THE HEALTH STATUS AND NEEDS OF INDIVIDUALS WITH MENTAL RETARDATION

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CHAPTER 1

INTRODUCTION

Purpose

In recognition of the need to improve the quality of life of individuals with mental retardation (MR), Special Olympics Inc. (SOI) commissioned this report to examine the health needs of children and adults with MR. The purpose of this report is three-fold: 1) to identify the current health status and needs of individuals with MR, 2) to identify services gaps in supporting these needs and 3) to propose specific recommendations to address the unmet health care needs of individuals with MR.

Early in the 20th century, individuals with MR were generally isolated, rather than encouraged to lead fulfilling and healthy lives (David, 1970; Rix, 1986, Campbell, 1999). The last 40 years, however, have seen dramatic changes in sentiments regarding those with MR, resulting in a turn in public policy towards an emphasis on normalization and inclusion (Rowitz, 1992; Kauffman and Hallahan, 1995; Parmenter, 1999). Other developed countries, such as Canada, the United Kingdom (U.K.), the Scandinavian countries and Australia, have seen similar movements (Malin, 1981; Rowitz, 1990; Parmenter, 1999).

As a result of these changes in developed countries, much debate and research has focused on the prevention of MR, deinstitutionalization, and the education and employment of individuals with MR (Tizard, 1971; Clarke, 1991; Anderson et al., 1998). In the U.S., these themes are reflected in court cases, legislative actions and federal initiatives, including Wyatt v. Stickney (1972), Public Law 94-142 and its successor, the Individuals with Disabilities Education Act (IDEA), the Americans with Disabilities Act (1990) and reports by the President's

Committee on Mental Retardation (Anderson et al., 1998). Globally, a variety of international organizations, such as the International Association of Scientific Studies on Intellectual Disability, have been developed to support and study both the prevention of MR and the public education concerning individuals with MR (Clarke, 1991). The health status and health service needs of individuals with MR, however, have received little attention over the past four decades.

This lack of attention to health status is surprising, particularly in light of the tremendous gains in life expectancy which have resulted from medical and public health advances. The life expectancy of individuals in the U.S. increased 27.26 years between 1900 and 1990 (NCHS, 1999), and in 1997, the average life expectancy was 76.5 years (Anderson, 1999). Similarly, the life expectancy for individuals in Western Europe increased in the past century, resulting in a current average life expectancy of 74.0 years (Population Division, 1998). Increased longevity is evident not only in the general population, but also among individuals with MR (Rowitz, 1992; Janicki and Breitenbach, 2000). Currently, the average life expectancy of older adults with MR is 66.1 years, but younger adults with MR are expected to live as long as their peers without MR (Janicki et al., 1999). With improved assistive technology and effective public health programs that control most infectious diseases, not only are individuals with mild MR living longer but some individuals with more severe MR also have increased life expectancies (Eyman et al., 1988). As a result, these individuals have recently been faced with the same chronic diseases, including cardiovascular disease, cancer and diabetes, which confront the general adult population (Moss and Turner, 1995 in Barr et al., 1999).

Although effective health prevention strategies and treatments exist for many diseases (Bunker et al., 1995; U.S. Preventive Services Task Force, 1996), not everyone benefits equally from these medical interventions. The poor, minorities and the socially disadvantaged

disproportionately have poor health outcomes and lack access to adequate health care services (Hertzman et al, 1994). Individuals with MR are particularly vulnerable to having unmet health care needs, as they are faced with many challenges in understanding and maintaining their health (President's Committee on Mental Retardation, 1999). Individuals with MR may have difficulties understanding the effects of behavior on health, the risks and benefits of medical treatment, and the process of accessing appropriate and necessary health services (Barr et al, 1999; President's Committee on Mental Retardation, 1999). In addition, when health care services are utilized by this population, health providers may have difficulties recognizing and treating various diseases, obtaining accurate medical histories and communicating with patients who have cognitive and language disabilities (Schor et al., 1981; Minihan and Dean, 1990; Lennox et al., 1997)

The lack of access to appropriate health care services also may be a relatively new problem for individuals with MR, resulting, at least in part, from the deinstitutionalization of the 1970s and 1980s. Between 1967 and 1997, as individuals with MR were mainstreamed into the community, there was a 71% reduction in the number of individuals in state MR/developmental disability facilities (Anderson et al., 1998). Trends of declining populations in MR facilities also are evident in other developed countries, such as Great Britain, where there was a 36% reduction in the number of individuals in long-stay hospitals between 1980 and 1990 (Hart, 1998). As a result of deinstitutionalization, all but the most severely disabled individuals with MR are expected to function in the community environment. Many of these individuals can and do achieve levels of functioning that were not previously thought possible (President's Committee on Mental Retardation, 1999). Not all, however, have their health care needs adequately addressed in the community, due to a limited availability of community resources and a lack of

access to both knowledgeable care providers and a continuity of care (Savino et al., 1973; Saenger et al., 1979; Newacheck et al., 2000). In addition, the recent increase in managed care, and its emphasis on cost-containment, may exaggerate the impact that poor access to quality medical care has on this population (Kastner, 1991; Department of Health, 1995 in Jones and Kerr, 1997, President's Committee on Mental Retardation, 1999). As a result, unmet health care needs may be an unintended consequence of deinstitutionalization. Although controversy remains regarding the quality of care received in institutions (Landesman and Butterfield, 1987; Lowe et al., 1995), individuals in residential centers were at least likely to have a usual source of care and be seen by providers experienced in the treatment of individuals with MR (Durkin, 1996).

Consequently, to develop a coherent set of recommendations for the improvement of the health of individuals with MR, a thorough review of the literature on the current health status of those with MR was commissioned by SOI. In preparation for this report, several steps were taken to ensure a thorough review of academic and public policy documents. Researchers searched Medline and PsycInfo for peer-reviewed articles on the physical, mental, dental and ocular health of people with MR, as well as the availability and accessibility of health care services for these individuals. Many of these studies utilized administrative data accessed from service delivery databases. In addition, publications and reports were obtained from national and international organizations focusing on MR, including the American Association for Mental Retardation (AAMR), The Arc of the United States, and the International Association for the Scientific Study of the Intellectual Disabilities (IASSID). Based on a search of GPO Access and the Internet, government documents that relate to the health and health service use of individuals with MR also were obtained. Further, individuals from several federal agencies (including the

Centers for Disease Control and Prevention, the National Council on Disability, the President's Committee on Mental Retardation, the U.S. Bureau of Census and the U.S. Department of Health and Human Services) were contacted and interviewed. Although numerous articles exist regarding the health status and needs of individuals with MR, not all are scientificially rigorous or pertinent to this manuscript. Therefore, while approximately 1,100 articles were considered, only 548 were admitted into this review.

Individuals from academic institutions and those involved in programs for individuals with MR through SOI, including Drs. Paul Berman, Sandra Block, Steve Corbin, Matthew Janicki, Steven P. Perlman, and H. Barry Waldman, also provided additional information. National U.S. datasets, including the National Health Interview Survey (NHIS), the National Health Expenditure Survey and the Survey of Income and Program Participation, also were reviewed to determine the availability of data related to individuals with MR.

Following a review of the definition and prevalence of MR, this report examines the physical, ocular, mental and dental health needs of individuals with MR. Next, the health care services available and accessible to this population are discussed. The report concludes with a list of recommendations, proposed to improve the health of individuals with MR.

Definition of Mental Retardation

Introduction

Valid measurement is the cornerstone of reliable epidemiological studies. Inappropriate measurement can result in a misclassification of either exposures or outcomes (in the case of this review, the classification of individuals with or without MR), which may lead to inconsistent or biased results (Armstrong et al., 1992; Kelsey et al., 1996; Rothman and Greenland, 1998). To ensure the correct classification of individuals into the categories of interest, definitions should

be precisely specified from the outset of any study (Rothman, 1986). This is particularly important when examining social, psychological or cognitive impairments, such as MR, because often no objective biological measurement of these conditions exists (Kelsey et al., 1996).

An accurate and consistent definition of mental retardation is critical because of its impact on the prevalence, or count, of those with MR. However, despite the importance of consistency, MR is not always defined in the same way across research studies or service agencies, even within the same state (Koller et al., 1984; Borthwick-Duffy et al., 1994). While some definitions rely on IQ scores alone to classify individuals with MR, some only use adaptive behaviors for classification, and others include both IQ scores and measures of adaptive skills (Whitman et al., 1990; Borthwick-Duffy et al., 1994). In addition, many studies are based on broad categories of either severity (using labels such as mild, moderate, severe and profound MR) or etiology (utilizing the terms cultural/familial and organic MR).

Definition of Mental Retardation

The most commonly cited definition of MR comes from the AAMR. Most recently (1992), the AAMR has defined MR as the onset of significant limitations in both general intellectual and adaptive functioning during the developmental period (18 years and under). Intellectual limitations refer to an Intelligence Quotient (IQ) which falls two standard deviations below the population mean of 100 (<70), and adaptive functioning limitations refer to impairments in at least two out of ten skill areas (AAMR, 2000). MR is also defined in the Diagnostic and Statistical Manual of Mental Disorders, 4th edition (DSM-IV) by the American Psychiatric Association (APA). Similar to the AAMR definition, the DSM-IV has three

diagnostic criteria for MR, including sub-average intellectual functioning (IQ < 70), impairments in adaptive functioning and onset before age 18 (APA, 1994).

Although the core criteria for MR are similar between the AAMR and the DSM-IV definitions, there are important differences between the two. First, while the DSM-IV definition of MR has a strict IQ cutoff of 70, the 1992 AAMR definition indicates that if an individual presents with other signs of MR, the IQ cutoff may be raised to 75 (Schalock et al., 1994; Reiss, 1994). Second, although both definitions include a sub-classification system, the bases of the two sub-classification systems differ. The AAMR definition includes a scale measuring the extent of support needed to function in the environment, focusing on an individual's strengths, support systems, capabilities and interaction with the environment (Schalock et al., 1994; King et al., 1997). In contrast, the DSM-IV definition specifies the degrees of MR severity based on the level of IQ (mild=50-55 to 70, moderate=34-40 to 50-55, severe=20-25 to 35-40 and profound <20-25) (APA, 1994). Further, although not formally part of the definition of MR, the APA includes MR in the DSM-IV, thereby classifying MR as a mental disorder. The AAMR, however, explicitly states that MR is neither a medical nor a mental disorder (AAMR, 2000).

Considerable controversy exists over the use of the 1992 AAMR definition, however. While the definition was intended to broaden the definition of MR so that more individuals would be eligible for services (Reiss, 1994; MacMillan et al., 1995), several researchers believe that the 1992 definition compromises the conceptual and psychometric integrity of the 1983 definition of MR (MacMillan et al., 1995). Prior to 1992, for example, the AAMR definition focused on deficits at each developmental stage, using a severity scale (similar to that used by the APA) to emphasize IQ scores and expected age-appropriate behaviors (AAMD, 1983). In 1992, however, the AAMR increased the possible upper IQ score to 75, set general adaptive

behaviors as a criterion and developed a sub-classification system based on levels of needed supports (MacMillan et al., 1993). Critics of the new definition believe that setting the IQ score limit to 75 may result in a classification of MR for individuals who have skills similar to their peers without MR, and may lead to an over-classification of minorities as having MR. Further, reliance on IQ has been criticized because of the cultural biases inherent in this measure (Hobbs, 1975; Zigler et al., 1984). Additional concern revolves around the measurement of adaptive behaviors and needed supports, which are thought to be poorly defined and to ignore developmental factors, thereby increasing the potential for misclassification. Consequently, some authors believe that a sub-classification system of MR should rely on etiology rather than poorly measured levels of supports (MacMillan et al., 1993).

The definitions of MR discussed thus far, however, ignore etiology. In contrast, Zigler and colleagues (1967; 1984; 1986; 1987a; 1991) argue that an appropriate classification of MR employs both IQ score and etiology of the retardation. Consequently, they suggest categorizing MR into cultural/familial and organic groups, based on the presence or absence of a known organic etiology. This two-group approach is one of the most well documented distinctions in the mental retardation literature over the last century.

Cultural/familial MR refers to individuals with IQs of 50-70, who do not have any identifiable physiological or genetic deficit. Although individuals with cultural/familial MR have lower intelligence than individuals without MR, the stages of cognitive development do not vary between these two groups. Those with cultural/familial MR, however, cognitively develop at a slower rate and do not reach the same cognitive levels as the general population. Consequently, individuals with the same mental age (or cognitive ability), regardless of chronological age, should perform similarly on cognitive-linguistic tasks. Emotional and

motivational factors, however, influence the performance of individuals, and may account for certain behavioral differences between those of the same mental age (Zigler, 1967; Zigler et al., 1984; Zigler and Hodapp, 1986; Zigler and Hodapp, 1991).

In contrast, organic MR is attributable to an identifiable physiological deficit. Individuals in this group typically have IQ scores below 50, although individuals with IQ scores between 50 and 70 also can be classified as having organic MR. The cognitive development of individuals in this group is generally not thought to be comparable to those either without MR or with cultural/familial MR. The behavior of individuals in this group, then, is primarily the result of their physiological deficit (Zigler, 1967; Zigler et al., 1984; Zigler and Hodapp, 1986; Zigler and Hodapp, 1991). Some researchers, in fact, believe that all individuals with MR should be classified in the organic group. As science advances, they argue, physiological deficits will be discovered even among those with no present known organic etiology (Knobloch and Pasamanick, 1961 in Zigler and Hodapp, 1986; Richardson, 1981 in Zigler and Hodapp, 1986).

Even the two-group approach, however, may be too broad a classification system to adequately account for the heterogeneity of each group. While the cultural/familial group is thought to have at least 3 different subtypes (Zigler and Hodapp, 1986), there are hundreds of identified etiologies of organic MR (Lubs and Maes, 1977; Grossman, 1983). It is inaccurate, then, to view individuals with MR as fitting into one of two homogenous classes (Burack, 1990), particularly because many experts in the area embrace the theory of polygenic inheritance (for a description of the theory, see Zigler and Hodapp, 1986).

Although these different definitions of MR do overlap, and are therefore somewhat comparable, multiple classification systems can make comparisons across studies difficult. In addition, the consistency of MR classification has been further complicated by the use of

imprecise labeling. In the U.S., for example, many individuals with mild MR have adopted the label "learning disabled," in order to avoid the stigma associated with "mental retardation" (Palfrey, 1994). The label "learning disabled," however, technically refers to individuals of normal intelligence who are not performing at their maximum ability level (AAMD, 1983). Moreover, in England, the term "learning disabled" is used to identify individuals with mental handicaps (Bhrolchain, 1989). This term, then, has become non-specific and includes individuals with a variety of conditions, including those both with and without MR. This type of imprecise labeling can be problematic, because it can lead to difficulties in conducting needs assessments and allocating services, as well as interpreting studies that use this classification.

Non-Categorical Classification of Mental Retardation

In addition to being defined inconsistently, MR is often grouped together with other conditions. For example, mental retardation is one of many conditions included in non-categorical classifications, such as "disability," which encompass conditions and diseases of different etiologies. In general, this approach has been adopted because it focuses on the similar medical, behavioral and cognitive problems found across illnesses, classifying individuals together based on functioning, rather than diagnosis. In contrast, the categorical approach uses diagnostic labels that do not convey the variability of morbidity within specific diseases (Stein et al., 1993; Stein and Silver, 1999). Eligibility for Social Security Income (SSI), for instance, was previously based on categorical diagnoses. As a result, SSI was denied to those who did not meet severity criteria with a single diagnosis, ignoring the cumulative functional effects of many conditions (Stein et al., 1993). Thus, the non-categorical approach is particularly beneficial for individuals with comorbid conditions, because it increases their likelihood to be eligible for a range of services. Consequently, the non-categorical approach is widely used in legislative

initiatives, such as recent education- and employment-related amendments (Stein et al., 1993), and in policy initiatives put forth by agencies such as the National Policy Center for Children with Special Health Care Needs (Ireys et al., 1999).

Nevertheless, there are problems associated with the non-categorical approach. When different conditions are grouped together, it is difficult to determine the specific medical and social needs of an individual with a certain diagnosis. Disability, for example, is defined broadly to include several conditions, including MR, developmental disabilities, serious emotional disturbances, ongoing orthopedic disorders, genetic disabilities and chronic illnesses (Ireys et al., 1999). Since the needs associated with these different conditions vary greatly, using this term to represent any one of these groups gives very little information about the needs of an individual with a specific condition.

Summary and Implications

Because the definitions of MR used across research efforts vary, this report indicates the definition employed when describing study results. Although some research efforts focus on conditions such as Cerebral Palsy and Autism, these studies are not included in this review, since individuals with these conditions do not uniformly have MR. Data on individuals with Down Syndrome (the one condition for which MR is a criterion) however, are presented. Further, although individuals with MR are included within non-categorical classifications, such as developmental disabilities, utilizing these terms in research makes it difficult to conclude anything specific about MR. Thus, in this report, efforts were made to avoid studies employing non-categorical definitions.

Prevalence of Mental Retardation

Introduction

As mentioned above, prevalence data are crucial to the allocation of funding and the development of services, as well as to the comparison of findings between different research efforts. The prevalence of mental retardation is affected by many factors, including the definition of MR, the population studied and advances in medical technology. As discussed in the previous section, the definition of MR is an integral part of the determination of MR prevalence in the population. In addition, the population studied influences the prevalence found and indicates how generalizable that count may be. Most research uses either population-based or service use-based (administrative) data. While many European countries maintain registries of individuals with MR (making population-based studies common in those countries), no such registry or comprehensive national survey exists in the U.S. One national survey of the U.S. population, the NHIS, did have one question regarding MR, but because of the low prevalence found in 1981, the question was dropped in 1988 (Boyle et al., 1994). In addition, in 1994, a supplement to the NHIS (NHIS-D) was employed to collect population-based data regarding disabilities. The definition of MR used in the NHIS-D, however, was not consistent with either the AAMR or the APA definition; rather, the NHIS-D classification focused on previously diagnosed MR, conditions frequently associated with MR, and functional limitations in learning. Further, although MR involves disabilities of development, individuals with MR did not necessarily meet the criteria (three or more functional limitations) to be classified with a developmental disability, as defined by Public Law 98-527, in the NHIS-D (Research and Training Center on Community Living and Institute on Community Integration, 2000).

Since 1990, the Survey of Income and Program Participation (SIPP), another U.S. population-based survey, has documented MR among those households randomly selected for participation. It does not, however, make a specific effort to sample households of individuals with MR or other disorders. As a result, given the low probability of identifying individuals with MR in a randomly selected population, the SIPP cannot be considered a comprehensive account of those with MR (U.S. Bureau of the Census, 1999). In addition, both the NHIS and the SIPP underestimate the prevalence of disabilities among children and adults, because individuals living in institutions or group homes are excluded from the surveys (U.S. Bureau of the Census, 1999). In contrast to many European studies, then, most research efforts in the U.S. do not use population-based samples; rather, they rely on the number of individuals who utilize special services to estimate the prevalence of MR in the overall population.

Advances in medical technology have had a great impact on the prevalence of MR as well. Throughout the century, medicine's ability to treat the comorbid conditions of individuals with MR, and thus increase their survival time, has improved (Primrose 1984; Whitman et al., 1990). For example, individuals with Down Syndrome tend to suffer from thyroid and heart conditions, which can be better detected and treated today than in the past (U.S. Preventive Services Task Force, 1996; Saenz, 1999; Singer et al., 1995). Therefore, the increased life expectancy of these individuals results in a higher prevalence at any one point in time.

Further, several factors potentially affect the number of individuals who are actually born with MR. The rise in prenatal care, increased genetic screening and improvements in neonatal testing, for example, tend to increase the likelihood that children are born healthy. In contrast, other factors, such as increased prenatal substance use, tend to counter-act these effects and

increase the prevalence of MR (Grossman et al., 2000). In sum, it is difficult to predict how the synergy of these factors affects the ultimate prevalence of MR.

