

Testimony
United States Senate Committee on Finance
"Barriers to Work for Individuals Receiving Social Security Disability Benefits"

Presented by
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Mr. Chairman and members of the Finance Committee, over 200 years ago Thomas Jefferson wrote of our inalienable rights, that of life, liberty, and the pursuit of happiness. At the time, the right to the pursuit of happiness did not include blacks, the Native Americans, or women. It did not and still does not include the disabled. I will discuss this pursuit of happiness, how the disabled are excluded, and changes necessary to include us in that right.

The pursuit of happiness may mean great wealth, nice cars and big houses. It may be power and prestige, being a mover and shaker in the business world. To many it may simply be enough to get by on in a house with a white picket fence, a swing set in the backyard for their kids and grandkids as they grow old together with the love of their life. Whatever the vision, the vast majority of the disabled are left out.

I found this out after I broke my neck on a trip to Hungary. With no insurance, and mounting medical bills, I had to turn to government assistance for help. I had to sell the cows I had invested in since a young boy to become eligible for Medicaid. The Medicare I'd paid taxes for wouldn't require such sacrifice but wouldn't help for two years either.

When I tried going back to work I found my right to the pursuit of happiness was gone. I wanted the prestige of working a full-time job and modern technology makes that a possibility but found if I make more than \$900/month, according to Social Security, I am no longer considered disabled. Regardless how much I make my hands and legs won't work and I'll have disability related expenses. Over the course of a lifetime personal care, adaptive equipment and wheelchair related expenses for a disabled person can total well over \$1 million more than an able-bodied person faces.

I wanted to work and make my own money, not wanting to be a beggar or a burden on others. I'd gladly have given up my \$600 Social Security check but I was told I had to stay eligible in order to get Medicaid assistance for the personal care and other expenses Medicare doesn't cover. I got a part-time job but was disheartened to learn I had to give all my earnings over \$540 a month to Medicaid as a spend-down to retain eligibility. I loved my job working with the kids though, so I kept at it.

I was even more disheartened later, when I learned I would have been better off if I had never worked and paid into Social Security since I would be eligible for SSI instead of SSDI. Under SSI I would be allowed to make more money, cuts to financial assistance would be gradual, and I wouldn't have a spend-down for Medicaid assistance.

I face these basic choices; either I don't work and just let the government take care of me through SSDI payments, Medicaid, housing assistance and food stamps, I work part-time and give my paycheck to the government, or I have to somehow find a job with a \$50,000 starting salary so I can pay my own way. The first two options are discouraging and the last unrealistic.

There needs to be a fourth option. It needs to be realized that a disability is a physical or mental condition, not an economic condition. I realize the programs are designed to discourage people from getting on them, but they do more to discourage those who truly need the help. We need programs that will bridge the gap between the part-time job and the \$50,000 a year job, covering the extra 20-30,000 dollar yearly disability related expenses until we are promoted

enough that we are finally able to pay our own expenses. The entire system would be better if we were at least working to help pay for it.

Honorable Senators, in Jefferson's day the disabled rarely lived and if they did, were shut away in homes and forgotten. Now, 21st-century technology keeps us alive and healthy, we live independently and can get out into the community. We should not have to stay home and stifle our abilities just because something in our brains or bodies doesn't work right and we need an extra hand.

Policies must be upgraded so we can truly live, live with hope and dignity, enjoying the right to the pursuit of happiness. Honorable Senators, I urge you to leave a legacy. Help change the policies so we also get access to that last inalienable right.

Thank you for the opportunity to speak with you on behalf of disabled people everywhere. I'll be happy to entertain any questions.

Addendum

Chairman Baucus and honorable members of the finance committee, I am honored at the responsibility of representing the disabled at this hearing. I am glad we have the opportunity of presenting our case to you and hope we can rectify the situation very soon so that we also can access the American dream. I will share my story.

BARRIERS I FACED

- I would not be covered by Medicare for two years after my disability
- The only option for assistance was Medicaid
 - I had to sell my cows and pay the money to the hospital because I couldn't have over \$2000 in assets
 - I lost the only way I could see of regaining financial independence
- Following are disincentives and frustrations I faced when going back to work
 - Low SGA (Substantial Gainful Activity) amount
 - If I make over \$900 a month I lose Social Security benefits and with that, I was told, my Medicaid eligibility
 - Medicaid spend-down
 - Any income over \$540 per month has to go to Medicaid
 - Income is based on gross income, not net income
 - Medicare didn't have such strict rules, but didn't pay personal care expenses
 - Private insurance through work would not pay personal care expenses
 - Subsidized housing costs
 - Also based on 1/3 of gross income
 - There is no upper limit equal to current market value
- I needed purpose and saw that kids were fascinated by me, while adults seemed awkward and afraid
 - To intervene, I started volunteering at Head Start
 - I worked part time in an after-school program
- I was offered a promotion to three-quarter time
 - I could get no definite answers from Social Security and Medicaid as to how my benefits would be affected
 - I took the job and reported it
 - My Medicaid caseworker advised me to pay spend-down of \$500 rather than actual expenses of over \$2000.
 - Subsidized rent increased
 - I made no extra money but I loved the extra purpose and responsibility
- Three years later I was charged with a Social Security overpayment and ordered to repay \$4750... within 30 days please
- I appealed but it was denied

- I was informed about IRWE's (Impairment Related Work Expenses) and Trial Work Period at a Ticket to Work seminar
 - I had unknowingly used my trial work period when it was \$200 per month
 - I was told my Medicaid spend down was an IRWE and to submit proof of payment
- Later, a different agent at Social Security ruled that the spend-down was not an IRWE because it paid for Medicaid, not "direct" medical expenses.
 - I appealed until I was upheld
- Since then, fearful of facing another Social Security overpayment, or otherwise jeopardizing my personal well-being, I have only worked part time and volunteered with Head Start, Eagle Mount, Reading Rocks and the 2006 political campaign to fill my extra time with meaningful activity
- I have learned I would have been better off if I had never worked and paid into the Social Security system
 - I would be eligible for SSI rather than SSDI
 - I could make more money without being penalized
 - Social Security payments would be cut back gradually rather than the all or nothing of SSDI
 - I would have no spend-down for Medicaid coverage so would not be limited to \$540 per month

OTHER BARRIERS

- Cost of adaptive equipment
 - Many disabled cannot work without adapted devices to reach, grasp or speak, and cannot afford the technology without assistance
- Marriage Penalties
 - If we marry, we may lose eligibility for Medicaid assistance
 - Hope for marriage and supporting a family is a major reason for returning to the workplace.

RECOMMENDATIONS

- Raise SGA amount
 - Amounts are so low we have to stifle our abilities and only work part time so we are eligible for assistance with medical costs
 - These costs can amount to over \$1 million in the course of a lifetime
 - It forces us to remain on food stamps and in government subsidized housing to be able to make ends meet
 - **BENEFIT:** If we could make more money we can also spend more and help the economy
- Allow us to work and maintain health benefits (make a bridge from part-time, to full-time employment, to self-sufficiency)
 - **BENEFIT:** If we work we have purpose and are happier and healthier, thus decreasing medical expenses
 - **BENEFIT:** We have to have the extra assistance so should at least be allowed to help pay for it

- **BENEFIT:** As we move to self-sufficiency we get private insurance and use less assistance from Medicaid