Improving the Care of Older Adults with Developmental Disabilities

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AS with the population in general, the life expectancy of adults with developmental disabilities (DD) continues to increase. Adults with developmental disabilities are now more frequent consumers of health care because they are living longer and fewer are living in institutions.[1] A subset of the population of persons with developmental disabilities includes those with intellectual disabilities (ID), defined in the International Classification of Diseases (ICD-10) as a "condition of arrested and incomplete development of the mind which is especially characterized by impairment of skills manifested during the development period, contributing to the overall level of intelligence."[1] The recent Surgeon General's Conference on Health Disparities and Mental Retardation highlighted the special needs of this population: "Compared with other populations, those with ID/DD of all ages experience poorer health, and more difficulty in finding, getting to and paying for appropriate health care."

The assessment of physical health in adults with intellectual disabilities is both rewarding and challenging. Real opportunities exist to improve the physical health of this group through early identification of health problems to reduce future morbidity and mortality.[2] However, many health care providers have not had direct clinical experience with this growing population and as such may feel inadequate to provide-care for them.[3] Compounding this lack of appropriately trained health care providers is the fact that the population of persons with developmental disabilities is diverse, and most have multiple needs. There are many subgroups within this population which present additional challenges to care. As examples, three subgroups (Down syndrome, Fragile X, Williams syndrome) of this population will be described briefly as better knowledge and understanding will help improve quality of care.

Down syndrome remains a significant cause of disability in developing countries. Approximately one in 800 births may have chromosomal abnormalities resulting in Down syndrome. The life expectancy for persons with Down syndrome increased from approximately 25 years in 1983 to 52 years in 1997.[4] This group may experience, especially with aging, high rates of certain conditions when compared to the age-matched general population. Such conditions include Alzheimer's dementia, thyroid abnormalities (particularly hypothyroidism), cataracts, osteoporosis, atypical seizures and sleep apnea.[5] In addition, older adults with Down syndrome may have congenital heart disease, gastrointestinal disorders, and leukemia. Preventive strategies need to be applied more aggressively to this special population in order to reduce morbidity and mortality. One recommendation in this regard is that all persons with Down syndrome at the age of 40—men and women—should have a baseline bone density test. Such screening will contribute to more timely

ABBREVIATIONS USED IN TEXT
developmental disabilities = DD
International Classification of Diseases = ICD-10
intellectual disabilities = ID

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and appropriate treatment of bone loss.

Another condition for screening is Alzheimer's dementia. This may be completed using a variety of specialized tools including the Brief Praxis Trial. These tools are adapted for use with persons with Down syndrome, although they usually have to be conducted by specially trained personnel.[6] Further studies are needed for this condition as recent findings suggest a possible correlation between cognitive decline and mitochronrial dysfunction for persons with Down syndrome.[7]

The most common form of inherited mental retardation in males is Fragile X Syndrome. This condition results from changes in the X chromosome. Males are affected more than females. Affected males may have certain physical characteristics or may be normal appearing. Such characteristics may include mental retardation, large size, macro-orchidism, hyperactive behavior, and a large forehead or ears with a prominent jaw.[8] Genetic testing is available not only to confirm the diagnosis but also to assess familial risk. Many times persons with disabilities may not be appropriately diagnosed with this condition especially when dramatic physical characteristics as described above may be absent.

A third (not uncommon) cause of developmental disabilities is Williams syndrome with an incidence of one in 20,000. Such persons normally have mild intellectual impairment but usually have a 20% reduction in brain size. Physical characteristics include a wide mouth and upturned nose. Such persons may experience more rapid cognitive decline with aging. Persons with Williams syndrome may be at increased risk for heart failure, and may also experience hypertension and hypercalcium.[8]

In addition to the genetic syndromes highlighted above, one significant form of functional limitation and morbidity for the developmentally disabled population is emotional and behavioral health disorders. Better research is needed not only on the incidence and prevalence of behavioral disorders in this group but also on finding appropriate and effective treatments. Depression, obsessive-compulsive disorders, eating disorders and sleep disturbances are but a few conditions which may significantly reduce function in persons with intellectual or developmental disabilities.[9] Treatments need to be investigated for a variety of conditions in order to maximize function. Overuse of inappropriate medications or unproven therapies must be avoided.

The area of preventive care for adults with developmental disabilities is expanding. Such preventive strategies offer a real opportunity to delay or avoid diseases for certain high-risk groups. Appropriately screening for dementia, osteoporosis, sleep apnea and thyroid disorders, for example, may uncover previously undiagnosed conditions. Appropriate reinforcement of such screening practices need to be expanded to ensure more timely care of such diseases by the general health-care community.

The "Report of the Surgeon General's Conference on Health Disparities and Mental Retardation"[3] identified six areas of opportunity that would improve all aspects of care for this population. They include: 1) the expansion of health promotion activities and programs; 2) the education of individuals and care takers about self-care and needs; 3) the development of strategies to reduce care barriers for families of individuals with mental retardation; 4) improvements in occupational safety for persons with mental retardation; 5) the expansion of knowledge and understanding of health and mental retardation; and 6) improvement in the overall quality of health care for persons with mental retardation. These six areas will improve standards of care, access to care, and facilitate the development of appropriate best-practice guidelines.

In order to meet the special needs of this aging population, it is obvious that there must be improvement in both direct clinical care and overall health-care systems. Most importantly this will include the training of all types of health-care providers in the care of older persons with developmental disabilities. Appropriate, uniform curricula need to be developed for professionals and allied health-care students that can address these specific health-care issues in a meaningful manner. Health-care financing and reimbursement for these groups needs to be improved, and overall systems of special care of those with developmental disability need to be designed to create appropriate financing linked to meaningful outcome measures that is respectful of the diversity among persons with such disabilities.[3]

As with other older groups, maximizing health care function requires appropriate provision of a variety of supports and services indirectly related to the provision of health care. Such older age services include providing for social needs, housing and transportation needs, work and retirement needs, as well as special care needs. Retirement and residential accessibility programs with relevant sources of financial support must be developed to add quality to the lives of nonworking older adults. Innovative and creative approaches may include joint residences with older persons without disabilities. Trying to improve overall health care and function in older adults with developmental disabilities will be impossible without the inclusion of such supports and services.

Finally we need to develop interested personnel and systems to encourage research on the care of older adults with disabilities. Funding for such efforts has to be available at the Federal, state and local levels. Protocols and policies have to be developed that ensure the safety and privacy of the individual but allow for meaningful and relevant research studies.

Opportunities exist to improve the quality of life and function of older adults with disabilities as never before. We must strive to meet such needs in the same manner as efforts are ongoing to improve the quality of life in all older adults.

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