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Testimony on the Social Security Administration's Employment Support Programs for Disability Beneficiaries

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I appreciate the opportunity to submit comments on behalf of myself as a previous SSDI beneficiary and as the Advocacy Director at Arizona Bridge to Independent Living (ABIL), the Center for Independent Living in Phoenix, Arizona. For the last twenty years, I have created programs and advocated to remove barriers to independence and self-sufficiency. It is hard to be living with dignity and self-determination when living in poverty. Living on SSDI or SSI is living in poverty. That is why ABIL, as one of the few centers for Independent Living that has provided advocacy and programs to help people with disabilities increase their financial stability and self-esteem through employment in a variety of ways over the years. This 2011 is ABIL's 30th anniversary as a non-profit center serving Arizonans with disabilities in Central Arizona. We started a temporary employment staffing service for people with disabilities in Phoenix in the 1990's which helped us clarify the employment barriers people with disabilities experienced. We also worked our way out of the temporary staffing business, changing the landscape of the business, because of the relationships we developed with other staffing agencies that now routinely employ people with disabilities – a dramatic change over the last twenty years! Of course, we were also very involved in providing public education and technical assistance on the Americans with Disabilities Act during those years.

We became very involved in the development and advocacy for the passage of the Ticket to Work and Work Incentive Improvement Act of 1999 as a result of what we learned about the employment barriers experienced by Americans with disabilities. Many of those barriers still exist today, but a few, thanks to the Ticket legislation have been reduced. Those barriers in 1999 were:

- **Pervasive lack of understanding of the existing SSA work incentives** within and outside SSA in the community of service providers. At that time, there was one SSI expert and one SSDI or Title II expert in each office but no one could help explain to the SSA beneficiary that was a concurrent beneficiary, qualifying for both SSI and SSDI, how the programs and work incentives interfaced.
 - **Work incentives were complicated** and different from program to program which made it difficult for beneficiaries, their families and community service providers, including Vocational Rehabilitation, to understand.
- **Beneficiary (and their advising service providers) had pervasive fear of loss of necessary health care** benefits as a result of work and earned income; and in many cases they were correct.
- **Beneficiaries' fear of the consequences of unsuccessful work attempts** or exacerbations of their disabilities if they needed to get back onto SSA disability benefits.
 - **Why were beneficiaries and their support systems so afraid?** This fear came as a result of the difficult and long application process during which many lost their homes, automobiles and, in some cases, marriages due to the poverty of employment income loss during the long application and appeal process that most went through. In the case of SSDI beneficiaries, the very citizens who had worked and paid into the system through payroll deductions and then became disabled, had expected the "system" to help them. Instead, they experienced an insulting, long and costly battle to prove their inability to work as they struggled with their disability. Going to work back then felt like a **huge** risk and left many beneficiaries feeling bitter and insecure about their prospects for the future and loss of trust in the government system which sent them conflicting and confusing letters in the mail. I know because I took that risk.
 - Back then, if SSA disability beneficiaries tried to work, they were viewed with suspicion that they were faking their disability and so most were afraid to earn even \$1 and report it to SSA.
- **Lack of cooperation between government agencies and public program rules** around working and earned income were often at odds with each other. If a beneficiary tried to work, they faced a sudden loss of all benefits, or thought they did. There was little cross agency collaboration to improve employment outcomes for people with disabilities. (i.e., Medicare/ Medicaid, SSA, Vocational Rehabilitation, food stamps, housing programs). For instance, how could a Vocational Rehabilitation counselor that has a core value to "do no harm" to the clients he/she works with recommend someone go to work if it meant they would lose needed health care?

- **Lack of job readiness and job skills**, especially for youth with disabilities whose parents didn't promote employment because of fear of losing health care, cash benefits and few program supports.