U.S. Prevalence of Mental Retardation

It is estimated that as many as 2.0-7.5 million Americans of all ages may have MR, and that 1 in 10 families are directly affected by mental retardation (President's Commission on Mental Retardation, 1997; Grossman et al., 2000). Many reports have suggested that the population prevalence of MR in the U.S. is as high as 3.0% (Tarjan et al., 1973; Zigler and Hodapp, 1986; President's Commission on Mental Retardation, 1997). A U.S. study using administrative data, however, found the prevalence among children to range from 0.3% to 3.1% in different regions of the country, with a national average of 1.1% (King et al., 1997). Similarly, the Metropolitan Atlanta Developmental Disabilities Surveillance Program, a population-based study which only used IQ score as the criterion for MR, found an overall prevalence of 0.9% among 3-10 year-old children (Boyle et al., 1996). Further, although the NHIS-D used its own definition of MR, it reported that .78% of the population had MR, with a prevalence of .45% for children 0-5 years, 2.0% for children 6-17 years, and .52% for individuals 18 years or older (Research and Training Center on Community Living and Institute on Community Integration, 2000).

Further, because teachers are often the first to notice mild developmental problems, most identified mild MR is initially detected during school years. The Atlanta population-based study, for example, indicated that while the prevalence of mild or moderate MR was only 0.5% for children 3-4 years of age, the prevalence rose to 1.2%, when older, school-aged children were studied (Boyle et al., 1996). It has been suggested, however, that only 50% of children with MR

are identified at a young age because the failure to adapt normally and grow intellectually may not become apparent until later in life. Early identification may be further hampered by the fact that most pediatricians do not generally use standardized instruments to detect developmental delays (Grossman et al., 2000). In addition, because of their high level of functioning, those with mild MR are often unknown to special services once they leave school, and so, as adults, these individuals may not be counted as having MR in studies using administrative data. Moreover, many diagnosed children do not meet criteria when tested later in life. This suggests that either childhood or adult diagnoses are not adequately evaluating adaptive functioning (Forness, 1972 in King et al., 1997), or that IQ scores and functioning may vary over time (Zigler et al., 1984; Zigler and Hodapp, 1986; Loveland and Kelley, 1988 and Dykens et al., 1994 in King et al., 1997).

The majority of individuals with MR have historically been classified as having mild, cultural/familial MR. In the Atlanta population-based study 0.84% of 10 year-olds had IQs between 50 and 70 (mild MR), and 0.36% had IQs less than 50 (moderate to profound MR) (Yeargin-Allsopp et al., 1997). In addition, Boyle et al. (1996) reported that two-thirds of the children with MR in this study were classified as mild. Further, the prevalence and type of MR found in this study varied with race and gender, with Black males having percentages of mild, moderate and severe MR 3.1 times as high as those for White females. Percentages of profound MR (most likely organic), however, did not vary by race in this study (Boyle et al., 1996).

Part of the variation in the U.S. reported prevalence of MR is clearly due to differences between research efforts. For example, researchers making extrapolations based on birth estimates may report a higher prevalence than the number of cases counted in studies using

either population-based or administrative data (Tarjan et al., 1973). The results of these latter studies, however, consistently indicate a prevalence of 1.0%.

International Prevalence of Mental Retardation

In other developed countries, the prevalence of mild MR appears to be lower than it is in the U.S. Percentages of MR or mental handicap in Sweden, for instance, have been estimated to be between 0.3% and 0.7% (Grunewald, 1979; Golding, 1982; Halldin, 1984, Zigler and Hodapp, 1986). Interestingly, although the prevalence of mild MR has been found to be lower in Sweden than in the U.S., the two countries have reported comparable percentages of severe MR (Zigler and Hodapp, 1986). Sweden's low prevalence of mild MR may seem surprising, given that at least some of the Swedish studies use a higher IQ cutoff (<80) to define this condition. However, Sweden has few psychologists, and testing is not as widespread there as it is in the U.S. (Zigler et al., 1984). Additionally, Swedish prevalence estimates of MR are based on the subjective opinions of teachers and clinicians, who are reluctant to label mildly cognitively impaired children (Zigler, 1987b). Further, since Sweden keeps a registry of individuals with MR, many Swedish studies are population-based, which may lead to a more accurate population prevalence than that estimated in the U.S. In addition, Sweden is a welfare state, and has many programs available for those with mild MR. As a result, many of these individuals are cared for in the community, and may never even be thought of as having MR until their IQs (at least males) are formally tested for entry into military service (Zigler et al., 1984; Zigler and Hodapp, 1986; Zigler, 1987b). When estimates from the community are combined with estimates from armed forces testing, the prevalence estimates for MR increase to 2.21%, similar to that found in other countries (Zigler, 1987b).

Other developed countries also have registries of mental retardation, which makes population-based studies more feasible than in the U.S. The overall prevalence of moderate and severe MR, arrested development or severe abnormality among children and adults in England has been found to range between 0.3% and 0.5 % (Wing, 1971; Holt et al., 1973; Elliot et al., 1981; Goh et al., 1994). A study using a surveillance registry in British Columbia found the overall MR prevalence rate to be similar (0.4%), with 0.1% mild, 0.1% moderate, 0.05% severe, 0.04% profound and 0.01% unspecified MR (Herbst and Baird, 1983). In Ireland, using an IQ cutoff of 50 (severe MR), the rate of MR among adults 20-29 was found to range from 0.4 to 0.6% (Mallon et al., 1991).

In less developed countries, percentages of MR are generally found to be higher, from 1.6%-3.0% (Islam et al., 1993). However, several recent studies have found the prevalence of MR to be quite low. For example, in The People's Republic of China, the use of intelligence tests in several districts found a prevalence that ranged between 0.4% and 0.7% (Kuo-Tai, 1988). Similarly, a study in Cape Town, South Africa, using administrative data, found the prevalence of severe MR to be 0.3% (Finedlander et al., 1982), and a population-based study of prevalence in Bangladesh found a rate of 0.6% for severe MR and 1.4% for mild MR (Islam et al., 1993). Further, a study that went door-to-door in India, using the Binet-Simon scale to define MR as an IQ<80, has indicated a prevalence rate of 0.4% in the general population and 1.0% among children (Satapathy et al., 1985).

Summary and Implications

Most prevalence studies, then, utilize IQ alone to define MR. In the U.S., while the range of MR prevalence has been reported to be between 0.3% and 3.0%, most studies using

administrative or population-based data have found a prevalence of 1.0%. In contrast, international studies, using population-based registries and somewhat different definitions of MR, report the prevalence to be less than 1.0%. The U.S. prevalence of severe MR, however, is comparable to that of other countries; in fact, some studies have found lower percentages of severe MR in the U.S. than in other countries. Since most mild or moderate MR is identified among school children in the U.S., the discrepancy in the prevalence of those conditions may due to international differences in school-based testing and services requirements (Palfrey, 1994), as well as mainstreaming practices. Further, the low prevalence of MR in some countries may be due to socio-cultural factors. In China, for example, there is a one child per family policy (Kane and Choi, 1999) and a strong preference for terminating pregnancies with genetic abnormalities (Mao and Wertz, 1997), both of which may affect the number of children born with MR.

These comparisons indicate that the international discrepancies in prevalence may, in part, be due to the different populations, definitions of MR, and methods of identification used in research studies. Moreover, cultural and political differences among countries may influence both the number of individuals with MR and the numbers that are counted in research studies. Despite these discrepancies, however, individuals with MR are present in all countries, and their needs, including their health needs, merit attention.

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CHAPTER 2

PHYSICAL HEALTH CONDITIONS CONTRIBUTING TO THE MORBIDITY AND MORTALITY OF INDIVIDUALS WITH MENTAL RETARDATION

Introduction

For the purpose of this report, physical health conditions refer to chronic conditions that are common causes of death (such as cardiovascular diseases, cancer, diabetes, lung diseases, and unintentional injuries), risk conditions related to these chronic diseases, and childhood conditions and prevention measures that influence the long-term health and functioning of individuals (such as otitis media, pediatric asthma, child maltreatment and immunizations). Other physical health conditions, such as ocular and oral health conditions, are not included in this definition, and will be discussed in separate chapters.

Lacking large population-based studies, evidence documenting the prevalence of these physical health conditions among individuals with MR comes primarily from small community registries or administrative data from outpatient clinics or residential facilities. Since many individuals with MR do not receive services on a regular basis (Howells, 1986; Singer et al., 1986), however, studies using outpatient samples may underreport the prevalence of health conditions that do not always prompt medical interventions. Conversely, prevalence estimates from institutions may overreport the prevalence of certain health conditions, because those in hospitals or long-term residential settings are generally the most severely physically impaired and are likely to be monitored at regular intervals (Eyman et al., 1986).

Prevalence estimates are also affected by the identification of symptoms, either by the individuals with MR or by the caregiver. Often limited in communication skills, individuals with

MR rely on caregivers to identify symptoms and report them to providers. Providers, then, must detect clinical manifestations of disease among individuals who lack communication skills to provide descriptions of symptoms. Consequently, syndromes based largely on reported symptoms rather than physical signs or specific routinely administered tests may also be underidentified.

Mortality and Morbidity

Despite overall gains in life expectancy, gaps still exist between individuals with MR and individuals in the general population. In Western Europe and the United States, the overall life expectancy at birth is 74.0 to 76.5 years and life expectancy at 65 years is 81.7 to 82.7 years (Hoyert et al., 1997; WHO, 1997). In contrast, individuals with mild or moderate MR have an average life expectancy at 45 of 66.1 years, while those with severe MR have an average life expectancy at 45 of 53.6 years. Thus, the life expectancy of individuals with MR decreases with increased severity of MR and increased severity of physical impairments (Janicki et al., 1999; Eyman et al., 1990; O'Brien et al., 1991; Eyman et al., 1993), suggesting that those with mild or moderate MR have different health trajectories than those with severe or profound MR.

Further, life expectancy may be related to place of residence, although the results of the research are inconsistent. Hayden (1998) points out that some researchers have documented higher mortality rates among individuals with MR in institutions compared with those in the community, while others have suggested that individuals in the community have higher mortality rates (Strauss et al., 1998).

Living longer than individuals with severe MR, those with mild or moderate MR are more likely to have age-related health conditions similar to the general population. With a few

exceptions, the prevalence of physical health problems (including cardiovascular disease, cancer, cerebrovascular disease, lung conditions and diabetes) of individuals with MR is similar to that of the general population. This chapter will focus on the health conditions of adults and children with MR and specific health problems prevalent in individuals with Down Syndrome. The health problems selected for review were based on the leading causes of death in the U.S. population and the health priorities of *Healthy People 2000* and *Healthy People 2010* (US DHHS 1990, US DHHS 2000a).

Adult Health Conditions

According to the National Center for Health Statistics (NCHS), the most common causes of death in the United States include cardiovascular diseases, malignant neoplasms or cancer, cerebrovascular diseases, lung diseases, diabetes and unintentional injuries (Hoyert et al., 1999). Not surprisingly, the U.S. has made the prevention and treatment of these conditions a priority in *Healthy People 2000* and *Healthy People 2010* (US DHHS 1990, US DHHS 2000a). These same conditions also impair the health of individuals with MR. The most common causes of death among individuals with MR are cardiovascular diseases, respiratory illness and neoplastic conditions (Thase, 1982; Carter and Jancar, 1983; Dupont et al., 1987; O'Brien et al., 1991; Hayden 1998; Strauss et al., 1998; Janicki et al., 1999; Chaney and Eyman, 2000). This section will review the prevalence of these conditions among adults with MR.

Cardiovascular Disease

Cardiovascular disease is the leading cause of death in the U.S. and internationally, accounting for 31.4% of deaths in the U.S. general population and 30.9% of deaths in World

Health Organization (WHO) member states (Hoyert et al., 1999; Turner and Moss, 1996; WHO, 1999). Manifestations of cardiovascular disease, including myocardial infarction, angina pectoris and sudden death, affect nearly 59.7 million individuals or 21.9% of the U.S. population each year (US DHHS, 2000b). Consequently, *Healthy People 2000* and *Healthy People 2010* have heart disease as a priority area for health improvement in the U.S. (US DHHS, 1990; US DHHS 2000a).

As individuals with MR age, they suffer the same risk of cardiovascular disease as the general population. Cardiovascular disease is one of the most common causes of death among individuals with MR, accounting for 10.3% to 50.0% of deaths depending on the population studied (Carter and Jancar, 1983; Dupont et al., 1987; O'Brien et al., 1991). Prevalence estimates of cardiovascular disease in individuals with mild or moderate MR living in the community range from 6.7% to 55.2%, with individuals being at increased risk of disease as they age (Minihan, 1986; Minihan and Dean 1990; Janicki and Jacobson, 1986 and Badry et al., 1989 in Day and Jancar, 1994; Beange et al., 1995; Hand and Reid, 1996; van Schronjenstein Lantman-de Valk et al., 1997; Cooper 1998; Kapell et al., 1998). In addition, individuals with Down Syndrome are three to four times more likely to have cardiac conditions compared with individuals without Down Syndrome (Thase 1982; van Schronjenstein Lantman-de Valk et al., 1997; Kapell et al., 1998).

The prevalence estimates of cardiovascular disease, however, are lower among individuals with profound MR living in institutions (O'Brien et al., 1991; Turner and Moss, 1996). For example, O'Brien et al. (1991) found that 30% of all deaths among individuals with profound MR were related to heart disease compared with 44.4% among individuals with mild to moderate MR. If the lower prevalence is, in fact, real, it may be related to either lifestyle factors

that influence blood pressure, cholesterol levels, obesity, cigarette smoking and physical activity (Pitetti and Campbell, 1991; Turner and Moss, 1996), or the fact that among the institutionalized, those who live longer are healthier. Alternatively, the difference may be due to incomplete measurement of the conditions under study. For example, Ziring et al. (1988) pointed out that 8.9% of those recently deinstitutionalized had previously undetected cardiac conditions, suggesting that cardiac conditions may be underdiagnosed among individuals in institutions.

Cancer

The second leading cause of death in the U.S. and the United Kingdom (U.K.) is cancer, accounting for 23.3% of deaths in the U.S. and 25.0% of deaths in the U.K. (Hoyert et al., 1999; Turner and Moss 1996). Cancer deaths are primarily attributable to lung cancer (49.5 per 100,000), breast cancer (25.6 per 100,000 women), prostate cancer (25.4 per 100,000 men) and colorectal cancer (17.6 per 100,000) (Ries et al., 2000). In the U.S., nearly 40% of individuals are diagnosed with cancer during their lifetime (US DHHS, 1998). The most commonly diagnosed cancers are prostate (149.7 per 100,000 men), breast (109.7 per 100,000 women), lung (55.2 per 100,000) and colorectal (43.9 per 100,000) (Ries et al., 2000). Because cancer affects so many individuals in the U.S., the Surgeon General made early detection, treatment and prevention of cancer a national priority in *Healthy People 2000* and *Healthy People 2010* (US DHHS, 1990, US DHHS, 2000a).

Cancer is also a health concern among individuals with MR. Cancer is among the most common causes of death among individuals with MR, with estimates ranging from 7.4% to 34.0% depending on the population studied (Carter and Jancar, 1983; Dupont et al., 1987). In fact, after adjusting for age, the prevalence of most cancers among individuals with MR living in

the community is thought to be similar to that found in the general population. For example, in a study of the prevalence of cancer among older community residents with MR in the Netherlands, Evenhuis (1997) found cancer prevalence estimates similar to those in the Dutch population. He found that 22.9% of individuals with MR were diagnosed with cancer, including breast, prostate, lung, gastrointestinal and skin cancers.

One exception to these similar trends is among individuals with Down Syndrome (Jancar and Jancar, 1977; Turner and Moss 1996; Scholl et al., 1982; Baird and Sadovnick, 1988; Franceschi et al, 1991; Hasle et al., 2000). For example, in a recent study examining the prevalence of leukemia and solid tumors in the Danish Cancer Registry, Hasle et al. (2000) found that children with Down Syndrome are more likely to have leukemia compared with children of the same age in the general population (children ages 0-4 years, standardized incidence ratio: 56.4; children ages 5-19 years, standardized incidence ratio: 7.7). Individuals with Down Syndrome, however, were half as likely to have solid tumors compared with the general population, even after adjusting for age.

In contrast to community-based studies, in one institution in England, Cooke (1997) found that 13.6% of all deaths were due to cancer, an overall prevalence rate that was lower than the 26% found in the general population in England during the same time period. Although age-adjusted estimates were not presented, the prevalence of cancer among individuals with MR declined during a time when longevity increased in this population, suggesting that decreased life expectancy did not explain the lower prevalence of cancer among individuals with MR. Another important finding from this study was that the types of cancer varied between individuals with MR in the institution and those in the general population. In contrast to the leading cancer deaths in the general population, they found very few deaths due to lung, breast or prostate cancer;

rather this study found a high proportion of gastrointestinal cancer among individuals with MR (55% in the MR population versus 26% in the general population). The high prevalence of gastrointestinal cancer was thought to be related to gastrointestinal reflux and chronic constipation that is common among individuals with MR living in institutions. Others have also documented a high prevalence of gastrointestinal cancer among individuals with MR in institutions (Jancar and Jancar, 1977).

The prevalence of cancer is also associated with severity of MR. In the U.S., O'Brien et al. (1991) found that among those individuals living in one southeastern residential facility, those with mild or moderate MR were more likely to die of cancer than individuals with profound MR. Additional studies examining the prevalence of cancer in the U.S. are limited. One study that examined mortality in 14 individuals with MR in the community provided anecdotal evidence that one of the 14 individuals died of undetected cervical cancer, a potentially avoidable cause of death (Kastner et al., 1993).

Cerebrovascular Disease

Cerebrovascular disease is a common term to describe ischemic and hemorrhagic strokes or transient ischemic attacks that result in a lack of blood flow to the brain. This disease is the third leading cause of death in the U.S. (Hoyert et al., 1999), with an estimated 731,000 incident (first time) strokes each year (Sacco et al., 1999). It is one of the most prevalent conditions among individuals 65 and older in the U.S. (NSA, 1999; US DHHS, 2000a). In fact, more than 4 million or 4.3% of Americans 45 years and older are living with the effects of stroke (NSA, 1999). Like cardiovascular disease, the detection, prevention and treatment of cerebrovascular

disease has been a national priority in *Healthy People 2000* and *Healthy People 2010* (US DHHS, 1990; US DHHS, 2000a).

Since the population of individuals with MR is aging, the risk of cerebrovascular disease, like that of cardiovascular disease and cancer, is increasing in this population (Turner and Moss, 1996). Few studies, however, have examined the prevalence of stroke among individuals with MR. In a community-based study in England, Cooper (1998) documented a cerebrovascular disease prevalence of 9.0% among individuals with MR 65 years and older, which she noted to be greater than that of the general population (although general population estimates were not provided). No individuals with MR under 65 years of age who participated in the study had a cerebrovascular disease. In another community-based study of 70+ year olds in the Netherlands, Evenhuis (1997) found that 2.8% of individuals with MR reported a history of stroke, a prevalence estimate similar to that in the general population. Although it is unclear whether individuals with MR are more likely to have a stroke compared with the general population, it is clear that the aging MR population faces a serious risk of cerebrovascular disease.

Chronic Obstructive Pulmonary Disease (COPD) and Other Respiratory Conditions

Chronic obstructive pulmonary disease (COPD) is used to describe two respiratory conditions, chronic bronchitis and emphysema. Both conditions cause a shortness of breath and coughing that gets worse over time. COPD and other respiratory conditions, such as pneumonia and influenza, are the fourth and sixth leading causes of death in the U.S., respectively. COPD accounts for 4.7% of all deaths and pneumonia and influenza account for 3.7% of all deaths in the U.S. (Hoyert et al., 1999). According to the U.S. National Heart, Lung and Blood Institutes, over 13.5 million Americans report having COPD (5.1% of the U.S. population) (US DHHS,

1995). Pneumonia and influenza have seasonal variations reaching their peak prevalence in winter. They are more commonly reported among the elderly and individuals with chronic health problems than among young, healthy individuals (CDC, 2000). In the year 2000, the U.S. Centers for Disease Control and Prevention reported a prevalence of 33% of individuals infected with influenza (CDC, 2000). Western European studies find a similar prevalence of COPD, pneumonia and influenza (Lung and Asthma Information Agency, 1995; WHO, 1999).

Most of the reviewed studies of individuals with MR report prevalence estimates of general respiratory conditions, inclusive of COPD and respiratory infections, although a few research efforts have focused on COPD or other specific respiratory conditions. Increased prevalence of respiratory conditions, and infections in particular, have been shown to be associated with increased age, institutional residence, severity of MR and severity of physical impairment. For example, studies conducted in the community and in institutions have shown that the probability of having a respiratory condition increases linearly with age (Janicki and Jacobson, 1986 in Day and Jancar, 1994); Day, 1987 in Day and Jancar, 1994).

