Autism spectrum disorders (ASDs) are among the most common of the severe developmental disabilities, yet little is known about older adults with ASDs—indeed, how the disabilities and dependencies that result from aging interact with those resulting from ASDs. The aging of the population in Western countries, the increasing rate of diagnosis of ASDs, and the burgeoning use of services for ASDs are converging to create a large, growing influx of older adults with ASDs that could impose tremendous humanistic and economic burdens on the healthcare system and society. An understanding of the epidemiological, biological, psychological, and social aspects of ASDs in older adults is essential for preparing to meet their needs, but studies on ASDs in these individuals are practically nonexistent. This article outlines observations and recommendations of a multidisciplinary expert group convened in March 2010 to characterize gaps in knowledge regarding ASDs in older adults and defines research directions to help individuals, the healthcare system, and society prepare for meeting the needs of this population. The proposed research agenda could help improve the lives of older adults with ASDs and inform research and clinical practice involving younger individuals with ASDs. J Am Geriatr Soc 59:2151–2155, 2011.

Key words: autism; autism spectrum disorders; older adults; aging

Autism spectrum disorders (ASDs)—which include autistic disorder, Asperger's disorder, and pervasive developmental disorder—not otherwise specified—are a group of neurodevelopmental disorders characterized by the core deficits of abnormal social interaction; impaired communication; and repetitive, stereotyped behaviors and interests with an onset before the age of 3 years. Historically thought to be rare, ASDs now are second only to intellectual disability (also referred to as mental retardation) as the most common, severe developmental disability in the United States. According to the most recent estimate from the Centers for Disease Control and Prevention (CDC), the prevalence of ASDs in U.S. children was approximately 0.9% in 2006—up from 0.6% in 2000 and 0.7% in 2002. The number of diagnosed cases of ASDs and the number of children receiving services for ASDs have increased markedly in the past decade.

Although initially described as a disorder of infancy and often conceptualized as a childhood disorder, evidence now demonstrates that autism is a lifelong condition. Autism and Asperger's syndrome were first scientifically described in the 1940s. Children studied at that time are now entering their seventh and eighth decades of life, but little is known about the characteristics of older individuals with ASDs or about the needs of these individuals. The aging of the population in western countries, the increasing rate of diagnosis of ASDs, and the burgeoning use of services by persons with ASDs make the need to learn more about aging and autism a high priority.

Although in recent years research has begun focusing on young adults with ASDs, the overwhelming bulk of research on ASDs has involved children and adolescents. Evidence of the effectiveness of current interventions for ASDs in children and adolescents (reviewed in) raises the question of whether similar interventions would benefit middle-aged and older adults, especially those whose condition has not been previously recognized or treated. It is also possible that different interventions might be effective at different ages. Furthermore, older individuals with ASDs whose social and care needs family members have met could lose these supports with the death or incapacity of their parents or siblings. The effect of these events and
the care needs that are likely to emerge as a result are unexplored.

The per capita lifetime direct and indirect costs of ASDs in the United States are estimated at $3.16 million, a number that does not account for the costs of individuals with ASDs in the sixth decade of life and older. Analyses showing that the largest contributor to the estimated $1.28 million per capita lifetime direct cost of ASDs is care during adulthood, which dwarfs expenditures in childhood such as special education and supportive and medical care highlight the need to look beyond young people in efforts to mitigate the burdens of ASDs.

A multidisciplinary group convened in Chapel Hill, North Carolina, in March 2010 to review current knowledge and identify gaps in knowledge regarding ASDs in older adults. This group included experts in developmental disabilities, epidemiology, gerontology, health policy, neurology, patient advocacy, psychology, psychiatry, neurobiology, and genetics, many of whom have specific expertise related to aging of adults, with and without developmental disabilities. This article summarizes the observations of and recommendations from that meeting.

**ASD ACROSS THE LIFE SPAN: SYNOPSIS OF CURRENT UNDERSTANDING**

**Prevalence**

Several population-based prevalence studies of ASDs in children and adolescents have been conducted since the 1960s (reviewed in2,11). Generally, prevalence estimates for ASDs have increased with time, from approximately 5 per 10,000 in the 1960s and 1970s, to approximately 10 per 10,000 in the 1980s, and up to 72 per 10,000 in the 1990s.2 The most current and reliable U.S. estimate from the CDC puts the prevalence of ASDs at approximately 1% in 2006.3 Similarly high prevalence rates have been reported recently in other countries.12-15 This increase in the prevalence of ASDs is partly attributable to changing diagnostic and classification criteria (the diagnosis of pervasive developmental disorder—not otherwise specified was not established until 1987 and the diagnosis of Asperger's disorder was included in 1994), evolving social policies and reporting standards, and increased awareness of ASDs, but whether these factors wholly account for the increase in prevalence is not known.2,16

