

Ticket to Work and Work Incentives Advisory Panel

TW & WI  
AP

# Beneficiary Summit

## Voices for Change:

Beneficiaries Paving the Way to Work  
*A Roadmap to Program Improvement*



**The Ticket to Work and Work  
Incentives Advisory Panel**

**Voices for Change: Beneficiaries  
Paving the Way to Work**  
*A Roadmap to Program Improvement*

**Beneficiary Summit**  
February 6 – 7, 2007  
Atlanta, GA





### Beneficiary Summit Delegates and Planners

**First Row Seated Left to Right:** Marciela Hernandez – IL, Rhonda Webb – AZ, Shanickey Kirkwood – MS, Mikelle Learned – CO, Wayne Ross – MA, F. Jay Sullivan – CT, Brucina Tyler – MI; **Second Row Seated Left to Right:** Jessica Lehman, Planner – CA, David Cox – AL, Jim Brown – MT, Maryann Matuska – WA, Natalie Alden, Planner – FL, Chris Clasby, Planner – MT, Robin Renshaw – NV, Zila Schemel – WV, Monique Butler – GA, Brian Bard – DE; **Third Row Left to Right:** Tracy Mixson – NC, Cavin Castenada – HI, Lorie Szydal-Rich – OR, Raphael Rivas – NJ, Doreen Stone – ME, Monica Newton – NH, Sharon Giovanazzo – NY, Joy Tuscherer – SD, Nancy Ford-Winters – IN, Angelica Lopez – TX, Janice Oak – OK, Wayland Wong – CA, Kenneth Rodgers – MN, Emilio Gandara – PR, Jim Sparks – SC, Mary Rogers – NM; **Fourth Row Left to Right:** Michel Bagbonon - VA, Richard Leslie – WY, Jessica Norwood – OH, Jonney Sanchez – UT, Paula Stockdale – TN, Carol Wright – LA, Guy Doherty – VT, Rachel Quade – ID, Yvonne Smith – DC, Dustin Shreve – AR, Michelle Martini – WI; **Fifth Row Left to Right:** Edward Allard – RI, Glenn Koons – PA, Roger Crome – MO, Kevin Webb – KY, Lauifi Tauilili – AS, Debra Hughell – IA, Scot Wheat – AK, Jack Mindrup – NE, Wanda Rosario – VI, Jason Teregeyo – MP, Ardis Bazyn, Planner – FL, Kim Allen – MD; **Not Pictured:** Joseph Benito – FL, Joe Steffy – KS, Marlene Warnke - ND



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## Executive Summary

While trying to address the causes of the low employment rate of individuals with disabilities, service providers, government agencies, advocates, and other professionals have been asked their theories. However, few have asked for solutions directly from the individuals using the programs. *Voices for Change: Beneficiaries Paving the Way to Work*, a summit planned by and for Social Security disability beneficiaries, was conducted in Atlanta, Georgia on February 6 and 7, 2007. The Ticket to Work and Work Incentives Advisory Panel (the Panel) hosted the summit in direct support of Goal 1 of the Panel's strategic plan, to elevate and incorporate the beneficiary perspective. The summit gave the Panel an opportunity to obtain direct, unfiltered feedback from beneficiaries about Social Security programs and how they could be improved.

The Panel selected a planning committee of seven current and recent disability beneficiaries who were also disability advocates and leaders; these individuals played a major role in the planning of the summit. Delegates to the summit were selected from a pool of over 300 applicants to represent all 50 U. S. states, the District of Columbia, Puerto Rico, U.S. Virgin Islands, American Samoa, and the Commonwealth of Northern Mariana Islands. Summit planners and delegates were selected to achieve the broadest possible diversity in disability, culture, age, race, and gender.

The overarching focus of the summit was to elevate and incorporate the beneficiary perspective into policy discussions and program improvements. Summit workgroup sessions were conducted on three planned theme areas. Recommendations from each workgroup were then presented to the entire delegation, prioritized, and organized. At the end of the summit, the delegates signed their names in support of the resulting recommendations.

Key recommendations from the summit are provided on the next page. The full list of beneficiary recommendations is provided in Appendix B.

Following the summit, a session was conducted to brief representatives from the Panel, the White House, Social Security Administration (SSA), the Centers for Medicare and Medicaid Services, the Department of Labor, the National Council on Disability, and the Social Security Advisory Board.

The Panel will use the results of the summit to formulate recommendations for inclusion in its final report to the President, Congress, and the Commissioner of SSA.



The delegates plan to establish a sustainable beneficiary-led organization that can work in partnership with SSA and Congress to increase employment among people with disabilities.

For information on the progress of the delegate-led organization please send an email to [info@voicesforwork.org](mailto:info@voicesforwork.org) or visit [www.voicesforwork.org](http://www.voicesforwork.org).

