Mental Health Disorders Among Individuals with Mental Retardation: Challenges to Accurate Prevalence Estimates

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SYNOPSIS

Objectives. The objectives of this literature review were to assess current challenges to estimating the prevalence of mental health disorders among individuals with mental retardation (MR) and to develop recommendations to improve such estimates for this population.

Methods. The authors identified 200 peer-reviewed articles, book chapters, government documents, or reports from national and international organizations on the mental health status of people with MR. Based on the study's inclusion criteria, 52 articles were included in the review.

Results. Available data reveal inconsistent estimates of the prevalence of mental health disorders among those with MR, but suggest that some mental health conditions are more common among these individuals than in the general population. Two main challenges to identifying accurate prevalence estimates were found: (*1*) health care providers have difficulty diagnosing mental health conditions among individuals with MR; and (*2*) methodological limitations of previous research inhibit confidence in study results.

Conclusions. Accurate prevalence estimates are necessary to ensure the availability of appropriate treatment services. To this end, health care providers should receive more training regarding the mental health treatment of individuals with MR. Further, government officials should discuss mechanisms of collecting nationally representative data, and the research community should utilize consistent methods with representative samples when studying mental health conditions in this population.

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Over the last 40 years, public policy regarding individuals with mental retardation (MR) has changed dramatically, from emphasizing isolation to focusing on normalization and inclusion.[1–3] As a result, much debate and research has centered around the prevention of MR, deinstitutionalization, and the education and employment of individuals with MR.[4,5] In this new environment, concern has also arisen for the mental health of those with MR. For instance, a Surgeon General's conference on this issue was held in 2002.[6]

It is important for service and treatment planning to understand how many people with MR have mental health conditions. In order for resources to be allocated appropriately, it is also important to know how these prevalence estimates compare to estimates for the general population. Two main challenges, however, often inhibit reliable and valid prevalence reports. First, health care providers face difficulties in diagnosing mental health conditions among their patients with MR. Second, research studies on mental health disorders and MR are often constrained by methodological limitations. Consequently, although higher rates of mental health impairments have been found among individuals with MR than in the general population,[7–10] reported prevalence estimates are inconsistent, which inhibits confidence in these findings.

Before describing the challenges to identifying accurate prevalence estimates of mental health conditions among those with MR, this article describes why this population may be at high risk for such disorders. Then, the two main challenges to obtaining accurate prevalence estimates are examined, using the existing literature to illustrate these challenges. The article concludes with recommendations to improve both the diagnosis of mental health conditions among individuals with MR and the methodological rigor of the research conducted in this area.

METHODS

This review was part of a larger study that addressed the health status of, and service accessibility for, individuals with MR. To conduct the literature review, we searched MEDLINE and PsychInfo for peer-reviewed articles and book chapters published in 1980–2003 on the mental health status of this population. In addition, government documents identified through GPO Access and other Internet search engines, as well as publications obtained from eight prominent national and international organizations (e.g., the American Association for Mental Retardation and the National Alliance for the Mentally Ill) were reviewed.

Although approximately 200 documents were considered for this review, only 52 were included. Due to the limited methodological rigor of published research in this area, the standard biomedical inclusion criteria for review articles[11] were not used to select empirical articles for this paper. Instead, we included all studies, with the following exclusions. First, research reports that referred to more general developmental disabilities (i.e., those that did not focus on MR specifically) were not included. Second, articles describing case studies were excluded from this review. Third, international studies were not included unless they referred to localities with general population mental health prevalence estimates that are similar to those found in the U.S., as estimated in the 1999 Surgeon General's report on mental health.[12] Further, for international work to be included, the published article had to provide additional pertinent information that was not available from U.S. research, such as results based on population-based data. Similarly, there are few U.S.-based studies that examine mental health conditions among children with MR, so an international study examining this population was included. Based on these criteria, 12 empirical articles and 37 non-empirical/review articles describing mental health conditions among those with MR were included in this review. For comparison purposes, three additional articles that describe mental health conditions in the general population were also included.

Since the term "mental health disorders" refers to a heterogeneous group of conditions, such an aggregation may result in misleading associations. In an effort to avoid erroneous conclusions, this article discusses specific conditions when possible. In the literature, however, different conditions (such as schizophrenia, dementia, mood disorders, and substance use) were often grouped together and termed "mental health disorders." As a result, we sometimes refer to a general category of "mental health disorders" which includes several diagnosable and non-diagnosable disorders.

