

Commentary

## Key goals and indicators for successful aging of adults with early-onset disability

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### Abstract

Substantial improvements have occurred in the longevity of several groups of individuals with early-onset disabilities, with many now surviving to advanced ages. This paper estimates the population of adults aging with early-onset disabilities at 12–15 million persons. Key goals for the successful aging of adults with early-onset disabilities are discussed, emphasizing reduction in risks for aging-related chronic disease and secondary conditions, while promoting social participation and independence. However, indicators suggest that elevated risk factors for aging-related chronic diseases, including smoking, obesity, and inactivity, as well as barriers to prevention and the diminished social and economic situation of adults with disabilities are continuing impediments to successful aging that must be addressed. Increased provider awareness that people with early-onset disabilities are aging and can age successfully and the integration of disability and aging services systems are transformative steps that will help adults with early-onset disability to age more successfully. © 2014 Elsevier Inc. All rights reserved.

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Numerous biological, behavioral, and social factors influence the aging process. However, behavioral factors are often viewed as highly important because they consistently predict onset of disability and death<sup>1</sup> and are modifiable. Engaging in healthy behaviors is touted to add years of life and more quality to those years.<sup>2</sup> Preventive health services and medical treatment have also been suggested to play a role in reducing disability and extending life.<sup>3</sup>

Models of successful aging<sup>2</sup> consider how aging-related outcomes can be improved mainly by fostering healthier

individual behaviors, such as avoiding smoking, alcohol abuse, unhealthy diets and inactivity, with a goal of deferring disability to the very end of the human lifespan,<sup>4</sup> or to put it another way, to delay or altogether avoid “aging into disability.” “Aging with a disability” refers to the aging process for the millions of individuals who have an early onset of disability at birth, in childhood or early adulthood. This paper addresses how well people with early-onset disabilities are positioned to age successfully.

Many people with early-onset disabilities are living longer than in the past, including those with Down syndrome, spinal cord injury, traumatic brain injury, spina bifida, cerebral palsy and several other conditions,<sup>5–7</sup> presumably due to improvements in medical treatment, rehabilitation, and social conditions. It has also been observed that some individuals with early-onset disabilities are developing secondary conditions and aging more rapidly than the general population, although the mechanisms generally are not very well understood.<sup>5,6,8</sup>

At this time, we must recognize that most children and adults with early-onset disabilities will experience the benefits and challenges of aging in adulthood. Increased life expectancy enables more individuals with early-onset disabilities to obtain higher education and pursue employment careers that in turn help them to age more successfully. Yet individuals with early-onset disabilities navigate the life course managing a primary condition (and those conditions diagnostically associated with a primary

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condition) and they face the risks of developing secondary conditions (the development of additional conditions due to having a primary condition).<sup>5</sup> Many require health services and other long term services and supports that can be difficult to access in sufficient quality and quantity.<sup>9,10</sup> They are also at risk of falling between the cracks of an aging services system that is not well prepared to serve younger adults with disabilities and a disability services system that is not well prepared to help them to age successfully.<sup>11</sup> Fortunately, this is starting to be corrected by integrating aging and disability services.<sup>12</sup>

The aim of this paper is to consider some key goals and indicators for the successful aging of adults with early-onset disability. First, the size of the population aging with early-onset disabilities is not well-understood<sup>10</sup> and is further considered. Second, popular models of successful aging have been developed with little attention to having an early-onset disability, as if aging successfully is out of the question for such individuals. Successful aging models in the context of having an early-onset disability are considered to help elucidate some of the goals of aging with a disability. Third, in order to age as successfully as those without disabilities, adults with early-onset disabilities should have comparable values on indicators for successful aging as similar individuals without early-onset disabilities. The inevitable conclusion is that adults with early-onset disabilities are not positioned to age as successfully as adults without disabilities and steps need to be taken to address these gaps.

### **Aging of individuals with early-onset disabilities**

A number of disabling conditions occur early in life and are not curable; individuals have them the rest of their lives. Some of these early-onset conditions have shortened life substantially, but over the past several decades life expectancy has increased for those with spinal cord injury, traumatic brain injury, cerebral palsy, polio, and Down syndrome and other intellectual disabilities. In the past, persons with Down syndrome seldom reached adulthood but now they are living into midlife and beyond. Their mean age at death increased from 9 years in 1929 to above 50 years by the 1990s.<sup>13,14</sup> It has also been noted that the causes of death for older persons with intellectual disabilities (ID) are similar to the general population, with heart disease, cancer, and stroke being most common.<sup>15</sup>

The Institute of Medicine considered the evidence on aging with a disability for four primary conditions for which the evidence was deemed strongest: spinal cord injury, cerebral palsy, polio, and Down syndrome. Evidence for the development of secondary conditions and premature aging was reviewed. A notable example of premature aging is the early development of Alzheimer's among middle-aged adults with Down syndrome. However, it is not clear to what extent that may be due to associated conditions (such as hypothyroidism which can cause memory problems), secondary conditions (such as memory loss due

to prescribed drugs), or environmental factors. Further, while each primary condition has a specific set of issues and risks for secondary conditions and aging, individuals with disabilities also face the typical risk factors for aging as they live to midlife and beyond.

### **How many adults are aging with an early-onset disability?**

Estimates of the overall population with disabilities in the United States come from censuses and surveys, but few provide any information to identify adults with early-onset disabilities.<sup>10</sup> Using the 1994 National Health Interview Survey on Disability (NHIS-D), Verbrugge and Yang<sup>16</sup> studied adults (ages 18+) who reported difficulties performing instrumental and basic activities of daily living (IADL, 6 items and ADL, 6 items) and selected physical activities (8 items—walking, bending, standing, climbing stairs, lifting, reaching, grasping, and holding). Approximately 11.5 million adults reported difficulty with any of these items. For each item, persons were asked at what age the difficulty began. Selecting the earliest age of onset within each domain, thirty percent of adults of all ages reporting a basic ADL difficulty had an onset at 44 years of age or younger. The corresponding figures are 34% for those with an instrumental ADL difficulty and 39% for those with a physical activity difficulty. The results suggest that from one third to 40% of the adult population with disabilities had an onset of disability at or before age 44. However, these selected domains are not fully representative of all adults with early-onset disabilities who are aging.

Another approach is to use the Harris survey on disability that collects information on age of onset. That is a telephone survey of 1001 noninstitutionalized persons with disabilities last fielded in May and June of 2010. Disability is defined according to the broad definition used in the Americans with Disabilities Act, specifically whether the individual has any limitation in work, school, housework, or other activities due to chronic disease or impairments or considers him or her self, or is considered by others, to have a disability.<sup>17</sup> In 2010, that definition was also applied to eleven other Harris surveys on other topics, yielding an estimated national prevalence of disability from 13 to 16% among adults ages 18 and older. From the survey on disability, 19% of all adults with any disability reported having an onset of disability from 0 to 19 years of age and 21% from 20 to 39 years of age. According to the 2010 National Health Interview Survey, there were 230 million adults ages 18 and older in the civilian noninstitutionalized population.<sup>18</sup> Given the prevalence range mentioned above (13–16%), we can infer that from 12 to 15 million adults are aging with an early-onset disability that occurred prior to age 40. Combined with the results of Verbrugge and Yang, it is clear that adults who are aging with early-onset disabilities comprise a large population whether disability is measured by function or more broadly by complex activities.

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