The Ticket to Work legislation was nothing less than revolutionary, if not perfect, because it:

- Addressed the system barriers by invoking changes to promote employment in several government programs.
- Created new work incentives that address the employment barriers described above
 - Medicaid Buy-In state options
 - Extended Medicare coverage
 - Student Earned Income
 - Extended Period of Eligibility
 - Expedited Reinstatement process
- Developed a cadre of community public benefit experts that previously didn't exist, who have been trained and certified to understand how earned income affects benefits. Now beneficiaries and their families and service providers can obtain advisement and support for beneficiary employment goals through the, then, Benefits Planning Assistance and Outreach, now Work Incentive Planning and Assistance –WIPA projects. The result is that SSA rules are no longer a secret. They can be used effectively without adding a burden to SSA's already heavy workload and reducing beneficiary fears. Beneficiaries reason that if the work incentives are public knowledge, then they must be real and safe to use!
- Provided the Medicaid Infrastructure Grants (MIG) that have been essential to getting the different agencies, community organizations and beneficiaries to the same table to resolve misunderstandings and remove employment barriers systemically.
- SSA field offices now have trained assigned staff, Work Incentive Liaisons with work incentive expertise and a state Work Incentive Coordinator to interface with the SSA field office staff, WIPAs and ENs to resolve issues, discrepancies and conflicts that arise.
- SSA, the MIGs and WIPAs have worked over the last 11 years to dismiss the pervasive and persistent myth/misunderstanding that people with disabilities can not afford to work and that the Ticket legislation changes are real and will last. It hasn't been easy to renew trust enough for people to take this risk. We are only part way there. It is a tragedy, to me, if they are not reauthorized because there is no other entity that has taken this lead. In Arizona, our MIG has been essential to help all the state and local agencies that provide services to people with disabilities to have a universal message that employment is good for people with disabilities. They have helped to outreach beneficiaries and service providers to "market" the Ticket and work incentives.
- Provided essential technical assistance from very knowledgeable topic experts for the WIPA projects and the MIGs.
- Created a new source of employment support through the entrepreneurial concept of Employment Networks (ENs) and the "Ticket". The "Ticket" and ENs

have been much maligned and it is true that there are not very many effective ones. ABIL happens to have one of the more productive ENs because we understood from our own experience the intent of the Ticket, the opportunity it provided and a personal understanding that some people, even with severe disabilities, want to work and are able to do so. With our Independent Living model of programs by and for people with disabilities, we have supported many people back to work. I have observed three flaws in the courageous EN/"Ticket" concept. More recently SSA has addressed these issues.

- **No technical assistance was provided to ENs** in the beginning, as was provided to MIGs and BPAO/ WIPAs which was much needed for this total systems change effort. ENs were not required to get training and certification in the SSA work incentives like WIPAs were. Most ENs didn't understand how to manage an effective EN under this entrepreneurial concept and had no technical assistance to help them.
- **Reimbursement process:** Service providers that contracted with the Veterans system or the Vocational Rehabilitation (VR) system got reimbursed to work with people with disabilities whether they actually ever got them to work or not, and whether the person stayed employed more than 90 days or not. Whereas, the ENs were totally different, only getting reimbursed after they accomplished the employment goals of moving beneficiaries toward self-support through employment, for up to five years! I don't think SSA understood what a system change this was. The EN concept grew out of the disability community because we knew that people needed employment support options in addition to VR. We knew that not everyone could get services or need services from VR. We also wanted outcomes of true sustained employment. We knew, from our experience, many people returning to work, or working for the first time would need sustained support to stay employed. It's been difficult to manifest truly effective Employment Networks because most traditional employment providers couldn't afford to provide services with a long wait to get reimbursed from SSA for their services,
- **Marketing of the Ticket early on.** SSA has struggled to find effective ways to market the "Ticket" and help support the start up of effective ENs without the funds to do so. Even now, beneficiaries are sent out information during their first year on benefits about the Ticket and work incentives. If the beneficiary works during that first year they are likely to be disqualified for ever having been disabled enough to get benefits and be required to pay back all cash benefits received. The SSA requirement to be eligible for benefits is that the beneficiary be disabled for 12 months or longer.

