

June 8, 2017

The Honorable Orrin Hatch
Chair, U.S. Senate Committee on Finance

The Honorable Ron Wyden
Ranking Member, U.S. Senate Committee
on Finance

The Honorable Kevin Brady
Chair, U.S. House Committee on Ways and
Means

The Honorable Richard Neal
Ranking Member, U.S. House Committee on
Ways and Means

The undersigned organizations are concerned that the second article in a *Washington Post* series on the Social Security disability programs—titled “[Generations, Disabled](#)” (June 4, 2017 print edition)—paints a misleading and inaccurate picture of these essential programs.

As with the previous article, “[Disabled, or Just Desperate?](#)”—which contained major [data errors](#) and received [broad criticism](#) from experts and advocates including The Arc of the United States, the Center for American Progress, and the Center on Budget and Policy Priorities—Terrence McCoy’s reporting again fails to tell the whole story. Light on evidence and heavy on anecdote, the latest piece profiles a family in rural Missouri with several disabled family members including a mother and her adult daughter who receive Social Security disability benefits. With [record numbers](#) of Americans today living in multigenerational households, and given that disability often runs in families, it is no surprise that Mr. McCoy found one such family. Unfortunately, the article perpetuates dangerous and mean-spirited myths about the Social Security disability programs and the people they help, even going so far as to allege that families “pray” for their children to experience disability or illness.

Nearly all American workers and their families are insured for Social Security and have a stake in the future of Social Security’s disability programs. The undersigned organizations urge Congress to ensure that any discussions about how to strengthen the nation’s Social Security system are informed by facts—not well-debunked myths and offensive stereotypes.

Social Security Disability Benefits Provide Modest but Vital Support

About 57 million, or 1 in 5 Americans, live with disabilities. One in 10 Americans has a severe disability. Our nation’s Social Security system includes two essential sources of support for people with disabilities and their families: Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). Signed into law by President Nixon in 1972, SSI helps people with disabilities—and low-income seniors—afford the basics. SSI helps people meet their daily needs, pay for out of pocket medical and disability-related expenses, and avoid extreme hardship and homelessness. In total, SSI provides modest

support to about [8.3 million Americans](#): 1.2 million children and 4.8 million non-elderly adults with significant disabilities, and 2.2 million seniors.

SSI's modest benefits average only about \$540 per month, [or \\$18 per day](#). The maximum federal SSI payment for an individual ([\\$735 per month in 2017](#)) is less than three-quarters of the federal poverty line for a single person. Nevertheless, SSI protects nearly [half of recipients from deep poverty](#) (half the federal poverty line).

The Social Security Disability Standard is Strict and Most Applications Are Denied

As with Mr. McCoy's previous article, missing from his most recent piece is the fact that most applicants for Social Security disability benefits—including SSI—are denied. Across the U.S., approximately 37 million children and non-elderly adults have a disability, but [only 6.1 million](#) receive SSI due to disability. To qualify for SSI on the basis of a disability, applicants must meet the Social Security Act's strict disability standard – which the Organisation for Economic Co-operation and Development (OECD) describes as one of "...the most stringent eligibility criteria..." among OECD member nations. Individuals must also have extremely low incomes and assets in order to qualify for SSI.

Most SSI applications are denied under this stringent standard, and ***just about 3 in 10 are approved, even after all stages of appeal***. SSI recipients have severe impairments and conditions such as cancers, kidney failure, congestive heart failure, intellectual disability, and multiple sclerosis. Many are terminally ill, and [nearly 250,000](#) have died each year in recent years.

SSI Keeps Families Together and Reduces Institutionalization

No one prays for disability or illness. But for individuals with disabilities and families with a disabled member, SSI makes it possible to live in the community and for families to stay together. Without SSI, many would face homelessness or be forced into institutions—a harmful, costly, and unthinkable return to segregation that would undo decades of progress in inclusion for people with disabilities, and erode the promise of equal participation in American life accorded by the Americans with Disabilities Act and [the Supreme Court's Olmstead decision](#).

For families with children with disabilities, SSI makes it possible to keep their families together. Raising a child in the United States is already expensive, between food and clothing, rising housing costs, and the skyrocketing price of childcare. Raising a child with a disability can bring a score of [additional costs](#), such as for special therapies, specially trained child-care workers, medically prescribed diets, diapers for older children, adaptive equipment, and transportation to doctors and specialists—many of which are not covered or are inadequately covered by insurance or have high copays. In addition, families often lose income when a parent must take time off to take the child to medical appointments or reduce work hours to care for the child.

