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Center for International Rehabilitation Research Information and Exchange (CIRRIE)
515 Kimball Tower
University at Buffalo, The State University of New York
Buffalo, NY 14214
E-mail: ub-cirrie@buffalo.edu
Web: http://cirrie.buffalo.edu

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Epidemiology of Intellectual Disability

Pallab K. Maulik, M.D., Ph.D., M.Sc.
Department of Mental Health
Johns Hopkins School of Public Health

Catherine K. Harbour, Ph.D., M.P.H.
Department of Health Behavior and Society
Center for Communication Programs

Introduction

Intellectual Disability (ID, also known as mental retardation) is a condition of arrested or incomplete development of the mind. ID 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 (WHO 1992). For a definite diagnosis, lower intellectual functioning should lead to reduced ability to adapt to the needs of daily living. ID is known by different names in different countries. According to data collected from 147 countries, some common terminology is: mental retardation (most common term in 76% of the countries), intellectual disability (57%), mental handicap/ disability (~ 40%). Other terms like learning/developmental disability and mental deficiency/subnormality are also used (WHO 2007).

ID is the most common developmental disorder. Its effect on the individual, family, and community can be immense, since most individuals are affected from an early age. Rehabilitation of people with intellectual disability (PWID), and reducing the burden due to ID, have been public health challenges for a long time. PWID can benefit from social welfare and education programs, and can both benefit from and contribute to a workplace, however PWID may need somewhat different facilities in the social welfare, education, and employment sectors than do those without an ID, and policy is necessary to guarantee these facilities. Researchers have identified a number of factors that affect policy changes for intellectual disability and include economic conditions, legal issues, political will to implement laws pertaining to intellectual disability, medical developments, changes in socio-demographic trends, and cultural norms (Fujiura & Parish 2007). Epidemiological studies have helped to assess the magnitude of the problem and plan appropriate services for PWID, but the progress of such research has been affected by the history of the disorder, changing definitions and diagnostic classification systems, existing laws and norms in societies.

History

While details about the history of intellectual disability are provided in another chapter of this encyclopedia (Harbour and Maulik 2010), this section provides a brief outline of the history to provide a context for the epidemiological research.

The earliest reference to intellectual disability dates to the Egyptian Papyrus of Thebes in 1552 B.C. (Harris 2006). Prior to the 18th century people with adequate social skills and mild ID probably received little or no special attention, and those with severe ID might have been cared for in monasteries (Beirne-Smith et al. 2006). Jean-Marc Itard is credited with creating the first systematic intervention program for a PWID in late 18th century France, and the first residential facility was founded in the mid 19th century in Switzerland. Psychological tests to assess intelligence were developed in the 20th century, which increased case identification, but for some cases also led to interventions that today would be considered unnecessary if not cruel. The eugenics movement believed "feeblemindedness" to be heritable and sought to prevent childbearing among those diagnosed as "feebleminded" through forced segregation and sterilization. The movement was strongest in the late 1800s and early-to-mid-1900s and was embraced by governments including that of some U.S. states and of Nazi Germany (Bachrach 2004, Radford 1991). Later scientific advances disproved the heritability of ID. More recent international, national, and local policies have demonstrated a stronger commitment to securing civil rights and providing quality services for PWID and their families, in parallel to those with other types of disabilities, as well as supporting research related to ID (Beirne-Smith et al. 2006).

Definition and classification

Some of the most important issues for definition and classification are discussed here. A more detailed discussion may be found in textbooks (Harris 2006; King et al. 2009). Initial attempts to develop classifications for mental illness in the late 19th century were based on etiological and physical correlates of observable traits, followed by differentiation based on level and severity of cognitive impairment (Harris 2006). Tests to quantify level of intelligence were developed in the early 1900s, and the Intelligence Quotients (IQ) became the norm, with "subaverage" IQ defined as an IQ score below 85. The term 'mental retardation' was used by the American Association of Mental Retardation (AAMR) for the first time in 1961.

In 1992 and 2002, AAMR changed the basis of classification from one based primarily on IQ to one based on adaptive behavior across ten domains. While consumers supported this change because it allowed a more functional- and community service-oriented diagnosis and evaluation, the change created some problems for clinicians and researchers, since no validated tools were available for measuring adaptive functioning for each domain. Researchers continued to use IQ as a basis for defining ID as did clinicians. The current diagnostic systems – International Classification of Diseases – 10th Revision (ICD 10) (WHO 1992), Diagnostic Statistical Manual of Mental Disorders – 4th Edition, Text Revision (DSM-IVTR) (APA 2000) and International Classification of Functioning, Disability, and Health (ICF) (WHO 2001) – have continued to use IQ to define severity levels and have adopted the approach of AAMR to include disability and adaptive behavior as defined within one's cultural and environmental context.