My perspectives are colored by my personal experience. I have had a chronic health condition (severe psoriasis and psoriatic arthritis) since age 9 (I am now 63) that has prevented me from being able to work at times in my life. I was an SSDI beneficiary

from 1973 until 1980. At that time, the only work incentive I knew about was Section 8 housing that helped subsidize a portion of my rent and that gradually ramped down as my income increased. Going back to work was one of the scariest things I have ever done to make a better life for my daughter and myself. I didn't know what I was capable of at that time after years of failed medical treatments for my skin condition. My arthritis had improved from medical treatment, but I didn't know what I would do if I had a disability exacerbation. I was only in "remission" for chronic arthritis. I lacked self-confidence from years dealing with the medical system and public benefits systems that depleted my self-esteem in spite of three years of college and previous work experience. I was brought up with a strong work ethic, which only made me feel worse about myself. The SSDI cash benefit helped me survive, but living in the poverty had been devastating and left me feeling like a beggar. Because of my skin condition, I'd become embarrassed to be in public. Eventually, I returned to college twice getting a Masters degree in counseling – a career I thought I could do, even if my disability exacerbated.

My plan worked and I eventually found ABIL and the Independent Living center where I have worked for the last twenty years. Over the years with the passage of the ADA, the view of disability has changed as it now viewed from a civil rights model and not just a medical perspective. Our American society has progressed, to a more social model of disability, I believe in part from the implementation of the ADA. More people understand now what those of us with disabilities have understood for a long time, that there are times when we are unable to work because of our disabilities and other times when we can work with our disabilities and are effective employees. Sometimes we need accommodations and/or appropriate supports including access to affordable health care (including personal assistance). However, many of our public programs, including Social Security are still based on that old medical model and the view that you're either "severely" disabled and unable to work or you're "improved" or fixed and not disabled. The word "disabled" has become a conundrum. For instance, the disability determination units that are deciding if a person is eligible for the Medicaid Buy-In program for people with disabilities that work has to judge whether a person is "disabled" enough to qualify for the program when in every other instance the very definition of "disabled" is that the person cannot work.

In our WIPA project at ABIL, we use a peer model and employ people with disabilities as certified Community Work Incentive Coordinators (CWICs). Some are previous SSA beneficiaries, so that they can model for SSA beneficiaries that they can work. My staff consists of persons with a variety of "severe" disabilities including Spina Bifida (chair user), paraplegia (chair user), Muscular Dystrophy, Lupus and Multiple Sclerosis. They are great marketers of the Ticket and the SSA work incentives and fulfill what I believe is the vision of the Ticket to Work legislation. We are living it and promoting it. We provide Customer Satisfaction Surveys to the beneficiaries that receive a benefits summary and analysis with their WIPA services. Beneficiaries often tell us how glad they are to have our services "at last" and are glad that someone can explain the SSA rules to them in a way they can understand.

Our WIPA project is statewide and we receive \$300,000 per year. The Phoenix area has over half the state's population and the rest of the state is very rural. We have had no increase in funding over the last 11 years, despite changes in the cost of living and the increase in experience and expertise of our staff. No additional funding also despite the demand for our services has increased as more people become aware of the SSA work incentives. Over half of our referrals come from our state Vocational Rehabilitation agency and SSA field offices because they value our expertise so much. We are proud of the work we have done supporting people to work their way out of poverty. Our project cost, per beneficiary last year, was \$244. From 4/1/10 to 3/31/11, 217 beneficiaries reported starting work and 45 reported increasing their wages. We provided written benefits summary and analysis for 530 beneficiaries to help them understand how earned income would affect their cash, medical and other public benefits. We provided 177 SSI, SSDI and Ticket presentations to 2,273 beneficiaries and service providers.