RESULTS AND DISCUSSION

Risk for mental health disorders among those with MR

Both biological and psychological factors are believed to affect the risk of mental health disorders. Some conditions, for example, may be caused by biochemical abnormalities in the brain.[13] Just as with individuals in the general population, individuals with MR may suffer from such irregularities and associated mental health conditions. In fact, those with MR may have higher rates of genetic abnormalities and brain damage than the general population;[9] those higher rates may be associated with a higher prevalence of mental health conditions.

Psychological and social factors can also affect mental illness.[13] As Zigler and Burack point out, individuals with MR are capable of experiencing the same disappointments and difficulties as those without MR.[7] In addition, individuals with MR who are aware of their limitations may be at high risk for mental health problems, as such recognition may lead to self-concept problems, emotional disturbances, and depressive reactions.[14,15] Parental and peer rejection, negative social relationships, limited supports, and exposure to degrading situations also may make functioning in the community difficult for those with MR.[15–18] Children with mild MR, for example, have been found to be more rejected by peers and express more dissatisfaction and anxiety about peer relations than those without MR.[16] Such feelings may affect an individual with MR more than someone in the general population because those with MR tend to have greater sensitivity and fewer interpersonal coping skills.[7,19]

Prevalence estimates in the literature confirm that mental health disorders are at least as common among individuals with MR as they are in the general population. The 1999 Surgeon General's report estimates that 21% of adults in the general population have a mental health condition.[12] U.S.-based studies have found percentages of dual diagnosis (the

historic term for the presence of MR and a mental health disorder) ranging from 17% to 36% among adults.[20–23] In the general population, 5% to 12% of children have been reported to have mental health conditions.[12,24–27] U.S.- and European-based studies have found the prevalence among children with MR to range from 14% to 60%.[21,22,28]

Challenges to accurate prevalence data: difficulties in diagnosing mental health disorders

These vast ranges of prevalence estimates may indicate challenges to obtaining accurate counts of mental health disorders among those with MR. Some of these figures may represent an underestimation of dual diagnosis because mental health conditions are often difficult to identify in this population. In fact, historically, mental health conditions were rarely diagnosed in individuals with MR because many behavioral and emotional problems were thought to be due to institutionalization.[9,29] Further complicating the matter, it has even been noted that the effects of prolonged institutional care are difficult to distinguish from symptoms of schizophrenia among those with severe MR.[30]

Symptoms of mental health disorders have often been seen as characteristic of MR.[7,19] While today it is recognized that mental health conditions exist in individuals with MR and are separate from MR,[18,19] distinguishing symptoms of mental health conditions from those of MR can actually be quite challenging.[9,18,31–37] The presence of MR, for instance, often diminishes the diagnostic significance of behavior that would otherwise be indicative of a mental health disorder. Consequently, symptoms of a mental health disorder are often attributed to the MR, rather than evaluated as a potentially separate condition. Reiss et al., who termed this phenomenon *overshadowing,* provide an example of this in research conducted with psychologists evaluating hypothetical cases.[38] Clinicians in this study were more likely to give the diagnosis of mental health disorder to an individual without MR than to a patient with the same case description plus the diagnosis of MR.

In addition, different developmental trajectories can result in different presentations of symptoms.[39–41] For example, mood-incongruent psychotic features may be more frequent symptoms of depression among those with MR than among individuals in the general population.[41]

For those with severe MR, symptoms of mental health disorders may be even more challenging to identify.[42] Individuals with severe MR, for example, may present with bland symptomatology, a phenomenon known as *psychosocial masking,* which makes diagnosis difficult.[14,35] Further, the severe cognitive limitations in individuals with severe MR create a *baseline exaggeration* effect, which makes the identification of additional disorders challenging, if not impossible.[14,32,35] And, those with severe MR may have limited receptive and expressive language skills and deficits in abstract thinking (referred to as *intellectual distortion*) or limited ability to tolerate stress, leading to anxiety-induced decompensation (referred to as *cognitive disintegration)* due to their disability[14,32,35,43] and are often passive and compliant. These challenges make diagnoses of mental health disorders difficult in this population. Cognitive disintegration, for example, is often difficult to distinguish from obsessive-compulsive disorder (OCD), a diagnosable mental health condition. Diagnosis of OCD is even further complicated by the fact that patients with severe MR are often nonverbal, so that the diagnosis of OCD depends more heavily on a combination of caregivers' abilities to identify symptoms and clinicians' observations[18,32,37] than on patients' accounts.

