Issues Affecting the Lives of Older Persons With Developmental Disabilities

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Developmental disabilities are conditions occurring before age 22 that cause significant functional impairments in areas such as independent living, self-care, receptive and expressive language, learning, and economic self-sufficiency (1). Persons with developmental disabilities represent a heterogeneous population with varying abilities, and their disabilities may result from a variety of conditions such as cerebral palsy, mental retardation, learning disorders, autism, and epilepsy (2).

The term "dual diagnosis" is often applied to the cases of individuals with both a developmental disability and a psychiatric disorder. Like members of the general population, persons with a developmental disability may be diagnosed with a treatable mental disorder. Fleisher (3) has advocated for a multidisciplinary approach and careful long-term observation of the environment and behavior of persons with developmental disabilities to arrive at a correct psychiatric diagnosis.

The elderly population with developmental disabilities is increasing at a rate similar to that of the elderly population in general (4). Improved medical treatments, health care, and living conditions have combined to produce an increased life expectancy. The elderly developmentally disabled population has unique needs for residential options, long-term financial and legal planning, and medical care (5).

Amendments to the Older Americans and Developmental Disabilities Acts have emphasized the need for services planning and development of public policy (6). Yet a 1991 survey of large private and state-operated facilities for developmentally disabled persons found few specific accommodations for elderly residents (4). The same survey noted that small-group settings and foster homes provided the older individual with greater opportunities for leisure and recreation.

The concept of aging may need to be modified when it is applied to a population with developmental disabilities. Several studies cite premature aging and an earlier decline in functional skills (7). For example, Alzheimer's disease has been found in persons with Down's syndrome in the third decade of life. Evenhuis (8) has found a high incidence of early gait and speech deterioration and increases in epileptic seizures and myoclonus in this population.

DSM-IV classifies mental retardation and learning disorders among the disorders first diagnosed in infancy, childhood, or adolescence (9). Mental retardation is characterized by an IQ of 70 or below and at least two impairments in adaptive functioning. Disorders of learning, motor skills, and communication are included on axis II of *DSM-IV.* Other contemporary definitions emphasize the range of a person's functional and cognitive abilities. Because of the heterogeneity of this population, descriptions of developmentally disabled individuals vary depending on the observer, the purpose of the description, and the criteria used. Various descriptions may reflect inclusion criteria for epidemiological studies, services funding, and special interest groups, or they may emphasize the population's specialized institutional and residential care needs.

The American Psychiatric Association (APA) task force report on psychiatric services to mentally retarded and developmentally disabled adults estimated a 1 percent prevalence rate for mental retardation (10). The report cited prevalence rates of .37 to .59 percent for mild mental retardation (IQ between 50 and 70) and rates of .3 to .4 percent for moderate, severe, and profound retardation combined (IQ between 20 and 50). The overall prevalence of developmental disabilities is estimated at 1.6 percent in the total population and 1.49 percent in the adult population.

Because of different definitions of mental retardation, developmental disability, and aging, we could find no epidemiological estimates of the overall size of the elderly developmentally disabled population. This group does not appear to have been included in the Epidemiologic Catchment Area study, nor is it mentioned in comprehensive texts on geriatric psychiatry. Updated epidemiological studies, including assessment of individuals with mental retardation and those with dual diagnoses, are needed (11).

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Mental health issues

The APA task force on psychiatric services to mentally retarded and developmentally disabled adults estimated that the prevalence of mental disorders is significantly higher among mentally retarded persons than in the general adult population, ranging between 33 and 70 percent for various disorders (10). Many individuals have coexisting problems such as language disorders, impaired mobility, and hearing or visual impairments that may worsen with advancing age. Persons with brain injury who have additional impairments can lose more communication skills over time and become increasingly isolated. This progressive loss of control over their environment is a significant contributing factor to behavioral dysfunction. Behavioral disorders are worsened when others have inappropriate expectations and when attention to the unique nature and extent of each disability is lacking.

In the 1970s, successful advocacy efforts by parents of persons with mental retardation, which were motivated by the desire to distinguish mental retardation from mental illness and avoid the stigma of mental illness, caused a separation of funding resources for mental health and mental retardation services. This dichotomy also is reflected in the training of psychiatry and primary care residents. The guidelines for training programs in psychiatry and family medicine developed by the Accreditation Council of Graduate Medical Education do not specifically mention mental retardation. APA's 1995 curriculum guide in psychiatry and mental retardation (12) has not yet been integrated into residency training programs.

Behavioral problems are often not assessed or managed with the expertise required. Hence, developmentally disabled persons who are dually diagnosed or behaviorally disturbed often do not have the benefit of state-of-the-art use of anticonvulsants, newer atypical antipsychotics, and antidepressants.