Additionally, there is a higher prevalence of respiratory conditions among individuals 45 years and older living in institutions (1.1% to 33%) (Nelson and Crocker, 1978; Rubin, 1987; Day, 1987 in Day and Jancar, 1994; Minihan, 1986; van Schronjenstein Lantman-de Valk et al., 1997; Evenhuis, 1997), compared with those living in the community (1.5% to 5.1%) (Janicki and Jacobson, 1986 in Day and Jancar, 1994). Specifically, individuals with MR living in institutions are highly susceptible to respiratory infections. In fact, nearly one-half of all deaths in institutions are accounted for by pneumonia and influenza, with a disproportionate number of individuals having severe or profound MR (Polednak, 1975; O'Brien et al., 1991; Turner and Moss, 1996).

Differences between the prevalence of individuals living in the community and the prevalence of individuals with severe MR living in institutions are most likely related to the severity of both MR and physical impairments, as well as the associated limitations in physical activity. Among individuals living in residential facilities, for example, individuals with moderate or severe MR have been found to be more likely to have COPD compared with individuals with mild MR (van Schronjenstein Lantman-de Valk et al., 1997). Further, individuals living in institutions are more likely to be immobile and/or have difficulties swallowing and, thus, are more susceptible to respiratory infections (Turner and Moss, 1996; Kennedy et al., 1997). In addition, as a result of their congregate living arrangement, individuals with severe MR have greater exposure to infectious agents.

Individuals with severe MR are not the only subpopulation of individuals with MR to suffer from high rates of respiratory infections. Researchers have also suggested that young individuals with Down Syndrome are susceptible to such infections (Baird and Sadovnick, 1988), because of accelerated immunologic aging (Nespoli et al., 1993) and physical malformations that may hinder drainage of sinuses (Saenz, 1999).

Diabetes Mellitus

Diabetes mellitus is a disease in which the body has an inadequate supply of insulin, a hormone needed to metabolize food into energy. Obesity is a major risk factor of diabetes (CDC, 1998), and individuals with this disease are at higher risk of heart disease, stroke, high blood pressure, blindness, kidney disease, amputations and dental disease (CDC, 1998). Diabetes is the seventh leading cause of death in the U.S. (Hoyert et al., 1999), accounting for 2.7% of all deaths. Additionally, over 15.7 million individuals in the U.S. (5.9% of the

population) and over 1.4 million in the U.K. (3.0% of the population) have diabetes mellitus (CDC, 1998; Diabetes UK, 2000). With a high prevalence of the disease in the U.S., *Healthy People 2000* and *Healthy People 2010* have made preventing and reducing diabetes a priority in the nation's health (US DHHS, 1990; US DHHS, 2000a).

Although not a major cause of death among individuals with MR, diabetes and its associated risks are important health concerns. Individuals with MR have similar prevalence estimates of diabetes as individuals in the general population. In community studies in the U.S. and in Western Europe, the prevalence of diabetes among individuals with MR has been found to be 1.6% to 9.1%, with those over 65 having a two-fold increase in the risk of diabetes compared with those less than 65 years (van Schronjenstein Lantman-de Valk et al., 1997; Cooper, 1998; Kapell et al., 1998). Further, studies examining the prevalence of diabetes among those with MR residing in institutions found a lower prevalence than that found in community-based studies of individuals with MR (.8%-2.8%) (Hogg et al., 1988 in Day and Jancar, 1994; Minihan and Dean, 1990).

In addition, compared with the general population, individuals with Down Syndrome have an increased probability of being obese (Cronk et al., 1985 in Fujiura et al., 1997; Bell and Bhate, 1992). Perhaps as a result, there is some evidence to suggest that individuals with Down Syndrome have a higher probability of having diabetes and of having the disease at a younger age than individuals without Down Syndrome (Burch and Milunsky, 1969; Farquhar, 1969; Van Goor et al., 1997; Kapell et al., 1998).

Unintentional Injuries

Unintentional injuries (e.g., motor-vehicle, drowning, residential fires, poison consumption, falls) are the leading cause of death among young people (ages 1-34 years) and the fourth overall leading cause of death in the U.S., accounting for 4.1% of all deaths (Hoyert et al., 1999). The WHO also reports that 6.5% of deaths in WHO member states are attributed to unintentional injuries (WHO, 1999). Additionally, the NCHS reports that 31 million visits to the emergency room result from unintentional injuries each year (Burt and Fingerhut, 1998). The risk of injury is so great that most individuals will experience an unintentional injury at some point in their life. As a result of the high prevalence of injury, the Surgeon General has made reduction in mortality and morbidity due to unintentional injuries a national priority in *Healthy People 2000* and *Healthy People 2010* (US DHHS, 1990, US DHHS, 2000a).

Individuals with MR are at least as, if not more, likely to die from an unintentional injury compared with the general population. In a British Columbia study of the causes of death among individuals with Down Syndrome aged 30 and younger, Baird and Sadovnick (1988) reported that injuries occurred in the Down Syndrome population as frequently as in the general population (prevalence estimates ranging from < .1% to 8.2%). In a population-based study of deaths in Denmark, however, Dupont et al. (1987) found that individuals with mild or moderate MR aged 15-34 years were at increased risk of death due to accidents compared with the general population of the same age.

Although no studies could be found examining non-fatal accidents and injuries among adults with MR in the population, a few studies have examined sports-related injuries at Special Olympics, Inc. (SOI) events. Perlman (1994) summarizes the prevalence of sports-related injuries from SOI events in 12 states and the previous four world games, with a total of 701,988

participants. He reported an overall injury claim prevalence of .05%, with estimates ranging from .01% to .21% depending on the sporting event, although comparison to the general population is not possible since there are no comparable data for individuals without MR. McCormick et al. (1990) found a slightly higher prevalence of sports-related injuries at the Special Olympics competition in Galveston, Texas, with 3.5% of 777 athletes requiring medical care for sports-related injuries. Thus, like the general population, unintentional injuries and accidents are an important health concern among those with MR.

Health Behaviors

The prevalence of certain health behaviors, such as poor nutritional habits leading to obesity, decreased physical activity and smoking, has become a major concern to policy makers and researchers interested in the overall health of the nation. Obesity, physical activity and tobacco consumption are primary modifiable risk factors for most chronic diseases, and, as such, are listed among the leading health indicators for health in *Healthy People 2000* and *Healthy People 2010* (US DHHS, 2000a).

Obesity

Obesity is associated with cardiovascular disease, breast, prostate and colon cancers, cerebrovascular disease and diabetes (National Task Force, 2000). According to *Healthy People 2010*, the number of overweight individuals has risen in the past four decades, with 11% of children ages 6 to 19 years being overweight or obese and 23% of adults being obese between 1988-1994 (US DHHS, 2000a).

Obesity is more common among individuals with MR than in the general population, with overall prevalence estimates ranging from 29.5% to 50.5% (Simila and Niskanen, 1991; Bell and Bhate, 1992, Rimmer et al., 1993; Rubin et al., 1998). In fact, in a convenience sample of select participants, Touger-Decker and Matheson (2000) found that more than 66.0% of children with MR who participated in the New Jersey 2000 Special Olympic Games were overweight. The prevalence of obesity in the MR population has been found to vary with living situation and etiology of MR. Individuals living at home have the highest prevalence of obesity (55.3%) followed by those living in a group home (less than 16 residents) (40.9%), while individuals living in institutions (more than 100 residents) have the lowest prevalence of obesity (16.5%) (Rimmer et al., 1993; Prasher, 1995). In addition, individuals with Down Syndrome are 1.5 times more likely to be obese compared with individuals with other etiologies of MR (Bell and Bhate, 1992). With the majority of individuals with MR living in the community, it is imperative that obesity be considered a major health problem facing individuals with MR.

Physical Activity

Regular physical fitness is an important health maintenance activity that is associated with decreased body fat, decreased risk of cardiovascular disease and diabetes and enhanced psychological well-being (US DHHS, 2000a). The U.S. Surgeon General has made regular physical activity a national health priority in *Healthy People 2000* and *Healthy People 2010* (US DHHS, 1990, US DHHS, 2000a). Among adults in the general population, only 15% participate in regular physical activity of 30 minutes per day and 40% engage in any leisure physical activity (US DHHS, 2000a).

Like individuals in the general population, individuals with MR are unlikely to participate in physical activities, either because they lack the motivation or the opportunity to be involved in fitness programs (Rimmer, 2000). Few studies, however, exist on the prevalence of individuals with MR participating in routine physical activity. One study examined the leisure activities of 207 adults with MR living at home in Dublin, Ireland. In this study, McConkey et al. (1981) found that most individuals with MR ages 15-64 participated in activities that were sedentary, such as watching television (73.4%) and listening to the radio or records (41.1%). The prevalence of individuals with MR participating in outdoor sports ranged from 21.1% to 47.5%, with those more physically and mentally impaired being less likely to participate in outdoor sports. Although comparison to the general population is difficult given the lack of age-stratified information presented in the study, McConkey et al. (1981) reported the prevalence of physical exercise among non-retarded children 16-24 years as 44.0%. No information was presented on the prevalence of participation in outdoor sports. In a more recent U.K. health screening study of 120 individuals with MR living in the community, Martin et al. (1997) found that 48.2% had done some physical activity over the past four weeks compared with 93.5% in the general population.

More research has been done on cardiovascular fitness among individuals with MR (Beasley, 1982; Pitetti and Campbell 1991; Pitetti et al., 1993; Fernhall, 1993; Fernhall et al. 1998; Lancioni and O'Reilly, 1998). Cardiovascular fitness, an important aspect of physical activity, is related to the ability to perform light to moderate levels of physical labor. Fernall (1993), in a review of physical fitness among individuals with MR, reports that adults with MR have lower cardiovascular fitness levels than the general population, suggesting that individuals with MR may lead more sedentary lifestyles. Others have also found that individuals with MR

have lower cardiovascular fitness levels compared with those in the general population (Pitetti and Campbell; 1991).

SOI has recognized the need for individuals with MR to have the opportunity to participate in physical activities, including team and individual sports. SOI provides year-round opportunities for individuals with MR to participate in sports training and athletic competition, with one of the explicit goals being development of physical fitness (SOI, 2000). Besides the primary athletic competition program, SOI also has developed basic fitness guides and training materials for SOI coaches to raise awareness of proper diet and nutrition among athletes. Further, these guides encourage athletes to participate in daily exercise not only during SOI programs but also in their own home (Todd, personal communication). Additionally, SOI has developed four specific programs to encourage individuals at increased risk for sedentary lifestyles to participate in physical activities. These programs include a motor activities training program for individuals with severe MR, a unified sports program integrating individuals with mild MR with their peers without MR, a play activities program for young children with MR ages 6 and 7 years and an athlete leadership training program (Sharkey and Hunt, 1999).

Smoking

Cigarette smoking is a major preventable cause of disease and death in the U.S. and internationally (US DHHS, 2000a; WHO, 2000). Smoking is a major risk factor for most of the major health conditions discussed above, including cardiovascular disease, cancer, cerebrovascular disease and lung disease. In 1997, 24% of adults in the U.S. reported smoking cigarettes (US DHHS, 2000a). As a result, the Surgeon General and the WHO has made

reduction in tobacco consumption a national and international health priority (US DHHS, 2000a; WHO, 2000).

Prevalence estimates of tobacco consumption by individuals with MR vary by living condition and severity of MR. In a community-based study in the southern area of Melbourne, Australia, Tracy and Hosken (1997) found that 36% of individuals with MR sampled indicated that they smoked cigarettes compared with 26% in the general population. In a clinic-based study conducted in New Jersey, Hymowitz et al. (1997) found that 30% of 64 adults with mild MR reported that they were current smokers, which is only slightly higher than the smoking prevalence estimate for the U.S. general population. Burtner et al. (1995) examined the consumption of tobacco in a Florida residential facility for individuals with MR. With a prevalence estimate similar to that of the general population in 1995, they found that 20.5% of individuals with mild or moderate MR used tobacco products, including cigarettes, chewing tobacco, cigar and snuff. In comparison, only 4.3% of individuals with severe or profound MR used tobacco products. In a study of cardiovascular risk factors, Rimmer et al. (1994) examined the prevalence of smoking 10 cigarettes a day among individuals with MR living in a residential facility, living in a group home and living at home with family. They found that individuals with MR in the group home had the highest prevalence of smoking (20.8% of men and 6.7% of women) compared to individuals with MR living at home (6.9% of men and 2.1% of women) and individuals with MR living in an institution (3.8% of men, 0.0% of women). These studies suggest that individuals living in institutions and individuals with more severe MR are less likely to smoke, while individuals living in group homes and individuals with less severe MR have smoking habits similar to the general population.

The prevalence of smoking also has been studied in select SOI populations, with prevalence estimates below those observed in community-based and institution-based studies. Among 704 Special Olympic athletes who participated in the 1996 New Jersey Special Olympic Special Smiles program, 7.0% reported that they currently smoked (Feldman et al., 1997). A similar smoking prevalence of 4.3% was found among Special Olympic athletes who participated in the 1997 San Francisco Bay Area Special Olympics Special Smiles program (White et al., 1998). There is some evidence, however, that smoking status may not be accurately measured by self-report among individuals with MR. In a recent study at the 2000 New Jersey Special Olympic Games, 70 SOI atheletes aged 18 to 78 were asked to identify their smoking status and to complete a carbon monoxide (CO) test of smoking status. Among those who identified themselves as smokers, 27% had negative CO test results. Among those who identified themselves as non-smokers, 18% had positive CO test results (Giniger, 2000). Thus, although some studies have shown a lower prevalence of smoking among select populations of individuals with MR, the self-reported data from these studies may not adequately reflect the true prevalence of the population.

Many of the studies reported here suggest that individuals with mild or moderate MR and individuals living in group homes are as likely to consume tobacco products as individuals in the general population. Therefore, smoking education and prevention efforts are as essential for this population as it is in the general population.

Child Health Conditions and Prevention Measures

Otits media, asthma, child maltreatment and immunizations, were put forth as research priorities in the children's health arena by the Agency for Health Care Policy and Research, now

called the Agency for Healthcare Research and Quality (US DHHS, 1997a). Although these conditions and prevention measures are areas of concern among children in the general population, and, thus, among children with MR, little information is available on the prevalence and long-term consequences of these illnesses and behaviors among children with MR.

Otitis Media

Young children are particularly susceptible to otitis media, or middle ear infections, because they have developing immune systems that have difficulty fighting infections, immature eustachian tubes that prevent optimal fluid drainage, and may have enlarged adenoids that interfere with the eustachian tube opening. Otitis media not only can cause severe pain, but, if left untreated, also can cause permanent hearing loss (US DHHS, 1997b). Additionally, recurrent otitis media can have a negative impact on speech and language development, cognitive achievement and social and emotional development (Evenuis and Nagtzaam, 1997). Otitis media is one of the most prevalent childhood conditions, affecting 75% of children under the age of 3 years at least once (US DHHS, 1997b). An estimated 17% to 29% of infants have one episode of acute otitis media and an estimated 26% of preschool children in the United States have recurrent otitis media (Lanphear et al., 1997).

The prevalence of otitis media among children with MR has not been adequately explored. There are some reasons to believe that children with Down Syndrome are at increased risk of middle ear infections due to midfacial malformations and increased susceptibility to infections (Saenz, 1999). Although not focused specifically on otitis media, one study of 293 residents of an English institution found that 40% of individuals with Down Syndrome and 29% of individuals with MR without Down Syndrome had ear, nose and throat conditions (Donague

and Abbas, 1972). Dahle and McCollister (1986) compared the prevalence of ear problems in children with Down Syndrome to children with other forms of MR. They found that hearing impairment and infections were more prevalent among children with Down Syndrome. Given the potential impact of otitis media on development (Whiteman et al., 1986), early identification of middle ear infections among children with MR, who are already at risk for delays, is important.

Pediatric Asthma

Asthma is characterized by recurrent breathing problems brought on by inflammation of the lining of the lungs. The severity of asthma, as with most conditions, varies by individual. While some individuals are severely limited in their activities by the condition, others have only periodic symptoms of the disease. The negative consequences of asthma, however, can be avoided with appropriate disease management. Since 1980, the prevalence of asthma has been on the rise in all age, race and sex groups. In 1980, 4.2% of children were affected by asthma, but by 1994 the prevalence of asthma rose to 7.4% of children, a 74% increase over a 24-year period (US DHHS, 2000c).

Little research has been done on the prevalence of asthma among children with MR. In a study of health status and needs of children with MR, Ackland and Wade (1995) reported the prevalence of medical conditions of 249 students in Victoria, Australia. With a prevalence estimate similar to that in the U.S. population of children, asthma was diagnosed among 6.4% of the children with MR.

No research exists on the negative consequences of asthma (such as reluctance to participate in physical activities) or on asthma management among children with MR, although

one British study examined deaths from asthma in individuals less than 45 years old with MR. Reviewing death certificates of all residents in Southmead Health Authority, Stuart et al. (1990) found a high prevalence of asthma mortality among 5-44 year olds, with a morality rate twice that of the general U.K. population. Making confidential inquiries into the factors associated with the deaths, they found that several factors contributed to the high mortality rate, including communication difficulties between the patient and caregiver or provider, and delays in providers responding to an asthma attack. Given that disease management may be more difficult with children with MR who have limited communication skills compared with their peers without MR, increased attention should be given to self and caregiver management of this common childhood disease.

Child Maltreatment

Maltreatment is an all too common childhood condition in the U.S., with approximately 984,000 children being victims of substantiated or indicated abuse or neglect in 1997 (US DHHS, 1999). The most common form of maltreatment is neglect (54% of victims), followed by physical abuse (24%), sexual abuse (13%), emotional maltreatment (6%) and medical neglect (2%). It is estimated that 1,196 of nearly one million victims of child maltreatment died from abuse or neglect in 1997 (US DHHS, 1999). These estimates are based on reports by child protective services, which only account for those select cases that are known to agencies, and, therefore, may under-represent the true prevalence of child maltreatment.

Children with MR also face serious consequences from abuse and neglect, although there is limited research on overall prevalence estimates of maltreatment in this population. As Waldman et al. (1999) point out, children who are abused are over four times as likely to have

MR compared with non-abused children (Sullivan and Knutson, 1994 in Mansell et al., 1998). The causal direction in the association of child maltreatment and MR, however, is not clear. Physical abuse and neglect may result in MR (due to brain damage) or individuals with MR may be more likely to be abused and neglected.

In a study of 445 intellectually handicapped children in Castilla-Leon, Spain, Verdugo et al. (1995) interviewed professionals about signs of abuse and/or neglect. They found that 11.5% of children with an intellectual handicap aged 0-19 years had some evidence of maltreatment compared with 1.5% of children with no intellectual handicap. Among those who had evidence of maltreatment, 92% experienced physical neglect, 82% experienced emotional neglect, 65% experienced emotional abuse and 31% experienced physical abuse and 2% experience sexual abuse.

In addition, sexual abuse appears to be more prevalent among children with MR compared with children in the general population. Although not strictly focused on children with MR, Crosse et al. (1993) reported that children with disabilities are 1.8 times more likely to experience sexual abuse compared with children without disabilities (in Mansell et al., 1998). Other researchers have also found an increased prevalence of sexual abuse among children with disabilities (Sobsey and Varnhagen, 1989; Sobsey and Doe 1991; Sobsey 1994 and Valenti-Hein and Schwartz, 1995 in Reynolds, 1997).

Several researchers have speculated about the reasons for the increased prevalence of abuse among individuals with MR, and have cited stress and strain on the family, unrealized parental expectations of the child, emotional and social isolation of caregivers, children's inability to report abusive experiences, children's dependency on caregivers and lack of awareness about abusive situations as potential contributors (Solomons, 1979; Reynolds 1997;

Waldman et al., 1999). Although there may exist a detection bias in who is identified as a victim, it is clear that individuals with MR are at least as, if not more, likely to experience maltreatment compared with their peers without MR.