Limited patient communication skills create a diagnostic challenge for some clinicians such as primary care providers, who have not been specifically trained to diagnose mental health disorders among individuals with MR.[36,37] Lennox et al. found that 93% of general practitioners felt that they would benefit from additional training in MR.[44] Even many psychiatrists lack experience diagnosing mental health disorders in this population. A study of Australian psychiatrists, for instance, found that 75% of those surveyed felt that they hadn't received sufficient training in dual diagnosis, and 39% preferred not to treat the dually diagnosed.[45]

Since those with mild MR are less likely to have trouble communicating or severe baseline symptoms, the process of diagnosis is much less difficult for this group than for those with severe MR.[42] Consequently, individuals with mild MR may be more likely to be given a mental health diagnosis than those with more severe MR. It is unclear whether those with more severe MR are less likely to have such problems or merely less likely to be identified with mental health conditions.[14,18]

Challenges to accurate prevalence data: methodological limitations of published research

Even when individuals with MR are correctly diagnosed with mental health disorders, methodological limitations of the existing research may affect the accuracy of prevalence estimates and play a part in the wide variance in prevalence noted above. Table 1 summarizes the limitations of the empirical research reviewed here and Table 2 illustrates the varying estimates found in these studies.

Type of data. One issue affecting prevalence estimates is the type of data used in research studies. Population-based data are based on large samples that aim to represent the entire population. Despite their potential generalizability, however, population-based data have limitations. They can underestimate the true prevalence of dual diagnosis if institutionalized individuals are not included in the sample, or if those who seek services in the community are not accurately identified.

Most domestic studies of dual diagnosis have been conducted with small sample sizes and have used medical records or registry data from hospitals or clinics, which count the number of patients admitted or served (administrative data).[18,24,30] Administrative data generally represent only individuals seeking services and thus have limitations as well. For example, the reported dual diagnosis prevalence based solely on administrative data from community settings may under-represent the true prevalence of mental health problems in the MR population[46] since many individuals with both mental illness and severe MR live in institutions and do not use community-based mental health services. Administrative data from institutions alone may over-estimate the prevalence, since those with psychiatric impairments are more likely to be institutionalized than those who do not exhibit psychiatric symptoms.[21] Estimates from studies using

Table 1. Description and methodological limitations of studies citing prevalence estimates of mental health disorders among people with MR

Author	*Title*	*Sample/ study design*	*Method of case ascertainment*	*Limitation(s)*
Birch et al. 1970[56]	Mental Subnormality in the Community: A Clinical and Epidemiologic Study	104 8- to 10-year-old residents of a small town	City/school health records	Older study; potential biases because health records may not have included children who were institutionalized.
Borthwick-Duffy and Eyman 1990[18]	Who Are the Dually Diagnosed?	78,603 clients who received services from the California Department of Developmental Services	Computerized system of client information	Results rely on accurate diagnosis in system; potential biases because study was limited to individuals who were referred for services.
Crews et al. 1994[14]	Dual Diagnosis: Prevalence of Psychiatric Disorders in a Large State Residential Facility for Individuals with Mental Retardation	1,273 residents of an institutional setting	Psychiatric and behavioral problems identified through the institution's database	Difficulties making diagnoses at this institution due to a limited number of trained staff; potential biases because study was limited to institutionalized individuals.
Eaton and Menolascino 1982[19]	Psychiatric Disorders in the Mentally Retarded: Types, Problems, and Challenges.	114 participants in a community-based program who were diagnosed with a psychiatric disorder(s) and MR	Psychiatric assessment	Potential biases because study was limited to dually diagnosed individuals in a community setting.
Edgerton 1986[52]	Alcohol and Drug Use by Mentally Retarded Adults	141 individuals with MR from a variety of community settings	Ethnographic data collection	Methods of sample ascertainment are unclear.
Gillberg et al. 1986[47]	Psychiatric Disorders in Mildly and Severely Mentally Retarded Urban Children and Adolescents: Epidemiological Aspects	164 children with MR identified for a population-based survey through register searches and screenings	Registry searches and psychiatric examination/ assessment	Potential biases because it was unclear if children residing in institutions were included in registers; study was limited to urban residents.
Glick and Zigler 1995[53]	Developmental Differences in the Symptomatology of Psychiatric Inpatients with and without Mild Mental Retardation	112 state psychiatric hospital patients with mild MR	Survey of services provided for patients with MR; chart review	Potential biases because study was limited to residents of psychiatric institutions.

