United States Senate
COMMITTEE ON HEALTH, EDUCATION, LABOR & PENSIONS
Tom Harkin, Chairman

Fulfilling the Promise:
Overcoming Persistent Barriers to Economic Self-Sufficiency for People with Disabilities

Majority Committee Staff Report

September 18, 2014

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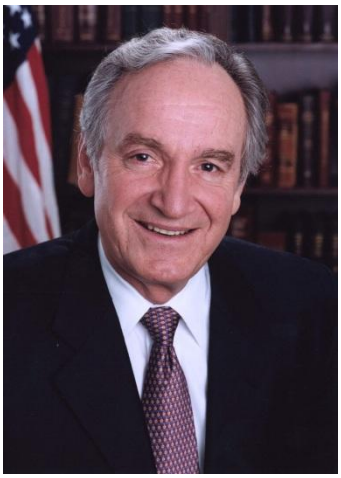
AN OPEN LETTER FROM CHAIRMAN HARKIN



The Americans with Disabilities Act was signed into law over 24 years ago. The law set four goals for the country and its citizens with disabilities: equality of opportunity, full participation, independent living, and economic self-sufficiency. In the time since the ADA passed, we have made extraordinary progress. The ADA's enactment radically changed the landscape of the country and enfranchised persons with disabilities in ways that were previously unimaginable. Those with disabilities can now move about towns and cities because of curb cuts. They can cross at intersections because of traffic lights that talk and tell a person when it is safe to cross the street. Polling places are accessible to voters with physical and intellectual disabilities. Movies are captioned and entertainment and sports venues have accessible seating. These and thousands of other changes make it possible for those with disabilities to be active participants in their communities and to take part in society as equals.

While great advancements have been made, Americans with disabilities still face significant hardships. Particularly with respect to employment and poverty, much work remains to be done in order for Americans with disabilities to achieve full equality in American society.

For most of my career I have focused on increasing the employment of people with disabilities. As I noted in my HELP Committee report in 2012, *Unfinished Business: Making Employment of People with Disabilities a National Priority*[1], employment is the "accessible pathway out of deep poverty and into the mainstream of the American middle class."

Unfortunately, twenty-four years after the signing of the ADA, Americans with disabilities remain disproportionately poor and face significant barriers to joining and remaining in the middle class. On the most important economic measures such as unemployment, annual earnings, and poverty, people with disabilities often are in the worst condition compared to almost any other group. For instance:

- **Twice as many Americans with disabilities live in poverty compared to those without disabilities.** Over 28 percent of non-institutionalized adults aged 21-64 with a disability in the United States live in poverty compared to 12.4 percent of those without a

[1] Senate Committee on Health, Education, Labor and Pensions website, http://www.harkin.senate.gov/documents/pdf/500469b49b364.pdf

disability; greater than the rate for any other demographic category including African-Americans, Hispanics, or female-headed households.[2]

- **Less than 30 percent of working-age Americans with disabilities participate in the workforce.** Of the over 20 million Americans with disabilities who are of working age, less than 30 percent work, compared to over 78 percent of non-disabled Americans.[3]
- **Americans households with an adult member with a disability earn 38.4% less than households without an adult member with a disability.** The average annual household income for with an adult of working age (ages 21-64) in 2012 was approximately $37,300 compared to $60,600 for households with a member with a disability.[4]

These facts are deeply troubling and merit further investigation. We have worked to make this country physically accessible to those with disabilities. Now we must tackle the barriers to economic independence and self-sufficiency.

I instructed my HELP Committee staff to investigate the barriers that people with disabilities face as they seek to rise out of poverty and enter the middle class. We heard from over 400 people with disabilities who have experienced poverty. Their stories were detailed and informative. Their experiences touched on many issues, but six issues were dominant:

- Having a disability is both economically and socially costly;
- People with disabilities fear that earning or saving too much money will result in termination of supports they receive that are critical to their ability to live their lives independently and as part of their communities;
- Saving for emergency and unanticipated expenses is really impossible;
- Time and energy are squandered on navigating complex bureaucratic systems in order to secure their basic needs;
- Many feel separated from the economic mainstream because of a lack of adequate transportation and accessible, affordable housing; and
- Almost all reported experiencing employment discrimination, persistently low expectations, inaccessible workplaces, and discriminatory pay.

[2] Institute for Research on Poverty http://www.irp.wisc.edu/faqs/faq3.htm
[3] Bureau of Labor Statistics http://www.bls.gov/news.release/disabl.nr0.htm
[4] 2912 Disability Status Report http://www.disabilitystatistics.org/StatusReports/2012-PDF/2012-StatusReport_US.pdf?CFID=14963485&CFTOKEN=923a6577ab0a747f-D635BB7B-5056-B400-0DACE7F2C98064A9&jsessionid=84306ceadb4d79adfc007a3447151a3d0444

As I have stated, during the past 40 years we have made great advances in creating opportunities for people with disabilities, removing barriers, and protecting their rights. To address the concerns expressed by people with disabilities in this report we need to take the next steps toward economic self-sufficiency. These steps include:

- Addressing the cultural biases and prejudices that remain about the ability of people with disabilities to do meaningful work;

- Ensuring that support programs not only provide support but create a path to the middle class;

- Removing the complexities and bureaucratic barriers to applying for supports that allow people with disabilities to live independently;

- Increasing the availability of accessible housing and transportation; and

- Ensuring access to high quality education coupled with high expectations for students with disabilities.

With over 28 percent of people with disabilities living in poverty, we have not yet achieved the goals of the ADA. We must face the challenges heard in the stories contained in this report, clear the barriers for people with disabilities to become part of the middle class, and fulfill our responsibility to ensure opportunity for all.

I urge my colleagues on the HELP Committee and in the Senate to listen closely to the stories in this report and to work to eliminate the barriers identified in order to provide all our citizens, including those with disabilities, with the opportunities to be economically self-sufficient in this great country.

Introduction

"I LIKE to work, and would rather care for myself."

America changed when the Americans with Disability Act was signed into law over twenty-four years ago. In 1990, the civil rights of people with disabilities that were fought for by disability advocates and their allies became the law of the land.

With the passage of the ADA, people with disabilities were guaranteed the right to equal access to employment, state and local government services, commercial facilities and businesses, transportation, and telecommunications. This meant, for the first time in the history of the United States, that those with physical, mental, intellectual, sensory, and chronic health disabilities had the right to be able to enter a local courthouse, to be able to cross the street, to be able to attend a movie or baseball game, to be able to dine in a local restaurant, or to be considered for employment based on their skills and knowledge rather than to be dismissed from consideration because of their disability.

The ADA changed the physical and communications landscape of America. Since its enactment, ramps have been installed to allow access to places as varied as museums and police stations. Traffic lights at major intersections now "speak" so that a person who is blind will know when to cross the street. Captions are available for all television programs, including those streamed via the internet. The way we communicate, via telephone, text messaging, or e-mail, is accessible to those with all types of disabilities. Access to the American way of life for people with disabilities has become a reality.

However, for many of those with disabilities, two areas of American life have been stubbornly resistant to change: employment and participation in the middle class.

In July 2012, the Senate Committee on Health, Education, Labor, and Pensions published a report titled, *Unfinished Business: Making Employment of People with Disabilities a National Priority*. The report highlighted the emergence of the "ADA Generation;" young people who have grown-up since the passage of the Individuals with Disabilities Education Act and the Americans with Disabilities Act. Thanks in large part to those laws and the societal changes that have emerged as a result of their implementation, these young Americans have high expectations for quality education and access to competitive integrated employment that allows for full participation in the American middle class.

Unfortunately, for millions of Americans with disabilities, young and old alike, that expectation has not been realized. Despite the removal of most physical, communication, and legal barriers,

a significant percentage of the approximately twenty million[5] working age adults with disabilities find themselves facing difficult economic circumstances caused in part by high rates of joblessness, low pay, limited savings, and additional costs and time demands due to their disabilities. While millions of hardworking Americans across the country share these experiences, people with disabilities are disproportionally likely to experience these economic challenges. For a country that is dedicated to creating equal opportunity for all who are willing to work, these disparities are unacceptable.

One way to understand the economic situation of people with disabilities is to compare their rates of poverty to the non-disabled population. In the richest nation in the world, far too many of our fellow Americans live in poverty, whether or not they have a disability. However, Americans with disabilities experience poverty at rates unseen by any other subpopulation of the country.[6] According to the Census Bureau's 2013 American Community Survey, 28.8 percent of non-institutionalized adults aged 21-64 with a disability in the United States live in poverty compared to only 12.3 percent of those without a disability.