The ICD10 is the most widely used classification system across all member countries of the World Health Organization (WHO 2007). According to ICD10, the levels of severity are mild (IQ of 50-69), moderate (35-49), severe (20-34), and profound (<20). Deficits in

functioning across a number of domains and levels of disability can be assessed in detail using the ICF. From an epidemiologic perspective, ID prevalence rates vary according to the definitions and classification system being used. Using IQ<70 as the only criteria, researchers estimated that in the United States the prevalence of ID was around 3%. However, by including other criteria such as deficits in adaptive behavior, or defining less severe ID as learning disabilities, or accounting for variable rates of case identification and mortality across different age-groups, the estimates were reduced to 1% (King et al 2009). Increasing the IQ cut-off score from 70 to 75 almost doubles the number of PWID because of the general population distribution of intelligence. Even across different states within the U.S., prevalence rates among school children vary, from 3.2/1000 in New Jersey to 25.4/1000 in Kentucky, due to varying case definitions, level of completed education, and income level of the family (Massey and McDermott 1995). Intellectual disability is also conceptualized differently across cultures and countries and this is reflected in the many definitions used across countries (WHO 2007).

Epidemiology

This discussion provides an overview of ID across general populations and includes studies based on administrative data and those involving large populations. These studies focus on intellectual disability per se, and not on the ID associated with specific causes (e.g. Down's Syndrome, autism, low birth weight, etc). Moreover, studies specific to institutionalized population or clinic-based populations are not included in this discussion. The review is based on a literature search involving electronic databases of peer-reviewed published studies with emphasis on studies published after 1980.

Earlier studies

Some of the earliest epidemiological studies in this area are from Iceland and Denmark (Hübertz 1843), where the prevalence of "mental defectives", as identified from information provided by the clergy, was 2.3 and 0.9 per 1000 population in the two countries, respectively. Helgason (1964) used the national register of Iceland and tracked children born in 1895-97 to estimate "intellectual subnormality" which is comprised of "intellectual inferiority" (IQ 75-89) and "mentally deficient" (IQ<75) groups. Overall about 4% of the population had intellectual subnormality with a slightly higher prevalence among males. The rates were found to be higher in the rural population, especially among males and those from the lowest socio-economic class. Drillien et al (1966) found that among children born in Edinburgh between 1950-56, the rates of "mental handicap" (IQ<70) were about 1/1000. Males and those belonging to the poorest community had the highest prevalence. While amongst those with IQ between 55-69, about two-thirds had no known etiology, the majority with IQ<54 had a known cause. Down's Syndrome and cerebral palsy were the most common identifiable causes in the population.

More recent studies

Incidence and prevalence estimates from studies conducted after 1980 have varied. There are many factors that can affect the estimates of intellectual disability, such as diagnostic criteria, severity of illness, gender, age, study population, and socio-economic status.

Prevalence estimates

Table 1: Selected studies with prevalence estimates from different countries

Country (Reference)	Source of study population	Definition used	Total study population	Prevalence per 1000 population
Australia (Beange & Taplin 1996)	Administrative data on 20-50 year olds	AAMR classification of 1983	104584	3.3 Male = 3.4 Female = 3.2
Australia (Leonard et al 2003)	Administrative data on children 6-15 years	DSMIV	240358	14.3
Canada (Bradley et al 2002)	Administrative data and population based study on 14-20 year old adolescents	ICD 10	35485	7.2
China (Zuo et al 1986)	Survey of 0-14 year old children	AAMR definition	7150	7.8 Male = 7.8 Female = 7.9
China (Xie et al 2008)	Household survey of children aged 0-6 years	Specific disability criteria	60124	9.3 Male = 10.1 Female = 8.3
Ethiopia (Fitaw et al 2006)	Population based study on adults	ICF	24453	3.9
Finland (Rantakallio et al 1986)	Administrative data on specific birth cohort of children	ICD9	12058	5.6 (Mild mental retardation) 6.3 (Moderate-severe mental retardation)
Ireland (including Northern Ireland, UK) (McConkey et al 2006)	Administrative data of adults	ICD10	3961701	6.3
Norway (Stromme et al 1998)	Administrative data on specific birth cohort of children	DSMIV	30037	6.2 Male = 8.4 Female = 5.7
USA (Murphy et al 1995)	Administrative data on 10 year old children	DSMIII	89534	12 Male = 13.8 Female = 10.1