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administrative data must be interpreted carefully, as they are often reported as percentages of individuals seeking services or living in institutions, not of those in the general population who have MR.

Thus, prevalence estimates may depend on the type of study conducted. For example, research on conduct disorder among children with MR has found mixed results. One European population-based study found a prevalence range

Table 1 (continued). Description and methodological limitations of studies citing prevalence estimates of mental health disorders among people with MR

Author	Title	Sample/ study design	Method of case ascertainment	Limitation(s)
Iverson and Fox 1989[23]	Prevalence of Psychopathology Among Mentally Retarded Adults	165 adults with MR identified by a community service center	Informants completed a standardized assessment tool.	The instrument was based on DSM III criteria, which are limited when applied to those with MR; potential biases because government-sponsored services may yield a biased sample of clients.
Jacobson 1982[22]	Problem Behavior and Psychiatric Impairment in a Developmentally Disabled Population: I. Behavior Frequency	30,578 mentally retarded indivi-iduals partici-pating in developmental disabilities services in New York State	Data abstracted fromthe NY Developmental Disability Survey Information database	Potential biases because mildly retarded individuals are less likely to use services than those with moderate or severe MR, and people with mild MR who do use services may be more likely to have mental health disorders than others with mild MR.
Reid 1980[49]	Psychiatric Disorders in Mentally Handicapped Children: A Clinical and Follow-up Study	60 children with intellectual disabilities receiving psychi-atric services in a clinic	Review of documentation by clinician	Potential biases because study was limited to individuals attending a psychiatric clinic.
Reiss 1990[20]	Prevalence of Dual Diagnosis in Com munity-Base Day Programs in the Chicago Metropolitan Area	205 randomly selected participants of community-based day programs for people with MR	Rating scales completed by teachers, caregivers, or supervisors	Potential biases because study was limited to individuals using community day programs.
Reiss 1982[40]	Psychopathology and Mental Retardation: Survey of a Developmental Disabilities Mental Health Program	66 individuals who used an outpatient clinic oriented toward mental health services for indi-viduals with MR	Diagnoses made at staff conferences by three clinical psychologists	Potential biases because study was limited to individuals attending a mental health clinic.

for this condition among children with MR (4.5% to 12%)[47] that is similar to U.S.-based estimates of conduct disorder in the general population of children (1% to 6%).[48] Conversely, research using administrative data in Europe has found conduct disorder to be more common among children with MR (45%).[49]

Identifying disorders. The methods used to identify a mental health disorder often vary, and these too can influence the prevalence estimates of such conditions for the MR population. While some studies use chart reviews to identify diagnoses noted in medical records, others use structured diagnostic assessments to identify dual diagnosis. The prevalence of dual diagnosis has been found to be much lower when chart reviews are used than when prevalence is determined by the use of specific diagnostic tools.[20] Reiss, for instance, found a 12% prevalence of mental health disorders in a community-based day program for individuals with MR using chart reviews and a 39% prevalence using screening tests.[20]

In addition, while some researchers study mental health conditions as defined in the *Diagnostic and Statistical Manual of Mental Disorders,*[50] others use different scales and interview instruments for diagnosis.[14]

Type of mental health condition. As mentioned above, many review articles or articles discussing mental health conditions among those with MR do not specify the type of mental health condition being studied, referring only to "mental health conditions." Further, while some professionals prefer the term "psychiatric illnesses," others use the term "behavioral disorders" to indicate general mental health conditions.[24,36,51] Due to the heterogeneity of mental health conditions, the lack of specificity in diagnostic terminology is a

Table 2. Published prevalence estimates of mental health disorders in the general population and in people with MR

Condition	*General population*	*Adults with MR*	*Children with MR*	*People with mild/moderate MR*	*People with severe MR*
Anxiety disorder	13.1%–18.7% (adults and children)[12]	31.4%[20]	22%[49]	—	—
Schizophrenia	1%[12]	21%–30.3%[19,40]	—	16.7%[40]	46.7%[40]
Substance abuse	7%–51%[54]	0%–3.5%[20,53]	—	—	—
Conduct disorder	1%–16% (children)[48]	—	45% (administrative data)[49] 4.5%–12% (population-based data)[47]	—	—
Depression	7% (adults)[12]	8.9% (institutionalized)[14]	—	20%[40]	0%[40]
ADHD	4%–12% (children)[55]	—	11%[47]	—	—