The many negative effects of poverty are well-documented: lower academic success for adults and children; food insecurity; increasing odds of living in an unsafe neighborhood; working a more dangerous job; and increased stress and depression, which compound these other difficulties. These factors, combined with limited access to quality health care, can create new health problems or exacerbate existing ones. Simply put, poverty creates additional, significant hardships that can beget further poverty. According to the National Center for Children in Poverty, individuals who experienced poverty during their childhood have a 35-46 percent chance of being poor in their adulthood.[7]

Similarly, Americans with disabilities are less likely to participate in the workforce and are more likely to be unemployed than any group of Americans without disabilities. According to the Bureau of Labor Statistics, in July 2014, the workforce participation rate for people with disabilities aged 16 to 64, was 30.2 percent compared to 77.2 percent for people without disabilities. This is the lowest workforce participation rate of any group of working age Americans.[8] Likewise, for the same time period, the unemployment rate for people with disabilities was 13.3 percent, compared to 6.4 percent of people without disabilities.[9]

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[5] http://disabilitycompendium.org/compendium-statistics/population-and-prevelance/1-6-civilians-ages-18-64-living-the-community-for-the-u-s-

[6] http://www.nclej.org/poverty-in-the-us.php

[7] Wagmiller, R and Adelman, R "Childhood and intergenerational poverty

[8] http://www.bls.gov/news.release/empsit.t06.htm

[9] Workforce participation rate is the percentage of people working, full or part-time for that group. The unemployment rate is the percentage of people in that group actively searching for employment but not employed.

Despite the highest unemployment rate and the lowest workforce participation rate of any group in America, 80 percent of people with disabilities reported they wanted to work in a recent survey, compared to 78 percent of those without disabilities.[10] Unfortunately, finding and maintaining full-time employment is very difficult, and for those who do, the pay is often less than that of their non-disabled peers. In 2013, 33.7 percent of workers with disabilities were employed part-time compared to 18.7 percent of those with no disability.[11] Similarly, the average annual income for people with disabilities aged 21-64 in 2012 was approximately $36,400 compared to $42,400 for workers without disabilities.[12]

These numbers clearly demonstrate the unmet potential for employment among those with disabilities but do little to explain these disparities. Americans with disabilities, whether they are able to work or not, confront many unique challenges. For many people with disabilities, they experience greater costs of daily living. Significant portions of their income are put toward the higher costs of finding or creating accessible housing, the added financial and time costs of arranging adequate transportation, arrangements for personal care attendants, and higher out-of-pocket medical expenses. As a result, people with disabilities have less discretionary income and are able to save less for the future or for significant expenditures such as a car, house, or higher education.[13]

According to a July 2014 publication from the National Disability Institute, 53 percent of respondents with disabilities were certain they *could not* come up with $2,000 for an unexpected expense compared to 23 percent of non-disabled respondents. Similarly, only 22 percent of people with disabilities had at least one household retirement account, compared to 59 percent of people without disabilities. Homeownership among people with disabilities was less common (39 percent) than for people without disabilities (59 percent), and planning for college was considerably lower. While over half of the total U.S. population does not have savings for emergencies (56 percent), the number is even higher for people with disabilities at 81 percent.[14]

The story for people with disabilities over the past quarter century has been one of greater access to public services, businesses, entertainment, telecommunications, and almost every aspect of American life. Despite greatly increased access, however, people with disabilities remain far more likely to be impoverished, to be out of the workforce, and to be experiencing the detrimental effects of living in poverty.

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[10] http://news.rutgers.edu/news-releases/2008/09/people-with-disabili-20080922#.U-oZAGOTJqA
[11] http://www.bls.gov/news.release/disabl.t02.htm
[12] http://www.disabilitystatistics.org/reports/acs.cfm?statistic=5
[13] http://www.jrf.org.uk/system/files/1859352375.pdf; http://www.crr.unsw.edu.au/media/File/DP147.pdf;
[14] http://www.realeconomicimpact.org/data/files/reports/NDI_financial_capability_report_july_2014.pdf

"Disability Marginalizes You; Poverty Keeps You Marginalized"

Given that 28 percent of those with disabilities live in poverty, it is clear that even with the progress that has been made, many do not have the opportunities to realize their full potential. While a significant number of the people with disabilities receiving supports are unable to work, it is also clear that an unacceptable number of working age adults with disabilities who want to work and who are capable of work are continuing to encounter barriers that are preventing them from obtaining the economic certainty and stability of the middle class.

For that reason, the Senate HELP Committee majority staff conducted an investigation with 400 people with disabilities who currently or once had lived in poverty. Individuals responded to a questionnaire and a small group was interviewed to better understand their experiences.[15] The responses to the questionnaire and the interviews contained many stories of the difficulties of living with a disability and the barriers to entering the American middle class. Individuals told of discrimination in hiring practices and on the job. They shared experiences of difficulties with reliable transportation. They spoke of program requirements that prohibited them from saving money for future expenses and investments. And they talked about the added expenses they experienced due to their disabilities.

Upon reviewing all of the responses to the questionnaire and listening to the in depth interviews, six themes emerged related to the economic well-being of people with disabilities:

(1) the increased economic and social costs of having a disability;
(2) the fear that earning or saving too much money will result in termination of government benefits and the loss of needed health care, housing, and food;
(3) the inability to save for emergencies and large anticipated expenses;
(4) the difficulties in navigating a complex bureaucratic system in order to obtain basic needs;
(5) the alienation from the economic mainstream caused by a lack of adequate transportation; and
(6) difficulties finding accommodating workplaces and overcoming persistently low expectations, pay and employment discrimination.

These themes are illustrated with the words and experiences of people with disabilities in the sections that follow.

[15] See Appendices A-G for details about collecting information for this report and the responses from people with disabilities.

The Economic and Opportunity Costs of Disabilities:
"It is Expensive to be Poor"

As noted by a majority of the respondents to the Committee's questionnaire, having a disability is extremely expensive. As a result, many respondents report struggling to meet their current needs and even more report finding it difficult, if not impossible, to save for the future. In fact, debt is more common among individuals with disabilities, as people with disabilities face higher costs for health care, transportation, housing, and long term services and supports than their non-disabled peers.[16] [17]

The higher costs that result from a disability take two different forms. One is the increased financial burden that results from expenses such as medical co-payments, uncovered medical and therapeutic treatments, and expenses for equipment and supplies such as specific types of catheters, diabetes test strips or seating cushions for a wheelchair. In addition to these costs, people with some types of disabilities have increased expenses for specific types of clothing and aids for daily living such as software or notebooks to track expenses and tasks.

The other type of cost is the opportunity cost of the added time it takes to live with a disability. Individuals with disabilities have the added cost of requiring or needing additional time to perform tasks and accomplish activities that someone without a disability does not have to consider or expend. For example, preparing for work in the morning may take an individual without a

Jane

A single mother of five, Jane is a 60-year-old woman with autism and a neuro-muscular disability. Four of her children also have autism, including a son who continues to live at home. While caring for her children, Jane owns and operates a small business.

Jane frequently spends additional time and money because of her family's disabilities. She must buy food that does not contain whey, soy, or gluten because of her son's food allergies. She must also spend extra on medications, school supplies, and supervision for her son. Further, Jane must spend additional time advocating for benefits and accommodations, reducing the amount of time that she can spend working.

Jane believes that government assistance for her and her family is essential to avoiding poverty. To successfully transition away from government supports and afford the costs of her family's disabilities, she believes that she "would have to make $50,000-$60,000."

Jane feels that living in poverty requires considerable effort from people with disabilities: "The assumption is that disabled people are incompetent, that we don't have family obligations, [and] that we are stealing from the system. But being poor is a full-time job."

[16] Mathematica http://futureofchildren.org/futureofchildren/publications/docs/22_01_04.pdf; http://www.crr.unsw.edu.au/media/File/DP147.pdf; http://www.theguardian.com/uk/2010/apr/19/poverty-disability-warwick-university-debt
[17] http://www.realeconomicimpact.org/data/files/reports/NDI_financial_capability_report_july_2014.pdf

disability 45 minutes, including getting out of bed, washing, dressing, and eating breakfast. For a person with a physical disability, an autism spectrum disorder, a sensory disability, or an intellectual disability, the amount of time to accomplish the same tasks may be 90 minutes to more than three hours. This additional time is a huge cost burden that decreases the amount of time an individual has to prepare for daily tasks, work, or care for their own family members.

Additional Fiscal Expenses

The fact that having a disability results in extra costs is self-evident, but experienced on an individual level, those costs can be a huge drag on economic mobility. Examples of additional fiscal expenses were pervasive throughout the responses to the questionnaire and in the interviews conducted with participants. Cheryl, a middle-age woman with cerebral palsy indicated that even with her benefits from Medicaid to pay for her wheelchair, she has extensive additional expenses that she must pay related to her mobility and her self-care. She reported paying an average of $200 per month for upkeep and repairs for her chair in order to ensure she remains mobile. She also reported needing to purchase specific surgical gloves and urine collection bags that are not covered by her benefits in order to be independent. She reported that these additional medical expenses averaged $150 per month.

Another respondent from Colorado listed the additional expenses she has that are not covered by Medicaid. She must purchase special toileting wipes for her attendant to care for her toileting needs, syringes to clean her ears due to a secondary condition from her disability, special padding for her headrest to reduce the likelihood of pressure sores on her head, and a special mattress that allows her to turn every two hours in order to reduce the likelihood of bed sores. These expenses run into the thousands of dollars annually and are not covered by insurance or any other benefits.

