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The Politics of Aging for Americans with Long-term Cognitive Disabilities

A new, growing and barely visible issue

Chuck Yanikoski

It used to be that people with long-term cognitive disabilities rarely lived long enough to become aged. But things have changed and are driving a significant emerging concern for the future.

Before autism became the most common cognitive disorder in children, Down Syndrome held that distinction. But no one worried about these kids reaching old age. According to the U.S. Center for Disease Control (CDC), the life expectancy of a baby born with Down Syndrome in 1960 was a mere 10 years. By 2007, the average person with Down Syndrome was living to age 47.¹

This also means that half now live past age 47, and therefore many of them are or will be entering true old age.² Furthermore, the brains of people with Down Syndrome appear to age more quickly than others in at least one respect: early incidence of Alzheimer's Disease. The best current estimate is that 90% of 70-year-olds with Down Syndrome will have already developed Alzheimer's.³ So they present a particular challenge for families and care providers.



Image courtesy of the Down's Syndrome Association

Autism will eventually offer even greater challenges. Autism wasn't even defined until 1943, and at the time, and for decades afterwards, it was considered a rare condition. But the CDC has most recently estimated that one in every 68 American newborns will land on the autism spectrum.⁴ People with milder forms of autism have a somewhat lower long-term survival rate, largely because of suicidal actions presumably taken because of their social isolation.⁵ It is not clear, however, that those impaired enough to be oblivious to their social situation face significantly greater mortality than the general public. Most of them will grow up, grow old, and be difficult to care for because of a combination of intellectual, speech, social, and sometimes sensory and physical complications.

So overall, while only about 5% of Americans age 65+ (in 2010) had an intellectual disability (other than Alzheimer's or other forms of senility),⁶ we can expect this percentage to grow significantly in the future.

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Alzheimer's research is well funded, and while that's also reasonably true for autism, the emphasis in autism research continues to focus on genetics and on childhood issues. We may have some hope that a method of prevention or even a cure for Alzheimer's can be found in the next decade or two, but this is unlikely for autism. And even if autism eventually can be prevented in newborns, the hope of a cure for those who already have it seems remote, and in any event certainly cannot be counted on.

There are already hundreds of thousands of people diagnosed with autism with significant intellectual impairment in the pipeline—mostly in early intervention or school programs, though the number of adults with these conditions is also increasing. Eventually most will fall into one or another category of the medically very needy elderly.

Others are already there. If we count emotional disabilities as cognitive rather than physical, other generational bubbles already exist. For example, about 15.2% of all male Vietnam veterans (and 8.5% of females) exhibit post-traumatic stress disorder (PTSD).⁷ These men and women are mostly already in their 60s. Another significant group from Iraq and Afghanistan will be coming along later. And there's at least anecdotal evidence that aging and retirement can increase the severity of PTSD, perhaps because the increase in free time means more opportunities to brood over and relive the past.⁸

There is also the simple fact that the Baby Boomers are now all in their 50s and 60s, except the very oldest, who are turning 70 this year. The impact of this age cohort

on caregiving and medical needs for the disabled is already very noticeable, but it's still in the early stages of a dramatic increase. Even if this group exhibits only the normal level of cognitive disability, the burden in terms of competent caregivers and dollars invested in facilities, staff, and treatment will be immense.

This essay is not attempting to address the needs of people who develop cognitive disabilities when they are already in or near their elder years. But the likely large demand for services for these Boomers will probably make it harder to find the funding and the skilled staff needed to care for those with even greater problems.

The impact

Why are those with long-term disabilities, despite their smaller numbers, a looming problem that's distinct from the larger group of Baby Boomers who will develop senility of one kind or another? Consider that:

- The long-term disabled group remains under the radar. Hardly anyone is thinking about them, other than those directly involved.
- They're broke. For the most part they have had little or no earnings during their many years of disability, and they lack savings, insurance, and other assets to help offset the costs of care.
- They have little family help. People with lifelong cognitive disabilities rarely marry and have children, so the first line of defense for most people with senility is absent for most members this sub-group. By the time they themselves are aged, their parents are long gone, and any siblings they might have are also aging. Relatives or friends good-hearted enough to help with care have probably been doing it for years, even decades, and their capabilities and good will are often tapped out.
- Their needs are often greater than the needs of those with age-related dementia. Though both groups typically require 24/7 supervision, unusual or difficult social behaviors are more common with people on the autism spectrum or people with PTSD or other emotional imbalances. Those with serious IQ deficits in addition to the other cognitive and physical problems of old age can be very much in need of closer supervision and more intensive care.

Few facilities are set up to provide such care. In connection with my own work as former President of SAGE Crossing Foundation (and husband of its founder, Linda H. Davis), I've had the chance to observe the experience of the premier provider of services to adults with autism in the U.S.—Bittersweet Farms, in Whitehouse, Ohio.