ADHD = attention deficit/hyperactivity disorder

major limitation to understanding prevalence estimates. In fact, whether the prevalence estimates of certain mental health disorders are higher for people with MR than for those in the general population depends on the condition studied. For example, the Surgeon General's report indicates that an estimated 13.1% to 18.7% of the general population have anxiety disorders.[12] Reiss found the prevalence among those with MR to be higher; he reports that 31.4% of individuals at a community-based day program for individuals with MR had such a condition.[20] A similar comparison can be made for children. The Surgeon General's report estimates the one-year prevalence of anxiety disorders among children ages 9–17 years to be 13%,[12] while a small European study of a psychiatric clinic for children younger than 16 years of age with mental handicaps found that 22% had anxiety disorders.[49] Likewise, schizophrenia is believed to occur in only 1% of the general population,[12] compared with administrative reports of 21%[19] and 30.3%[40] of individuals with MR seeking psychiatric services.

Conversely, there has been a much lower prevalence of substance abuse reported among individuals with MR than in the general population.[9,20,52–54] The general population prevalence estimates have been reported to be 8% for illicit drug use, 51% for alcohol use, and 7% for heavy alcohol use.[54] In contrast, Reiss found that none of the 205 participants at a community-based day program for individuals with MR were alcohol or drug abusers,[20] and Glick and Zigler reported mild substance abuse in 3.5% of 112 psychiatric inpatients with mild MR.[53] For other conditions, the prevalence estimates do not appear to be very different for people with MR and the general population. For example, the reported prevalence of attention deficit/hyperactivity disorder (ADHD) among European children with MR (11%)[47] is somewhat comparable to the range of estimates reported for the general child population in the U.S. (4% to 12%).[55]

Severity of MR. In addition to differences between conditions, differences in severity levels of MR may contribute to the wide range of prevalence estimates of diagnosed mental health disorders. Many studies have found that the prevalence of general mental health disorders among individuals with MR is highest among individuals with mild MR.[18,21–23] Since individuals with mild or moderate MR are more likely to be aware of their limitations, these individuals may be at higher risk of certain mental health disorders (such as depression) than those with severe MR. Children with moderate MR, in fact, have been shown to be more likely to be rejected by parents than individuals with profound MR.[19] As a result, both adults and children with mild or moderate MR may be at a higher risk of reacting to stressful life events with an affective disorder than those with severe or profound MR. Alternatively, as described above, the differences in prevalence estimates may be due to the fact that mental health disorders are easier to diagnose among those with mild or moderate MR.

For example, a study using California administrative data found that 16% of individuals with mild MR were psychiatrically diagnosed, while only 5.7% of those with severe or profound MR had a dual diagnosis.[18] Reiss, however, found that the relationship between severity of MR and mental health may vary with the condition studied.[40] Based on a survey of individuals referred to an outpatient clinic for individuals with developmental disabilities, Reiss reports schizophrenic symptomatology to be more frequently diagnosed among individuals with severe MR (46.7%) than among individuals with mild MR (16.7%). In the same study, he found that 20% of individuals with mild MR were diagnosed with depression, compared with none of those with severe MR. In contrast, a study of institutionalized individuals that did not account for severity of MR found the prevalence of depression to be 8.9%,[14] which is fairly similar to the 7% prevalence in the general population.[12] Without accounting for severity, then, comparisons can be misleading.

Differences between cases of mild and severe MR in estimates of the prevalence of dual diagnosis, however, may also be due to the type of study conducted. In contrast to most of the administrative studies cited above, population-based studies have generally found that individuals with more severe MR have a higher general prevalence of dual diagnosis than those with less severe MR.[21,47,56] For example, one popula-

tion-based European study reported prevalence estimates of psychiatric disorders of 60% among those with IQ scores <60, and just over 20% among those with IQ scores in the 60–69 range.[56] Thus, while most studies based on administrative data report more mental health conditions among individuals with mild MR, studies using population-based data report a higher prevalence among those with severe MR. As discussed above, this may be because those with both severe MR and a mental health condition are likely to be institutionalized, and thus unlikely to be captured in administrative data that do not include institutions. Further, institutionalized individuals may be more likely to be treated by experienced mental health providers who are capable of making difficult diagnoses, than are those with mild or moderate MR who live in community settings. In fact, those living in institutional care have been reported to have a higher prevalence of dual diagnosis (18.6%) than individuals living with their families (5.1%).[18]

Further, the discrepancies in prevalence estimates may be due to confounding factors such as familial supports and interactions with peers. Those with mild MR (who are more likely to live in the community) may have greater opportunities to benefit from supports such as family contact, while those with severe MR (who are more likely to live in institutions) may have more access to other supports, such as interactions with peers. Since these factors may play protective roles in this population, it is necessary to account for these external factors to truly understand the distribution of dual diagnosis among those with mild and severe MR.