Last year, 113 beneficiaries that received benefit summary and analysis service responded to our customer satisfaction survey and they report the following about the WIPA services they received:

- 55 were working at the time they met with the CWIC for counseling
- 45 reported they were more confident about understanding the SSA rules around employment
- 76 replied they were more confident about working after meeting with the CWIC
- When asked on a scale of 1 (none) to 5 (extremely) the level of *fear* they had about working *before* meeting with the CWIC, the average rating was 3.74. When asked on the same 1 to 5 scale how afraid they were of working *after* meeting with the CWIC, they reported an average score of 2. They reported their fear had dropped almost 2 full points on that 1 to 5 rating scale.

I believe this feedback indicates the value of WIPA services to SSA beneficiaries. It is not unusual for someone who first got information and referral services from us to return to us several months or even years later because they have decided to try employment finally. It takes a long time to change a system and to change attitudes.

In closing, I would like thank this committee for your attention and efforts to increase the employment of persons with disabilities that want and can work. Your efforts to remove systemic barriers so that Americans with disabilities can move from being the poorest of the poor in our country to tax-paying employed citizens is extremely important. As you consider changes and improvements to SSA, CMS and other public programs to improve employment opportunities for Americans with disabilities, I urge you to consider the following suggestions:

1. Increase funding to SSA and DOL for work incentive related programs. Currently, the vast majority of SSA disability funding goes towards Title II and Title XVI income support which a small percentage goes towards employment support programs. Many more people could and would go to work if they had the

- employment support, ongoing health care, personal assistance, assistive technology, job training, career development, job coaching, etc.
2. Continue to have a cross agency/government program effort to remove employment barriers.
 3. Continue to provide funding for technical assistance for the Ticket programs including the MIGs, WIPAs, PABSS and Employment Networks.
 4. Continue Medicaid Infrastructure Grants, at least for those states that have had grants less than 10 years because it takes that long to get silos to cooperate, collaborate effectively and identify and remove barriers located in policy and law.
 5. Continue Employment Network Options – Please don't "throw the baby out with the bath water". Rather, create rules that weed out the bad ENs and supports the good ENs by listening to the most effective ENs and the beneficiaries they serve. Beneficiaries still need access to employment support outside the limited VR system meant for the most severely disabled individuals.
 6. Include people with disabilities that are employed in the creation and oversight of programs.
 7. If you're going to continue the WIPA programs, which of course I hope you do, fund them at least at the level to keep up with inflation over the last 12 years and require SSA to have standard universal outcome criteria for program effectiveness evaluation. Have representation from current WIPA projects and previous SSA beneficiaries be involved in the development of this standard outcome criteria. Keep in mind that SSA has only started collecting our come data during this most recent economic downturn when you evaluate the success of the program. People with disabilities are often the last hired and the first let go during poor economic climates. Arizona has been particularly hard hit.
 8. Increase the Student earned Income Exclusion work incentive to promote employment experience for youth with disabilities. Require all youth transition plans to include work incentive counseling.
 9. Expand the age that beneficiaries can use various work incentives and programs like the Medicaid Buy-In, WIPA, PABSS and EN work incentives. Youth need to have the ability to start part time employment as early as 14 to be commensurate with their peers' early employment experience. Many people want to continue working and some cannot afford to stop working at retirement age or at 65. Our SSA age of retirement is increasing and likely in this budget, environment will increase even more. Remove the upper age limit for all work incentive programs.
 10. Include in the IEP process for youth participation in extracurricular activities because in the real employment world, those experiences are just as important as scholastic achievement to successful employment.
 11. Continue to simplify work incentives. The use of demonstration grants to study the results of different kinds of work incentives. This is important because it is critical to make changes that have been fully evaluated so that those persons with disabilities who are unable to work and need the support the SSA disability programs supply are not harmed.
 12. Continue to remove any programmatic disincentives to employment.

13. Increase opportunities for educational and job training. Most programs are limited to specific populations, like those laid off during the economic downturn. We need more re-careering opportunities..

Thank you for the opportunity to submit testimony on this extremely important issue. I would be happy to respond to any questions you might have.

Respectfully submitted,

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