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Introduction to the Special Issue on Aging

This special issue of *AJMR* is focused on aging in individuals with mental retardation/developmental disabilities (MR/DD). Aging in this population was barely on the radar screen of scientists, clinicians, or policy analysts as recently as 20 years ago because MR/DD was seen primarily as a pediatric diagnosis, with an emphasis on its developmental course during the early childhood period. It is now well-recognized that developmental disabilities last a lifetime and that the aging process is as relevant to this population as it is to society at large. Indeed, the study of aging in individuals with MR/DD has yielded insights that have broader implications beyond our field and this population. This is an exciting time for the *Journal* to be devoting an entire issue to the topic of aging because it signifies that a sufficient amount of research on this topic has been conducted that warrants attention by our entire field.

The nine papers in this issue cover a broad landscape scientifically and methodologically. Not surprisingly, Down syndrome is the focus in five of the papers. Down syndrome has captured a great deal of interest among researchers concerned about aging in individuals with MR/DD because of the increased risk and earlier onset of dementia in this population. Whereas early researchers sounded an alarm about the inevitability of dementia in people with Down syndrome, based largely on the universal neuropathology evident in this population after age 35 to 40, contemporary investigators have sought to identify risk factors that explain why some older adults with Down syndrome develop clinical symptoms of dementia whereas others do not. Bush and Beail review the research on the biological and psychological factors that may account for this heterogeneity. They also review research on the prevalence of dementia in individuals with Down syndrome, difficulties assessing dementia in the presence of mental retardation, and the potentially unique clinical manifestation of the symptoms of dementia in this population. All of these topics preview papers that appear in the special issue.

In particular, valid assessment of dementia in adults with Down syndrome and other types of MR/DD remains an extremely problematic challenge in both research and clinical practice. Schultz, Aman, and colleagues report on the validity of diagnosing dementia using measures of cognition and behavior that were developed for the MR/DD population and offer recommendations for optimal assessments that can differentiate between adults with and without dementia. Silverman and colleagues tackle the problem of making a diagnosis of dementia with data collected at just a single point in time. Longitudinal data are certainly preferable in diagnosing this progressive condition, particularly in a population with preexisting intellectual deficits; however, from a practical standpoint it is often necessary to make a judgment about the presence of dementia from data collected just once, and Silverman et al. offer a strategy that has been shown to be reliable and valid.

Although Down syndrome is associated with pathological aging, this issue contains two papers in which the authors discuss the effectiveness of interventions to *improve* physical fitness in adults with Down syndrome and to enhance psychosocial adaptation. Rimmer and colleagues describe a 12-week fitness intervention program for adults with Down syndrome, which shows significant positive effects in cardiovascular fitness, muscular strength, endurance, and weight control. In a companion paper, Heller and colleagues described the effects of this same intervention on psychosocial outcomes. Following participation in this intervention, adults with Down syndrome showed improved life satisfaction and lower levels of depression. Together, in these two papers, the authors point to strategies for enhancing the health, functioning, and quality of life of adults with Down syndrome who face elevated aging-related challenges. Interventions such as this one are critical for adults with Down syndrome; Braunschweig and colleagues reported that fully 89% of Down syndrome participants in their study of nutrition were overweight or obese, and none met the current guidelines for dietary intake of fruits and vegetables. Nevertheless, the adults with Down syndrome in the Braunschweig sample had

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lower than average levels of lipids and glucose, risk factors for Type 2 diabetes and cardiac disease.

In addition to the focus on aging and Down syndrome, this special issue includes papers on topics relevant to three other MR/DD populations: Prader Willi syndrome, fragile X syndrome, and an undifferentiated group of adults with mental retardation who do not have Down syndrome. Dykens reports that individuals with Prader Willi syndrome show a unique pattern of life course development, with a peak of maladaptive and compulsive behavior problems evident in young adulthood and a diminution of these symptoms later in adulthood. She underscores the need for lifespan studies of neurodevelopmental disorders because the biobehavioral profiles across the life course of many such disorders remain unexplored. Jacquemont and colleagues review the literature about a recently identified neurodegenerative disorder, Fragile X tremor/ataxia syndrome (FXTAS), which is manifested by premutation carriers of the fragile X gene. Although they do not have fragile X syndrome, these parents and grandparents of individuals with fragile X are at risk for adult-onset cognitive and motor dysfunction. Fragile X syndrome and FXTAS are examples of both neurodevelopmental and neurogenerative processes in individuals who have expanded FMR1 alleles.

Finally, Zigman and colleagues report on the incidence and prevalence of dementia in elderly adults with MR/DD who do not have Down syndrome. Research on this population makes it possible to test the cognitive reserve hypothesis of dementia, namely, that preexisting intellectual deficits may increase the likelihood of dementia in old age. Because the age-specific prevalence of dementia in individuals with MR/DD due to causes other than Down syndrome was found to be equivalent to or lower than the general population, Zigman et al. offer counter-evidence to the cognitive reserve hypothesis.

This collection of papers has the potential to make contributions to the knowledge base both within the field of MR/DD and to the study of aging in the general population. Within our field, research about aging and Down syndrome has crystallized to the point where it offers valuable implications for clinical practice, an outstanding example of translational research. We now have a better understanding of risk factors for dementia in this population, the course of the symptoms of dementia as they are expressed in individuals with Down syndrome, and strategies for assessment and clinical diagnosis. Furthermore, as we look beyond dementia toward the special health problems of adults with Down syndrome, we have a clearer understanding of nutritional challenges facing this population as well as fitness interventions that might enhance their health and quality of life.

Beyond our own field, however, research on aging in individuals with MR/DD has the potential to generate new insights and knowledge about the aging process in general. For example, it is possible that FXTAS is one of the most common previously undiagnosed causes of neurodegeneration in the population at large, and it was discovered in the context of research on fragile X syndrome. Similarly, research on dementia in nonsyndromal adults with MR/DD provides an excellent test of the cognitive reserve hypothesis.

There is a great deal of research on aging in individuals with MR/DD that is currently being conducted and a large landscape that has yet to be described. In particular, too little is known about the unique life course manifestations of the symptoms of specific MR/DD conditions. Furthermore, as populations tend to become more heterogeneous with age, study of the variation in genotype–phenotype association across the life course presents a ripe opportunity for study of gene by environment interactions.

The aging of the population with MR/DD also presents enormous challenges to the families and the service systems that support them. In parallel to the impressive amount of research that has been conducted on the biological and cognitive issues of aging, a rich portfolio of research has emerged on the familial and social consequences of aging. An upcoming special issue of *AJMR* (co-edited by Tamar Heller and Marty Wyngaarden Krauss) will contain a series of papers in which the issues faced by caregivers and other service providers regarding the aging of this population is examined.

Thanks are due to many people who made it possible for this special issue to be published. Bill MacLean's encouragement, flexibility, and counsel are very much appreciated, as is Yvette Taylor's expert editing of the manuscripts. Reviewers from both the MR/DD and aging fields offered unique and critical perspectives on the confluence of these two lines of research. To the authors of these papers, thanks are due most of all.—Marsha Mailick Seltzer, Guest Editor

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