Immunizations

Vaccines which prevent infectious diseases and death are considered one of the most important public health achievements of the 20th century (US DHHS, 2000a). As such, vaccinations of children has remained a national health initiative in both *Healthy People 2000* and *Healthy People 2010* (US DHHS, 1990; US DHHS, 2000a). In 1998, 73% of children in the U.S. received routine vaccinations, including immunizations against Hepatitis B, diphtheria, tetanus, pertussis, polio, measles, mumps, rubella and Haemophilus influenzae type b (US DHHS, 2000a; American Academy of Pediatrics, 2000).

Information on the immunization status for children with MR is sparse. In an early study of the medical care received by previously institutionalized children, Schor et al. (1981) found that 77.0% had up to date immunizations compared with 91.0% of children in the general population. Another study has examined the prevalence of routine immunizations among children with MR living in the community. McLaughlin et al. (1977) examined the immunization records of 134 children in a large northwestern school district, a sample population that may be generalizable only to the enrolled school population of children with MR and not to the institutionalized MR population. They found no statistical difference in the prevalence of completed immunizations between the 67 children with MR and the 67 age-, sex- and socioeconomic status-matched peers without MR (91% versus 81%, respectively).

Several studies have been conducted examining the prevalence and effectiveness of the Hepatitis B vaccine among children and adults with MR (Vajro et al, 1992; Arulrajan et al., 1992; Vellinga et al., 1999). These studies suggest that individuals with MR, specifically those with Down Syndrome and those residing in institutions, are at increased risk of Hepatitis B infection (Vellinga et al., 1999). Vajro et al. (1992) examined the seroconversion rate (the antibody response to a vaccine, which indicates that the vaccine was effective and that an individual is immune to the disease) of preschool children with Down Syndrome compared with children with other forms of MR. Despite prior evidence suggesting that individuals with Down Syndrome are more likely to lack an anti-Hepatitis B response compared with general population controls, they found that children in both groups had a complete seroconversion. Given that children with MR, in particular those with Down Syndrome and those in institutions, are at increased risk of infection, administration of routine vaccines in this population is imperative.

Health Conditions Among Those with Down's Syndrome and Rationale for Increased Prevalence

Certain health conditions are particularly prevalent among individuals with Down Syndrome and warrant further discussion. For example, conditions such as orthopedic anomalies, congenital heart defects and thyroid disease, although relatively infrequent in the general population, can be life-threatening conditions for individuals with Down Syndrome.

Atlantoaxial Instability

Individuals with Down Syndrome have many orthopedic anomalies, but few are as life threatening as atlantoaxial instability. Atlantoaxial instability is a laxity in the movement between the first and second cervical vertebrae and, thus, increases the risk of spinal cord injury

(Msall, 1999). It occurs in 10% to 40% of individuals with Down Syndrome, depending on the child's age and definition of instability (Tishler and Martel, 1965 and Alvarez and Rubin, 1986 in Cremers et al., 1993; Cope and Olson, 1987; Rubin, 1987; Pueschel and Scola, 1987; Pueschel, 1998). Despite the relatively high prevalence of atlantoaxial instability, there is no information about the prevalence of screening among individuals with MR, which may be due in part to the controversy surrounding the safety of the radiograph screening process and the questionable diagnostic value of the procedure (Pueschel, 1998). Therefore, effective and safe health screening procedures for asymptomatic atlantoaxial instability is an important consideration, in need of further exploration. Some researchers and providers, in fact, believe that atlantoaxial instability may limit an individual's ability to participate safely in sports (Saenz, 1999; Msall, 1999), while others have found restriction of activity based on the possibility of increased instability to be unnecessary for most children with Down Syndrome (Cremers et al., 1993; Morton et al. 1995).

Congenital Heart Defects

Children with Down Syndrome are significantly more likely to have a congenital heart defect than individuals in the general population. Approximately 40% to 60% of children with Down Syndrome have a heart defect (Spicer, 1984; Pueschel, 1990; Martin, 1997) compared with 0.8% in the general population (Mitchell et al., 1971; March of Dimes, 1999). Due to advancements in medical technology, however, survival for children with heart defects has dramatically improved (March of Dimes, 1999). Consequently, some physicians recommend that infants with Down Syndrome have electrocardiogram and echocardiogram screenings so that those in need can be referred to a specialist for medical management (Pueschel, 1990; Saenz,

1999). No studies were found that determine the screening rate of congenital cardiac conditions among individuals with Down Syndrome, however.

Thyroid Disease

Diseases of the thyroid, the organ that regulates the body's metabolism, can lead to blood pressure disturbances, fatigue, changes in appetite, weight disturbances, difficulty with concentration and changes in gastrointestinal regulation (Thyroid Society, 2000). Thyroid disease affects nearly 20 million or 1.4% of Americans (Thyroid Society, 2000). Compared with the general population, individuals with Down Syndrome have an increased probability of having a thyroid disorder, including hypothyroidism or hyperthyroidism, with prevalence estimates ranging from 3% to 50% depending on the population studied and criteria for diagnosis (Rubin, 1987; Pueschel, 1990; Dinani and Carpenter, 1990; Ali et al., 1999). Unlike individuals in the general population, who are at increased risk of thyroid disease with increased age, individuals with Down Syndrome are more likely to have thyroid disease at an earlier age. Those with Down Syndrome are thought to be at increased risk of thyroid disease because they often have autoimmune abnormalities (Kennedy et al., 1992; Ali et al., 1999) and accelerated immunologic aging (Nespoli et al., 1993).

Only one study could be found that examined the screening rate of thyroid disease among children with Down Syndrome. In an interview with Australian parents who attended a conference on Down syndrome, Selikowitz (1992) found that 64.7% of 132 school-aged children with Down Syndrome had been tested for hypothyroidism within the past 18 months. Even within this highly motivated and, presumably, informed population, then, the screening rate of thyroid disease was relatively poor. Because thyroid disease is so common among children with

Down Syndrome, regular screening and early detection of thyroid conditions is essential (Murdoch et al., 1977 in Martin, 1997; Noble et al., 2000).

Summary and Implications

Similar to individuals in the general population, individuals with MR are at risk for chronic medical conditions, including cardiovascular disease, cancer, cerebrovascular disease, lung conditions and diabetes. Individuals with MR are also susceptible to the primary risk factors of chronic diseases including obesity, decreased physical activity and smoking. As in the general population, the risk of disease among those with MR increases with age. In addition, the disease prevalence varies by severity of MR. Individuals with mild or moderate MR are more likely to have cardiovascular disease and diabetes compared with individuals with severe or profound MR, while those with severe or profound MR living in institutions are more likely to have respiratory conditions compared with individuals with mild or moderate MR.

Further, one group of individuals with MR, those with Down Syndrome, who have autoimmune abnormalities, are at increased risk of cardiovascular disease, leukemia, respiratory disease and diabetes. Not surprisingly, the risk factors associated with these diseases are more prevalent among those with Down Syndrome, namely obesity and decreased physical activity. Besides the common adult health conditions, individuals with Down Syndrome are also more likely to have diseases that are less common among individuals in the general population, including atlantoaxial instability, congenital cardiac conditions and thyroid disease.

Although common childhood conditions, such as otitis media, asthma and child abuse, have also been reported among children with MR, very little information exists about the

prevalence or manifestations of these conditions in children with MR. The research that does exist suggests that children with MR are at increased risk of otitis media and of being maltreated.

Despite these increased risks of health conditions, however, little research exists on effective prevention programs and treatment strategies for this group of children and adults. One example of this lack of attention is the paucity of information on the immunization status of children with MR, one important public health measure. In addition, as will be discussed in a subsequent chapter, although individuals with MR have similar physical health problems as those in the general population, they are less likely to receive adequate medical services compared with those in the general population.

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CHAPTER 3

MENTAL HEALTH DISORDERS AMONG INDIVIDUALS WITH MENTAL RETARDATION

Introduction

Individuals with MR, like their peers without MR, also suffer from considerable morbidity due to mental health problems. Since MR is a diagnosable mental health condition, the presence of both MR and another mental health disorder is known as dual diagnosis. Similar to the prevalence of MR and physical health conditions among those with MR, the prevalence of dual diagnosis varies with the populations studied (AACAP, 1999).

Although some large scale, population-based research exists, most studies of dual diagnosis are conducted with small sample sizes and use administrative data (e.g. hospital admission data) (Ineichen, 1984; Borthwick-Duffy and Eyman, 1990; Szymanski, 1994). The use of administrative data, however, may under- or over-estimate the prevalence of dual diagnosis in the population, depending on the sampling strategy used. For example, since many individuals with mild MR do not use services in the mental health care system (Borthwick-Duffy and Eyman, 1990), the reported dual diagnosis prevalence based on administrative data may under-represent the true prevalence of MR and mental health problems (Borthwick-Duffy and Eyman, 1990, King et al., 1997). Conversely, since those with psychiatric impairments are more likely to use services than those without impairments, these administrative estimates may over-estimate the prevalence of dual diagnosis. Research studying individuals referred to psychiatric services, for instance, may over-represent the population prevalence of individuals with mental health disorders (Borthwick-Duffy, 1994).

In addition to methodological constraints regarding sampling strategies, research on mental health disorders among individuals with MR also suffers from inconsistent diagnostic methods and difficulties diagnosing these conditions in this population. Nevertheless, the research presented in this chapter indicates a high prevalence of dual diagnosis.

Diagnosis of Mental Health Disorders Among Individuals with MR

In addition to sampling strategies, the methods used to diagnose mental health disorders influences the prevalence of such conditions among individuals with MR (i.e., dual diagnosis). While some research uses diagnoses noted in medical records (chart reviews), others use structured diagnostic assessments to identify dual diagnosis. When chart reviews are used, however, the prevalence of dual diagnosis has been found to be much lower than the prevalence as determined by the use of specific diagnostic tools (Reiss, 1990).

Further, while some researchers study mental health conditions as defined in the APA's *Diagnostic and Statistical Manual of Mental Disorders*, others use different scales and interview instruments for diagnosis (Crews et al., 1994). In addition, some professionals prefer the term "psychiatric illness," while others use the term "behavioral disorder" to indicate general mental health conditions (Szymanski 1994; Emerson et al, 1999; Moss, 1999). In this report, the term "mental health disorder" will be used to encompass both psychiatric conditions and behavioral problems.

In addition to the methodological issues involved in documenting dual diagnosis, there are two main challenges to the process of actual diagnosis of mental health disorders among individuals with MR. First, providers are often reluctant to diagnose mental health conditions among those with MR and second, there are often difficulties involved in identifying symptoms

in this population. Historically, mental health conditions rarely were diagnosed in individuals with MR because many behavioral and emotional problems were thought to be either characteristic of MR (Eaton and Menolascino,1982; Zigler and Burack, 1989) or due to institutionalization (Day, 1993; Moss et al., 1997).

Although today it is recognized that mental health conditions exist in individuals with MR, and are separate from MR (Eaton and Menolascino, 1982; Borthwick-Duffy and Eyman, 1990), the presence of MR often diminishes the diagnostic significance of behavior that would otherwise be considered indicative of a mental health disorder. In other words, symptoms of a mental health disorder are often attributed to the MR, rather than evaluated as a potentially separate condition. Reiss et al. (1992), who termed this phenomenon *overshadowing,* provide an example of this in research conducted among psychiatrists evaluating hypothetical cases. 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.

Symptoms of mental health conditions among individuals with MR, however, may be difficult to identify. Although, in principle, the diagnosis of mental health problems in individuals with MR is similar to that of individuals without MR (Tuiner and Verhoeven, 1993), diagnosis in this population can actually be quite difficult (Gabriel, 1994; Borthwick-Duffy and Eyman, 1990; Sturmey, 1999; Moss, 1999; Weissblatt, 1994; Moss et al., 1997; Prosser et al., 1998; AACAP, 1999), particularly among individuals with severe MR (Reiss and Valenti-Hein, 1994). Because of cognitive limitations, different developmental trajectories and limitations in lifestyle, individuals with MR will often present with different symptoms of mental health disorders, compared with those without MR (Reiss, 1982; Menolascino et al., 1986).

The most difficult conditions to diagnose among individuals with severe MR are psychosis and cognitive disorders (Weissblatt, 1994). For example, it is often hard to distinguish the effects of prolonged institutional care from symptoms of schizophrenia among those with severe MR (Ineichen, 1984). Further, severe cognitive limitations (known as *baseline exaggeration*), are common among those with severe MR, and make the identification of additional cognitive disorders challenging, if not impossible (Sovner, 1986 in Crews et al., 1994; Sturmey, 1999). Those with severe MR also may present with bland symptomatology, a phenomenon know as *psychosocial masking*, that makes diagnosis difficult as well (Sovner, 1986 in Crews et al., 1994; Sturmey, 1999).

In addition, those with severe MR may have limited communication skills, (referred to as *intellectual distortion* [Sovner, 1986 in Crews et al., 1994; Sturmey, 1999]) or maladaptive behaviors (referred to as *cognitive disintegration* [Sovner, 1986 in Crews et al., 1994; Sturmey, 1999]) due to their disability, and are often passive and compliant. Any of these conditions or behaviors may obscure or confound symptoms, making diagnosis difficult (Reiss et al., 1982; Gabriel, 1994; Borthwick-Duffy and Eyman, 1990; Crews et al., 1994; Prosser et al., 1998). For example, those with severe MR are frequently non-verbal, making conditions such as obsessive compulsive disorder difficult to diagnose (AACAP, 1999). As a result, diagnoses may depend on caregivers' abilities to identify symptoms and clinicians' observations (Brothwick-Duffy and Eyman, 1990; AACAP, 1999), rather than patients' accounts.

Since older children, adolescents and adults with mild MR are less likely to have trouble communicating, the process of diagnosis is much less difficult among these groups than among younger children or those with severe MR (Reiss and Valenti-Hein, 1994). As a result, individuals with mild MR may be more likely to be given a mental health diagnosis than those

with more severe MR, although it is unclear whether those with more severe MR are less likely to have such problems or merely less likely to be identified with a problem (Borthwick-Duffy and Eyman, 1990; Crews et al., 1994).

Given these difficulties and the limited training that most clinicians have in working with individuals with MR, many providers prefer not to work with these patients. Consequently, when clinicians do treat individuals with MR, they are generally not experienced enough to make accurate diagnoses (Moss, 1999). An Australian study of 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 (Lennox and Chaplin, 1996).

Rationale for Mental Health Morbidity

Despite these diagnostic difficulties and ambiguities, higher rates of mental health impairments have been found among individuals with MR than in the general population (Zigler and Burack, 1989; Dosen, 1993; Moss, 1994; Moss et al., 1997; Embregts, 2000; Reiss, 1990). As Zigler and Burack (1989) point out, individuals with MR are capable of experiencing the same disappointments and difficulties as those without MR. Due to their increased sensitivity, however, an episode of "failure" may affect an individual with MR more than it would someone in the general population (Zigler and Burack, 1989).

Further, low intelligence may actually increase the risk of mental health problems for those who are aware of their limitations, as such a recognition may lead to self-concept problems and depressive reactions (Reiss et al., 1982; Crews et al., 1994). Similarly, parental and peer rejection, negative social relationships, limited supports and exposure to degrading situations may all make functioning in the community difficult (Siperstein et al., 1997, Eaton et al., 1982;

Reiss and Benson, 1984; Taylor et al., 1987; Borthwick-Duffy and Eyman, 1990), and increase the likelihood of having mental health problems (Gabriel, 1994). Since individuals with mild or moderate MR are more likely to be living with their families and to be aware of their limitations, these individuals may be at higher risk 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 (Eaton et al., 1982; Eaton and Menolascino, 1982), and children with mild MR have been found to be more rejected by peers and express more dissatisfaction and anxiety about peer relations than those without MR (Taylor et al., 1987). 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.

In addition, mental health conditions may be more common among individuals with MR due to biological risk factors (Reiss et al., 1993). Those with MR, for example, may suffer from more genetic abnormalities and brain damage than the general population (Moss et al., 1997), which may be associated with a higher prevalence of mental health conditions. For example, central nervous system damage, which is common among those with MR, may increase the vulnerability of individuals to develop other mental health disorders (Eaton and Menolascino, 1982).

Prevalence of Mental Health Morbidity

General Mental Health Morbidity

Mental health disorders in individuals with MR have been estimated to occur at a rate 3-6 times greater than that in the general population (Eaton and Menolascino, 1982; Walters et al., 1995; Maino, 1996). Research studies among individuals without MR have reported a

prevalence of mental health disorders ranging from 7%-26% (Bergeron et al., 1992; Surgeon General, 1999). The prevalence of dual diagnosis reported in both the U.S. and international literatures, however, is extremely inconsistent. In fact, a review of the literature done by Borthwick-Duffy (1994) indicates that studies using different definitions and sampling strategies estimate the prevalence of dual diagnosis to range from less than 10% to more than 80%. Lower prevalence estimates, however, are obtained when client records are examined, while higher prevalence estimates are documented from clinical evaluations. Reiss (1990), for instance, found the prevalence of mental disorders in a community-based day program to vary from 12%, using chart reviews alone, to 39% using screening surveys and 60% using clinical evaluations.

Among adults, the Surgeon General (1999) reports that 21% of those in the general population suffer from a mental health condition. Similarly, research using administrative data in the U.S. has found percentages of dual diagnosis to range from 17% to 36% (Reiss, 1990; Jacobson, 1982; Iverson and Fox, 1989 in Borthwick-Duffy, 1994). Further, European studies estimate the prevalence of dual diagnosis to range from 12% of individuals with severe MR, using administrative data (Kushlick, 1975 in Borthwick-Duffy, 1994), to 27%, using population-based data (Lund, 1985 in Borthwick-Duffy, 1994). Given that much of the literature indicates a higher prevalence of specific mental health disorders among individuals with MR, this reported similarity in prevalence estimates between adults with and without MR may be due to the methodologies used or the specific conditions studied in these research efforts.

Among children, 5%-21% of the general population have been reported to have mental health conditions (Bergeron et al., 1992; Szymanski, 1994; Costello 1999; Friedman et al., 1998; Surgeon General, 1999). Conversely, studies using administrative data in the U.S. have found the prevalence of dual diagnosis to range from 14% to 60% (Jacobson, 1982; Menaloscino, 1965

and Chess and Hassibi, 1970 in Borthwick-Duffy, 1994). As described above, research using populations referred to psychiatric services report a higher prevalence of dual diagnosis (87%) (Phillips and Williams, 1975 in Borthwick-Duffy, 1994).

Further, studies using administrative data in Europe have found a prevalence of dual diagnosis among children similar to that reported in the U.S., ranging from 9% to 43% (Kushlick, 1975, Haracopos and Kelstrup, 1978 and McQueen et al., 1987 in Borthwick-Duffy, 1994). In addition, while Rutter et al.'s (1970) British population-based study reported a prevalence of mental health disorders of about 7% among children without MR (Borthwick-Duffy, 1994), European population-based studies report a prevalence of childhood dual diagnosis of 30% to 64% (Rutter, 1970 in Borthwick-Duffy, 1994; Gillberg et al., 1986).

Mental Health Morbidity and Severity of MR

As with other health conditions described in this report, the prevalence of diagnosed mental health disorders tends to vary with severity of MR. Many studies have found that the prevalence of mental health disorders is highest among individuals with mild MR (Iverson and Fox, 1989 in Borthwick-Duffy, 1994; Borthwick-Duffy and Eyman, 1990; Jacobson, 1982). For example, administrative data from California indicates that 16% of individuals with mild MR are psychiatrically diagnosed, while only 5.7% of those with severe or profound MR have a dual diagnosis (Borthwick-Duffy and Eyman, 1990). These findings are consistent with the notions that MR is easier to diagnose among those with mild or moderate MR, and that because of their living situations and awareness, those with mild or moderate MR are more prone to mental health disorders than individuals with severe or profound MR.

International studies, however, indicate a different association. Many population studies in Europe have found that individuals with more severe MR have a higher prevalence of dual diagnosis (Rutter, 1970 in Borthwick-Duffy; Gillberg et al, 1986; Gostason, 1985 in Borthwick-Duffy, 1994; Goh and Holland, 1994). For example, one European study reported prevalence estimates of such disorders to be 60% among those with an IQ<60, and just over 20% among those with an IQ between 60 and 69 (Birch et al., 1970).