They've been doing this work for over 30 years, and a couple of their earliest and oldest residents have recently needed to go into nursing home care. However, it's has been very hard to place them, or for them to remain long in a placement, because their speech and behavior are well outside the norm, even for people in memory care, and most care providers don't know how to deal with them and are not legally required to try.

Eventually, when the numbers grow larger, perhaps special facilities will be created for elderly adults with these conditions. But that will cost money, and will require caregivers—and plenty of them—with special training.

The politics

It's fair to say that this problem, though it already exists, is barely visible on the political landscape. In all likelihood, that's because the problem is still mostly in the pipeline, manifesting itself only in scattered cases that don't attract broad attention.

It would be nice to think that as the problem grows, the issues will be addressed in a compassionate and effective way. But there is no assurance of that.

The 2016 Republican Party platform stands against discrimination because of disability, opposes the non-consensual withholding of care or treatment from the disabled, supports the ABLE Act (enabling the disabled to have tax-advantaged savings of up to \$100,000 without being disqualified for government benefits), and supports other measures beneficial to children and working-age adults with disabilities.

The 2016 Democratic Party platform also affirms the rights of people with disabilities, and offers a wider array of specific supports for them. Among these are pledges of government funding to “support the millions of people paying for, coordinating, or providing care for aging relatives or those with disabilities,” and “tax relief to help the millions of families caring for aging relatives or family members with chronic illnesses or disabilities.” (Note, however, not specifically for relatives who are aging *and* disabled. Such citizens aren't being excluded here, but they're also not being recognized.)

These platforms are consistent with the underlying philosophies of each party, including Republican preferences for small government and individual self-reliance, and Democratic preferences for more active government and taking care of the disadvantaged.

Even so, official platforms do not always reflect the priorities of actual candidates for office, let alone elected officials. Near the beginning of 2016, Equal Entry, a firm marketing technology and training materials for the disabled, searched key terms relating to disability on the websites of the two main Republican and Democratic Presidential contenders. This produced two hits on the Donald Trump campaign site and three on the Ted Cruz site, compared to 36 on the Hillary Clinton site and 144 on the Bernie Sanders site.⁹

However, disability (like LGBT identification) crosses party lines, and just as we have seen many Republicans begin to support LGBT rights when a close family member came out, others have taken up the cause of the disabled when it cropped up close to home. Nor is this unique to politicians. In a needy world full of great causes, concern about the disabled naturally tends to be greater among those with an affected child or other close relative. (This was not a particular cause or interest of my own, to be honest, before my autistic son Randy was diagnosed.)

The positive side of this is that with cognitive disabilities, especially autism, becoming more commonplace, there are both the hope and the likelihood that more politicians will put some of their focus on these issues.

PTSD among veterans may be at the leading edge. This has already been a hot issue in both the press and the Veterans Administration, and to some extent in the 2016 political campaigns. While the particular needs of aging Vietnam vets with PTSD have rarely been addressed or even acknowledged so far, we can probably expect interest to develop and ameliorative steps to be taken in coming years.

Other aging adults with long-term cognitive disabilities will probably have to wait, perhaps a long time. Meanwhile, it will be up to the families and guardians of these citizens, the advisers to those families and guardians, and to the caregivers who are on the front lines, to make the best of what is typically a very difficult situation.

1. CDC Data and Statistics on Specific Birth Defects: Down Syndrome, <http://www.cdc.gov/ncbddd/birthdefects/downsyndrome/data.html>.

2. As it happens, I used to have a first cousin with Down Syndrome who lived well into her 50s. But when her mother, who took care of her (and vice versa) died at the age of 99, my cousin Meg was put into institutional care and died soon thereafter.

3. "Researchers Study Alzheimer's Disease in People with Down Syndrome," Columbia University Medical Center, November 24, 2015. <http://newsroom.cumc.columbia.edu/blog/2015/11/24/researchers-study-alzheimers-disease-in-people-with-down-syndrome/>

4. CDC Data and Statistics on Autism Spectrum Disorder (ASD), <http://www.cdc.gov/ncbddd/autism/data.html>

5. Sallie Bernard, "The Other Public Health Crisis." https://www.autismspeaks.org/sites/default/files/docs/the_other_public_health_crisis.pdf

6. Though many of them had some form of senility in addition to their other disability. Matthew W. Brault, "Americans With Disabilities: 2010," U.S. Census Bureau Population Reports, July 2012. <http://www.census.gov/prod/2012pubs/p70-131.pdf>

7. "Findings from the National Vietnam Veterans' Readjustment Study," U.S. Dept. of Veterans Affairs.
<http://www.ptsd.va.gov/professional/research-bio/research/vietnam-vets-study.asp>
8. Coleen Mastony, "Stress hits some vets late in life," Chicago Tribune, November 11, 2013.
http://articles.chicagotribune.com/2013-11-11/news/ct-met-late-onset-ptsd-2-20131111_1_vietnam-veterans-nightmares-vietnam-war
9. "Accessibility 2016: Where Do the Candidates Stand?"
<http://equalentry.com/articles/accessibility-2016-where-do-the-candidates-stand/>



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