THE COSTS ASSOCIATED WITH THE HUNTINGTON’S DISEASE PARITY ACT

This bill directs the Commissioner of Social Security to revise the medical criteria for evaluating disability in a person diagnosed with Huntington’s Disease and waives the 24-month waiting period for Medicare eligibility for individuals disabled by Huntington’s Disease. **We estimate that the annual cost of this bill would range from $10.5 million to $13 million annually.**

Huntington’s Disease (HD) is a genetic neurodegenerative disease that causes total physical and mental deterioration over a 12 to 15 year period. Eliminating the 24-month Medicare waiting period in cases of individuals with disabling HD will ensure individuals will get crucial care in the early stages of the disease.

Eventually, every person affected by HD will lose the ability to live independently. Symptoms include uncontrolled movement, dementia, and psychiatric disorders. The sequence in which symptoms develop and the pace of symptom development vary from person to person. Regardless of the manifestation of the symptoms, there is no cure for HD.

**BASIS FOR THE ESTIMATED COSTS**

We estimated the total cost of the waiver in two steps: first we estimated the cost per-patient; second, we estimated the number of patients who would benefit from the waiver. The product of the per-patient cost and the number of patients yields the annual total cost.

To estimate the per-patient costs to the Medicare program for waiving the 24 month waiting period for patients with HD, we applied CMS’s system for predicting the annual medical and pharmaceutical costs of people enrolled in the Medicare Advantage (MA) program. This system uses a risk-adjustment model based on Hierarchical Condition Categories (HCC) along with beneficiaries’ demographics. The system covers medical cost in Parts A and B as well as pharmaceutical costs in Part D. For our estimate of per-patient costs, we adjusted for

- the diagnosis of HD by using the HD diagnosis modifier, and
- the relatively lower age of the HD population by using the age 35-64 modifier, and
- the “new enrollee” modifier for drug costs.

Based on our estimate, the average annual cost of the waiver per HD patient would be $10,900. To estimate the number of people who would benefit from the waiver, we used a meta-analysis: The incidence and prevalence of Huntington's disease: a systematic review and meta-analysis.¹ A meta-analysis is a quantitative evaluation of multiple study results; essentially, it is a scientific consensus on the best available estimate. According to this study, the incidence of HD is .38 per 100,000 people. Given the current US population, this approximates 1,200 people per year could benefit from removing the 24 month waiting period. Thus, the annual cost of our bill is equal to the product of the per-patient cost of $10,900 and 1,200 patients benefiting each year, approximately $13 million.
Using the incidence rate to estimate the number of people who will benefit from this policy change may overestimate the cost of the policy given that the current rate of application and allowance for Social Security disability amongst people with HD is much lower than the rate of incidence of HD. In 2012, 269 claims were filed for persons with HD and 203 of those were allowed. In 2013, 449 claims were filed for persons with HD and 332 of those were allowed.

**INTERACTIONS**

Two factors could interact with the number of HD patients benefiting from the waiver to affect the total cost: a potential expansion of enrollment in disability insurance and the offsetting savings to Medicaid through expanding Medicare participation. Mathematica Policy Research considered both of these issues in its recent white paper on eliminating the Medicare waiver period for all persons with disability insurance. They determined that the impact of new demand for disability benefits could not be quantified given the current state of research.

Mathematica Research also found a large proportion of all people with disability insurance used Medicaid, thus, they concluded that Medicaid savings would accrue if the Medicare waiting period was waived. The Congressional Budget Office (CBO) reached a similar conclusion about offsetting Medicaid savings in their analysis of HR 353\textsuperscript{ii}, a bill to waive the 24-month Medicare waiting period for people disabled by ALS (amyotrophic lateral sclerosis). Mathematica estimated Medicaid savings to be 14 to 20 percent of Medicare’s costs; CBO’s estimate of Medicaid was much lower at 3 percent of Medicare’s costs. The estimates may differ because the medical needs of the patients affected by the policies differ—Mathematica considered all disabled patients and CBO considered only those with ALS. Thus, Medicaid savings could lower the total cost of this policy as much as 20 percent, for a total annual cost of $10.5 million annually.


\textsuperscript{ii} HR 353 was titled the Amyotrophic Lateral Sclerosis (ALS) Treatment and Assistance Act of 1999; introduced in January of 1999; and, passed as part HR 5661, the Medicare, Medicaid, and SCHIP Benefits Improvement and Protection Act of 2000.