The discrepancy between American and European research has several potential explanations. First, the inconsistent finding may suggest that there is no association between severity of MR and dual diagnosis (McCaren and Bryson, 1987 in Borthwick-Duffy, 1994). Second, the inconsistencies may be due to research methodology. Studies based on administrative data found more dual diagnosis among individuals with mild MR, while studies using population-based data reported a higher prevalence among those with severe MR. This may be because those with severe MR and a mental health condition may be more likely to be institutionalized, and thus less likely to be captured in administrative data.

Third, studies that examined specific conditions indicate that the association may vary with condition (Corbett et al., 1975 and Koller, 1983 in Borthwick-Duffy, 1994; Reid, 1980). For example, based on a survey of individuals referred to an outpatient clinic for those with developmental disabilities, Reiss (1982) reports that 20% of individuals with mild MR were diagnosed with depression, compared with none of those with severe MR. As discussed above, individuals with mild MR may have difficulties "fitting in" with their peers and feel unaccepted and thus unsatisfied with their lives, which may lead to depression. Those with severe MR, however, may not be as aware of their social situation, and thus may not be as depressed.

This same study, however, found schizophrenic symptomatology to be more frequently diagnosed among those with severe MR (46.7%) than among individuals with mild MR (16.7%). Although a psychotic diagnosis is more difficult among individuals with severe MR than those with mild MR, individuals with severe MR are more likely to live in institutions, where experienced mental health providers are more accessible than they are 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%) (Borthwick-Duffy and Eyman, 1990). The higher prevalence among those with severe MR in Europe, then, may be due to the distribution of individuals among residential settings, with individuals in institutions receiving more comprehensive diagnostic assessments than those living in the community.

Specific Conditions

Adult Mental Health Conditions

The types of mental health disorders found in those with MR are similar to those found in their peers without MR (Reiss et al., 1982; Eaton and Menolascino, 1982). Among adults in the general population, the most common mental health disorders consist of anxiety disorders, affective disorders and substance abuse. Although schizophrenia is not very prevalent, it merits attention due to its severity and persistence (Surgeon General, 1999). The most common disorders cited among adults with MR and intellectual disabilities in both the U.S. and Australia are anxiety disorders, psychotic disorders and personality disorders (Reiss, 1990; Lennox and Chaplin, 1996; Moss et al., 1997). As discussed above, affective disorders are important, albeit less common, conditions among individuals with MR, and thus warrant attention here as well. Further, individuals with Down Syndrome report a high prevalence of dementia. In contrast,

there has been a much lower prevalence of substance abuse reported among individuals with MR than in the general population (Reiss, 1990; Moss et al., 1997). The prevalence of the above mentioned conditions will be presented in this chapter.

Anxiety Disorders

Although earlier research studied the condition "neurotic disorder," this term, which closely resembles the presently used term "anxiety disorder," is no longer used in the mental health literature. For the purposes of this report, "anxiety disorder" will be used to refer to both anxiety and neurotic disorders.

Anxiety disorders usually present as clinically significant unpleasant emotions, such as fear, dread and alarm, in the presence of stressors. The Surgeon General (1999) reports that between 13.1% and 18.7% of the general population suffers from an anxiety disorder. In contrast, Reiss (1990) found that 31.4% of individuals at a community-based day program for individuals with MR suffered from an anxiety problem, and that for 6.4%, anxiety was a major problem.

Although the prevalence of anxiety among individuals with MR is higher than that in the general population, anxiety disorders have been found to be difficult to diagnose in individuals with severe MR. In fact, although Day (1983) reports a prevalence of anxiety disorders of 28% among individuals with MR, only 4% of these cases were among moderately and 0% were among severely mentally handicapped individuals (Fraser and Nolan, 1994).

Obsessive-compulsive disorder (OCD), one of many anxiety disorders, is characterized by recurrent obsessions or compulsions that are severe enough to be time-consuming or cause

marked distress or significant impairment (APA, 1994). This condition generally manifests itself in adolescents or young adulthood (Surgeon General, 1999); its prevalence in the general population is estimated to range from 1%-2.4% (Surgeon General, 1999).

Among individuals with MR, the prevalence of OCD has been reported to be 3.5% (Fraser and Nolan, 1994). OCD may present atypically among individuals with MR, with hand washing, self-injury, sterotypic movements and anxiety dominating the symptomatology (King, 1993 in Verhoeven and Tuiner 1999; Stavrakaki, 1999). In contrast, the most common symptoms in the general population include concern over order, symmetry or contamination with germs or bodily fluids, doubts, or loss of control of violent or sexual impulses (Surgeon General, 1999).

Anxiety is important to understand, as severe cases can be violent and disruptive, and interfere with functioning (Stavrakaki, 1999). Acting out may be particularly problematic among individuals with MR, as a result of the frustrations associated with an inability to verbally communicate (Fraser and Nolan, 1994). While some believe that this condition is associated with the same pathology that causes the intellectual disability, others associate anxiety disorders with trauma and abuse (Stavrakaki, 1999).

Affective Disorders

Affective disorders include states of abnormally low mood (depressive disorders) and states of abnormally elevated mood (manic states) (Clarke, 1999). In the general population, the one-year prevalence of affective disorders is reported to be 7% (Surgeon General, 1999). In comparison, the point prevalence among institutionalized individuals with MR has been reported to be 8.9% (Crews et al, 1994). As discussed above, this percentage among institutionalized

individuals with MR may reflect the low prevalence of depression diagnosed among those with severe MR. Crews et al. (1994), however, did find that over half of those with dual diagnosis (57%) suffer from an affective disorder. The most common mood disorders include major depression and bipolar disorder (Surgeon General, 1999).

Depression is an affective disorder characterized by low mood and decreased energy (Clarke, 1999). In the general population, the prevalence has been estimated to be between 5% and 25% (Stavrakaki, 1999; Kessler et al., 1996). Among adults with MR, depressed mood is the most common psychological symptom (Laman and Reiss, 1987; Fraser and Nolan, 1994). The administratively determined prevalence of diagnosed depression among individuals with MR, however, has been estimated only to be between 3% and 6% (Reiss, 1990). In fact, among individuals with mild MR receiving disability benefits from New York State, 6.2% were found to have depressed mood (Laman and Reiss, 1987). Although these percentages may seem low compared with the general population prevalence, they may underestimate the true prevalence of depression in the population with MR because they are derived from service-based data. Further, experts in the field believe depression to be underdiagnosed among those with MR (Reiss, 1994), due in large part to an atypical presentation, including aggressive behavior, self-injury, psychomotor agitation and irritable mood (Meins, 1995 in Verhoeven and Tuinier, 1999).

The causes of depression among individuals with MR are thought to be the same as among those in the general population, and include biological and genetic factors, as well as stressful life events, which may be numerous in this population (Stavrakaki, 1999). In addition, depression is often associated with the low levels of social support and poor social skills often experienced by individuals with MR (Schloss, 1982 in Benson et al., 1985; Reiss and Benson, 1983; Laman and Reiss, 1987). The impact of depression on individuals with MR is significant,

as it has been shown to be associated with aggressive behavior, anger, irritability, antisocial behavior and conduct problems (Laman and Reiss, 1987).

Bipolar disorder consists of manic behavior or the combination of both mania and depression, and is not as common as depression. The Surgeon General Report (1999), in fact, reports about 1.7% of the general population (age 18 to 54) to have a bipolar disorder. Among individuals with MR, bipolar disorder is rarely reported. This may be due to the atypical symptomatology, namely perplexity, lability and irritability, associated with bipolar disorder in this population. In fact, whether this symptomatology should be characterized in this domain is a matter of debate (Verhoeven and Tuinier, 1999).

Psychotic Disorders

Psychotic disorders have been defined as disturbances of perceptions and thought processes (Surgeon General, 1999). While the Surgeon General (1999) estimates the prevalence of nonaffective psychosis in the general population to be 0.2%, Reiss (1990) found a prevalence of psychosis among individuals with MR attending a community day program to be 5.8%.

Schizophrenia, one type of psychotic disorder, is characterized by distortions in thinking and perception, and inappropriate or flat mood states (Clarke, 1999). In general, schizophrenia is believed to occur in only 1.0% of the general population, compared with 3.0% of the population with MR (Clarke, 1999; Weissblatt, 1994; Fraser and Nolan, 1994; Surgeon General, 1999). Using administrative data, however, Eaton and Menolascino (1982) found the prevalence of schizophrenia to be 21%, and Reiss (1982) reported it to be 30.3%, among adults with MR.

In the past, stereotypic behaviors seen in individuals with severe MR were thought to be indications of schizophrenia (Hayman, 1939). Due to the degree of language skills necessary to

diagnose schizophrenia, however, this view is no longer accepted. In fact, as described above, schizophrenia is currently rarely diagnosed among individuals with severe MR, and some do not believe that it is even possible to make such a diagnosis among individuals in this group (Reid, 1993). Rather, a less specific diagnosis of psychotic disorder, not otherwise specified, is often made among individuals with severe MR (AACAP, 1999).

Personality Disorders

Personality disorders consist of long-term problems in adjustment (Reiss et al., 1993). The Surgeon General (1999) reports an anti-social personality prevalence of 2.1% among the general population, and Kassen et al. (1999) report that 23.6% of their community sample of young adults were diagnosed with a personality disorder.

Although some debate exists as to whether personality disorders can be observed among individuals with low mental age (such as children or those with MR) (Reiss, 1994), these disorders have been cited as some of the most common psychiatric diagnoses among individuals with MR (Day, 1985 in Fraser and Nolan, 1994; Emerson et al., 1999). Reid and Ballinger (1987), for example, found that among individuals in a hospital for the mild/moderately handicapped, 56% had abnormal personalities and 22% suffered from personality disorders (Fraser and Nolan, 1994). Similarly, Duncan et al. (1936) found 33% of institutionalized individuals with MR to have a personality disorder, and Eaton and Menaloscino (1982) reported that 27.1% of individuals at a community-based program had one of these conditions.

Dementia

Individuals with MR are now surviving long enough to be at risk for age-associated conditions such as dementia of the Alzheimer type (Tuinier and Verhoeven, 1993). Adults with Down Syndrome, for example, experience a higher rate of dementia at a relatively earlier age than those without Down Syndrome (Janicki and Dalton, 2000). In fact, most individuals with Down Syndrome who live past 35 years show Alzheimer-like neuropathology (Holland, 1994).

Substance Abuse

Substance use has not been found to be as common among individuals with MR as in the general population (Koller et al., 1982 and MacEachron, 1979 in Edgerton, 1986). The general population prevalences for illicit drug use and alcohol use have been reported to be 11.9% and 66.4%, respectively (SAMSHA, 1998). In contrast, of the 205 participants at a community-based day program for individuals with MR, Reiss (1990) found that no individuals suffered from alcohol or drug abuse, and Glick and Zigler (1995) reported that 3.5% of 112 psychiatric inpatients with mild MR were substance abusers. In addition, Edgerton (1986) reported that among four samples of adults with MR living in a variety of community settings, individuals were less likely to use alcohol or other drugs than a comparison group of individuals without MR. This is somewhat surprising, since studies in both the U.S. and the U.K. have found large numbers of deinstitutionalized individuals with other mental health disorders, who may face the same adaptation problems as those with MR, to be substance users (Arce et al., 1983, Wynee, 1984 and Melick et al, 1979 in Edgerton, 1986).

Child Mental Health Conditions

Due to the changing nature of children's environments and brain development, the sociocultural environment in which they live affects their mental health even more than it does that of adults (Surgeon General, 1999). Among children in the general population, the most common mental health disorders are anxiety disorders, affective disorders, and attention deficit and disruptive disorders. These same disorders, with the addition of schizophrenia, are also the most commonly reported mental health disorders among children with MR (Chess and Hassibi, 1970 in Borthewick-Duffy, 1994 Embrets, 2000; Szymanski, 1994; AACAP, 1999).

Anxiety Disorders

The combined prevalence of anxiety disorders is higher than that of virtually all other mental disorders of childhood and adolescence (Costello et al., 1996 in Surgeon General, 1999). The Surgeon General (1999) reports the one-year prevalence of anxiety among 9-17 year olds to be 13%. In contrast, a small study of a psychiatric clinic for children with mental handicaps under the age of 16 reported 22% to suffer primarily from an anxiety disorder (Reid, 1980). Since children with MR are more dependent on their caregivers than children without MR, they may be more likely to react to changes in their routine, resulting in higher prevalence estimates of anxiety in this population.

Affective Disorders

Depression in childhood differs from depression among adults. Children with major depression, for example, do not experience psychotic features as often as depressed adults do, and when they do, the features are not presented in the same manner. Further, major depression

is more likely to be associated with an anxiety disorder in children than in adults. In fact, two-thirds of children and adolescents with major depressive disorder also suffer from another disorder (Surgeon General, 1999).

In the general population, the prevalence of depression has been estimated to be 6.2% for children 9-17 (Surgeon General, 1999). As with adults, the prevalence of depression is lower among individuals with MR, and it is easier to diagnose among children with mild MR than those with more severe MR. In Sweden, the prevalence of depression has been reported to be 1.5% among children with severe MR and 4% among children with mild MR. Again, this may be due to the lack of family and peer support felt by children with mild MR, who are often expected to function "alone" in the general society to a greater extent than other subgroups of MR (Stavrakaki, 1999).

One reason that depression is important to consider among children is that it increases the risk of suicide. In fact, over 90% of children who commit suicide are believed to have had a mental disorder. Among children in the general population, the prevalence of suicide is 1.6 per 100,000 among 10-14 year olds and 9.5 per 100,000 among 15-19 year olds (Surgeon General, 1999). Although many people do not associate suicidality with MR, in a study of a psychiatric hospital, 21% of admissions for dual diagnosed youth demonstrated suicidal behavior either before or during the hospitalization (Walters et al., 1995).

Attention Deficit and Disruptive Disorders

The most common attention deficit and disruptive disorders include attention deficit/hyperactivity disorder (ADHD) and conduct disorder. In the general population, the prevalence of ADHD is estimated to be 3% to 5% (APA, 1999). Among children with MR, poor

attention and hyperactivity, the hallmarks of ADHD, are common reasons for mental health referrals (AACAP, 1999). Since most of the criteria used to diagnose ADHD are based on behavioral observation, not verbal communication, this disorder can be diagnosed fairly easily among non-verbal individuals with MR (AACAP, 1999). Consequently, the prevalence of ADHD among those with MR, 4%-11%, has been found to be somewhat similar to that in the general population (Feinstein and Reiss, 1996 in AACAP, 1999; APA, 1999).

Further, among children with Down Syndrome, Green et al. (1989) found that even between the ages of 2 and 4 years, a discrete group could be identified as showing measurable attention deficit. Although this study was small, the authors concluded that the deficit was not associated with mental age, parenting style or medical factors; rather, they believed it to be intrinsic to Down Syndrome (Stores et al., 1998). ADHD is important to recognize because although many children outgrow their symptoms, children with ADHD often develop other disruptive disorders in their teenage years (Surgeon General, 1999).

Children or adolescents with conduct disorder behave aggressively by fighting, bullying, intimidating, physically assaulting, sexually coercing, and/or being cruel to people or animals (Surgeon General, 1999). Conduct disorder among children in the general population has been reported to range from 6%-16% among boys and 2%-9% among girls (APA, 1999).

Among individuals with MR, a Swedish population-based study found that 4.5% of those with severe MR and 12% of those with mild MR suffered from conduct disorder (Gillberg et al., 1986). Similarly, reports by Gath and Gumley (1986; 1987) indicate that 11% of school children were rated to have conduct disorder by parents and teachers. A much smaller study of a psychiatric clinic for children with MR, however, reported that as many as 45% of the study population primarily manifested a conduct disorder (Reid, 1980), and Richardson et al. (1985)

reported that 33% of children and adolescents with mild MR suffer from this disorder (AACAP, 1999). Although the prevalence, then, is not clear, a significant percentage of children with MR do suffer from conduct disorder. Given that rates of depression, suicidal thoughts, suicide attempts, and suicide itself are all higher in children diagnosed with a conduct disorder (Shaffer et al., 1996 in Surgeon General, 1999) than in children in the general population, this is an important condition to consider.

Psychotic Disorders

Since schizophrenia tends to develop during adolescence and young adulthood, the appearance of schizophrenic symptoms before age 12 is rare (APA, 1999; Rapoport, 2000). Schizophrenia develops very slowly in children, so that most children with schizophrenia show delays in language and other functions long before their psychotic symptoms appear (Rapoport, 2000).

Perhaps because of its rarity, no reports of the prevalence of schizophrenia among children in the general population were identified for this report. The classification of children with schizophrenia among children with MR may be more frequent because some believe that children with psychosis often function at a mentally retarded level (Eaton and Menolascino, 1982). Eaton and Menolascino (1982), in fact, found the prevalence of schizophrenia to be 5% among children (<21 years) with MR, and 9% of children with Down Syndrome have been reported by parents and teachers to be classified as psychotic (Gath and Gumley, 1986; Gath and Gumley, 1987). A Swedish population-based study, however, found a lower prevalence of schizophrenia among children, with 1.5% among individuals with severe MR and 1% among those with mild MR (Gillberg et al., 1986).

Other Disorders

Since MR can be a feature of pervasive developmental disorder (PDD), children with both of these conditions usually are not considered to be dually diagnosed. Because of its prevalence among individuals with MR, however, PDD deserves mention here. PDD is indicated by disordered cognition or thinking, difficulty in understanding and using language and difficulty in understanding the feelings of others or the world around them (Surgeon General, 1999). Autism, the combination of social, communication and imagination-behavior restriction (Wing and Gould, 1979 in Gillberg, 1999), is the most common form of PDD. Autism has been reported in .05%-.17% of children in the general population, in 5% among those with mild MR, and in 15% among individuals with moderate or profound MR (Bryson et al., 1998 in Gillberg, 1999; APA, 1999).

In addition, many studies report the prevalence of behavioral disorders, although the definition of this term is not clear. Nevertheless, this "condition" certainly represents functional issues and thus merits attention in this report. In the U.K., the prevalence of severe behavioral disorder among children with severe MR has been reported to be 20% among children and adolescents (Wing, 1971 and Kushlik and Cox, 1973 in Holt, 1994).

Further, among children with Down Syndrome, about 30% have been rated by their parents and teachers as behaviorally disordered (Gath and Gumley, 1986; Gath and Gumley, 1987). Although a British study of children indicated that those with Down Syndrome had a higher prevalence of behavioral disturbance than those without Down Syndrome, however, children with other intellectual disabilities showed a higher prevalence than either of these groups (Stores et al., 1998).

Summary and Implications

Due to differences in methodology and diagnoses, comparisons of the prevalence of mental health disorders between individuals with MR and the general population are challenging at best. Further, given that dual diagnosis tends to be difficult, if not impossible, among individuals with severe MR, the percentages of mental health conditions reported here may underestimate the true percentages in this population. Nevertheless, the studies highlighted here indicate a high prevalence of dual diagnosis.

The mental health conditions reported among individuals with MR are very similar to those found in the general population. Adults with MR tend to suffer less from substance abuse than those in the general population, but are more often diagnosed with anxiety disorders, psychotic disorders and personality disorders. Although affective disorders are less often diagnosed in adults with MR than in the general population, the prevalence of these conditions is believed to be higher than the cited studies indicate. In addition, individuals with Down Syndrome suffer from dementia as they age, and children with MR tend to suffer from anxiety disorders, affective disorders, psychotic disorders, ADHD and conduct disorder.

Most U.S.-based studies find a higher prevalence of depression among individuals with mild or moderate MR than those with more severe MR. Schizophrenia, however, has been found to be more prevalent among individuals with severe MR. These associations may be due to the nature of the disorders. Since individuals with mild MR are more likely to live with their families, and experience and be aware of every-day stressors, they may be more susceptible to affective disorders than those with severe MR. In addition, the relationship between schizophrenia and severity of MR may be due to difficulties in diagnosing certain mental health

conditions among individuals with MR. Because those with severe MR are more likely to live in institutions than those with mild MR, the former group may have greater access to experienced mental health care providers, who are capable of making difficult diagnoses.

Further, European studies have found more mental health disorders among individuals with severe MR. This may be due to the types of populations and disorders studied, differences in diagnostic practices or the distribution of individuals among residential settings. For example, since in the U.S. dually diagnosed individuals with severe MR are more likely to live in institutions than with their families, they may not be captured in research using administrative data. Given that European studies tend to use population-based samples, they may be more likely to diagnose mental health disorders among individuals with severe MR than administrative studies conducted in the U.S.

