

# Introduction to the Special Issue on Aging: Family and Service System Supports

This issue of *AJMR* is the second of the two-part series focused on aging and developmental disabilities. In the first, published in March 2004 and edited by Marsha Mailick Seltzer, the authors addressed developmental trajectories based on syndromes and environmental interventions. This follow-up issue is focused on implications of the aging process on the family and on health and social service system supports. The seven papers include a rich variety of perspectives and methodologies, providing an international perspective and both quantitative and qualitative approaches. The studies span several countries, including the United States, Australia, Israel, and Ireland. The methodologies range from cross-sectional studies in which age groups are compared, longitudinal studies of interventions, best practice and needs assessment surveys of organizations to life history narratives.

Throughout the world families are the major providers of care for adults with developmental disabilities. Although out-of-home residential supports increase with age, most persons with developmental disabilities remain in family care throughout their lifetime. With their growing life expectancy, many of these adults are either living with elderly family members or outliving their parents. For example, in the United States, over one quarter of these family caregivers are estimated to be over the age of 60 years and another one third are 41 to 59 years of age. Many of them are not known by the service system or receive very few services, unlike younger family caregivers who are more accustomed to receiving and have higher expectations for services. As these caregivers and their adult child age, the demands placed on the service system far surpass availability. This is particularly true for residential services, which are beset by long waiting lists in most developed countries.

In three of the articles in this issue, the authors address forms of support to families and adults with disabilities who live with them.

McCallion and his colleagues focus on a growing phenomenon: grandparents assuming primary care for their grandchild with developmental disabilities. These families often face high stress, resulting in psychosocial and physical health concerns. Through participation in support groups, grandparent caregivers experienced significant reductions in symptoms of depression and increases in their sense of empowerment and caregiving mastery.

In a large cross-sectional study in the United States, Pruchno and her colleagues examine the patterns and correlates of service utilization by adults with developmental disabilities who live with their families. The highest level of unmet needs were for recreation and social activities. Blacks were more likely than Whites to have unmet needs for dental services, vocational training, occupational therapy, psychological services, and social work. Economic factors, the unavailability of services, and mother's burden also played a strong role in accounting for many of the above unmet services.

Acknowledging that older parents of adults with developmental disabilities are frequently isolated from services, Llewellyn and her colleagues use qualitative methods to investigate the differential nature of older parent caregivers' engagement with services in Australia. They found that parents' perceptions of their own status were derived from a complex interaction of their values and beliefs, their actions in relation to their adult child, the constraints and resources available to them, as well as their relationships with service agencies. Using a narrative life history approach, Llewellyn et al. described four typologies of families with regard to their level of engagement with the service system, ranging from the least to the most engaged: go it alone, reluctant partner, tandem partner, and services in charge.

Over the last 4 decades, there have been significant changes in the residential service system. Large segregated institutions are being replaced by

smaller supported living residences in community settings. Many of the persons who are currently moving out of large segregated settings are older adults, who constitute a large portion of those residents who had been left in these settings. Examining where people with developmental disabilities live helps us understand how environmental conditions affect their well-being and quality of life. In another study from Australia, Young and Ashman report on the impact of deinstitutionalization on a cohort of adults with intellectual disability who had lived for most of their life in a large institution before it was closed. Many of these residents were older and had severe levels of intellectual disability. In this 2-year follow-up longitudinal study, the authors found that movement into the community was associated with increased adaptive behavior skills, choice-making, and objective life quality (e.g., community access, routines, possessions, social networks, and living conditions).

As adults with developmental disabilities age, they have increased health problems and concomitantly increased needs for health care and end of life care. These type of services are addressed in two articles. Using the Greater Rochester Area Health Status Survey (an instrument developed in the United States), Merrick and his colleagues examine health status and services among older adults with intellectual disability living in residential care centers in Israel. With age, perception of health status declined and use of health services increased. Also, there were increases in cardiovascular disease, cancer, sensory impairments, hyperlipidemia, and type II diabetes. However, Merrick et al. found that cardiovascular disease was reported less frequently than it was in the general population, suggesting underdiagnosis of cardiovascular impairments. They reported that over half of these adults with intellectual disabilities did not engage in any exercise. Despite the fact that Israel provides universal health services to all citizens, the authors noted that changes in health status and health care of individuals with advancing age were similar to those found by researchers in the United States. Because these Israeli investigators relied on individuals who lived in residential care centers, whereas the American researchers using the same survey tool had a sample that included a community-based group, it is not surprising that the Israeli sample was less likely to be hospitalized and made less frequent use of emergency room services. Merrick et al. pointed out

that in both countries there is a need for a greater emphasis on preventive health care for middle-age and aging adults with intellectual disabilities.

With the growing probability that adults with intellectual disabilities will outlive their parents and with more adults who have intellectual disabilities living in community settings, there is a need to develop end of life care services for this population. Botsford reports on the results of a national survey conducted by a collaborative initiative by Volunteers of America that assessed the current status of end of life care for this population, their families, and formal caregivers. The survey covered services currently provided, obstacles to care, methods for monitoring end of life care, and strategies for improving such care. Survey findings highlight what is needed to improve end of life care: (a) formal caregivers require practical guidelines and resources and (b) organizations need increased staffing and training as well as reduced obstacles at a policy level. Botsford provided numerous ideas for developing programs and changing policies that could improve end of life care for adults with developmental disabilities.

In general, much of the disabilities literature does not even contain discussion of gender differences. Researchers are now examining such differences and have even begun to investigate the lives of older women with intellectual disabilities, as reflected in this special issue. These women are often poorer, in worse health, less educated, and more dependent on government supports than are other people with disabilities. Leroy and Walsh use extensive life history narratives to examine the demographic, economic and personal safety nets, health, social roles, and well-being of Irish and American older women with intellectual disabilities. They found that these women had very limited resources, social networks, and opportunities. Although their health was generally good, it often limited their activities. Despite the hardships and economic, social, and emotional limitations they were experiencing, many of these women reported that this was the happiest time in their life. These findings endorse the complex multidimensional aspects of quality of life as perceived by aging women with intellectual disabilities.

Taken together, this collection of articles provides a picture of the high unmet needs of the growing population of older adults with intellectual disabilities and their families across various countries. This population lives with a variety of stressors that could place them at higher risk for

health and social problems. The authors of this special issue emphasize the need for better support for families, including those targeting various family members (e.g., grandparent primary caregivers); more residential, health care, and social recreational supports in the community; and better end of life care. They also point to the variability in families with regard to their engagement in the service system and use of specific types of services.

There are still many gaps in the research. We need a better description of the demography and well-being of family caregivers, particularly those from minority populations and families living in poverty. We have few studies on the impact of intervention programs (e.g., end of life care, dementia care) and public policies (e.g., family support policies, waiver services, managed health care) on the health and well-being of older adults

with intellectual disabilities and their families. Finally, there has been little research on the impact of changes in the physical environment and provision of assistive technology to increase the ability of adults with intellectual disabilities to “age in place” and enjoy continuing participation in community living.

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