Becky, a woman in her 30s with a chronic mental health disability, reported she needed to track every expense and that "I spend a lot of time thinking about how to strategize maximum value." When referring to having a disability she said it is "a part-time job thinking about how to make things work."

Justin, a young man with cerebral palsy that limits his ability to walk reported that the cost of mobility is very high. Unlike those without a mobility disability, he and his family had to invest in an accessible vehicle that cost over $135,000. Those expenses were paid by his family in order to ensure he was able to get to work and have a more independent life.

Some expenses are unexpected and unseen. A young woman with cerebral palsy from South Carolina wrote about the costs of basic living expenses. She indicated that rent in accessible buildings is considerably more expensive than in inaccessible buildings. She stated, "This means

I must pay more money for a basic amenity when I would be just as happy living in the cheaper apartment complex if it had an elevator." A respondent in Maryland confirmed this additional expense. She said that "when…housing is accessible, it costs more than an average home because it is usually newer." Furthermore, she emphasized that even after she was able to find accessible housing, her quality of life did not improve across the board. "I cannot visit some friends or family members though because their homes are not accessible. This can lead to social isolation for people with disabilities."

Finally, even everyday items can end up being more expensive for a person with disability. Toya, a woman in her 30s with cerebral palsy, reported needing new shoes every month because of her walking pattern. "We constantly got to buy new shoes," she explained. Similarly, another respondent said that she needs to purchase "special clothes because of my body distortions…and lots of day to day adaptive equipment that insurance doesn't cover." One respondent reported that suppliers of "special" or "adaptive" clothing and equipment "price gouge" because the demand is relatively low. An example of this type of "specialized equipment" is furniture risers, or hardware that raises furniture, such as a table or a chair, to the level a person with a physical disability so they can more easily use it. DisabilityProducts.com offers a set of eight risers for $49.95. A similar product is available from Amazon.com for $19.95.

Many respondents reported that having a disability necessitates going to doctors and therapists more often, thus increasing out of pocket expenses for co-payments, even when Medicaid, private insurance, or other benefits pay for health care. These additional medical and therapeutic visits also add to transportation expenses those without disabilities do not have.

Other expenses are directly related to an individual's disability but are not covered by health care or other benefits. A woman in her 30s with an anxiety disorder reported that "I have had to go to counseling because I am not able to take meds for my disability so I am learning to self-regulate." Her counseling to address her anxiety responses at work was not covered by health care insurance, yet it is necessary in order for her to maintain her job.

Opportunity Costs

In addition to the financial costs described above, many respondents indicated that having a disability means more planning, more preparation, more research, more daily and periodic tasks and more advocacy compared to the activities of people without disabilities.

When addressing the issue of time resources, Ann, a young woman who is blind, told the Committee when talking about her daily living tasks that "everything just takes so long. There is no additional time…" She expressed a desire to work an additional job but stated that the

additional time it takes her to prepare for work and take transportation to and from a job makes it impossible to work a second job.

Time is also an expense for those living in rural areas. Rose, a middle age woman with a chronic mental health disability reported that a task as simple as obtaining an annual dental check-up takes her a full day away from work. The closest dentist who can work with her is 100 miles away.

Another cost is the limitation in choices for some people with disabilities. Because of auditory processing or sensory input concerns, some individuals with chronic mental health disabilities or autism spectrum disorder, cannot use generally available public services. Many respondents indicated that crowded public transportation was not an option for them because of their disabilities. One person with a traumatic brain injury indicated he could not use public transportation because the tactile and auditory input overwhelmed him and he could not function after riding the bus or train.

The additional costs of disabilities, both fiscal expenses and time expenses, place greater burdens upon individuals with disabilities, increase their daily monetary output, reduce their ability to save, and reduce their ability to work longer hours, work a second job, or even search for a better paying job, all strategies that individuals without disabilities use to lift themselves out of poverty. As a Kansas respondent said, "[Y]ou pay more for goods, have to use credit for emergencies, have lower deductions for insurance…and you pay more for transportation. It is expensive to be poor."

Inadequate Availability of Accessible, Affordable Housing and Accessible Transportation:
"*I can't afford housing. I have to live with my parents.*"

A key to obtaining economic self-sufficiency and retaining employment is reliable transportation and affordable housing. Except for the few towns and cities where it is economically possible to live close to your place of employment, almost all workers need some type of transportation to their job. The lack of available accessible housing and the lack of reliable accessible transportation combine to make it even more difficult for people with disabilities from becoming employed and moving into the middle class.

Despite the ADA requirements for accessible public transportation, there are persistent gaps in compliance that continue to create significant obstacles for people with disabilities.[18] In 2003, the Department of Transportation reported that over a half a million people with disabilities never leave home because of transportation difficulties.[19] These findings are substantiated by survey respondents who explain how a lack of adequate transportation can cause people with disabilities to become alienated from the economic mainstream.

The wait for accessible housing, through locally operated Section 8 programs, can be years. A woman in her fifties with cerebral palsy confirmed this problem. "In order to

Toya

Toya is a 32-year-old single mother of two. She and her youngest child have hereditary spastic diplegia, a disease similar to cerebral palsy, that requires her to use a wheelchair. She works as an AmeriCorps Trainee in Omaha, Nebraska.

Toya struggles to get to work by public transit. Every day, she wheels herself five blocks to the bus stop and take three connecting buses. After reaching the final bus stop, she must wheel another three blocks up and down a hill. If everything goes according to plan, it takes Toya approximately two hours to get to work. Unfortunately, broken wheelchair lifts, late buses, and uncooperative drivers frequently delay her trip. "Often," she said, "buses roll by my stop so they don't have to pick me up [because of my disability].

Although Omaha offers a curb-to-curb paratransit service, Toya says that the program is "too much money to ride daily and isn't reliable." Logistical difficulties and long waits present further headaches.

Toya worries about the impact of her disability on her future employability. Forced to rely on public transportation, she must find an employer with "flexibility and understanding" when buses break down or wheelchair lifts don't work.

Nonetheless, she remains determined to work "just like everybody else and not just sit and collect a check every month."

[18] http://www.civilrightsdocs.info/pdf/transportation/transportation-and-disabilities-v%205-2.pdf
[19] U.S. Department of Transportation: Bureau of Transportation Statistics. (2003). Transportation Difficulties Keep Over Half a Million Disabled at Home.

find housing you're put on a list that is years long. I keep having to call them and see if somebody died and make sure my name stays on the list."

A young man with cerebral palsy from the Midwest emphasized the lack of available housing. "There are virtually no choices for me in my community. There is no accessible housing – and if there is it is very expensive...If I could find a place to live – with transportation – I could keep my job…and not be forced to rely on my parents to get to and from work. I worry that as my parents get older that they will not be able to care for me and drive me to work and that I will be forced to quit my job and go back on SSI – a horrible choice."

In urban areas, the difficulty of finding housing is often exacerbated. One woman in the Midwest reported that "the wait list for public housing is closed…and has been for some time. I cannot afford even afford drug infested Single Room Occupancies on $721/month and $36/month food stamps. I live at home with a parent in the basement for $300 month. I cannot even afford to buy milk or breakfast food. My father provides that. I would easily be homeless without family housing."

Similarly, the lack of accessible transportation contributes to increased costs for people with disabilities and exacerbates the difficulty in obtaining and retaining employment. By law, public transit services must provide accessible transit within three quarters of a mile of fixed routes. However, accessible housing near that distance of a fixed route bus or light-rail line is hard to find and often more expensive, and gaps in local public transit agencies make it even more difficult for many people with disabilities to get to and from work.

One middle-aged woman with cerebral palsy reported that, for her, transportation was a barrier to finding and keeping a job. "I always had to find a job by the bus line. This limited my opportunities and made me reliant on the bus, which is not the most reliable form of transportation for work. I do not have my license so public transportation was my only option."

Another woman with cerebral palsy talked about the para-transit programs that have been put in place due to the ADA. "There are para- transits all over the U.S. However because of all the budget cuts a lot of places only go where a line haul [fixed route] bus goes which cuts off some areas that you may want to get to."

She goes on to describe the difficulties of using a system designed for people with disabilities that is separate and not equal to the services of public transit services. She says, "Para-transit are so busy and are run by people that don't understand what it's like to have to wait hours on end sometimes up to 2 or more hours to be picked up or brought home. You call their dispatch to find out where the van is and you are told they're just around the corner. An hour later you call back and they are still around the corner. However, when they are early they have a time frame

and if you're not out there within their 3 minutes [time frame], they leave without you. And [they] also make you pay twice what a normal ride cost[s] for a no show fee."

A man in his 30s with a physical disability also describes this problem of a separate system. He wrote in his response about using the paratransit system, "I have a paratransit ADA card, but there [are] long travel times to work or shopping destinations. My work is located outside my local zone which requires long wait times at transfer stops. To go to work it could take me 2 hours plus to travel 9 miles and I have to call the day before to arrange this at 6:00 a.m."

