Younger-Onset Alzheimer’s Disease Parity Act (HR 6646, 115th Congress)

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House of Representatives

The Policy

Synopsis
HR 6646 [11], the Younger-Onset Alzheimer’s Disease Parity Act, would modify the definition of “older individual” in the Older Americans Act of 1965 [12]. The change would extend coverage of the Older Americans Act of 1965 to include individuals under the age of 60 who have Alzheimer’s disease or other similar neurodegenerative brain diseases.

By changing this definition, approximately 250,000 Americans [13] with younger-onset Alzheimer’s disease would be eligible to receive federal assistance for essential treatments and services for living with the disease, including education, home care, adult day care, meal delivery, and transportation. Further, by raising awareness of the prominence of younger-onset Alzheimer’s disease, the bill might help to combat social stigma and help change the under-diagnosis of younger-onset Alzheimer’s disease that currently exists.

The change could also help to fill a gap in which undiagnosed individuals may lose employment without having triggered employment disability benefits. Further, the changes could address the issue that the younger individuals are more likely to have dependent children while beginning to suffer this disease.

Context
The Older Americans Act of 1965 assists disabled Americans who are 60 years of age or older, including those with Alzheimer’s and related diseases. This assistance is provided by [14] funding a number of different programs including meals-on-wheels, family caregiver support, and health services. The latest extension [15] of funding for the Older Americans Act was passed with overwhelming bipartisan support in the 114th Congress, and signed into law on April 19, 2016. Funding is now effective through 2019.

According to [16] the Alzheimer’s Association, individuals affected by an earlier onset of Alzheimer’s disease will have similar needs to individuals covered under the Older Americans Act of 1965, but lack the same level of support or social understanding. Further, those with younger-onset Alzheimer’s disease may have dependents and/or a working spouse, which could magnify the support required by an individual and their family. Current policy and programs do not provide for these individuals, creating a larger burden for individuals and the families of individuals with younger-onset Alzheimer’s disease before the individual reaches 60 years of age.

Policy History
This is the second time that Representative Rice has introduced this bill, with an earlier version introduced on December 8, 2016 (HR 6520 [17], 114th Congress). HR 6520 (114th Congress) was introduced [18] in the House and referred to committee.

The Science
Science Synopsis
Alzheimer’s disease [19] is a brain disorder that typically develops after the age of 60 and, in 2014, was estimated to affect over five million Americans [20]. Alzheimer’s disease is characterized by impacting an
individual’s capacity to think and remember, progressing eventually to an inability to do simple tasks, according to the National Institute on Aging [21] (NIA). Complications associated with Alzheimer’s disease is reported as the sixth leading cause of death, but it may be as high as the third leading cause of death for Americans [19]. Brains of those individuals with Alzheimer’s disease have both structural issues (e.g. plaque build-ups) and functional issues (e.g. loss of communication between parts of the brain).

Younger-onset Alzheimer’s disease, which affects less than 10% of all people with Alzheimer’s disease, is characterized by the emergence of Alzheimer’s disease symptoms in an individual younger than 65 years of age. Some cases of younger-onset Alzheimer’s have been linked to genetics [19], with ongoing research [19] pursuing even more links.

Individuals with Alzheimer’s progress through stages [22] of the disease – early stage Alzheimer’s produces rather mild symptoms, middle stage of the disease presents with moderate symptoms, and individuals with late stage Alzheimer’s are afflicted with severe symptoms. Those diagnosed with Alzheimer’s live an additional four to eight years post-diagnosis, on average, but can live up to twenty more years. Because there is no cure for Alzheimer’s (medicines that treat the disease only control symptoms) and individuals who are diagnosed can live a number of years following diagnosis, the NIA released information [23] to assist with caregiving. In general, those with Alzheimer’s are suggested to benefit from services including home healthcare services, meal services, adult day care services, and respite services, among others.

Scientific Assumptions

- **Alzheimer’s disease and younger-onset Alzheimer’s disease are only different based on the age of onset** (Section 2(1)): Although Alzheimer’s disease and younger-onset Alzheimer’s disease are similar, the primary symptoms [24] associated with each disease differ; younger-onset Alzheimer’s disease patients more frequently developing non-memory symptoms.

- **Symptoms of younger-onset Alzheimer’s disease are like other forms of Alzheimer’s disease in most individuals** (Section 2(4)): The possible symptoms for both diseases closely mirror each other, but the rate of types of symptoms [24] differ drastically in individuals with younger-onset compared to normal-onset Alzheimer’s disease.

The Debate

Scientific Controversies / Uncertainties

There is still uncertainty as to what causes early-onset Alzheimer’s, and this may contribute to issues with finding proper treatments. Current ideas of causes include genetic mutations in the PSEN1 gene [25], head trauma [26], and a potential association [27] between Down Syndrome [28] and an individual’s rate of developing early onset Alzheimer’s disease.

Endorsements & Opposition

- Alzheimer’s Impact Movement, letter of support [29], August 1, 2018: “The Alzheimer’s Association and AIM are pleased to support the Younger-Onset Alzheimer’s Disease Parity Act, HR 6646.”
Representative Kathleen Rice (D-NY-4), press release, July 30, 2018: “Every American living with Alzheimer’s disease deserves access to the best available care, regardless of their age.”

Status

HR 6646 was introduced in the House on July 31, 2018 and referred to the Committee on Education and the Workforce.

Recommended Citation


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