



Investment in research today will yield health benefits for the next generation of adults with Down syndrome

Boosting research investment into the health and wellbeing of adults with Down syndrome would improve their quality-of-life outcomes, reduce caregiving costs, and extend the lifespan of adults with Down syndrome by five years, according to a report commissioned by LuMind IDSC, the Alliance for Aging Research, BrightFocus Foundation, and the National Down Syndrome Society.

The research, conducted by social scientists, demographers, and statisticians from the international data institute RAND, used a statistical modeling framework to answer three key questions:

- What is the status of the cognitive health and longevity of adults with Down syndrome?
- What is the status of caregiving related to Down syndrome-associated Alzheimer's disease for the older adult Down syndrome population?
- How could research investment affect trends in cognitive health, longevity, and caregiving in the next 50 years?

The findings, *Modeling the Impact of Research Investment on Down Syndrome Associated Alzheimer's Disease*, are published on the RAND website and are available [here](#).

It is the hope of the study sponsors that the report will be of use to researchers, foundations, and pharmaceutical and biotech companies that may be considering research into the large medical needs of adults with Down syndrome. The report shows significant medical and financial benefits to individuals with Down syndrome and their caregivers would result from treatments and other solutions discovered through additional research.

Of particular interest to this study, and to the Down syndrome community in general, is the formidable prevalence of Alzheimer's disease among adults with Down syndrome.

To estimate the impact that additional research could have on the wellbeing of people with Down syndrome, the statisticians used demographic information to track the survival rate and longevity of adults with Down syndrome and extrapolated it using established modeling methods, playing out over several different scenarios over the next 50 years.

Having calculated the age-specific likelihood of developing Down syndrome associated Alzheimer's disease, the age-specific likelihood of death (with and without Down syndrome associated Alzheimer's disease), and historical patterns in the average number of births in the U.S. of people with Down syndrome each year, the statisticians were able to empirically measure trends in longevity for the next three generations of people with Down syndrome. The impact of "innovations" in treatment of Down syndrome associated Alzheimer's disease resulted in extended longevity and five years of good health (i.e., years without a Down syndrome associated Alzheimer's disease diagnosis).

Figure 2. Predicted Life Expectancy for U.S. Adults with Down Syndrome, by Down syndrome associated Alzheimer’s disease Status, in 2020 and 2070

Although the model scenarios did not specify the kinds of treatment innovations that would impact future health outcomes, the analysis highlighted early diagnosis and intervention for Down syndrome associated Alzheimer’s disease as important factors in driving down the prevalence and related mortality. The analysts pointed out that without investment in research, even with a modest increase in longevity (along the same trajectory rate as has been seen since 1964), future adults with Down syndrome would live longer by five years (indicated above in blue), but they would still be subject to a high likelihood and same duration of coping with Alzheimer’s disease (indicated above in orange).

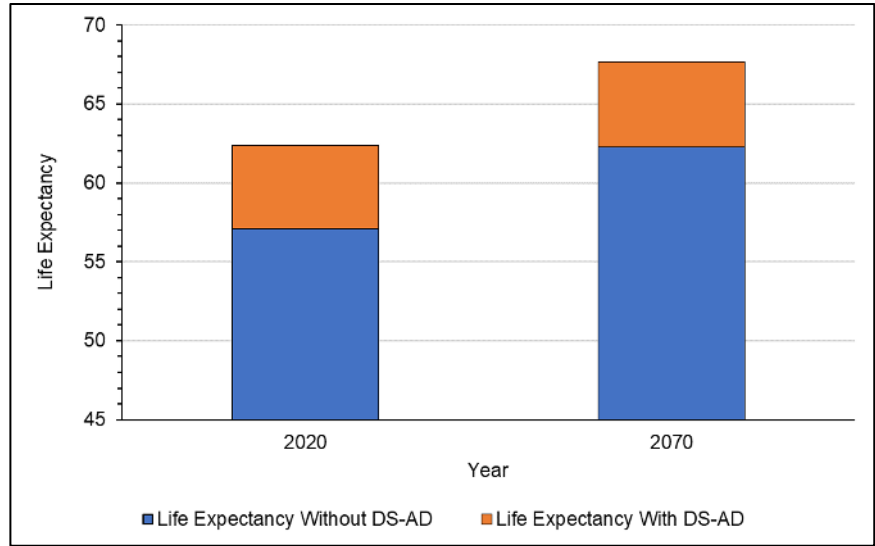
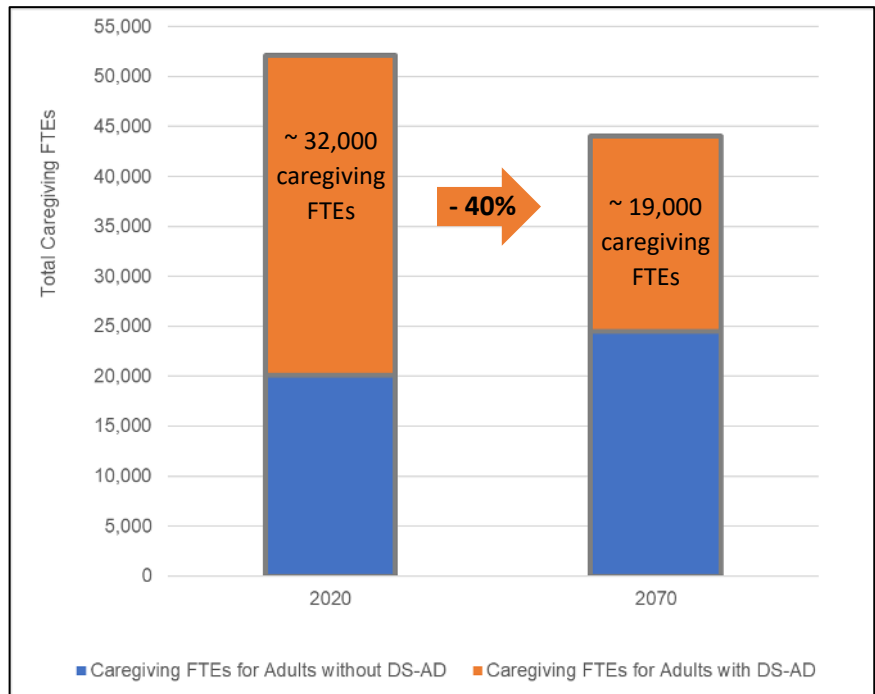