Mik

Mik was sexually abused as a child, leading to severe post-traumatic stress syndrome. When Mik was 24, he was involved in a serious car accident that led to a traumatic brain injury and required him to drop out of college. As a result, Mik is extremely sensitive to loud noises and has been unable to find steady employment, take public transportation, or find adequate housing.

For the past 19 years, Mik has been homeless. He is unable to sleep in homeless shelters because they are unwilling to accommodate his aversion to loud noises. "People don't take me seriously when I ask for accommodations in the shelter environment," he said. "[Shelters] don't see the ADA as [providing] equal treatment, but special treatment."

Far from being unique, he said that many other individuals with physical and mental disabilities are being denied from homeless shelters that are unwilling to make accommodations. "Eventually [those of us with disabilities] don't waste any energy going to places that are the same old story."

Many respondents reported they use unreliable cars as their primary means for getting to work. A man with a psychiatric disability reported, "I would love to get a reliable car. It would give me access to more job opportunities and would make moving around the city easier. Because my primary income source is Social Security, I do not qualify for a loan without a co-signer. At my age, there are not a lot of people who are willing to co-sign a loan. Without a reliable vehicle, there are limited options that would allow me to increase my work to the level of self-support. If my current car were to die, I do not believe I would be able to keep my job." His situation illustrates how the lack of reliable transportation and the inability to save assets keeps an individual with disabilities in poverty.

The lack of transportation adds to the resource costs for people with disabilities. Because fixed route accessible transportation often does not go to the locations a person needs to go for medical appointments, treatments, assistive technology repairs, and other related services, respondents reported they frequently need to rely on taxi services or other disability specific transportation services. The reliance on these types of services often costs a full day, and there is often little or no flexibility in the scheduling for these services.

A woman in the South with an intellectual disability said, “Transportation is the biggest problem I’ve had. I don’t drive and have to depend on public transportation, cabs, or arranging rides with service providers. Public transportation is limited…and cabs are expensive. I can’t go everywhere I need to exactly when I would like because almost all transportation is provided by service providers and I have to work with their schedules.”

The lack of transportation contributes to isolation as well. A woman in a large Mid-Western city reported that because accessible buses cannot travel to the alley where her wheelchair lift allows her to exit the building, she cannot get transportation during the winter months when snow blocks the alleys. She cannot travel the distance to the street where the accessible bus can stop because her chair will not go through the snow. The bus cannot enter the alley where she leaves the building because of snow blocking the sides of the alley and potholes that put the low suspension of the accessible bus at risk. During 2014, she could not leave her apartment for three months and travel anywhere because of these barriers, which exacerbated her depression and caused her to lose her job.

Transportation for all individuals living in poverty remains a challenge to obtaining and retaining employment. However, because of the added needs of individuals with disabilities related to transportation, specifically accessibility for many different types of disabilities, including physical, psychiatric, intellectual, visual, and speech, lack of transportation by itself is a formidable barrier. Combined with inaccessible housing, and housing far from places of employment and far from transportation corridors, the lack of transportation causes individuals to, as one woman said, “Stop trying to be part of the workplace.”

Balancing Work and Benefits

"There is not a smooth transition to get off state and federal benefits"

In order to achieve a basic level of economic security, many respondents participate in or have previously participated in a variety of government programs. These programs provide services ranging from health insurance, income replacement, housing, and food assistance (see Table 1), but eligibility criteria for each program may differ creating a web of uncertainty for beneficiaries. Most of these programs are means tested; that is, in order to be eligible a person or family must have income or assets below a certain threshold, but significant confusion and conflict is created because requirements for programs vary in how much an individual can earn before losing eligibility or having their benefits reduced. For those people with disabilities who want to work, this presents a serious problem.

Rosecaron

Rosecaron is a 56-year-old widow with a psychiatric disability. She recently retired from a full-time job to work as a personal care attendant for her daughter, who has autism and epilepsy. She receives $21,000 per year in this role, and consequently is now ineligible for Medicaid, SNAP, energy assistance, and Section 8 housing.

"I probably lost money becoming a salaried employee," Rosecaron said. "This is the trap…Even if you get a minimum paying job, it won't be enough for medical care, housing, and other expenses."

Rosecaron has found it difficult to balance supporting her daughter while seeking gainful employment opportunities. Her daughter will soon be starting college at a culinary school in Florida that does not provide specialized supports for individuals with autism. She plans to move with her daughter and continue helping with her care and education, which will prevent her from finding another job.

As was demonstrated in the previous section, living with a disability can be extraordinarily expensive, adding financial and opportunity costs to the daily lives of those with disabilities in countless ways. For that reason, many individuals with disabilities who want to work need to find employment that provides them with enough financial resources, including health benefits, to meet the supports they need to be able to live and work in their communities. Otherwise, without outside support from family or friends, working full-time may result in individuals exceeding earnings limits and losing the supports they rely on.

The choices between services and supports and working are often confusing and place some individuals with disabilities in the position of foregoing work and higher wages in order to continue to receive benefits. As a result, given the sample of respondents, it is not surprising that many respondents express the fear that if they earn too much money they will no longer have

access to health care, housing, food, and, in some cases, the daily support services they need in order to get out of bed and care for themselves.

As a young woman from Tennessee with cerebral palsy put it, "IF someone with a disability does find work and they make 'too much,' they risk losing their disability benefits, which may make them worse off than before."

Respondents also emphasized that the earnings and asset thresholds to remain eligible for support programs are so low that if one does choose to work, it is impossible to replace the benefits one receives until one's income is many times above the earnings limit.

In some cases, the fears are not based on an accurate understanding of the risk, but instead result from a lack of clarity about the different eligibility criteria and requirements of separate benefit programs. However, in other cases, the programs truly lack needed flexibility. For instance, while Supplemental Security Insurance (SSI) provides direct cash benefits to eligible individuals, usually in the range of $700-$800 per month, the program also reduces benefits based on an individual's earnings. The program also only pays benefits to those with under $2,000 in assets.

In contrast, the program requirements of a different program, the Social Security Disability Insurance (SSDI) program, allows individuals to earn up to $1,070 per month or $12,840 per year ($1,800 per month or $21,600 per year for those who are blind) without losing eligibility. The SSDI program includes a number of important supports that are designed to encourage beneficiaries to try to work and, if possible, to work full-time.

In other cases, the fears and concerns expressed by the young woman from Tennessee are not based the lack of clarity of program eligibility requirements but on the loss of services.

More critical to many are the supports provided through Medicaid. For example, a young man in Illinois illustrated this concern. He uses personal care attendants for bathing, eating, transferring from his wheelchair to bed, and accomplishing related household chores. Without his personal care attendants, he cannot live independently. Although he wants to work, he will lose his personal assistants as a result of no longer being eligible for Medicaid if he obtains a job where he earns over $21,000 a year. At a salary of $21,000, he would be unable to pay for personal care attendant services, which can cost from $20,000 to $60,000 a year depending upon the amount of time needed for individualized support. In this case, this young man is forced to keep his income below $21,000 per year in order to retain his personal care services.

A man from Ohio explained the situation like this: "Once a person with a disability starts to make a decent income and accrue assets, they are cut off Medicaid, which is their life-line to Home and Community Based Services (HCBS), as attendant [services] are for me, as I need total

assistance with bathing, toileting, dressing, eating, etc. I didn't mind giving up SSI [income payments] for a decent income or to marry my wife, but losing HBCS through Medicaid has put us in hardship now."

As this respondent reports, the services that allow a person with a disability to be independent, live in their own home, and work, are often linked to income replacement benefits. That is, individuals eligible to receive SSI are also eligible for Medicaid. Recipients of SSDI also can be beneficiaries of Medicare after a two-year waiting period. Access to the services provided under Medicare and Medicaid are particularly important to many people with disabilities as these programs allow individuals to receive daily support services that help them with a range of activities from getting out of bed in the morning, to bathing, and getting to work.

Another respondent told a similar story about being underemployed and working fewer hours than he would prefer in order to keep his earning under the limit. He estimated that in order to replace the services of his personal care attendants and remain independent, he would need to earn at least $80,000 a year.

A young woman from California emphasized how disheartening the concern about losing benefits can be, as well as how it impedes personal progress and economic improvement. She stated, "Many individuals with disabilities are discouraged in their efforts to actively seek employment. The cycle of lack of work experience impedes the likelihood of a higher paying position and the fear of the loss of benefits is further perpetuated."

The fear of losing benefits in order to be independent can also have significant psychological effects. Many of the respondents mentioned experiencing depression as a result of feeling they were in a "Catch 22" when it came to making a decision about working or remaining eligible for benefits. One woman said, "[Y]ou cannot try to elevate yourself. If you try then you risk losing services. With SSI (Supplemental Security Income) you would have to start the application all over again. Mine took 6-7 years! I will never go through that again ever."

It is clear from the responses of those people with disabilities who completed the questionnaire that they believe if they earn too much money during a given month or if they save too much money they will lose their income replacement benefits, as well as their daily support services. Based on these fears, some individuals with disabilities chose to work fewer hours, work for lower pay, or not work at all, which increased the likelihood they will be living in poverty.