Families raising children with disabilities are [more than twice as likely](#) as other families with children to face material hardships such as homelessness, food insecurity, and utility shutoff. By helping to offset some of these costs, SSI allows families to care for children with disabilities in their own homes instead of in costly and isolating institutions. The financial support SSI provides also helps families maximize a child's opportunity to achieve an independent, rewarding, productive life including work in adulthood.

Disability Often Runs in Families

The Post's latest article makes much of the fact that in some families, more than one person in a household receives Social Security disability benefits, painting a highly stereotyped picture of a "culture of disability." Ignored in the text of the piece, however, is the data provided in a sidebar, which tells the real story: that disability often runs in families. There are a great many reasons for this. For example, siblings may experience similar disabilities due to genetics, shared exposure to environmental hazards—e.g. lead in the water—or common barriers to healthcare, such as doctor shortages or long waiting lists for care. Moreover, as documented in a recent [Institute of Medicine report](#) examining SSI for children with disabilities, family poverty increases the likelihood that a child will experience disability or illness, whether due to preterm birth, toxic stress, food insecurity, or other factors associated with low family income.

Many of these drivers are especially salient in rural areas, the focus of the Post's reporting. For instance, doctor shortages and other barriers to care are particularly prevalent in rural areas. And in rural communities, which are more likely to be home to an industry-based economy, where work tends to be more physically demanding and/or dangerous, families [may be more likely](#) to see a parent face disability, injury, or illness before reaching retirement.

Social Security's disability programs are nothing short of essential for the millions of people with disabilities who rely on them to remain in their communities instead of in costly and isolating institutions. And they make it possible for families to provide for children with disabilities and to keep families together. Rather than rehashing myths and recycling offensive stereotypes, we need to strengthen Social Security's disability programs to more effectively serve their missions: ensuring economic security for people with significant disabilities and severe illnesses, and enabling them to live independently with dignity and to transition back to work when possible.

Signed:

ACCSES
Advocacy and Training Center
AFL-CIO
Alliance for Retired Americans
American Association of People with Disabilities
American Foundation for the Blind
American Network of Community Options and Resources
Association of University Centers on Disability
Autistic Self-Advocacy Network
Bazelon Center for Mental Health Law
Brain Injury Association of America
California Alliance for Retired Americans
Center for American Progress
Center for Community Change Action
Center for Independence of the Disabled, NY (CIDNY)
Center for Law and Social Policy (CLASP)
Center for Public Representation
Coalition on Human Needs
Community Legal Services, Inc.
Disability Power & Pride
Disability Rights Education and Defense Fund
Easterseals
Economic Policy Institute Policy Center
Empire Justice Center
Global Policy Solutions
Gray Panthers
Institute for Educational Leadership
Institute for Policy Studies, Criminalization of Poverty Project
Justice in Aging
Latinos for a Secure Retirement
Legal Council for Health Justice
Lutheran Services in America Disability Network
National Alliance of State & Territorial AIDS Directors (NASTAD)
National Alliance on Mental Illness
National Association of State Head Injury Administrators
National Committee to Preserve Social Security and Medicare
National Council of Independent Living
National Council of La Raza
National Disability Institute
National Disability Rights Network
National Down Syndrome Congress
National Employment Law Project

National Organization of Social Security Claimants' Representatives (NOSSCR)
National Organization for Women
National Women's Law Center
Paralyzed Veterans of America
Service Employees International Union (SEIU)
Social Security Works
Strengthen Social Security Coalition
The Arc of the United States
Urban Justice Center

Peter Edelman, Carmack Waterhouse Professor of Law and Public Policy, Georgetown University Law Center, *in his individual capacity*

cc:

The Honorable Thad Cochran
Chair, U.S. Senate Committee on Appropriations

The Honorable Patrick Leahy
Vice Chair, U.S. Senate Committee
on Appropriations

The Honorable Mike Enzi
Chair, U.S. Senate Committee on Budget

The Honorable Bernie Sanders
Ranking Member, U.S. Senate
Committee on Budget

The Honorable Pat Tiberi
Chair, U.S. Senate Joint Economic Committee

The Honorable Martin Heinrich
Ranking Member, U.S. Senate Joint
Economic Committee

The Honorable Lamar Alexander
Chair, U.S. Senate Committee on Health,
Education, Labor and Pensions

The Honorable Patty Murray
Ranking Member, U.S. Senate
Committee on Education, Labor and
Pensions

The Honorable Rodney Frelinghuysen
Chair, U.S. House Committee on Appropriations

The Honorable Nita Lowey
Ranking Member, U.S. House
Committee on Appropriations