The table highlights some of the large population-based studies that report prevalence estimates using standard diagnostic systems. While among adults, the rates vary between 3-6/1000, among children the rates are between 3-14/1000. Especially among children the rates vary a lot depending on diagnostic systems, the age of the child, and source of the administrative data. For example, using clinical guidelines based on IQ would give higher estimates from those based on more comprehensive adaptive behavior and psychological assessments (King et al. 2009). Often children are identified only around the age of 10 years while at school, and diagnoses made earlier can vary due to developmental changes in early childhood. The reasons being that the pressures of school unmask below-average performances and deficits in adaptive behavior across different situations. Again, use of data from school systems would also depend on whether the child is enrolled in a public school system, as private schools often are not included in such databases. Even among adults, those with higher incomes may not avail themselves of government funding, and may not be included in such databases. For example, eligibility for Social Security Administration funding in the U.S. is based on income level, so it tends to report data from lower socio-economic strata only. In developing countries, most studies are based on clinical assessment, making it difficult to compare such studies with each other. Using a simple set of questions followed by clinical evaluation, Stein et al (1987) found that the prevalence of mental retardation (IQ<70) among 3-9 year olds in eight developing countries (including some populous countries like India, Brazil, Bangladesh, and Pakistan), varied from 9/1000 in Philippines to 156/1000 in Bangladesh. Some other studies using clinical diagnoses report prevalence rates ranging between 1/1000-6/1000 in studies from Ghana (Biritwum et al 2001), Thailand (Pongprapai et al 1996), and Cuba (Lopez et al 2005). Using IQ scores, Temtamy et al (1994) reported prevalence of 39/1000 in an Egyptian population, but unlike other studies the researchers included borderline cases in their analyses.

Incidence estimates

Fewer studies report incidence rates, and even then the research is mostly with children. In Finland, Heikura et al. (2003) found that the cumulative incidence of mental retardation of any severity was 12.6/1000. Also from Finland, others reported that the incidence varied from 5.5/1000 for mild mental retardation to 7.4/1000 for moderate-severe mental retardation (Rantakallio et al 1996). In the U.S., the cumulative incidence was 9.1/1000 (Katusic et al 1996).

Mortality estimates

Patja et al (2000) estimated mortality among PWID using data from a 35-year-long Finnish cohort, and did not find any differences in the life expectancy of people with mild mental retardation and the general population. Those with more severe forms had lower life expectancies compared to the general population. Life expectancy was similar across genders. Median life expectancy in a large Australian cohort was associated with the level of severity of intellectual disability. The rates were 74 years, 67.6 years, and 58.6 years, for people with mild, moderate, and severe disability, respectively (Bittles et al. 2002). The standardized mortality rate for people aged 20 years or older with moderate-to-profound intellectual disability in UK was on an average three times higher than the standardized mortality rate estimated for the general population (Tyrer et al. 2007).

Recent reviews have shown that lower childhood IQ is correlated with increased prevalence of cardiovascular diseases, respiratory diseases, and Alzheimer's disease (Kilgour et al. 2009). Low socio-economic status and exposure to negative environmental factors like smoking, obesity, and other unhealthy lifestyles affect this association. While specific etiological factors related to the more severe forms of mental disorder can increase the risk of death, with advances in medicine, life expectancy has improved.

Correlates of intellectual disability

Severity of disorder

The distribution of the affected population depends on the severity of the disorder. Among those with a diagnosis of ID, mild mental retardation affects about 85% of the population, moderate mental retardation about 10%, severe mental retardation about 4%, and profound mental retardation about 2% (King et al 2009).

Gender

Almost all studies report that the prevalence of mental retardation is higher among males than females, especially among children less than 15 years of age. Especially for mild mental retardation, males have about a 1.5-fold greater prevalence. A number of reasons are suggested for greater prevalence in male children, including more frequent identification among boys due to abnormal behavioral patterns in school, and increased adverse effect of maternal smoking and low birth-weight on neurological development among males. Gender differences are not evident among adults (Leonard et al. 2002; Gissler et al. 1999).

Social class and ethnicity

Researchers have found a correlation between low maternal education and prevalence of intellectual disability (Leonard et al. 2002). Lower socio-economic conditions are also associated with poorer health conditions, which may affect the growth of the fetus or young child and can lead to mental retardation. Few studies have analyzed data on ethnic differences in ID. One study on children in the U.S. found that ID was proportionately higher among African-American children, after controlling for socio-demographic variables (Murphy et al 1995). Another study in Australia found that ID was proportionately higher among Aboriginals than other population groups (Glasson et al. 2005).

Etiology

A number of factors are associated with increased risk of intellectual disability. Prenatal causes are genetic and congenital malformations and exposure to toxins. Perinatal factors are those related to infections and delivery-related causes. Postnatal causes are those associated with childhood infections, and physical and psychological growth of the child. However, most cases are of unknown etiology (30-50%). Preliminary analyses (PK Maulik, unpublished data) show that Down's Syndrome is the most common known cause and accounts for about 5-20% of all cases. The rates vary according to the study population. Congenital hypothyroidism accounts for 1-2% of cases. Other common

causes are low birth weight and prematurity, birth injuries and birth asphyxia, and childhood infections affecting the neurological system (PK Maulik, unpublished data).