The Inability to Accrue Assets and Savings:
"Unfortunately, unlike everyone else, I am not allowed to save for my retirement or I lose the benefit that is most important to me—the personal care attendant who makes sure I can get out of bed and into my wheelchair to get to work!"

In a similar vein, a more specific concern of the respondents and interviewees was the inability to save for the future. The vast majority reported that saving for the future or having a "rainy day fund" was both impossible and would also make them ineligible for certain benefit programs like SSI (and as a result Medicaid).

Many of the respondents stated that they lived so far below the poverty level that they had no way of saving money. One respondent from Florida said, "We…barely make it from pay check to pay check," while another from Arkansas said, "There is never enough money…I can't even make ends meet for the basics."

As previously discussed, some federal benefit programs place caps on the amount of assets an individual may own in order to remain eligible for benefits. For instance, Supplemental Security Income (SSI), restricts eligibility to those who have no more than $2,000 in assets, while not considering a beneficiary's home, car, and household goods. This means that a person cannot have a savings account, a checking account, or other types of financial assets greater than $2,000. This prevents individuals from accruing resources for future expenses such as education, starting a business, or for emergency situations. The

Cheryl

Cheryl is a 54-year-old woman with cerebral palsy and diabetes living in San Jose, CA. She has a master's degree and previously worked as a social worker in Michigan and California, but is currently unemployed. She volunteers 40 hours a week while looking for a job, because she doesn't want to "just sit at home."

Cheryl's disability is costly, as she must pay for support personnel, paratransit services, adaptive shower equipment, medical supplies, and a motorized wheelchair, battery and parts that "cost the same as a small car." To offset these costs, she receives SSI, SSDI, Medicare, Medicaid, Unemployment Insurance, and Section 8 housing. Without government supports, Cheryl believes that she would probably be in a nursing home: "There is no way I could support myself [without it]."

To maintain eligibility for many of these benefits, Cheryl must remain under the $2,000 asset limit. After losing her job, Cheryl liquidated and sold her 401k account, which subjected her to a penalty for early withdrawal. "I contributed with a bunch of able-bodied people for a number of years and then had to choose to be at the poverty level to get the help I need," she said.

The eligibility requirements prevent her from saving enough to move off of benefits. "[People] say you could have it so easy [receiving benefits], but we don't want to have it easy. We want to work like everyone else."

ability to save money for these, and other expenses, is a staple of what it means to achieve economic self-sufficiency. Many respondents receiving SSI need access to daily support services through Medicaid. Unfortunately, if they accumulated assets they could lose those vital support services.

Without the ability for individuals to accrue assets, the capacity to move out of poverty and into the middle class is greatly limited. Almost ten years ago, Ball and her colleagues stated that benefits programs such as SSDI, SSI, TANF, and Medicaid "may be helpful in the short term but are insufficient means to address disability issues over the long term."[20] What is needed are strategies to allow people with disabilities to accrue assets in order to go to college without accumulating further debt, save to start a small business, invest in partnerships, and purchase a home. These are the traditional, time-honored paths to the middle class. Without the ability to save and with the threat of losing one's personal support services if one does save money, people with disabilities are trapped. With the ability to save assets, people with disabilities will be able to "exert greater control over their lives and expand their capacity to take advantage of the diverse opportunities afforded by American society".[21]

Respondents' comments on two issues were pervasive. A respondent from Alaska said, "I have no nest egg. SS (Social Security) and Medicaid only allow a person to have $2,000! If I accumulate more than that…I could lose my benefits!" A respondent from Delaware expanded on this limitation. He said, "I can't save any money for the future or I will lose the benefits I have."

When asked about the ability to save money, one interviewee said, "The requirements of SSI make it difficult to save money, such as for medical emergencies, internship experiences, or purchasing expensive equipment." She went on to say that the cap on assets stops her from participating in certain educational experiences, like paid internships, that would provide her with contacts and opportunities that would better position her for more advanced employment.

Finally, a Colorado respondent summed up this theme by making a statement that, while not completely accurate, expressed the frustration felt by many people with disabilities: "[I]t seems to me that pwd [people with disabilities] are the ONLY group now singled out as unable to have assets of ANY kind."

[20] http://www.dsq-sds.org/article/view/652/829
[21] Hearing on Building Assets for Low-Income Families, Boshara and Cramer http://www.finance.senate.gov/imo/media/doc/rbtest042805.pdf

Bureaucratic Barriers:
"The benefit system is stacked against us."

In addition to fearing the loss of their benefits, respondents reported frustration in working with the various agencies and organizations responsible for administering those benefits. Initial application processes; wait times to receive benefits; changes in economic, geographic, and family form status; and general unresponsiveness of personnel and programs caused not only limitations on the ability to raise out of poverty but, in some cases, respondents indicated that these barriers pushed them back into poverty. They also reported that the barriers adversely affected aspects of their lives, from employment, to preventative health care, to access to devices that would allow them to live independently.

Some respondents told stories of program representatives that gave them advice that was irresponsible and detrimental to their well-being. A young man with autism reported that a Medicaid representative "told me I needed to get someone pregnant first to qualify. When I came back to Houston I knew I qualified as a disabled person and I applied as such, and received a rejection for not being over 65. They had altered my application as though I had applied as a senior. When I told them I had the original application and asked where they'd like me to fax it they told me it wasn't necessary, but I had applied at the wrong HHSC office,

Becky

Becky is a 35 year-old woman with a psychiatric disability. She has a bachelor's and a master's degrees, and previously worked as a data analyst, research assistant, and teacher. After a psychotic episode in 2010, Becky was briefly incarcerated for a non-violent offense. Now with a criminal record, Becky has been unable to find full-time work and requires government supports. She intends to use benefits to facilitate her rehabilitation and return to a career. "I have no plans to collect benefits for the rest of my life, or even for the next five years."

Becky reports that it is difficult for her to navigate the government bureaucracy to obtain benefits. "It's a survival skill that takes a lot of time and energy," she said. While she believes that some government employees are helpful, there are also a lot of "burnt-out case workers, who do the bare minimum."

For example, Becky once went to a job search program, but was denied for not having the proper documentation. "After returning home to collect the missing documents and returning, I was still told I didn't qualify because the requirements . . . posted online weren't the full requirements," she said. "There's just a lack of information."

Becky also reports that employees at the state vocational rehabilitation underestimate her potential, despite her advanced education. "[They] sometimes treat me delicately, as if I'm illiterate. They'll talk slow to me," she said. "It's a turnoff to services [and] can mess with your head."

and I needed to go across town. I did, but I never received a response.

For some supports that are essential and seemingly straightforward, respondents reported multiple steps and program contacts in order to receive benefits, sometimes resulting in not actually receiving the benefits despite being eligible. A young woman with a psychiatric disability with income below the poverty level was refused a covered medication needed to treat her resistant depression. The medication would have made it more likely for her to be able to leave her home, apply for jobs, and become more independent. As she reports, "[m]y clinician requested prior authorization and it was denied. I had to look up a similar medication on the internet by myself and ask my doctor to help me apply for a patient assistance program (Johnson & Johnson) to cover the medication. I also had to apply for a prescription savings card for a reduction in my medication while I was waiting to get approved from Johnson & Johnson. I had to do all of this advocacy on my own. I literally cannot function without my medication even for a day. My symptoms will return without my medication and Medicaid would not cover it."

Some respondents reported changes to their eligibility that were not explained or about which they were not given notice. A young woman with cerebral palsy was switched from one state Medicaid waiver program to another without notification and without an explanation. "I was told that I would be…transitioned to a waiver that would not provide me with the staffing in my home or the job coaching I needed. I was told I would just have to move home with family. My parents are aging and this was not possible. I choose to live as an independent person. Just like any other woman my age. I had to get help from the ACLU in order to get the…waiver I needed to ensure staffing for all of my daily care needs, as well as to keep my job coach."

Many respondents reported difficulty with programs designed to help them prepare for and gain employment. A blind man in his 40s reported being "more than dissatisfied with the State agency in terms of the vocational program." He described, suffering through an unsupportive process of job support and job searching over the last five years. "I have been "told" about only a couple of possible places of employment. These "leads" involved being given the internet addresses of the businesses. I had already obtained these websites on my own as the companies are among the largest employers in the local area and a natural place for anyone seeking employment to look. I also was given the website address of a company that is located over three hours from my home…In my opinion, that is not vocational services…I do not expect vocational counselors to 'get me a job.' I do expect though vocational counselors to provide more than a few websites over a five year period of time."

Respondents also reported what they considered unreasonable requirements to receive support services and a lack of knowledge about accommodations for people with disabilities. A young man with autism in the Southwest stated he had applied for SNAP benefits. As he stated, "the law require[d] 40 job search hours per week, but transportation did not count, neither did time on

the phone, and neither did Internet time unless it was at the Workforce Solutions office. I wasn't able to meet these requirements because of transportation and other issues and would repeatedly lose food stamps after a week and have to reapply. When I asked for assistance and said I needed a reasonable accommodation—among other things, not knowing how to make a resume, I was told they had ramps (which I don't need)."