While in the past most individuals with MR in the U.S. received mental health care in the institutions in which they lived, most Americans with MR currently live in community or family settings. As a result, accessible and appropriate community-based services are imperative in order to identify and treat mental health disorders in this population.

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CHAPTER 4

OCULAR IMPAIRMENTS AMONG INDIVIDUALS WITH MENTAL RETARDATION

Introduction

As previously discussed, the prevalence of a condition will vary with changes in the population studied. Most research on ocular anomalies among individuals with MR analyzes administrative data, examining individuals who use services in the community. Depending on the population sampled, however, administrative studies may under- or over-estimate the true prevalence of ocular impairments among individuals with MR.

Prevalence

Available data suggest that ocular impairments (refractive errors, strabismus, cataracts, keratoconus, nystagmus and poor visual acuity) are more common among individuals with MR than those without MR (Polcar, 1983; Levy, 1984; Ronis, 1989; Maino, 1996). While 25% of children in the general U.S. population are reported to be ophthalmologically impaired, as many as 72% of children with MR have been so categorized (Lawson and Schoofs, 1971). A similar, if not more striking pattern can be seen among older adults. For example, while in the general population 0.6% of those between age 60 and 69, and 9.0% of those over 80 have been reported to have ocular impairments (Thielsch et al., 1990 in Evenhuis, 1995), research in the Netherlands has found a prevalence of 18%-20% of moderate, and 8% of severe, visual impairment among institutionalized individuals over 60 years of age. Other studies have reported percentages of ocular impairments in individuals with MR over 50 years to range from 8% to 50% (Janicki and

Jacobson, 1986, Day, 1987, Moss, 1991 and Van Schrojenstein Lantmann-de Valk et al., 1992 in Evenhuis, 1995).

The most common cause of decreased vision in individuals with MR is uncorrected refractive errors (Maino, 1996), such as astigmatism, farsightedness and nearsightedness. While 15%-30% of the general population has a refractive error (Sullivan, 1988 and Regenbogen, 1985 in Gnadt and Wesson, 1992), 20%-60% of individuals with MR in the U.S. and Canada have been reported to require correction of refractive anomalies (Levy 1984; Woodruff et al., 1980; Gnadt and Wesson, 1992; Maino, 1996).

Similarly, British research of administrative data on individuals with MR found the prevalence of refractive errors to be 30% (Aitchison et al., 1990), and an administrative study in Japan reported the prevalence of such impairments to be even higher. In this study, Kuroda et al. (1987) found that more than 80% of children with MR had refractive errors (Kuroda et al., 1987). International research on specific sub-populations of those with MR, however, has found slightly lower prevalence estimates of refractive errors. A Swedish study of institutionalized individuals with MR, for example, reported that 23% had a considerable refractive error in the best eye (Jacobson, 1988), and in Hong Kong, the prevalence of refractive errors among those with profound MR (IQ<25) has been reported to be 24% (Kwock et al., 1996).

In addition, research has examined the prevalence of specific types of refractive errors, including astigmatism, hyperopia (farsightedness) and myopia (nearsightedness). Woodruff et al. (1980), for example, found the prevalence of astigmatism among institutionalized Canadian individuals with MR to exceed 30%. Further, Levy (1984) found higher percentages of hyperopia/astigmatism than myopia/astigmatism among Canadian adults with MR, although the

difference was more pronounced among males than females, and a similar pattern can be seen among individuals without MR. In contrast to most Western studies indicating that hyperopia is more prevalent among individuals with MR than myopia, however, Kwok (1996) found myopic and hypermetropic astigmatisms to be equally prevalent in Hong Kong.

Further, strabismus (the inability of both eyes to fixate on a target simultaneously because of ocular muscle imbalance) has been attributed to uncorrected refractive errors (Woodruff, et al., 1977). Similar to other visual impairments, the prevalence of strabismus among individuals with MR exceeds that of the general population (Woodruff, 1977). While the prevalence of strabismus in the general population has been found to range from 3.7% to 9.5% (Levy, 1984; Block et al., 1997), the prevalence ranges from 21% to 41% among American and Canadian individuals with MR (Lawson and Schoofs, 1971; Woodruff et al., 1980). Similarly, Aitchison et al. (1990) found the prevalence of strabismus to be 31% in a British administrative sample.

The prevalence of cataracts (opacity of the lens of the eye, the capsule or both) and keratoconus (swelling and scaring of the cornea) among individuals with MR also has been reported to be much higher than that in the general population (Woodruff, 1977; Levy, 1984). For example, while the percentage of lens anomaly reported for adults without MR has been 1.42%, administrative data in the 1980's indicated that between 2.68% (females) and 5.36% (males) of Canadian adults with MR suffered from cataracts. In this same study, keratoconus also was reported to be more common among males than females with MR (Levy, 1984). British administrative data, however, indicates the prevalence of cataracts to be as high as 11% (Aitchison et al., 1990). These high prevalence estimates among individuals with MR may be due to the association between cataracts, keratoconus and Down Syndrome (see below).

Severity of MR has also been found to be associated with the prevalence of visual impairments, with individuals with severe MR having more ocular problems than those with mild or moderate MR. Woodruff (1980), for example, found higher percentages of astigmatism among institutionalized Canadian individuals with severe MR than among those with mild or moderate MR, but reported no difference in corneal power between these categories. Further, Hirsch (1959) reported that individuals with higher intelligence tend to be more myopic, and those with lower intelligence to be more hyperopic (Manley and Schuldt, 1970). In contrast, McCulloch et al. (1996) did not find a significant trend between severity of disability and refractive error among Scottish individuals with MR. They did, however, find a relationship between severity of MR and visual acuity (clearness or distinctness of vision). While 88% of institutionalized individuals with mild intellectual disability had good visual acuity, only 60% of those with severe disability and none of those with profound disability achieved this level. Similarly, the prevalence of strabismus in this study ranged from 25% among those with mild MR to 60% among those with profound MR.

Ocular Conditions Among Specific Populations

When the Special Olympics, Inc. (SOI) population was studied at the 1995 International Summer Games, the prevalence of overall ocular problems (29%) was comparable to that found in institutions (Block et al., 1997; Woodruff, 1980). Specifically, 27% suffered from poor visual acuity, 85% had refractive errors, 28% suffered from astigmatism, and 18.5% had strabismus (Block et al., 1997). Further, at the 1999 World Summer Games, the Special Olympics Opening Eyes Vision Health Program found as much as 25% of the screened population to have some form of strabismus (SOI, 1999).

Individuals with Down Syndrome are at a particular risk for ocular anomalies as they age (Aitchison et al., 1990). In fact, among older adults, ocular impairments tend to occur at an earlier age among individuals with Down Syndrome than in the general population (Flax et al., 2000). Visual impairments, then, are of growing concern due to the increased longevity of patients with Down Syndrome (Aitchison et al., 1990).

A Swedish study conducted in the late 1980's highlights the association between age and ocular impairment among individuals with Down Syndrome. Among 50 institutionalized patients with Down Syndrome, Jacobson (1988) found that 22 had a visual impairment, and 14 of the 22 (64%) had acquired the impairment as adults. Further, although Lyle and Jaeger (1972) reported the prevalence of keratoconus to range in the literature from 1% to 8% among children with Down Syndrome, Jacobson found a prevalence of 30% among institutionalized adults with Down Syndrome (Jacobson, 1988).

Generally, those with Down Syndrome are more likely to suffer from strabismus, nystagmus (constant, involuntary, cyclical movement), cataracts and keratoconus (Woodruff, 1977; Hestness et al., 1991; Millis, 1985 in Woodhouse et al., 1997), compared with individuals without Down Syndrome. The prevalence of strabismus has been reported to range from 22% to 43% among individuals with Down Syndrome (Berk et al., 1996 in Block et al., 1997; Shapiro and France, 1985; Pires Da Chuna et al., 1996). In addition, the prevalence of cataracts, which tends to increase as individuals with Down Syndrome age (Jacobson, 1988), has been found to range from 13% to 54% (Shapiro and France, 1985; Jaeger, 1980 in Pires Da Chuna et al., 1996), and the prevalence of keratoconus has been reported to be 15% (Shapiro and France, 1985), among individuals with Down Syndrome.

Further, despite the association between age and ocular anomalies in this population, children with Down Syndrome tend to have a high prevalence of ocular impairments. For example, one study found that among children with severe MR, 70% of those with Down Syndrome had poor visual acuity, compared with 30% of children without Down Syndrome (Gardiner, 1967). Additionally, a Brazilian study found a high prevalence of strabismus (38%) among children with Down Syndrome, although this condition was significantly more frequent among older children (Pires Da Chuna et al., 1996). Moreover, refractive errors have been reported in over 40% of children with Down Syndrome (Gardiner, 1967).

Not surprisingly, then, Welsh researchers have reported that children with Down Syndrome have a higher prevalence of astigmatism compared with children without Down Syndrome, although this difference was only statistically significant among older children (Woodhouse et al., 1997). The Brazilian study mentioned above also found a high percentage of astigmatism (60%), compared with strabismus (38%), among children with Down Syndrome (Pires Da Chuna et al., 1996). Further, a British study found more myopia than hypermetropia among children with Down Syndrome. Gardiner (1967) reports that among children with severe MR, 50% of the children with Down Syndrome were myopic and 15% were hypermetropic, while only 3% of children without Down Syndrome were myopic, and as many as 40% were hypermetropic.

Rationale for Increased Prevalence

Part of the increased prevalence of ocular impairments among individuals with MR may result from the proportion of aging people with intellectual disabilities, which has grown due to medical and social advances (Flax et al., 2000). In fact, as detailed above, older individuals with

MR, particularly those with Downs's syndrome, report a higher prevalence of visual impairments than individuals of the same age in the general population.

In addition, the high prevalence of visual impairments among individuals with organic MR may be due to the condition that caused the MR, which may actually restrict ocular growth (Woodruff, 1980). According to Gardiner (1967), for example, most eye anomalies among individuals with Down Syndrome are due to a lack of coordination of the eye during its growth. Further, as mentioned above, Down Syndrome is often associated with cataracts, which can cause visual loss (Evehuis et al., 1997). In other cases, however, visual impairment may result from long-term medication use, which often has ocular side effects (Bartlett, 1987; Polcar, 1983; Maino, 1996). Since individuals living in institutions are often prescribed more drugs than those in the community, this may account for the higher prevalence of visual impairments among individuals with severe MR, who are more likely to be institutionalized than those with mild or moderate MR (Woodruff et al., 1980; Polcar, 1983). Additionally, as will be discussed in chapter 6, a loss of visual efficiency and acuity may occur over time due to inadequate detection and treatment.

Summary and Implications

The prevalence of ocular deficits among individuals with MR, then, varies, depending on the population studied. Nevertheless, most research efforts have found high percentages of visual problems within this population. The most common conditions among individuals with MR, both in the U.S. and internationally, appear to be refractive errors and strabismus, although the distribution of hyperopia and mypoia tends to vary with the population studied. In addition, individuals with severe MR tend to have more visual anomalies than those with mild MR. While

this observation may be due to the etiology of the MR, it may also be due to the increased medication use associated with the institutionalization of individuals with severe MR. Further, those with Down Syndrome are highly likely to have strabismus, cataracts and keratoconus, particularly as they age.

Identifying ocular impairments in childhood is important because early correction can prevent further impairments over time. Further, visual impairment can limit the range of experiences and information available to a child, and thus, have a significant impact on a child's emotional, neurological and physical development (Mervis et al., 2000). This may be particularly important for children with MR. Combined with their other impairments, untreated or mistreated visual deficits may be a more devastating obstacle to children with MR (who may rely greatly on good functional vision) than to other children (who may be better able to compensate for visual impairments in other ways) (Gardiner, 1965; Krekling and Anderson, 1974; Markovits, 1975; Ronis, 1989; Maino, 1996; Evenhuis and Nagtzaam, 1997). Correcting ocular anomalies, then, can lead to both better functioning in society and educational and social benefits for children, adults and their families. Given this, it is crucial that ocular problems are identified early and, when possible, corrected.

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CHAPTER 5

DENTAL HEALTH AMONG INDIVIDUALS WITH MENTAL RETARDATION

Introduction

Poor oral health can have dramatic effects on an individual's quality of life. In fact, it can cause difficulties with eating, speech impediments, pain, sleep disturbances, missed days of work or school and decreased self-esteem (Locker et al., 1987; Hollister et al., 1993 and Broder et al., 1994 in Perlman and Broder, 1996). In recognition of the importance of oral health to individuals, the U.S. Surgeon General and the World Health Organization have made oral health a national and international priority (US DHHS, 1990; US DHHS, 2000a; US DHHS 2000b; WHO, 2000).

The overall oral health of a population can be described by DMFTs, which characterize the lifetime prevalence of dental caries in an individual or population by summing the number of decayed teeth (D), the number of missing teeth (M) and the number of filled teeth (F) (WHO, 2000). DMFTs range from 0 to 28 or 32 (depending on the inclusion or exclusion of wisdom teeth), with 28 or 32 indicating that all teeth have problems related to dental caries. Among 12-year old U.S. children, the average DMFT is 1.4 (WHO, 2000), while the average DMFT among U.S. adults aged 35-44 years is 13.6. Among Western European countries, DMFTs for 12-year old children range from .9 to 6.1 with a mean DMFT of 2.6. Adults from Western European countries have DMFTs between 8.8 to 22.9 (WHO, 2000).

Besides dental caries and tooth loss, other oral health concerns include gingivitis (inflammation of the gums) and other periodontal diseases (loss of connective and bone tissue that support the teeth). According to the National Health and Nutrition Examination Survey III,

48% of the U.S. adult population had gingivitis and 22% had other periodontal disease between 1988-1994 (US DHHS, 2000a).

Although the overall oral health of the population is improving, disparities still exist in oral health needs among subpopulations (Waldman, 1996; US DHHS, 1999; US DHHS, 2000a; US DHHS 2000b). Individuals with MR, for example, have poorer overall oral health and oral hygiene compared with the general population (Haavio, 1995; Feldman et al., 1997; Waldman et al., 1998). The oral health and hygiene of individuals with MR is associated with severity of MR, etiology of MR, residential arrangements and age of the individual (Gabre and Gahnberg, 1997). The prevalence estimates among those with MR reported in the literature, however, are subject to the some of the same problems as the prevalence estimates of other health conditions. Namely, oral health prevalence estimates are based on administrative data or small community registries that may not adequately reflect the true prevalence in the population. Additionally, the methodologic rigor with which some of these published studies were conducted is somewhat questionable, in that they provide little information about the measurement of MR or its severity among individuals, inconsistent information about a comparison group and few, if any, statistical tests for comparison between groups of individuals.

Prevalence

Dental problems are among the top ten limiting secondary conditions among individuals with MR (Traci et al., in press; Szalda-Petree et al., in press). According to a recent pilot study of consumers of Montana Developmental Disability services (79.8% of whom had mental retardation), Traci et al. (in press) found that the estimated prevalence rate of oral hygiene problems was 451 per 1000 individuals with developmental disabilities. Like the general

population, one of the most common oral health problems of children and adults with MR is dental caries. National and international studies, however, do not provide definitive data on the prevalence of dental caries among those with MR relative to the general population (Haavio, 1995; Shapira et al., 1998; Waldman et al., 2000a). The majority of authors have found that individuals with MR have similar prevalence estimates of dental caries to those of the general population (Pollack and Shapiro, 1971; Svatun and Heloe, 1975; Brown and Schodel, 1976; Tesini, 1981; Pieper et al., 1986; Costello 1990; Whyman et al., 1995; Gizani et al., 1997; Cumella et al., 2000). Some researchers, however, have found lower prevalence estimates of dental caries among individuals with MR, and others report higher prevalence estimates of untreated carries in this population (Tesini, 1981; Girgis, 1985; Forsberg et al., 1985; Barnett et al., 1986; Kendall, 1991).

Nowak (1984), for example, examined the dental health of 3,622 disabled individuals aged 0-16+ years living in the community. Based on examinations by dental hygienists, they found an average DMFT score of 6.44 among individuals with Down Syndrome, and an average DMFT score of 6.73 among individuals with other etiologies of MR, compared with an average DMFT score of 6.68 among individuals in the general population. They found, however, that the proportion of missing teeth (M) to filled teeth (F) was much higher among individuals with MR compared with the general population, suggesting that extraction, rather than restoration, is the primary treatment of dental problems among those with MR (Svatun and Heloe, 1975; Nowak, 1984).

Alternatively, other researchers have found that those with MR have a lower prevalence of dental caries (0.4 caries per individual) compared with the general population (Girgis, 1985; Forsberg et al., 1985, Barnett et al., 1986). This low prevalence of dental caries is primarily

found among individuals with severe MR living in institutions (Gabre and Gahnberg, 1994; Shapira et al., 1998). In fact, Butts (1967) found that children with severe MR living in institutions had fewer dental caries than children with mild or moderate MR. It is likely that the low prevalence of dental caries found among those with severe MR living in institutions relative to the general population results from the prior removal of decayed teeth and the low sugar diet served in institutions (Tesini, 1981). Some authors, however, have focused on the prevalence of untreated caries, rather than DMFT scores, which quantify the number of both treated and untreated caries. These studies report that both children and adults with MR have more untreated caries than the general population (Costello 1990; Cumella et al., 2000).

Another common oral health problem among children and adults with MR is gingivitis, with prevalence estimates of 1.2 to 1.9 times the estimates of the general population. Studies on the oral health of individuals with MR, conducted in communities in the U.S. and internationally, report prevalence estimates of gingivitis in the range of 60% to 97% among individuals with MR compared with an estimates of 28% to 75% in the general population (Murray and McLeod, 1973; Sturmey and Hinds, 1983; Vignehsa et al., 1991; Kendall, 1991; Cumello et al., 2000; Tesini, 1981; American Dental Association, 2000). Those who are older, those living in institutions and those with Down Syndrome tend to have higher prevalence estimates of gingivitis (Murray and McLeod, 1973; Svatun and Gjermo, 1977; Tesini, 1981; Forsberg et al., 1985; Vigild, 1985; Kendall, 1991). For example, Shapira et al. (1998) suggested that the increased prevalence of gingivitis among institutionalized individuals may be related to the mouth dryness associated with certain medications commonly used among individuals with MR living in such settings. Increased prevalence may also be related to the increased surveillance of gingivitis and poor oral hygiene among individuals living in institutions.

Other periodontal disease also has been shown to be more prevalent among individuals with MR, especially those living in institutions, compared with the general population. Sturmey and Hinds (1983) examined the dental hygiene of 26 U.S. adult residents with profound MR. They found that 33% had bruxism (wear on teeth due to grinding) and 20% lacked mastication (ability to close the mouth to chew food). In addition, Oilo et al. (1990) examined the wear of teeth among individuals with MR living in a Norwegian residential placement setting. They found that 5.3% of men and 2.8% of women had unacceptable tooth wear that required treatment compared with 1.2% in the general population.

Dental Conditions Among Specific Populations

The dental health of two unique populations, including Special Olympics athletes and individuals with Down Syndrome, deserve special attention. Special Olympics Inc. (SOI) has taken an active interest in the oral health needs of individuals with MR (Shriver, 1998; Perlman, 2000). Consequently, several studies have reported the prevalence of oral health screenings at Special Olympics events (Feldman et al, 1997; White et al., 1998; SOI, 1999). Feldman et al. (1997), for example, documented the results of a screening program of Special Olympic athletes who participated in the New Jersey Special Olympic Games in 1996. They found that 6-8-year old children with MR had similar patterns of dental caries as children of the same age in the general population (56% versus 53%, respectively). Adolescent athletes 15 years and over, however, were less likely to have dental caries than adolescents in the general population (54% versus 78%, respectively). Further, there appeared to be no difference between athletes aged 35 to 44 years and individuals of the same age in the general population who had tooth loss due to periodontal disease or dental caries (62% versus 69%, respectively). In contrast, athletes aged 65

years and older were more likely to have lost all of their natural teeth compared with their peers without MR (50% versus 36%, respectively). Additionally, preliminary evidence from SOI national and international administrative data collected in 2000 suggests that the overall prevalence of untreated dental decay among Special Olympic athletes in the U.S. is 24.6%, which is higher than the prevalence estimates in the U.S. general population (20.0% among school-aged children, 14.2% among working adults) (Kaste et al., 1996 and Winn et al., 1996 in SOI, 1999; SOI, 2000).