One study is relevant for establishing the prevalence of ASDs in older adults with ASD.9,17 Individuals aged 16 and older (N = 7,461) in households in England were screened using a diagnostic questionnaire followed by direct assessment by a trained examiner. The prevalence of ASDs was relatively stable in older age groups: 1.1% of 16- to 44-year-olds, 0.9% of 45- to 74-year-olds, and 0.8% of those aged 75 and older. These results confirm the lifelong nature of ASDs and suggest that the prevalence of ASDs has been relatively stable in birth cohorts within the age range studied. These results may underestimate the prevalence of ASDs in older adults because they did not adequately sample two sites in which there is a potentially a high prevalence: individuals diagnosed with intellectual disability and those in institutional settings.

U.S. Census Bureau estimates in 2006 projected a doubling of the U.S. population aged 65 and older by 2030. Assuming the life expectancy of individuals with ASDs is similar to that of the general population, based on current prevalence rates of ASDs in school-aged children, this population expansion would result in a prevalence of approximately 700,000 individuals with ASDs aged 65 and older in the next 20 years.

**Manifestations, Effect on Quality of Life, and Course of ASDs**

The nature and severity of ASD symptoms in childhood are heterogeneous. Predictors of poor functional status in childhood and adolescence include lower cognitive ability, later age at language acquisition, and later age at diagnosis.18,19 Although studies of young individuals with an ASD followed longitudinally for up to 5 years suggest that outcomes can improve over time in some cases,20-23 adults with ASDs generally do not attain normative outcomes, and a majority remain dependent on others.21,24 Likewise, multiple studies have demonstrated quality-of-life impairment in multiple domains, as well as persistent difficulties in communication and socialization, and, in adults, challenges with employment, housing, and community participation.25,26

Although the limited data reviewed above demonstrate that many individuals with an ASD live into later life, little is known about life expectancy and causes of death in adults with ASD. Some research suggests a shortened life expectancy and high death rates from causes such as seizures and accidents (suffocation, drowning)27,29 in individuals with more-severe ASD. Other serious mental disorders such as schizophrenia, which shares risk genes with ASDs, are associated with substantially shorter life spans.

**Associated Medical and Psychiatric Features**

Associated features of the ASDs include intellectual disability, present in approximately half of individuals with ASDs;2,30 psychiatric symptoms, including sleep disorders, anxiety, and depression;31,32 and epilepsy.33 Other conditions reported to occur commonly in children with ASDs include gastrointestinal disorders,34 feeding selectivity and aversions,35 and tics.36 Although gastrointestinal disorders and sleep problems have been documented in many children with ASDs, whether prevalence rates are greater than in the general population or in non-ASD control groups remains to be established. Recent research suggests that the prevalence of obesity in children with ASDs may be higher than in children without ASD37 although in older studies, obesity does not appear to be more common in children with ASDs than in the general population.1 Little has been published about associated medical and psychiatric problems in individuals with autism as they age. Although the presence of autistic symptoms may complicate care, the possibility of specific associations between autistic syndromes and medical and psychiatric comorbidities remains to be explored.

**Intervention**

Interventions for ASDs include specific education strategies and behavioral, speech, and pharmacotherapies.38-40
Although empirical support for these recommendations has been characterized as weak and the effect of intervention as modest, the field is in its infancy. The effects of these interventions on adult function are not known.

No medications are currently licensed to treat the core symptoms of ASD in individuals at any age. Medications are prescribed to treat associated features such as anxiety, depression, and insomnia and symptoms such as agitation, aggression, and self-injurious behavior. With few exceptions, the efficacy and safety of these interventions in ASD has not been established in well-controlled studies in any age group. In addition, families of children with ASDs use many “nontraditional” treatments despite the lack of documented efficacy, and the effect of these practices on later development is also unknown.