Some respondents recognized that it was not necessarily the fault of the representatives of these programs that caused problems, but the lack of adequate funding for necessary services. A middle-aged man with autism in the Pacific Northwest said, "The existing support systems are simply overwhelmed. The need is far greater than the available resources. The focus in my region is on mental health & substance abuse recovery, not dealing with developmental disabilities…I have experienced first-hand how little is known about helping individuals with developmental disabilities. Most of us are in mental health systems that often admit they have had little or no training in working with people like me."

A report issued in July 2013, *Separate and Unequal: States Fail to Fulfill the Community Living Promise of the Americans with Disabilities Act*[22], corroborates the lack of funding and infrastructure in many states.

Whether it is the interpersonal actions of program representatives or the regulatory and procedural requirements of benefits programs, the challenges of navigating program applications and updates results in individuals becoming frustrated and sometimes opting out of benefits for which they are eligible. At other times, respondents reported they needed to "plan for every detail and every possible contingency when I go to talk to my benefits counselor; it takes a full day to adjust anything and that is a full day I could be working." As one respondent from Maryland reported, "the stress of maneuvering through the systems to obtain services and items can be too much for some and lead some to give up."

[22] http://www.help.senate.gov/imo/media/doc/Olmstead%20Report%20July%2020131.pdf

Difficulties Finding Accommodating Workplaces and Overcoming Employment Discrimination, Persistently Low Expectations, and Discriminatory Pay

"People don't want to hire you because of the accommodations you need."

Frank

Frank is a single father with schizophrenia and an unrelated traumatic brain injury. Throughout life, he said, "people made fun of the way I talk" because of his disabilities. He left high school after being constantly bullied for his speech, but was able to get his G.E.D. four years later. He currently works as a utility person at a local Golden Corral, earning $7.25 per hour.

Frank reports that his disability has made it difficult to remain steadily employed. "Not many people want to give you chances once they find out you're on medicine or something is wrong with you." Frank said. "They think that if you have a disability they'll have to spend more time and energy on you."

Once employed, Frank said that further discrimination often occurs from peers that make comments about him, his speech, and his inability to quickly complete tasks. These conflicts make it difficult for him to get along well with others at work. "They say there's equal opportunity [in the workplace]," Frank said. "But there's really not if you have a disability."

Frank obtains financial support from a variety of government programs. He also receives transportation, counseling, and job training from a non-profit organization. Without these support services, he said, "I would probably be homeless." Frank has tried to obtain help from the state vocational rehabilitation agency, but has found that many of the job placement opportunities require physical labor and are not well-suited for some individuals with disabilities.

Despite significant efforts to educate the general public about disability issues and to change public attitudes toward people with disabilities dating as far back as the 1970s, attitudes and behaviors toward those with disabilities often remain paternalistic and lack the understanding that people with disabilities want to be contributing members of society. Persistently low expectations and lack of opportunity remain some of the greatest barriers to economic self-sufficiency and full participation in society.

These biases were communicated in almost all of the responses to the questionnaires and in the interviews conducted by staff. A young woman in the South with cerebral palsy stated the problem plainly: "People with disabilities have trouble finding employment due to enduring stigma and misconceptions about the cost of workplace accommodations."

Some of the respondents told about outright prejudice regarding their disabilities. A young man with autism learned that revealing his disability would often cause more problems for him rather than allow him to work with his supervisors to develop accommodations. When describing disclosing his autism to his manager he said, " I once disclosed to a manager confidentially because I thought it would make things easier, only to have her tell the rest of the management team and have them 'very concerned' about it. This was the one job I had a union rep, and he told them it had nothing to do

with my job and that was not something she was supposed to go around telling everyone, not that that did much at that point. I did get the message to stop telling people."

An older woman with physical disabilities emphasized that many employers do not look at people with disabilities as individual employees. She said, there is "[n]ot enough trust in our skills by private sector, because they lump us as a group and do not look at us as individuals capable of doing the jobs they require or [are] unwilling to accommodate us so we can. [There are] many misconceptions about people who use wheelchairs, have aphasia, or joint and mobility issues. They assume we have…poor cognitive functioning or intellectual disabilities just because we use wheelchairs or think none of us in wheelchairs can hear, so they scream at us."

Respondents repeatedly reported interviews that were cut short once a potential employer discovered the individual had a disability. One middle-aged man with autism said, "I have had more 15-minute interviews than I can count with people who were impressed with my credentials on paper but were crestfallen to find they belonged to me. Most recently, I failed in a group interview process even though the director personally recruited me."

A woman with a psychiatric disability in her 40s confirmed the difficulty of disclosing to employers. "Once I was told I would never work again due to a psychiatric disability. I don't know which was worse, hearing that awful ugly lie or believing it. People expect the worst of persons with mental health conditions. It is impossible to disclose to a potential employer a need for a reasonable accommodation without revealing that one also lives with a mental health condition. Yet, to do so almost inevitably means we will not get the job."

Some of the respondents emphasized that those who are sympathetic are not necessarily helpful. A woman in her mid-30s with cerebral palsy said, "There are some who have the attitude of "bless your heart", but those same people don't see the capabilities—only the disabilities."

Respondents reported that this attitude of sympathy carries over into what employers expect of people with disabilities. A young woman who is blind said, "Often, society places low expectations on individuals with disabilities; students with disabilities are not being challenged and presented with the same high expectations and opportunities as their able body peers. As a result, when many enter the workforce, they often lack the necessary qualifications and work experience employers look for. The employer is already skeptical about people with disabilities abilities to be productive and perform efficiently, the lack of experience further solidify their doubt."

Many of the respondents highlighted the need for more knowledgeable employers who could provide reasonable accommodations. A woman in her mid-30s with a psychiatric disability reported that she had no problem finding work, but that the environment of the workplace would

sometime trigger her psychiatric illness. In her words, it was "almost impossible to sustain employment having no supports for my disability. The limitations of my illness make it difficult for me to work in situations in which I am micromanaged. I also appreciate feedback and in jobs where there is little, it has exacerbated my anxiety. With treatment and a deeper understanding of my disability, I have become able to overcome these difficulties in volunteer settings (as training and preparation for paid work)."

A young woman with autism also highlighted the lack of understanding regarding accommodations and prejudice for those who request accommodations. She said, "[If you] need an accommodation like working in a quiet corner with less bright lighting…you're almost guaranteed to not get hired. Skills and abilities take a backseat to fitting in the corporate culture. What is needed isn't more legislation. What we need is education. Employers need to know that basic accommodations aren't that much of a burden, and workers with developmental disabilities need to learn to ask for what we really need in accommodations. But that's not happening. And we're not getting hired. No matter how good we are."

Regarding the attitude of employers, a woman with Down syndrome in her early 40s from Iowa summed up the situation: "I think that employers are just not interested in taking a chance, and they find excuses not to hire us. They are afraid they will get stuck in a difficult situation, but I always hear that many research studies have shown that people with disabilities make real good employees. The situation is very frustrating!"

Conclusions and Recommendations:

"The 'system'…makes a person choose among basic needs for survival such as …groceries or [to] pay for medication."

The passage of the Americans with Disabilities Act in 1990 and its amendments in 2008 have resulted in a society that is vastly more open to people with disabilities than it was a quarter century ago. Combined with the Individuals with Disabilities Education Act and the Rehabilitation Act Amendments of 1973, the ADA and the ADA Amendments have provided the United States with the most advanced disability policies in the world. Our policies and their implementation have been the foundation for disability policy for such places as the European Union, Ghana, Croatia, Ireland, and even the United Nations.

Our country has changed, and the inclusion of people with disabilities is measurably better than when these laws were passed. Yet people with disabilities continue to experience disproportionate levels of poverty and unemployment. To fully realize the vision of the ADA, we must provide the same economic and employment supports for people with disabilities that we have provided for physical access in order to create the opportunities for economic self-sufficiency.

The over 400 people with disabilities who responded to the Committee's questionnaire have provided insight into the daily lives of those with disabilities who live in the shadow of poverty. They are individuals with disabilities who want to work and want to be part of the economic mainstream. Their stories have shed light on six major factors that limit their ability to gain employment and contribute to a disproportionate number living in poverty.

The path to economic self-sufficiency starts with the ability of people with disabilities who want to work having an environment that enabled them to work. Quite simply, a job is the best way for a person with a disability, or any person, to earn a living, provide for their family, and enter the middle class. For that reason, to fully realize the vision of the ADA, we, as a nation, must recommit to breaking down the remaining barriers that continue to limit work opportunities for Americans with disabilities.

Addressing Cultural Biases and Prejudices

Breaking down those barriers begins by addressing the deep-seeded cultural biases and prejudices that too many hold when it comes to people with disabilities. These beliefs include the paternal attitude that people with disabilities need to be cared for and they are unskilled and lack intelligence. To address the beliefs that people with disabilities are not competent, cannot work, or are destined to be recipients of charity, we need a nationwide effort to communicate the

competency and value of people with disabilities and their desire to be part of the American workforce.