Summary and implications

The results of this review indicate that many challenges currently prevent the accurate estimation of the prevalence of mental health disorders among those with MR. Because health care providers often have difficulties diagnosing these conditions in this population, the percentages of mental health conditions reported here may underestimate the true percentages in this population. Further, due to limitations and inconsistencies in research methodology, comparisons between individuals with MR and the general population are challenging. In fact, as described in this article, reported prevalences of dual diagnosis can vary by many methodological factors, such as whether studies used administrative or population-based data.

These challenges have led to inconsistent estimates of the prevalence of mental health disorders among individuals with MR. Based on available data, however, there seems to be consensus that there is a higher prevalence of certain mental health disorders in this population than in the general public. Adults with MR are reportedly diagnosed more often with anxiety and psychotic disorders than members of the general population, but fewer people with MR are reported to be substance abusers than in the general population. Children with MR are more likely to have anxiety disorders than other children, but estimates for affective disorders and ADHD are similar. Studies of conduct disorder have yielded mixed results.

Further, the prevalence of mental health disorders has been reported to vary by the severity of MR. Whether that is due to diagnostic challenges in assessing people with severe MR, lifestyle issues for those with mild/moderate MR, differences in individuals' living situations, or methodological differences remains unclear.

Implications

While in the past most people with MR in the U.S. received mental health care in the institutions in which they lived, currently most Americans with MR live in community or family settings. To ensure that appropriate community-based services and treatment are accessible to this population, accurate prevalence estimates of mental health conditions among individuals with MR are needed.

Several systems-level changes could improve the estimates of mental health conditions for this population. For example, providers may not be, or at least may not feel, equipped to diagnose mental health disorders in this population. The curricula and training for all health care providers should be reviewed and updated to include specific education (both classroom hours and clinical experience) on MR. This should include clinical experience as well as classroom hours. There are, for example, specific exams designed for determining the nonverbal cues of the MR patient when assessing mental health,[57] and training in using such methods should be part of providers' education. In addition, practice guidelines could help to ensure the quality of care and raise providers' confidence that they are providing appropriate care. Specific screening and health supervision guidelines should also be developed to address the special mental health care needs of people with MR.

Further, the wide range of prevalence estimates may be due to the heterogeneity of mental health conditions. Since mental health is such a broad term, articles and discussions on this issue should report data on the prevalence of specific conditions, rather than overall estimates of dual diagnoses. In addition, different study methodologies can lead to very disparate results. Specifically, the current use of community-based data may underestimate the true prevalence and the use of institution-based data may result in an over-estimation of the prevalence of dual diagnoses. Because of the inconsistent methodologies currently used to identify mental health disorders among individuals with MR, it is not always possible to compare prevalence estimates across studies, which limits confidence in research findings.

To improve the quality of the prevalence estimates of dual diagnoses, the research community should improve data collection mechanisms. One way to do this would be to increase access to data that are truly population-based. The research community, policy makers, and other government officials should consider developing a national database or a national registry of individuals with MR (which would include individuals who live in institutional settings as well as in the community) to accurately determine the health and health care needs of this population. Another way to improve data quality would be to collect administrative data that are more representative of the population. As discussed above, the way that administrative data have been collected in the past has not always led to results that are representative of the whole population. Future studies that use administrative data should collect data from both community and institutionalized settings. Further, standardized and accepted methodologies should be duplicated, so that prevalence estimates can be compared across studies.

According to the literature, prevalence estimates of specific mental health conditions among individuals with MR range from 0% to 45%, depending on the condition being studied. The same prevalence estimates in the general population range from 1% to 64%. In order to truly understand the differences in these estimates, the diagnosis of mental health conditions should be improved for individuals with MR, the prevalence of specific conditions should be reported, and the research methodologies used should be representative and comparable across studies. Only when the prevalence of these conditions is understood will society be able to ensure that appropriate services are available to all those in need.

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