Further, the increased prevalence of gingivitis among Special Olympic athletes has been documented to be higher than that in the general population. Data from the 1996 New Jersey Special Olympic Games suggested that 68% of athletes aged 35-44 years had gingivitis compared with 42% in the general population (Feldman et al., 1997). In addition, recently compiled SOI administrative data from 1999 and 2000 found high overall prevalence estimates of gingivitis among Special Olympic athletes in the U.S. (42.0%), with estimates ranging from 23.5% to 73.0% (SOSS, 1999; SOI, 1999; SOI, 2000). In sum, SOI athletes tend to have an increased prevalence of untreated caries and gingivitis compared with the general population, while only older athletes have been shown to have an increased prevalence of tooth loss.

Individuals with Down Syndrome may be more susceptible to gingivitis and other periodontal diseases because they are thought to have underlying abnormal immunologic responses (Nespoli et al., 1993; Barr-Agholme et al., 1992 and Yavuzyilmaz et al., 1993 in Feldman et al., 1997; Beck et al., 1996). In a study of 120 children, Amano et al. (2000) found that children with Down Syndrome were more likely to have oral pathogens (or microorganisms capable of causing disease) associated with gingivitis compared with children without MR.

Rationale for Increased Prevalence

Since oral health is dependent on oral hygiene (US DHHS, 2000b), the increased prevalence of oral health problems among individuals with MR may be related to their oral health habits (Waldman et al., 2000b). In fact, the oral hygiene among individuals with MR has been shown to be consistently poor compared with individuals in the general population (SOI, 1999). Among individuals with MR, those with moderate or severe MR have been found to brush their teeth more regularly than those with mild MR (Gizani et al. 1997). Those with moderate or severe MR, however, often have impaired physical coordination and cognitive sequencing skills that limit independence in task completion (Sturmey and Hinds, 1983). Consequently, they generally need assistance from caregivers to complete oral hygiene tasks.

Studies of oral health behavior also have been completed among athletes participating in Special Olympics Games. White et al. (1998) documented the results of a study of self-reported oral health habits of participants in the 1997 San Francisco Bay Area Special Olympics Special Smiles program. They found that 71.5% of athletes reported brushing their teeth at least once per day, 27.1% reported brushing their teeth two to six times per week and 0.8% reported brushing their teeth once per week. Estimates varied by age of participants. Younger athletes (9-20 year olds) were more likely to report brushing their teeth two to six times per week, while older athletes (21-49 year olds) were more likely to report brushing their teeth once per day. Even among this relatively high functioning population of individuals with MR, in which there is expected to be an over-reporting of positive health behaviors (SOI, 1999), over one-fourth did not maintain oral hygiene habits on a daily basis, providing evidence for the importance of instruction and reinforcement of daily oral hygiene among individuals with MR (Waldman et al., 2000c).

Summary and Implications

The available data suggest that the oral health of individuals with MR is poorer than that of their peers without MR. Although there are inconsistent findings on the prevalence of dental caries among individuals with MR compared with the general population, the majority of evidence suggests that individuals with MR have more untreated caries than those in the general population. Given that treatment of caries is a prevalent and accepted part of good health behavior for much of the world, this lack of treatment, even in developed countries, suggests problems in access to dental services.

Likewise, there is evidence that individuals with MR are likely to have a higher prevalence of gingivitis and other periodontal diseases compared with the general population. The prevalence of these oral health conditions among individuals with MR, however, is dependent on age, etiology of MR and living situation. Older individuals with MR are at higher risk for poor oral health compared with younger individuals with MR and those in the general population. Further, individuals with Down Syndrome are more likely to have gingivitis compared with individuals in the general population. Additionally, although increased surveillance may influence the prevalence of disease detected, individuals living in institutions are at increased risk for gingivitis and other periodontal diseases compared with individuals in the general population.

As in the general population, good oral hygiene is an important measure to prevent oral diseases among individuals with MR. Interestingly, those with mild MR appear to have poorer oral hygiene when compared with those with moderate or severe MR, chiefly due to the

increased supervision of those with more severe MR. This suggests that efforts to improve the oral hygiene of individuals with mild MR may be a particularly effective intervention.

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CHAPTER 6

HEALTH SERVICES USE FOR INDIVIDUALS WITH MENTAL RETARDATION AND SUMMARY RECOMMENDATIONS

Introduction

Despite the high prevalence of health problems among individuals with MR, very little is known about the quantity and quality of services they receive to treat their health conditions. Similar to research on health status, most research conducted in this area relies on administrative-based data, taken from service providers, or small community registries, rather than large population-based data. Although individuals with MR commonly reside in the community and receive services there, the available data may not be representative of the overall population of community dwellers with MR.

In spite of the limitations of existing data, research indicates that most individuals with MR do not receive the services that their health conditions require. In fact, research on the access and quality of physical, mental, ocular and dental health care demonstrates that individuals with MR receive little medical care, compared with the general population (Howells, 1986; Wilson and Haire, 1990). Further, researchers have suggested that individuals with MR have four times more preventable mortality than individuals in the general population (Dupont and Mortenson, 1990 in Barr et al., 1999), suggesting that medical care may alter the health trajectories of individuals with MR.

Since the studies reviewed here are based primarily on health service data collected in the 1980s and early 1990s, they may not reflect current health services use, which has been shaped by the major health care reforms that took place in the 1990s. Given that individuals in the general population have indicated a reduction of preventive and specialty health care service use

due to these new initiatives (Hurley et al., 1993 in Szilagyi, 1998), the service use documented in this chapter most likely overestimates the current use of services among individuals with MR.

In light of the health needs of individuals with MR described earlier in this report, the low health services utilization of this population certainly represents an under-utilization of care. To explain this phenomenon, this chapter reviews the available research on access to health services for individuals with MR, using a framework based on a modified version of Andersen's behavioral model of access to care (Andersen and Davidson, 1996). In this framework, health service use is influenced by factors in the environment, as well as characteristics of individuals in the population. Environmental factors include health care delivery system characteristics (namely, the structure and integration of systems), the coordination of delivery systems (including provider factors) and the continuity and documentation of care. Individual characteristics are conceptualized in terms of predisposing factors (personal characteristics that existed prior to onset of disease), enabling resources (factors that permit an individual to get health care, such as health insurance) and need for care (either evaluated by professionals or perceived by the individual or caregiver).

Each of these factors can facilitate or impede health service utilization. After briefly reviewing the literature suggesting that health services are under-utilized by individuals with MR, this chapter focuses on the environmental factors and individual characteristics that serve as barriers to care for this population, and describes some efforts being made to overcome such constraints.

Health Care Service Utilization for Individuals with MR

Despite the previously documented need for physical, mental, ocular and dental health services for individuals with MR, adequate services in this population are not frequently utilized. Individuals with MR, for example, have been shown to consult general practitioners less than others with special needs, including those less than 5 years of age or those 75 years of age and older (Jones and Kerr, 1997). Similarly, those with both mental health and MR diagnoses may be one of the most underserved populations in the U.S. (Reiss et al., 1982). Services for the dually diagnosed have been found to be deficient in availability, accessibility and adequacy in the U.S. (Jacobson, 1998), and a great need to increase access to special psychiatric services for those with MR has been documented (Menolascino et al., 1986; Reid, 1972, Hucker et al., 1979, Wright, 1982 and Sovner, 1986 in Day, 1994).

Specifically, studies suggest that between 50% and 80% of individuals with MR have had contact with their primary care provider in the previous 12 months (Singer et al., 1986; Howells, 1986; Wilson and Haire, 1990; Howells, 1991; Lennox and Kerr, 1997; Piachaud et al., 1998). Among those who do seek medical care for physical health conditions, researchers have found that, on average, those with MR have 2.7 medical visits per year, which is similar to the general population of men (3.0 visits per year), but less than the general population of women (5.0 visits per year) and populations of vulnerable groups such as children and the elderly (5.7 visits per year) (Wilson and Haire, 1990).

Moreover, small community-based studies have found that only 30% to 47% of individuals with MR receive care from specialists (Singer et al., 1986; Allison et al., 2000; Piachaud et al., 1998), despite the finding in another small community study by Minihan (1986) that 92% of individuals with MR had medical needs that required specialty medical care. Tonge

(1999), for instance, found that while 41% of young people with developmental disabilities had disruptive antisocial behavior, only 10% received specialty mental health services. Similarly, among adults with moderate to profound MR in England, 75% of those with psychiatric illnesses have been found to receive no treatment (Cooper, 1997).

Further, referrals to psychiatric services tend to vary with severity of MR, with referrals decreasing as the severity of disability increases and functioning decreases (Borthwick-Duffy and Eyman, 1990; Driessen et al., 1997). Other patient characteristics have been associated with referral rates as well. Older individuals living alone, for instance, are more likely to receive psychiatric treatment than younger individuals living with others (Driessen et al., 1997).

Similarly, despite the clear benefits to early and frequent visual and oral assessments, research shows that individuals with MR receive less appropriate ocular and dental services than those without MR (Levy, 1984; Haavio, 1995). For example, at the SOI 1999 World Summer Games, the Special Olympics Opening Eyes Vision Health Program found that 32% of athletes had never had an eye exam, and almost 20% had not had their last eye exam within the two previous years (SOI, 1999a). Further, a study of Scottish hospitals indicated that 56% of patients with disabilities had no record of any past eye examination, and a disproportionate number of those who did have eye exams had only mild or moderate disabilities (McCulloch et al., 1996).

In addition, although Piachard et al. (1998) reported that 92% of individuals with Down Syndrome living in a borough of London used dental services in the past year, most researchers have documented that only 70.1% to 82.0% of individuals with MR use dental care services each year (Feldman et al., 1997; Manley and Pahl 1989; Allison 2000; Cumella et al., 2000). For example, in a Special Olympics, Special Smiles screening program at the 1996 New Jersey summer games, Feldman et al. (1997) found that 70.1% of athletes saw a dentist in the past year

and an additional 8.2% of athletes saw a dentist within the last two years. Additionally, screening data from the 1999 Special Olympics Games in North Carolina suggests that 41.8% of athletes required dental care beyond routine cleaning (SOI, 1999b).

The quality of health services received by those individuals with MR who do access care, however, may not be optimal. For example, despite the fact that individuals with MR have an increased prevalence of certain health conditions, such as thyroid disease, diabetes and obesity, many of these conditions are not addressed by primary care providers (Howells, 1986; Wilson and Haire, 1990; Jones and Kerr, 1997). Jones and Kerr (1997), in fact, found that 50% of individuals with Down Syndrome from five general practices in Wales never had a thyroid screening test. In addition, despite the establishment of screening tools and low threshold referral systems for the diagnosis and management of impairments, several researchers have noted that individuals with MR do not receive preventive or health maintenance activities, such as annual health screenings (Ineichen and Russell, 1987; Beange and Bauman, 1990a; Wilson and Haire 1990; Kerr et al., 1996; Jones and Kerr, 1997; Evenhuis et al., 1997).

Similarly, individuals with MR who receive mental health services often do not receive quality care. As discussed in a previous chapter, many mental health professionals lack training in providing care to individuals with MR (Moss, 1999). Given that individuals in this population may present with atypical symptoms (King, 1993 in Verhoeven and Tuinier, 1999; Stavrakaki, 1999, Meins,1995 in Verhoeven and Tuinier, 1999; Verhoeven and Tuinier, 1999) and have difficulties communicating with providers (Sovner, 1986 in Crews et al., 1994; Sturmey, 1999), the care they receive from inexperienced professionals may be compromised.

In addition, both the detection and the treatment of ocular anomalies are often inadequate among individuals with MR. This is particularly important because many ocular deficits are

correctable. In fact, Woodruff found that 49% of institutionalized individuals with MR had a correctable spherical refractive error, and 37% had a correctable astigmatism (Woodruff, 1980). Even among individuals who receive correction, however, a study of the 1995 Special Olympics World Summer Games found that many athletes were not using an adequate lens (Block et al., 1997). Similarly, McCulloch et al. (1996) found that 38% of Scottish hospital patients with disabilities did not have appropriate correction of refractive errors.

Early diagnosis and frequent assessments and intervention, however, can prevent the long-term effects of this increased prevalence of uncorrected visual anomalies (Woodruff, 1977; Woodruff et al., 1980; Bartlett, 1987). For instance, since the onset of most cases of strabismus is before five years of age, early intervention may prevent the loss of visual efficiency over time. Further, studies have shown that glasses are generally utilized by individuals for whom they are prescribed (Warburg, 1964 and Warburg 1970 in Jacobson, 1988; Jacobson, 1988). For example, Jacobson (1988) found that after 16-18 months, 74% of institutionalized individuals were still wearing their prescribed glasses, and Gardiner (1965) reports that 50% of those for whom glasses were prescribed in a school for children with MR were wearing the glasses after 3 months. This high utilization rate indicates the helpfulness of corrective lenses. In fact, correcting poor vision with appropriate glasses can have an enormous impact on children's functioning. In general, individuals receiving and using appropriate glasses show improvements not only in reading, writing and fine motor skills, but also in other areas, such as social interactions, challenging behavior and general achievement (Bader and Woodruff, 1980 in Polcar, 1983; Levy, 1984; Bartlett, 1987; Ronis, 1989; McCulloch et al., 1996; Evenhuis and Nagtzaam, 1997). Kuroda et al (1987), for example, showed that Japanese children with MR became more active and lively after using appropriate glasses.

Additionally, individuals with MR do not receive adequate dental care, despite the findings that they have poor oral health. One preventive measure against dental decay is the use of dental sealants. Recognizing the importance of this measure of preventive dental care, the U.S. Surgeon General set a target of 50% of school-children to receive dental sealants by the year 2000. To date, only 23% of 8-year old children in the U.S. have received dental sealants, but fewer children with MR have received such care (CDC, 2000; SOI, 1999b). Feldman et al. (1997) found that 14% of 1996 New Jersey Special Olympic athletes aged 8 years old had received a protective sealant, and 16% of adolescent athletes had received a protective sealant. Similarly, data from 32 Special Olympic Games indicate that only 13.9% of Special Olympic athletes in the United States (including both adults and children) have dental sealants (SOI, 2000).

Barriers to Care

There are numerous reasons, including both environmental factors and individual characteristics, why the health needs of individuals with MR are not being met. Both nationally and internationally, current systems of health care rely on an individual's ability to recognize the need for care, seek care when necessary and, to some extent, coordinate the provision of care. Even in Western Europe, where systems of care are designed to be coordinated, individuals are commonly left to manage their own care. Those with MR, however, often lack the ability to recognize health problems, and when they do identify the need for services, many environmental and individual barriers prevent them from receiving necessary care (Wilson and Haire, 1990).

Environmental Factors

The way in which health care is organized creates an environment that can either increase or impede access to services. In the past, individuals with MR received health services through contained systems of care within the institutions where they lived (Minihan, 1986). Deinstitutionalization, however, has forced individuals with MR to rely on community-based health providers for their health service needs (Garrard, 1982; Minihan, 1986; Waldman and Perlman, 2000). In response to this reliance, communities have developed different service delivery models to care for individuals with MR, largely based on the structure of the country's pre-existing health system for the general population. Health systems in the U.S. and Western Europe, for example, vary in the degree to which service sectors are financially integrated and bureaucratically organized, which has a direct impact on the coordination, continuity and documentation of care. In turn, these aspects of health services influence both access to and the quality of health care services for individuals with MR.

Health Care Delivery System

In the U.S., individual medical care (e.g., physical, mental, ocular and dental health care services), community preventive health services (e.g., immunization and screening programs) and health-related social supports (e.g., respite care and crisis intervention through social service agencies) (Halfon et al., 1996) are separate entities that are operated through different agencies. As a result, distinct sectors of care with different agendas, philosophies and funding streams have developed, leading to an overall fragmentation of health care for Americans (Halfon et al., 1996; Savino et al., 1973). In fact, few American communities have comprehensive health care that integrates services both between and within each sector of care (Davidson et al., 1995).

In an attempt to decrease the fragmentation of services and contain costs, health care financing recently has been reorganized into various managed care arrangements. Under managed care, the primary point of entry into the U.S. health care system is the primary care physician (Birenbaum, 1995 in Tyler et al., 1999), who has been designated the gatekeeper and, thus, to some extent the coordinator of care between and within all sectors (Kastner, 1991; Birenbaum, 1995). In addition to gatekeeping, managed care plans use utilization management and practice guidelines to encourage primary care service utilization and discourage the use of preventive care and specialty services. In fact, in many states, specialty care services such as dental care are not covered by state Medicaid managed care plans (Waldman and Perlman, 2000). Thus, managed care has resulted in a decreased access to preventive and specialty health services among individuals in the general population. Under the care of health maintenance organizations (HMOs), for example, individuals generally must endure longer waiting periods for care and a limited use of specialist providers (Kastner, 1991). Further, as HMOs have increasingly gained responsibility in the behavioral health sector, concerns regarding the access of individuals to psychiatric services has increased (Jacobson, 1998).

Like the general population, many individuals with MR who receive Medicaid have been transitioned into managed care plans (Kastner et al., 1997 in Walsh and Kastner, 1999; Hemp and Braddock, 1998). The current system of managed care, however, is particularly detrimental for individuals with MR, because these individuals have unique health care needs that often require coordination by providers experienced with MR (Ashbaugh and Smith, 1996; Birenbaum and Cohen, 1998). As discussed below, however, coordination of care or case management by the primary care provider is frequently ineffective in this population because these providers do

not view themselves as having the primary responsibility for the health care of individuals with MR (Barr et al., 1999).

In contrast to the fragmented health care system found in the U.S., Australian and Western European countries, such as Sweden, France and Great Britain, have opted for more integrated health service systems, in which health care is an insured and guaranteed consumer good or service financed through private insurers or state-supported systems. Since health, developmental and social service sectors of care have similar funding streams, and are organized primarily by local health authorities that track population needs (Rodwin, 1999), the coordination of health services may be less fragmented in these systems than in sector-based health care systems. Unlike the sector-based system of care, individuals with MR in more integrated health care systems rely on the advice of two MR teams (primary care and community), which are designed to liaise available health and social community resources with the needs of individuals with MR (Griffin, 1989; Lennox and Kerr, 1997). Since the general practitioner is the most frequent provider of health care for individuals with MR, he or she is an essential part of the primary care team (Howells, 1991; Lennox and Kerr, 1997). Community teams, in countries such as the United Kingdom (U.K.), provide disabled individuals with social service needs assessments, from which individualized care packages are devised. Multidisciplinary teams in London, in fact, currently plan the management of the dually diagnosed, integrating specialty psychiatric services and generic mental health services (Golding, 1982; Bouras et al., 1994).

In theory, these integrated systems of care are better able to manage the care of individuals with MR than sector-based systems of care. In practice, however, these Australian and European systems of care have been shown to fall short of providing adequate health care for individuals with MR. (Shapiro, 1974; Rodgers, 1994 in Bond et al., 1997; Cooper, 1997). Using

one region in the U.K. as an example, Myers (1982) suggested that inconsistencies in the philosophies and policies of the health and local authorities prevents true integration of care, and consequently results in poor overall health care of individuals with MR.

Coordination of Care through Primary Care Providers

Part of the difficulty in coordinating care between sectors is due to the assumption that the primary care provider will be the gatekeeper of care. Primary care providers, however, tend to avoid the role of care manager for individuals with MR because of a lack of training, financial disincentives and time constraints. For example, national and international research suggests that primary care providers often lack training on how to interact with individuals with MR, as well as the specialized medical, preventive and social service needs of individuals with MR and the resources available to this population (Fremont, 1968; Shonkoff et al., 1979; AACAP, 1999; Garrard, 1982; Greenhalgh 1994 in Barr et al., 1997; Davidson et al., 1995; Davidson, 1995; Martin et al., 1997; AACAP, 1999; Allison et al., 2000). In a study of family practice medical programs in the U.S., for example, Tyler et al. (1999) found that 84% of programs that responded provided residents with one or more experiences with individuals with MR and 60% of programs instructed residents on MR. Additionally, providers indicate a need to broaden their training (Holt and Huntley, 1973; Dobos Jr. et al., 1994; Lennox and Chaplin, 1996; Lennox et al., 1997). For example, in a study of general practitioners in Australia, Lennox et al. (1997) found that 69% of providers had experience with individuals with MR, but 93% of general practitioners felt that they would benefit from additional training on MR. Similarly, Lennox and Chaplin (1996) found that 79% of psychiatrists surveyed stated that they had not

received sufficient training in the general or behavioral management of those with dual diagnoses.