It is clear from the stories and comments of people with disabilities questioned for this report that prejudice, low expectations, and paternalism continue to limit opportunities to work and participate in the economy. The general public, workers in programs designed to support people with disabilities, and employers and potential colleagues without disabilities all need to be aware of the skills, knowledge, and abilities of people with disabilities. This effort must be informed by successes we have seen in companies such as Walgreens, IBM, Marriott, and many others, to actively recruit and support employees with disabilities. Individuals with disabilities must be treated with the respect and the same high expectations we afford those without disabilities.

Ensure Support Programs that Allow for Transition to the Middle Class

In addition to countering these insidious cultural beliefs, the respondents in this investigation communicated that basic policies designed to support people with disabilities often may limit the

The Workforce Innovation and Opportunity Act (P.L. 113-128)

On July 22, 2014, President Obama signed into law the Workforce Innovation and Opportunity Act (WIOA), passed by the Senate HELP Committee under the leadership of Sens. Murray and Isakson and ranking member Alexander and Chairman Harkin.

Title IV of WIOA is the reauthorization of the Rehabilitation Act, and it makes a number of significant changes focused on increasing opportunities for competitive, integrated employment for people with disabilities.

This reauthorization recognizes the underrepresentation of people with disabilities in the workforce and puts in place programs and requirements to increase opportunities for education, training, and experience in order to expand the employment of people with disabilities.

Young people with disabilities will now be eligible to receive pre-employment transition services beginning while they are still in school, arranged or provided by state vocational rehabilitation programs in coordination with their IDEA services. These services will ensure youth receive the skills necessary to interview for jobs, present their skills and experiences to prospective employers, and have knowledge and skills that can be used in competitive, integrated workplace settings. Young people will have the opportunity to participate in internships, practica, and part-time and summer jobs that will give them the experience to be ready for work.

Vocational rehabilitation programs provided by the states are required to accept applications from all individuals with disabilities and to work with them to find competitive integrated employment. In addition to the supports described above, people with disabilities may work with a job coach to help them learn their job and may receive support to go to post-secondary education in order to gain the skills necessary for a job. All of these efforts are designed to meet the goal of the ADA to provide people with disabilities with the opportunity to be economically self-sufficient.

ability of some to earn a wage and advance to the American middle class. Policies that limit supports to only those with almost no assets, remove basic daily support services because a person is being successful at learning a living, and create complicated bureaucratic procedures to secure and retain support services must be reformed without harming those Americans who rely on these programs to meet their basic needs. Nor must be accept the false choice that our nation does not have the resources to provide the necessary supports to people with disabilities so that they may work. Through creative and smart public policy we can ensure that all American with disabilities who want to work are able to do so without losing the critical supports they rely on to become full members of society.

Simplify and Clarify Procedures for Applying and Reapplying for Supports

Similarly, respondents to the HELP Committee questionnaire also repeatedly spoke of the bureaucratic barriers associated with the existing system of support that currently exist for persons with disabilities, and of the variability in quality between workers who staff those programs and supports. Based on this, it is clear that we must strengthen efforts to communicate clearly and simply to people with disabilities about support programs, their requirements, and their limitations so that they can make informed decisions about participating in those programs and earning a living. In addition, training for support staff, across programs, is necessary to ensure people with disabilities are receiving both accurate and comprehensive information about the services and supports available to them and the requirements to receive those supports.

Increase the Availability of Accessible Housing and Transportation

The respondents also repeatedly raised the issue of wrap-around supports; services that are important to living but are not directly related to working. The two most often mentioned were housing and transportation. Many of the respondents mentioned the severe lack of accessible, affordable housing that would support their efforts to work and care for their families. As for transportation, it was mentioned more than any other wrap-around service as the key to ensuring workplace participation. Without accessible, reliable transportation, numerous respondents told stories of being late for work, having pay docked, and losing their jobs. Great strides have been made in accessible residencies and bus and light-rail service, but more needs to be done. We must reinvigorate our national housing and transportation policies to ensure that people with disabilities can live in affordable, accessible housing that allows them to commute to work using reliable and accessible transportation. Only then will those with disabilities have the same opportunities to join the middle class as those without disabilities.

Ensure Access to High Quality Education with High Expectations for Students with Disabilities

Finally, as with all American citizens, those with disabilities must have access to the opportunity to benefit from high quality education. Since 1975, the United States has made a commitment to educate *all* of its children and to provide them with access to education that will allow them to be

successful in work and their communities. But respondents in this investigation reported receiving education that was limited in its content and of school personnel who did not expect them to graduate, let alone go on to post-secondary education. Despite almost 40 years of education for all children with disabilities, those participating in this study reported that access to the general and advanced curriculum was often limited. We must have a concerted, multi-sectorial effort to prepare young people with disabilities for competitive, integrated employment and to provide them with the educational opportunities that will allow them to fulfill their potential.

Conclusion

Our nation has made great advances for people with disabilities over the past 40 years. The ADA has made vast portions of America accessible to people with disabilities. Government services and supports are now widely available, including such basic activities of democracy as voting. But the successes of the past should not make us blind to the barriers that remain. Individuals with disabilities disproportionately live in poverty and, as reported in previous HELP Committee reports[23], they experience higher unemployment, lower wages, and significantly less participation in the workforce than other subgroups.

We can do better, and we must do better. The true judgment of the success of the ADA and other federal disability rights laws will be when every person with a disability has the opportunity to not only imagine the American dream, but to actually live it as a member of the middle class. We are not there yet; let's work to fulfill the dream for all Americans.

[23] *Unfinished Business: Making Employment of People with Disabilities a National Priority. (July 2012).* http://www.harkin.senate.gov/documents/pdf/500469b49b364.pdf

Appendix A: Questionnaire

HELP Committee Majority Staff Questionnaire on Disability and Poverty

1. Please provide the following information.
   Age;
   Gender:
   Race/Ethnicity:
   City and State where you live:
   Type of disability(ies):
   Marital status:
   Number of children:
   Educational history:

2. Do you currently receive or have you ever received any of the following (yes/no)?

   Medicaid
   Medicare
   Supplemental Security Income (SSI)
   Social Security Disability Income (SSDI)
   Unemployment Insurance (UI)
   Supplemental Nutrition Assistance Program (SNAP)
   Temporary Assistance for Needy Families (TANF)
   Pell Grants or other government student loans

3. Do you have a job? If yes, what is your job and how much are you paid? List any other jobs you've had in the past and how much you were paid.

4. Describe your experiences in getting and keeping a job. In particular, describe any difficulties you have had getting or keeping a job.

5. Have you been able to save money for the future? How have you been able to do this and what have the challenges been?

6. Tell us about any challenges you have faced related to education, health care, housing, and transportation.

7. Why do you think so many people with disabilities have difficulty transitioning out of poverty? Describe any difficulties you have encountered.

8. Are you willing to identify yourself and participate in a congressional hearing?

Appendix B: Methodology

To better understand the economic challenges facing people with disabilities, the HELP Committee staff developed a questionnaire that was distributed to 14 national disability organizations. These organizations then distributed the questionnaire to persons with disabilities living in poverty or who have lived in poverty in the past. These organizations included The Arc of the United States, the National Council for Independent Living, the Association of University Centers on Disabilities, the National Association of Councils on Developmental Disabilities, and Easter Seals. (For a full list of the organizations distributing the questionnaire, see Appendix C). Over 400 responses were received by the Committee over an eight-week period from mid-June to mid-August 2014. After reviewing the data and removing those that were completed by providers and parents of children with disabilities, the Committee analyzed 412 of the responses.

The demographic and quantitative questionnaire responses were analyzed and summarized. (See Appendix D for these summaries.) The open-ended responses were reviewed in order to identify common themes from the respondents' answers.

From the questionnaire respondents, Committee staff selected a subset of 22 individuals for a more in-depth interviews. In order to obtain diverse responses to the interview questions, staff identified these potential interviewees based on disability type (e.g., sensory, physical, psychiatric, and intellectual), geographic location, age, race, and gender. Of the 22 potential interviewees a total of 14 interviews were completed. (See Appendix E for a summary of the background of the interviewees). Notes were recorded during these interviews and were used to illustrate the themes identified from the questionnaire responses.

It is important to note that a review of this nature is anecdotal, and the findings cannot be generalized to all individuals with disabilities who live at the poverty level. Moreover, the opinions expressed by the questionnaire respondents and interviewees should not be treated as confirmed facts, especially with regard to the requirements of and participation in specific benefits programs. However, information from the respondents provides an important perspective on the hurdles encountered by individuals with disabilities as they try to achieve economic stability.

