studies limits the ability to corroborate results [48]. Even when studies have reported estimates for multiple years, clear time trends are not identified. Where an increase is observed, the possibility that it may reflect better identification rather than an increase in occurrence remains [51]. A consistent finding across studies is that over time, males continue to be over-represented [32, 50].

The authors of the reviewed studies have themselves identified limitations in the methods they have used. Regarding the use of surveys, Boyle et al. (2011) acknowledge that “inaccurate reporting can result from parental distress and the stigma associated with some of the conditions; the questions may be misunderstood or there may be variations in professional terminology used” (p. 1040) [48]. Lai et al. (2013), who used a

registry, note that only when the quantity and quality of services are high will administrative prevalence likely approach the true prevalence [51]. Boat and Wu (2015), who reported a slight drop in prevalence among children over time, point out that administrative sources such as “special education “child count” data have the advantages of being nationally representative and available annually, but do not necessarily rely on standard case definitions or diagnostic criteria that are comparable over time and across states/school districts” (p. 270) [53].

Beyond the data source, the case definition applied is also critical to the derivation of prevalence estimates. Two US studies using special education data provided different estimates for comparable years [32, 53]. Lin et al. (2015) demonstrated how different algorithms applied to the same administrative data can yield significantly different estimates of prevalence [45].

Despite limitations associated with the different methods used (i.e., survey versus administrative data), age-specific prevalence estimates are needed to inform service planning across distinct age-related sectors (children, adults, aging). While many studies focus on an

explicit age range, the use of standard age categories for reporting would enhance comparability. It is suggested that prevalence among 8-year-olds be a minimum requirement when presenting prevalence estimates among children as it is likely most will be identified by that age [32]. As many jurisdictions identify adults as individuals 18 years or older, 18 years should be the minimum age for reporting prevalence among adults. While new cases of intellectual disabilities are unlikely to be identified in adulthood, in light of the earlier mortality experienced in this group [58–62], it is advised to “include[e] all adults (if possible) and report in 10 year increments starting at <25 and extending to >=75 years” (p. 185) [63].

In addition to the effect of differential identification from year to year, stability in prevalence over time “might reflect a balance between increased potential for disability as more infants survive the neonatal period and reductions in other risk factors” [32] (p. 15). Of note, a review by Bosco et al. (2013) revealed that improved treatment of low birth weight infants in neonatal intensive care units was a significant contributor to the increased prevalence of intellectual disabilities [35]. In particular, Lai et al. (2013) identified intellectual disabilities and autism spectrum disorder as the largest contributors to the increasing disability prevalence in Taiwan from 2000 to 2011 [51]. As such, incidence of overall intellectual disabilities as well as those attributed to specific causes or intellectual disabilities with specific associated conditions (e.g., autism spectrum disorder) across birth cohorts should be monitored.

Through our review, we also identified a few instances of missed opportunities to report on the overall occurrence of intellectual disabilities. For example, two studies using large and nationally representative samples of children and youth analyzed data about the presence of intellectual disabilities; however, they did not provide an overall prevalence estimate [64, 65]. When subgroups are compared, results could easily be presented in such a way as to allow the calculation of an overall prevalence thereby making an additional contribution to the body of literature.

Conclusion

Over a relatively brief observation period (6 years), a number of studies aimed at determining the prevalence of intellectual disabilities were identified across nine countries; this highlights the global desire for this knowledge. From these studies, it appears that the global prevalence of intellectual disabilities may indeed be lower than 1 %. The heterogeneity of studies, however, prohibits definitive conclusions about a potential downward trend. Collaborative national and international efforts to address the issues identified may be needed to ensure increased comparability across studies.

Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no competing interests.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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- Of importance
- Of major importance

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