However, the APA task force report described several successful models of service, training, and research, including a university-affiliated model in Boston and a nationally funded inpatient center at the University of Nebraska (10). More than ten years ago, the need for curricula on aging and developmental disabilities began to be emphasized in institutions of higher learning (13). More recently, Menolascino and Fleisher (14) described a curricular model for the management of dually diagnosed persons, emphasizing special diagnostic skills, the important role of the caregiver, and preparation of skilled personnel. A program on aging in the developmentally disabled population developed by the department of psychiatry at Queen's University in Kingston, Ontario, includes a year-long fellowship in coordination with the department of family medicine (15).

A community-based crisis intervention model, funded through the New York State Office of Mental Retardation and Developmental Disabilities, has been developed in Rochester, New York (16). Behavioral interventions include operant care plans to reinforce desired behaviors and staff training in instituting the plans. The program has increased the capability of staff and families to manage problem behaviors and has enhanced coordination of care. Another New York State project, carried out by Peoples, Incorporated, of Western New York, included programming for elderly developmentally disabled persons in a specialized nursing home setting. Enhanced quality of life in late life is more likely in such a specialized setting than in general skilled nursing facilities.

Primary care

The increasing emphasis on providing support for developmentally disabled adults in the community, coupled with managed care mandates, makes it imperative that providers are competent to manage the complex medical and mental health needs of this population (17). The special needs of older patients with mental retardation, learning disabilities, sensory impairments, mental illness, and functional limitations require knowledgeable and competent practitioners and community services that can respond in an appropriate and timely manner. There is increasing awareness of the need for a multidisciplinary approach, improved training of professionals, and development of relevant models of care (18).

The American Board of Family Practice has registered about 2,000 practitioners with certificates of added qualification in geriatrics. A growing number of programs offer dual training and board certification in family medicine and psychiatry (19). Messinger-Rapport and Rapport (20) have presented a primary care approach for the developmentally disabled adult that emphasizes preventive care, health maintenance, and treatment of acute and chronic conditions that occur in elderly populations. A comprehensive geriatric assessment of elderly persons with developmental disabilities residing in the community was coordinated by the geriatrics fellowship program at the University of Medicine and Dentistry of New Jersey, the Center for Aging of the School of Osteopathic Medicine, and the New Jersey Division of Developmental Disabilities (21). The assessments identified an increased number of medical diagnoses, including hyperlipidemia, glucose intolerance, urinary incontinence, and dementia.

Elderly men and women with developmental disabilities may suffer from abuse or neglect (22); they may also become abusive to their even more elderly parents with whom they have lived all their lives. Care providers should be attentive to the potential for such situations and should contact local adult protective and crisis intervention services if they believe abuse has occurred. Providers must also evaluate the need for respite care and alternative living situations.

Natural life progressions

Natural progressions in life such as changes in work situations, retirement, change of living arrangements, and financial planning for later life have been dealt with inconsistently. Often legal means must be used to achieve equity for elderly developmentally disabled persons. Court cases have addressed the rights of mentally retarded people to education,

Selected agencies providing assistance in long-term planning for living arrangements for persons with developmental disabilities

National Clearinghouse on Developmental Disabilities and Aging
University of Akron
Akron, Ohio
800-538-6544

Aging Special Interest Group
American Association on Mental Retardation
Washington, D.C.
800-424-3688

Legal Counsel for the Elderly
Washington, D.C.
202-434-2170

Institute for Human Development
Kansas City, Missouri
816-235-1770

treatment, and just compensation. Legal concerns, finances, advanced health care directives, and alternative living situations must be discussed and arranged with an emphasis on each person's autonomy, dignity, and cultural milieu.

Living arrangements

Many persons with developmental disabilities live with their families. As both the developmentally disabled person and family members age, the need for respite care services, long-term financial planning, guardianship arrangements, and determination of future residential options increases. The American Association of Retired Persons (AARP) has identified several agencies that can be contacted for assistance with these issues (see box above).

Mengel and associates (23) described a support and education group formed for aging parents who served as caregivers. An interesting observation was the change in interaction between parent and child as both aged. They described situations in which the adult child helped to educate the parent about aging and mutual needs for assistance; sometimes the parent needed more care than the aging child, and the child was able to offer assistance. Another positive outcome of this group's experience was enhanced linkages between local service networks for the developmentally disabled and for the elderly populations.

Summary

Efforts to bring the aging developmentally disabled and mentally handicapped population into the mainstream of professional training and services are encouraging. The impact of managed care on the provision and quality of services for aging developmentally disabled persons who cannot advocate for themselves must be closely researched and monitored so that public funds are used to promote comprehensive and continuous care for this vulnerable population. ♦

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