Appendix C: Disability Groups Distributing the Questionnaire

The Arc of the United States

American Association on Intellectual and Developmental Disabilities (AAIDD)

American Association of People with Disabilities (AAPD)

Association of People Supporting Employment First (APSE)

Autistic Self Advocacy Network (ASAN)

Association of University Centers on Disabilities (AUCD)

Disability Rights and Education Defense Fund (DREDF)

Easter Seals

National Association of Councils on Developmental Disabilities (NACDD)

National Council for Independent Living (NCIL)

National Disability Rights Network (NDRN)

National Down Syndrome Society (NDSS)

National Federation of the Blind (NFB)

TASH

Appendix D: Respondents' Backgrounds

The questionnaire included a demographics section, which asked respondents to describe their backgrounds. The group of 412 respondents showed great diversity. Almost 60 percent of the respondents were female. The median age was 43 years with two thirds of the respondents between the ages of 29 and 57. Non-white respondents accounted for over 20 percent with the largest group being African-Americans. Almost 70 percent of the respondents were single, and just over 21 percent were married. Thirty percent of the respondents were parents.

The education level of the respondents was bimodal. Just over 40 percent had a high school degree. This is comparable to 41.6 percent of the general population that has a high school degree or less.[24] At the other end of the education continuum, 36 percent of the respondents had a four-year college degree or an advanced degree. This is higher by over four percentage points than the general population in which 31.7 percent have a four-year degree or greater[25].

Respondents' types of disability varied greatly. Over 23 percent of the respondents reported having a mobility disability. Almost 16 percent reported having an intellectual disability. Over 15 percent reported having a psychiatric disability. Other types of disabilities included autism (12.3 percent), chronic health conditions (8.1 percent) and brain injuries (5.0 percent).

Remembering the agencies were asked to distribute the questionnaire to individuals with disabilities who were living in poverty or at some point in their lives had lived in poverty, it is expected this group would be different from the general U.S. population. That expectation was borne out in a higher percentage of female respondents, respondents more likely to be single, and respondents who were far less likely to have children than the general population. There was also a heavy representation of specific disabilities in the group. Two thirds of the respondents identified as having physical, intellectual, psychiatric disabilities, or autism. In terms of educational, however, the respondents did reflect a similar profile to the general population.

Some of the demographic characteristics of the respondents are most likely due to the directions given to the agencies to distribute the questionnaire to individuals who had or still live in poverty. Further, women and those with specific disabilities such as intellectual and psychiatric disabilities, are more likely to be poor than men and individuals with other types of disabilities. For a full breakdown of the demographic characteristics of the respondents, see Appendix E.

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[24] U.S. Census Bureau. (2013). *Current Population Survey, 2013 Annual Social and Economic Supplement: Educational Attainment of the Population 18 Years and Over, by Age, Sex, Race, and Hispanic Origin* [Data file]. Available from https://www.census.gov/hhes/socdemo/education/data/cps/2013/tables.html

[25] Ibid.

Appendix E: Respondent Demographics

Table 1: Gender of Questionnaire Respondents

Gender (N=406)	Male	Female	Transgender
Number	161	242	3
Percentage	39.7%	59.6%	0.7%

Table 2: Age of Questionnaire Respondents

Age (N=401)	Mean	Youngest	Oldest	Standard Deviation
	43.2	17	79	14.4

Table 3: Racial/Ethnic Background of Questionnaire Respondents

Race/Ethnicity (N=402)	Number	Percentage
African-American	46	11.4%
Asian-American	4	1.0%
Caucasian	325	80.9%
Hispanic	9	2.2%
Mixed Race	13	3.2%
Native American	5	1.2%

Table 4: Marital Status of Questionnaire Respondents

Marital Status (N=403)	Number	Percentage
Single	281	69.7%
Married	86	21.3%
Divorced	25	6.2%
Widowed	11	2.7%

Table 5: Number of Children of Questionnaire Respondents

Number of Children (N=408)	Number	Percentage
None	277	67.9%
One	41	10.1%
Two or more	90	22.0%

Table 6: Education Level of Questionnaire Respondents

Education Level (N=382)	Number	Percentage
Less than High School	20	5.2%
High School or GED	136	35.6%
Some College	64	16.8%
Associates Degree	11	2.9%
Vocational/Technical Certificate	11	2.9%
Four-year degree	75	19.6%
Advanced degree	65	17.0%

Table 7: Geographic Region of Residency of Questionnaire Respondents

Geographic Region of Residency (N=391)	Number	Percentage
Northeast	108	27.6%
South	58	14.8%
Mid-west	159	40.7%
Mountain/Southwest	22	5.6%
Pacific	44	11.3%

Table 8: Self-Identified Primary Disability of Questionnaire Respondents

Disability (N=397)	Number	Percentage
Autism	49	12.3%
Brain Injury	20	5.0%
Blind	18	4.5%
Deaf/Hard of Hearing	14	3.5%
Intellectual Disability	63	15.9%
Learning Disability	32	8.1%
Chronic Health Condition	32	8.1%
Physical/Mobility Disability	93	23.4%
Psychiatric Disability	62	15.6%
Speech-Language Disability	1	0.3%
Non-specific Disability	13	3.3%

Appendix F: Participation in Government Support Programs

To better understand the level of assistance respondents received, they were asked their history of participating in any of eight federal support programs. Because all respondents currently or had experienced poverty, the participation rates are higher than the general population.

As expected, the respondents reported participating in disability specific programs at a much higher rate than the general population. For instance, 42.5 percent reported currently or in the past having participated in the SSDI program, a wage insurance program for those who have worked and become disabled. For general support programs, such as SNAP, the reported rate of participation was relatively higher than the general population indicating the greater level of poverty among people with disabilities.

Table 1: Government Support Program Participation of Questionnaire Respondents.

Program	Respondents	U.S. Population
Medicare (N=338)	52.7%	3.48%[26]
Medicaid (N=347)	64.8%	21.9%[27]
SSI (N=336)	49.7%	2.6%[28]
SSDI (N=334)	42.5%	3.8%[29]
Section 8 Housing (N=343)	18.4%	1.7%[30]
Unemployment (N=154)	13.0%	5.9% (18+)[31]
SNAP (N=345)	41.2%	14.5%[32]
TANF (N=344)	6.7%	1.1%[33]

[26] Centers for Medicare and Medicaid Services. (2014, March 27). *Medicare Enrollment Charts: Medicare Enrollment - Disabled Beneficiaries: as of July, 2012* [Data file]. Reflects (Disabled beneficiaries 0-64). Available from http://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/MedicareEnrpts/index.html?redirect=/medicareenrpts/

[27] Centers for Medicare and Medicaid Services. (2014). *Medicare and Medicaid Statistical Supplement, Table 13.4-Number of Medicaid Persons Served (Beneficiaries), by Eligibility Group: Fiscal Years 1975-2011* [Data file]. Retrieved from http://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/MedicareMedicaidStatSupp/Downloads/2013_Section13.pdf#table13.4

[28] United States Social Security Administration. (2014, February). *Annual Statistical Supplement to the Social Security Bulletin, 2013*. (SSA Publication No. 13-11700). Retrieved from http://www.ssa.gov/policy/docs/statcomps/supplement/2013/supplement13.pdf

[29] Social Security Administration, 2014; includes spouses/children of disabled workers receiving benefits)

[30] United States Department of Housing and Urban Development. (2014). *Picture of Subsidized Households: Housing Choice Vouchers* (2013 Based on 2010 Census Numbers) [Data file]. Available from http://www.huduser.org/portal/datasets/picture/yearlydata.html

[31] United States Department of Labor. (2014, August 28). *Unemployment Insurance Data: Latest Statistics*. Retrieved from https://workforcesecurity.doleta.gov/unemploy/data.asp

[32] United States Department of Agriculture, Food and Nutrition Service. (2014, July). *July Keydata Report (May 2014 data)* [Data file]. Retrieved from http://www.fns.usda.gov/sites/default/files/datastatistics/Keydata%20May%202014%20%288-8-2014%29.pdf

Appendix G: Background of Respondents Interviewed

#	Age	Gender	Race	Disability	Location
1	22	Female	Chinese American	Visual impairment	West Coast
2	49	Male	white	Autism	West Coast
3	54	Female	white	Cerebral Palsy	West Coast
4	66	Male	white	Spinal cord injury—quadriplegia	Midwest
5	60	Female	Not reported	Autism and an orthopedic disability	Midwest
6	56	Female	white	Chronic mental health disorder	Midwest
7	35	Female	African American	Schizoaffective Disorder	Midwest
8	49	Female	Hispanic	ADHD, Anxiety disorder, diabetic	South
9	27	Male	white	Cerebral Palsy, spastic quadriplegic	Midwest
10	50	Female	white	Intellectual disability	Southwest
11	32	Female	African American and American Indian	Familial spastic diplegia	Midwest
12	49	Female	white	Autism	West Coast
13	38	Male	African American	Schizophrenia	South
14	56	transgender	mixed	Traumatic brain injury, PTSD	Mountain

[33] U.S. Department of Health & Human Services, Administration for Children and Families, Office of Family Assistance. (2014, July 31). *TANF Caseload Data 2014: Total Recipients* [Data file]. Available from http://www.acf.hhs.gov/programs/ofa/resource/caseload-data-2014