Comorbid physical and psychological problems

Diagnosing comorbid conditions among PWID can be difficult, especially for those with more severe levels of disability. There is a lack of both appropriate diagnostic tools and of expertise to identify comorbid conditions in PWID. Case management presents a similar challenge. A number of physical disorders have increased association with intellectual disability, and these rates are generally higher among those with severe-profound severity levels. About 10% of PWID have a hearing impairment; seizure disorder is present in a third of institutionalized PWID and 3-18% of those with mild-moderate intellectual disability; and cerebral palsy is present in 30-60% of those with severe to profound intellectual disability (Harris 2006). In The Netherlands, adults with intellectual disability had twice the rate of physical health problems as normal adults in the community (Van Schrojenstein Lantman-de Valk et al. 2000).

A number of psychiatric disorders such as emotional and behavioral problems, affective disorders, psychotic disorders, and anxiety disorders, are more common among PWID than among the general population. Reviews report at least a 4-5 fold increased prevalence of psychiatric problems (Harris 2006). The prevalence rates depend on the type of disorder and the diagnostic systems used to estimate them, and on the severity of mental retardation. Often psychiatric disorders in those with more severe mental retardation are missed. The reason being that those with severe mental retardation either fail to report symptoms of other psychiatric disorders or their symptoms are completely overshadowed by their intellectual disability. Kerker et al. (2004) reported that compared to studies based on administrative data, population-based studies that included institutionalized patients with severe mental retardation reported higher prevalence of comorbid psychiatric disorders. The reason could be better identification by specialized staff, using detailed clinical interviews within institutionalized settings, than through questionnaires used with administrative data. Autism and other developmental disorders, attention deficit and hyperactivity disorder (ADHD), behavioral disorders, and cerebral palsy are common in children with ID (Shea 2006). Different studies in the review showed that among children with mental retardation, autism is present in about 25%, ADHD in about 10%, and cerebral palsy in 7-30%, depending on the severity of mental retardation. Among adults with Down's Syndrome, dementia is the most common cause of mortality and morbidity, and research from The Netherlands has found that often it has an earlier age of onset (8.9% in 45-49 year old age-group) compared to the general population (Coppus et al. 2006).

Future directions for epidemiological research

A large proportion of current research in the area of intellectual disability has focused on clinical aspects and genetics, however, there still is a lot that needs to be learned. Some future directions of epidemiological research in this area could be studying individuals with intellectual disability using longitudinal data that can measure changes across different developmental milestones, including transitioning to schools and jobs. Genetic links to ID also offer a promising area of research. More information is needed from

developing countries, especially those in Africa, Latin America and South Asia. While there are some clinic-based studies from such countries, including large countries like India, population-based epidemiological studies are lacking. Researchers reviewing intellectual disability in Africa and Latin America have noted numerous lacks: of epidemiological studies, of legislation, of infrastructure and expertise to identify and mange ID cases, and of appropriate rehabilitation facilities in many countries in these regions (Njenga 2009; Mercadante et al. 2009). While this review did not focus on services research, a brief review of available knowledge makes it apparent that more needs to be learnt about factors associated with use of services and the quality of available services. Intellectual disability may be diagnosed at birth or in early childhood. Some PWID may require some degree of assistive care for their entire lives, and parents often provide this care in the home environment. More research is needed into how best to support these caregivers (Chou et al 2009). In some countries of Europe at least, recent initiatives have sought to gather more information about different health indicators of PWID as part of the Pomona Project (2008), which represents an increased concern about the health of PWID. Project results are intended to help to develop better services.

PWID and their families may experience stigma and discrimination (Jeevanandam 2009). Epidemiological research on stigma and attitudes towards PWID and their families, within different communities and cultures, is also an important area of research. In Taiwan, for example, families with a child who has ID are labeled by society as "unsuccessful families" (Chou et al 2009). Cambodian families may see ID as karma for things done in a previous life (WHO 2007). As PWID increasingly move into community settings, they may experience or anticipate stigma, and may fear failure or discrimination when interacting with people who do not have an ID (Jahoda and Markova 2004). Some PWID feel stigmatized because of their association with institutions or treatment centers, and may try to hide their ID to avoid stigmatization (Ali et al. 2008). Some research has found that maltreatment is more prevalent for PWID than for people with no disability (Horner-Johnson and Drum 2006). Some PWID may be eager to prove their competence and promote a positive identity in community settings (Jahoda and Markova 2004). Njenga (2009) notes that PWID in Africa may confront stigma from medical personnel, both from traditional healers - who may believe that evil spirits cause ID - as well as from medical professionals with Western-style training. Finding ways to assure safe, healthy, and non-stigmatizing environments for PWID and their families is an important priority for research and programming.

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