Figure 3. Predicted Full-Time Equivalent Hours (FTEs) for Caregiving of Individuals with Down Syndrome Ages 45 Years and Older

Another area of investigation centered on the economic burden of the specialized care necessary to support adults with Down syndrome associated Alzheimer’s disease. Data from 2020 showed that the total caregiving hours (either by professionals or by family members) to be 35,000 FTE hours – that’s 35,000 people working 40 hours/week. When hourly rates are averaged out and are combined with the lost wages of those who stay home to care for a loved one, researchers estimated the annual cost of taking care of the current generation of adults with Down syndrome associated Alzheimer’s disease to be \$1 billion.

Applying that data to the 50-year model, the researchers estimated that caregiver hours after the Alzheimer’s diagnosis would be reduced by 40% if more attention is given sooner to increasing research for Down syndrome associated Alzheimer’s disease.



Importantly, the number of caregiver hours per day prior to an Alzheimer’s disease diagnosis is 2.5 hours per day, compared to 8.3 hours per day after an Alzheimer’s disease diagnosis.

The study sponsors invite all those interested in learning more about Down syndrome research to read the full report, [here](#). Key findings and recommendations from the RAND report can be viewed below. **Key Findings**

- Over the past 50 years, the percentage of the Down syndrome population aged 50 and older quadrupled from about 5 percent to nearly 20 percent of the population by 2020.
- Improvement in Down syndrome survival and four decades of declining births following the baby boom have dramatically increased the likelihood that individuals with Down syndrome survive to develop Down syndrome associated Alzheimer's disease.
- Prevalence of Alzheimer's disease among adults aged 65 and older is about six times higher among Americans with Down syndrome than in the general population.
- Caregiving for the adult Down syndrome population aged 45 or older is currently estimated to require 35,000 full-time equivalent (FTE) hours per year. Assuming this care is provided at the national average rate for home health and personal care aides or entails lost wages of equal value for family and other unpaid caregivers, Down syndrome caregiving is estimated to cost about \$1 billion annually.
- With continued improvements in survival and without investments in research that would yield improvements in Down syndrome associated Alzheimer's disease, the additional gains in life years will predominantly be spent living with Down syndrome associated Alzheimer's disease. Adults with Down syndrome are projected to have more than double the increase in the expected years of life with Down syndrome associated Alzheimer's disease than without (respective increases of 40 percent versus 15 percent).
- With continued improvements in survival but with investments in research that would yield improvements in Down syndrome associated Alzheimer's disease, treatment innovations reducing the onset of Alzheimer's disease in the general population could improve health, survival, and caregiving outcomes by as much as 40 percent over the next 50 years if made available to the Down syndrome population. Among the impacts are the following:
 - Longevity and years of life without Down syndrome associated Alzheimer's disease is expected to increase by five years.
 - Prevalence of Down syndrome associated Alzheimer's disease is expected to decrease by 10 percentage points.
 - Caregiving for adults with Down syndrome associated Alzheimer's disease is expected to decline by 12,500 FTE hours.

Key Recommendations

The findings suggest some health care, research, and policy action steps to ensure fair Alzheimer's disease treatment access for individuals with Down syndrome associated Alzheimer's disease. To support this access:

- Alzheimer's disease treatment approvals should include DS-AD, which requires inclusion of individuals with Down syndrome associated Alzheimer's disease in clinical trials along with attention to adequacy of sample sizes.
- Clinician education about these treatments should address guidance for use with patients with Down syndrome associated Alzheimer's disease.
- Timely detection of Alzheimer's disease among individuals with Down syndrome requires clinician and caregiver education.
- Initiatives to improve early detection of treatable Alzheimer's disease should include attention to those with Down syndrome associated Alzheimer's disease.