Long-Term Care

Published research suggests that few adults with an ASD live alone; many live with their families, particularly their parents. A minority of adults with ASDs are employed. Although current interventions might improve these outcomes in young individuals who receive treatment, many adults with ASDs have not been identified or treated and are likely to need alternative sources of support when they are no longer able to live with their parents. Because individuals with ASDs also have low rates of marriage and parenthood, reliance on children or spouses in the absence of parents will not meet their needs. Long-term care in Western societies is already facing a crisis in which demand will likely outpace supply for the foreseeable future. The increasing life expectancy of the population, in general, and the diminishing disparity in life expectancy of people with other developmental disabilities, in particular, compound this crisis. A recent report of the Institute of Medicine concluded that the U.S. workforce will not be prepared to care for the anticipated increase in the number of elderly individuals in the general population.

The report highlights the need not only for physicians and nurses, but also the much larger demand for direct care workers, who provide 70% to 80% of the daily hands-on care for disabled older adults. Exacerbating this situation is the lack of evidence that existing models of care can meet the needs of older adults with an ASD and that the current long-term care workforce is not trained to address the unique complexities of caring for individuals with ASDs. So for example, some symptom profiles common in older adults, such as late-life decline in sensory abilities (e.g., hearing and vision) may affect older individuals with ASD, who often typically have existing sensory abnormalities, differently. Nursing home care that is not sensitive to their need for routine, which when disrupted can result in extreme agitation, may adversely affect others. These examples and a wealth of others well known to those familiar with behaviors characteristic of ASD suggest the potential need for novel models of care and intervention strategies for this population of individuals.

NEUROBIOLOGY

The specific causes of most ASDs are largely unknown. Abnormalities in function and in putative biological mark-ers have been documented in individuals with ASDs and in animal models of ASDs involving the immune system, neurotransmitter systems, neuropeptide systems, and the endocrine system. Some findings suggest aberrant connectivity of important brain areas although their etiological significance has not been established.

Results of twin and sibling studies suggest a strong hereditary component of ASDs. The less-than-perfect concordance in monozygotic twins and the variation in manifestations and severity within concordant pairs support a role for environmental factors. Normal aging is associated with brain atrophy and changes in multiple neurochemical systems, some of which are also putatively abnormal in individuals with ASD. The superimposition of age-related and ASD-related deterioration in specific brain systems could theoretically result in greater impairments than expected with age-related decline alone. Trajectories of brain development in ASD are dynamic, with findings in young children (e.g., cortical overgrowth) differing from those seen in older adults (e.g., decreases in cortical volume), and brain aging in people with ASD may differ significantly from that in people with typical development. Specific associations with dementia and tremor or ataxia have been demonstrated with aging in individuals with Down syndrome and fragile X syndrome, genetically defined developmental disabilities that are often associated with the presence of autism or autistic features. Such findings in related neurodevelopmental disorders suggest the importance of descriptive studies of aging in ASDs in humans and rodent models to explore the possibility of later changes in underlying neurobiological substrates related to the presence of autistic symptoms.

RESEARCH QUESTIONS AND PRIORITIES: ASDS IN OLDER ADULTS

Addressing the lack of knowledge about ASDs in older adults will require an integrated, multipronged effort that yields data relevant to biological, psychological, sociological, and economic aspects of ASDs in this population. With only one published systematic study to date of adults aged 50 and older with an ASD, there is no information about these issues. The knowledge gaps identified above suggest the following priorities for research and research training.

- Develop diagnostic criteria and instruments for diagnosis and assessment of the needs of older adults with ASDs. Current diagnostic practice relies on early life history, which is less likely to be available in older adults suspected of having an ASD. Diagnostic criteria will therefore need to take into account adult manifestations of autistic symptoms and the specificity of adult symptom profiles for the diagnosis of an ASD. The development of reliable and valid diagnostic and assessment tools is a prerequisite for conducting descriptive studies of individual and convenience samples and epidemiological population-based samples. Based on recent findings suggesting stable rates of ASD across the life span, it seems likely that there exists a large population of older adults with ASD who have not been identified. No instruments are
CONCLUSIONS

There exists a large and heretofore-unrecognized population of elderly individuals with an ASD that will grow substantially over the coming decades. Although many more facets and consequences of ASDs in older adults than those enumerated here need to be elucidated, the proposed research initiatives will begin to define the magnitude of the problem of ASDs in the population; provide an indication of its potential effects on individuals, the health-care system, and society; and suggest initial approaches to addressing these issues. Little is known about the phenomenology and associated features of this condition as individuals age; about underlying neurobiological changes over time; and about specific medical, psychiatric, and social service needs, including the need for long-term care. Research on these questions is of critical importance. Such research has the potential to improve the lives of older individuals with ASDs significantly, to inform clinical practice and the development of policies to address this important health care disparity, and to generate new knowledge and hypotheses that can provide the basis for future research directions.

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