Dental schools have also reported minimal exposure of dental students to individuals with MR (Waldman and Perlman, 2000). Waldman and Perlman (1997) reported the results of a recent study that found that 47% of dental schools had eight or fewer didactic hours on the treatment of developmental disabilities and 65% of dental schools had 10 or fewer hours on clinical activities associated with individuals with developmental disabilities. Similarly, a study of the dental health providers who volunteered to provide dental screenings at the 1996 Special Olympic Games in Massachusetts found that 75% of dental health students and professionals had never worked with individuals with MR prior to the Games (Perlman and Broder, 1996). Not surprisingly, then, Perlman and Broder (1996) found that prior to the Games, only 45.9% of providers reported that they were very comfortable with individuals with MR, while 29.8% reported that they were somewhat comfortable and 16.2% reported neutral feelings about individuals with MR.

This lack of training and experience, then, may influence providers' willingness to provide treatment to individuals with MR as well as influence their attitudes and beliefs about individuals with MR. Waldman et al. (1999), for example, report that only 29% of dentists nationally participated in Medicaid managed care, the predominant health insurance for individuals with MR. Additionally, many authors have noted that health care providers have negative attitudes and stereotypes about individuals with MR and their ability to maintain their health status (Garrard 1982; Murdoch et al., 1984 in Lennox et al., 1997; Barker and Howells, 1990; Minihan, 1993; Greenhalgh 1994 in Barr et al., 1999; Martin et al., 1997; Lennox et al., 1997). Lennox and Chaplin (1996), for example, found that 39% of psychiatrists surveyed

would prefer not to treat people with both MR and mental health conditions. Beange (1996) points out that some doctors are concerned about disrupting their other patients if individuals with MR are kept waiting too long in the reception area. Further, Garrard (1982) notes that physicians make value judgments about the worth of individuals with MR in making diagnostic and treatment decisions, suggesting that physicians with negative attitudes may withhold treatment. Surveys of providers, in fact, have suggested that physicians have lower expectations and more pessimistic views on the roles of individuals with MR than other professionals and family members (Siperstein et al., 1994; Nursery et al., 1990 in Lennox and Kerr, 1997). As a result of these attitudes, many providers are reluctant to spend time managing the care of individuals with MR. Moreover, due to certain stereotypes, providers that do assume the role of coordinator may not refer these individuals to needed specialty care (Fischler and Tancer, 1984; Goodman and Cecil, 1987; Kelly and Menolascino, 1975 in Minihan et al., 1993; Bickley 1990; Minihan et al. 1993; Burtner and Dicks, 1994 in Perlman and Broder 1996).

Further, research indicates that present health care systems do not adequately reimburse providers (including dental) for the care given to individuals with MR, creating a disincentive to treat these individuals (Waldman et al., 1999). In fact, Hemp and Braddock (1998) documented that the majority of Medicaid managed care programs for individuals with disabilities use a risk-based plan in which primary care physicians are responsible for costs that exceed standard payments. Additionally, under most health systems, providers are reimbursed at the same rate for all patients regardless of case complexity, yet treatment consultation time is greater for individuals with MR than individuals in the general population (Lennox et al., 1997). As a result, when an individual with MR has co-existing conditions (Bouras and Szymanski, 1997), the primary care provider and another provider may each view the other as taking responsibility

for the management of care. This diffusion of responsibility (Fletcher et al., 1999) can be particularly problematic for dually diagnosed individuals, when care is sought from both a primary care physician and a psychiatrist (Reiss, 1994 in Fletcher et al., 1999). Since it is generally not to the financial advantage of either the mental health or the physical health care system to take primary responsibility for a patient's needs, neither may want to establish the "primary diagnosis" (Menolascino et al., 1986), which would indicate responsibility for coordination of care.

Additionally, the U.S. managed health care system is structured so that primary care physicians generally lack the time necessary to devote to the complex medical, preventive and social needs of individuals with MR (Department of Health, 1995; Lennox et al., 1997), making providers an overburdened and inefficient source of case management. Rather than providing comprehensive case management, then, primary care providers focus on the medical needs of individuals with MR with which they are most familiar, often overlooking or not examining important preventative and social needs (Beange and Bauman, 1990a; Wilson and Haire, 1990; Councilman, 1999).

As a result of poor coordination between service sectors, then, individuals with MR often have limited access to certain services, which leads to a poor quality of overall health care. In addition, researchers have documented that when individuals are referred for specialty care, the collaboration between primary care providers and specialists about the health of individual patients is limited (Cumella et al., 1992; Lennox and Chaplin 1995; Lennox and Chaplin, 1996 in Lennox et al,. 1997).

Continuity and Documentation of Care

Even when individuals with MR are able to access care, other organizational factors, such as a lack of continuity of care and insufficient documentation present barriers to the quality of care received by this population (Parker and Hirst, 1987; Haavio 1995; Crocker et al., 1987; Greenhalgh 1994 in Barr et al., 1999; Martin et al., 1997 in Barr et al., 1999; Cumella et al., 1992; Lennox and Chaplin 1995; Lennox and Chaplin, 1996 in Lennox et al., 1997; Wilson 1992 in Perlman and Broder 1996; Garrard, 1982; Crocker, 1988, Beange and Bauman, 1990b; Minihan and Dean, 1990, Minihan et al., 1993; Benage, 1996 in Lennox et al., 1997; Waldman and Perlman, 1997; Gordon et al., 1998). Health care for individuals with MR, for instance, lacks a continuity of providers. This was exemplified by a small study of individuals with MR living in the community, which found that only 17.7% of individuals had seen the same physician or been to the same clinic twice (Edgerton et al., 1994). The majority of individuals with MR did not have a regular source of care. Concern has also been expressed about the continuity of care when individuals with MR make transitions in their life, such as moving from pediatric to adult medical care (Parker and Hirst, 1987). Because individuals with MR have difficulty adjusting to unfamiliar surroundings and thrive in structured routines, consistent and familiar providers are particularly important to the treatment of these individuals.

Further, researchers have noted that access to health care is compromised for individuals with MR because there are insufficient tracking systems to inform individuals with MR when it is time for a routine checkup (Haavio, 1995). Documentation problems also are evident in the lack of available medical records recording case histories of individuals with MR (Crocker et al., 1987; Greenhalgh 1994; Martin et al., 1997 in Barr et al., 1999). In a study by Lennox et al.

(1997), 89% of general practitioners agreed with the statement that they had difficulty obtaining access to the medical history of a patient with MR. Despite the global emphasis on mainstreaming and normalization, then, both nationally and internationally, most community health care systems have been unprepaed to meet the health needs of individuals with MR outlined earlier in this report (Garrard, 1982; Minihan, 1986; Howells, 1991; Howells, 1996; Minihan and Dean, 1990; Hand and Reid, 1996; Birenbarum, 1995 in Tyler and Bourguet, 1997).

Individual Characteristics

Many characteristics of those with MR may prevent these individuals from receiving adequate health care services. While predisposing factors and the prevalence of enabling resources might hinder the ability to seek and receive quality health care once need has been established, the inability to identify the need for care may prevent individuals from ever even recognizing that such care is necessary.

Predisposing Factors

Individuals with MR may be reluctant to seek medical care because they are frightened of new surroundings and treatment procedures (Gordon et al., 1998; Evenhuis et al., 2000). In a survey of members of the Association of Retarded Citizens, for example, Gordon et al. (1998) found that 27.9% of individuals with MR were anxious about dental visits.

Once health care is obtained, several characteristics of individuals with MR may negatively affect the quality of care received. These constraints include poor communication between individuals with MR and providers, physical and behavioral difficulties in treating individuals with MR and an inability of individuals with MR to understand the importance of

adherence to treatment regimens. Most researchers, clinicians and patients recognize that communication between patients and medical providers is an essential component of quality care. Poor communication, however, is a significant barrier to quality health care for individuals with MR (Diamond, 1982; Howells, 1986; Barker and Howells, 1990; Bickley, 1990; Beange and Bauman, 1990b; Cumella et al., 1992; Minihan et al., 1993; Beange et al. 1995; Beange, 1996; Lennox et al., 1997). Because many individuals with MR have limited communication skills, providers must rely on caregivers' reports and observations to obtain accurate medical histories, to understand the health complaints of individuals with MR, and to communicate treatment regimens (Beange, 1996; Lennox and Kerr, 1997; Evenhuis et al., 2000).

Physical and behavioral impairments can also impede individuals with MR from receiving adequate medical care (Gardiner, 1965; Mayer et al., 1983; Gnadt and Wesson, 1992; Haavio, 1995). Individuals with MR may have comorbid neurological conditions, which may be heightened in unfamiliar situations, and thus make sitting through and cooperating with medical examinations and procedures difficult. This is exemplified in the problems of dental care delivery described by the Missouri Elks Mobile Dental Program (Dane, 1990). Dane (1990) notes that individuals with athetoid cerebral palsy, who have an increase in involuntary movements during stressful situations, often require restraints or general anesthesia to receive dental treatment. In addition, women with cerebral palsy with and without MR have been noted to have difficulty obtaining dental and gynecologic care as a result of neurological impairments (Turk et al., 1997 in Evenhuis et al., 2000).

Individuals with MR also may have difficulty adhering to treatment regimens (Lennox et al., 1997; Webb and Rodgers, 1999). As a direct result of their cognitive impairments, individuals with MR frequently have difficulty understanding the benefits to treatment

adherence. Additionally, perhaps due to the lack of continuity of care mentioned above, individuals with MR often do not develop a therapeutic relationship with medical providers, which would increase the likelihood of adhering to a treatment regimen.

Enabling Resources

Individual resources, such as health insurance, can also influence access to care. Although individuals with MR are entitled to Social Security Disability Income (SSDI) and Medicaid, not everyone in this population utilizes these benefits, and thus many face financial barriers to care. Dental care, for example, is not covered by most state Medicaid plans, and in those states where dental care is covered, reimbursement rates are low (Waldman and Perlman, 2000; Waldman and Swerdloff, 1999). Further, in a national study, Birenbaum and Cohen (1993) reported that 4% of those with severe or profound MR had no insurance coverage. Not surprisingly, the percentage of the uninsured who did not visit a physician in the 12-month study period was three times higher than that for insured individuals. Further, 20% of the sample parents of children with severe or profound mental retardation had experienced refusals or limitations in the health insurance they could purchase for their child, and about 15% of those with private insurance had policies that specifically excluded coverage for some of the child's health care. Consequently, the families of these children spent an average of 7% of their income on health care, and 10% spent over 15% of their total income on these services. For those with limited incomes, who are not receiving government benefits, health care costs can be an insurmountable barrier to services.

Need for Care

As documented previously in this report, individuals in this population have many health needs. Individuals with MR, however, often have difficulty determining when they are in need of medical assistance and rely heavily on caregivers to recognize signs of health problems or to schedule routine health care appointments (Wilson and Haire, 1990; Lennox et al., 1997; Webb and Rodgers, 1999). Caregivers, though, have been shown to have a poor understanding of symptoms and are often reluctant to seek care for individuals with MR, particularly when their health problems seem mild compared with their more complex medical conditions (Lennox and Kerr, 1997; Lennox et al, 1997). Additionally, perhaps because of a low availability of respite care, which can provide important support to caregivers, high caregiver turnover can prevent caregivers from recognizing changes in the health of individuals with MR or knowing the past medical histories of individuals with MR (Lennox et al., 1997; Hoare et al., 1998; Waldman and Perlman, 2000).

Efforts to Address Unmet Need

In response to the barriers faced by individuals with MR to receive quality health care services, many have suggested changes in the primary care physician's role in the treatment of individuals with MR (Pearson, 1968; Fremont, 1968; Adams, 1972; Merker and Wernsing, 1984; Crocker et al., 1987; Councilman, 1999). Despite physicians' general reluctance to treat those with MR, some advocates insist that primary care providers should assume responsibility for the health management of individuals with MR over a long period of time. According to these proponents, providers, including physicians and nurse practitioners, should make medical

and preventive care readily available, coordinate referrals to specialty care (including dental), educate family members or caregivers and coordinate with education and social service agencies.

Further, in order to address the lack of care for the dually diagnosed, some have suggested that clinicians provide services based on need, rather than primary diagnosis (Fletcher et al., 1999), thereby avoiding the diffusion of responsibility. Others have advocated that community mental health centers be opened to the dually diagnosed, who often have no place else to go (Reiss et al., 1990), and some have indicated that psychiatrists should be responsible for the assessment of those with MR (Reid, 1980), or at least take the role of educating physicians (McCreary, 1991).

In addition, countries and communities have responded differently to the unmet health care needs of individuals with MR. Some countries have actively evaluated the care of individuals with MR and provided guidance to local communities in service delivery for individuals with MR. For example, in the U.K., the Department of Health examined the health service needs and adequacy of the health system for individuals with MR in the 1995 report entitled, *Health of the Nation: Strategy for People with Learning Disabilities* (Department of Health, 1995). Further, general practitioners in the U.K. provided guidance to the care of individuals with MR with an Occasional Paper entitled, *Care of People with Mental Handicap* (Barker and Howells, 1990 in Howells, 1991).

In the U.S., a group of physicians organized the Sterling D. Garrard symposium on community health services for individuals with MR in 1986. From this workshop, Crocker et al. (1987) outlined ten essential components in health services for individuals with MR, including multiple options for the delivery of health care, usual source of care through a primary care provider, health care networks, coordination of care, comprehensive personal medical record,

standards for health service delivery, adequate reimbursement for providers, training of providers, and health service research and evaluation.

Further, recognizing that the U.S. health system is not designed to meet the unique health care needs of individuals with MR, demonstration projects and research programs have been developed that use a more integrated health care model either through case management or multidisciplinary teams (Perrin et al., 1972; Fujimoto et al., 1978; Cole, 1987; Schor et al., 1981; Griswold et al., 1987; Tesini, 1987; Ziring et al., 1987; Ziring et al., 1988; Chicoine et al., 1994; Criscione et al., 1995; Davidson et al., 1995; Pulcini and Howard, 1997; Braddock and Hemp, 1997). Despite the published research suggesting that care coordination is the key to effective health care service for individuals with MR (Gregg, 1967; Grossman, 1968; Davidson et al., 1995; Walsh et al., 1997; Evenhuis et al., 2000), however, no widespread integrated systems of care have been created for individuals with MR in the U.S.

In part, this may be because the U.S. government has not shown adequate leadership in the effort to increase health care utilization among individuals with MR. Most government resources focus on the prevention of MR, deinstitutionalization, and housing, education and employment of individuals with MR. Little information is even available at the federal level on the quality of health care and service utilization of individuals with MR.

Summary and Implications

Similar to studies on the prevalence of MR and other health conditions, research efforts on health care service use by individuals with MR are scarce. Studies that do address service use in this population tend to focus on non-representative samples of the population, and indicate that individuals with MR do not receive adequate physical, mental, ocular or dental health care.

Many barriers to care have been cited to explain the low utilization of services and poor quality of care among individuals with MR. The most compelling constraints include uncoordinated systems of health care, providers' lack of training and caregivers' lack of knowledge and abilities. Despite the influx of managed care in the U.S., American health care remains fragmented and difficult to access. Further, although Western Europe is thought to have a more centralized system of care, health care systems abroad have been shown to have problems with care coordination as well.

Within these fragmented systems of care, primary health care providers in the U.S. have been given the responsibility to coordinate care for individuals with MR. As a result of insufficient training, however, health care providers often resist treating such patients and are ineffective coordinators of care. Thus, individuals with MR must navigate themselves through a disorganized and disjointed system of care, without assistance in the overall management of the complex services essential to a comprehensive regimen of care. Health care for those with MR, however, cannot be maintained unless and until providers are willing and able to manage and treat the health care of this population.

Further, caregivers play a large role in ensuring that those with MR receive proper health care. Despite good intentions, however, caregivers often are not able to recognize when health care is needed, are not knowledgeable enough to access adequate care, and do not have adequate resources to relieve caregiver burden.

When individuals with MR were deinstitutionalized and entered the community, the responsibility of providing health care to this population entered the community as well. In order to meet accepted standards for adequate health care for these individuals, the health care system

will need to adapt to their diverse needs. Until that happens, however, providers and caregivers can play a large role in improving the health care of individuals with MR.

Summary Recommendations

Individuals with MR are susceptible to many of the same health conditions as individuals in the general population, but may experience more access and quality of care challenges than individuals without MR. Although this report identified a considerable volume of studies on the health of individuals with MR, most research efforts in this area are laden with methodological constraints. Consequently, to remediate the problems identified in this report, we recommend the following actions:

Policy

1. The U.S. federal government and national organizations must take a leadership role in turning the nation's attention towards the health of individuals with MR. For example, the President's Committee on Mental Retardation or the U.S. Surgeon General should produce a periodic report detailing the current health status and needs of individuals with MR. Agencies, such as the Arc, can play a large role in lobbying for such efforts.

2. Presently, many individuals with MR may not be receiving health services because they are under-insured. To ensure that individuals with MR can and do access necessary services, eligibility for publically funded health insurance programs (e.g., SSDI, CHIP and Medicaid) must be determined, and qualified individuals must be enrolled.

3. Public schools are provided with a great opportunity to improve the health of children with MR. By law, these schools are required to provide an Individualized Education Program (IEP) to every child with MR. As part of each IEP, the health needs of such children should be assessed and appropriate services accessed.

System of Care

4. Individual providers are often relied on to manage the health care of individuals with MR. Because of the fragmented delivery of care in the U.S., health care payors must reimburse for integrated service teams with case managers, capable of managing all

aspects of care over a long period of time.

5. Currently, the health care system provides financial disincentives to work with patients with MR. The present reimbursement system must be modified to encourage providers to treat individuals with MR, and financially reimburse those who choose to work with this population.

6. Providers are often ill prepared to treat individuals with MR because patients may not be capable of describing their medical histories, and the medical record system is not equipped to provide such information. The record system is in need of reform in order to address the lack of continuity of care received by this population. One way to do this would be to initiate a health passport system, where individuals with MR and their caregivers keep an ongoing record of their care, and are able to present it to their providers at each visit.

Clinical Care

7. One reason that the health care system does not adequately provide care to individuals with MR is that providers (e.g., physicians, nurses, psychologists, opthamologists and dentists) do not feel equipped to treat them. The curricula and training for all health care providers should be reviewed and updated to include specific education on MR. This should include not only classroom hours, but also clinical experience with this population.

8. Guidelines help to ensure the quality of care and to raise providers' confidence that they are providing appropriate care. Specific screening and health supervision guidelines should be developed for individuals with MR, addressing their special health care needs.

Individuals with MR and Their Caregivers

9. Given the shortcomings of our present health care system, caregivers are often relied on to coordinate the care of their charges. Caregivers should be provided with training, in order to help them understand how to recognize health problems and access appropriate care. Organizations such as the Arc should be enlisted as partners in the development of educational programs for caregivers.

10. The viewpoint of individuals with MR is lacking in the discussion of the health needs of this population. Individuals with MR should be given the opportunity (e.g., in focus groups) to express their views about the health care system and ways to improve access to quality care.

11. Individuals with MR should be educated about disease prevention, recognition of symptoms of health conditions and health maintenance. Developmentally appropriate teaching materials should be utilized with this population to promote self-sufficiency and human dignity.

Research

12. Because of the inconsistent definitions of MR used to identify individuals in this population, it is difficult to estimate accurately the number of people with MR, the health conditions that this population endures, or the individuals eligible for special services. The U.S. federal government must take the lead in developing a valid and reliable definition of MR, to be used for both research purposes and service eligibility criteria for this population.

13. Population-based data are necessary to determine accurately the health needs of the whole population of individuals with MR. These data can be obtained by reinstituting the National Health Interview Survey (NHIS) question regarding MR that was removed in 1988. Consideration also should be given to the development of a national registry of individuals with MR to track their health and health care issues.

When individuals with MR were deinstitutionalized and entered the community, providing health services for this population was not adequately planned. Individuals with MR, however, have many special health care needs, which increase in prevalence as they age. In order to improve the quality of life for individuals with MR, health care, among other, services, must adequately and appropriately be provided to this population.

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