# Voices for Change: Beneficiaries Paving the Way to Work

## *Key Summit Recommendations*

### **Employment and Work Incentives**

- Ensure access to health care and benefits
- Develop and implement a Work Support Program
- Raise the SSI resource limit to today's dollars
- Change the SSDI Extended Period of Eligibility (EPE)
- Remove the SSI marriage penalty
- Raise the Substantial Gainful Activity (SGA)
- Impose a statute of limitations on overpayments
- Create a short-term disability status and revise Expedited Reinstatement (EXR) provisions
- Improve the Plan for Achieving Self-Sufficiency (PASS) Program
- Involve beneficiaries in the development and implementation of any new program

### **Health Care and Long Term Services and Supports**

- Support family caregivers who provide personal assistant and other services
- Ensure access to a health care package for work, including self-employment
- Remove the 24-month waiting period for Medicare

### **Program Communication, Procedures, and Service Delivery**

- Make SSA policies and procedures easier to find, understand, and accessible
- Fund peer-to-peer mentoring to encourage work
- Enforce standards and accountability for schools, for SSA, and VR

### **Raising the Beneficiary Voice**

- Advertise the results of the Summit
- Create a sustainable beneficiary organization
- Establish a beneficiary voice within SSA, reporting to the Commissioner and Congress
- Fund, plan, and conduct future beneficiary summits and conferences



# 1 Introduction and Context

On February 6 and 7, 2007, *Voices for Change: Beneficiaries Paving the Way to Work*, a summit planned by and for Social Security disability beneficiaries, was conducted in Atlanta, Georgia by the Ticket to Work and Work Incentives Advisory Panel (Panel). This report documents the results and recommendations of the summit.

## 1.1 Employment for People with Disabilities

Despite passage of the Individuals with Disabilities Education Act (IDEA), the Americans with Disabilities Act (ADA), the Ticket to Work and Work Incentives Improvement Act (the Act), unemployment rates of people with significant disabilities have changed little in the past 15 years.

Between 1989 and 2004 the number of Social Security Disability Insurance (SSDI) recipients increased by 117 percent and the number of individuals receiving Supplemental Security Income (SSI) due to disability increased 66 percent. These growth trends dramatically outpace the general population increase of 18 percent. On average, people who enter SSI prior to age 18 are on the rolls for 27 years. Less than one percent of all beneficiaries leave the SSI and SSDI programs by transitioning to gainful employment.

**“Years ago when the Americans with Disabilities Act (ADA) of 1990 was enacted, prohibiting discrimination against individuals with disabilities in employment, housing, education, and access to public services, people were excited and thought it would give us more opportunities. I must agree it did, it gave us ramps into buildings, wider door ways, lowered telephone booths, etc. However, it did not give us equality. Until we are given an opportunity to work without stipulations, we will never be able to fully achieve our goals in life.”**

**Robin Renshaw  
Delegate, Nevada**

## 1.2 The Ticket to Work and Work Incentives Advisory Panel

The Ticket to Work legislation established the Advisory Panel within the Social Security Administration to advise the President, the Congress and the Commissioner of Social Security on issues related to work incentive programs, planning and assistance for individuals with disabilities and the Ticket to Work and Self-Sufficiency Program. The Panel provides insight, advice and recommendations that will lead to increased employment and greater economic self-sufficiency for people with disabilities. A complete listing of Panel members is shown in Appendix A.

Goal 1 of the Panel’s strategic plan is to elevate and incorporate the beneficiary perspective. Objective 1-2 of the strategic plan is to work with beneficiaries to plan and execute a beneficiary summit with clear outcome goals and follow-up strategy,

and to reflect the results in the final report of the Panel. The Panel has heard testimony from SSA beneficiaries regarding topics from the Ticket program to health care to how beneficiaries are treated when they visit an SSA field office. The Panel undertook this beneficiary summit to ensure that the beneficiary voice was an integral part of the Panel's recommendations.

**“I want to own my own business and make ... money. This will not be easy, but I know it's possible if I get the supports I need so I can work and have a good life.”**

**Joseph Benito  
Summit Delegate, Florida**

## **2 Summit Planning – by Beneficiaries for Beneficiaries**

The Panel, in accordance with its strategic goal of elevating and incorporating the beneficiary voice, established a Beneficiary Voice Subcommittee. This subcommittee led the planning for the Beneficiary Summit.

### **2.1 The Summit Planners**

The Beneficiary Voice Subcommittee selected seven beneficiaries with disabilities to assist in planning the summit. These individuals are advocates and leaders in the disability community. This group represented a diversity of disability types, ages, cultures, races, and geographic locations. The criteria for selecting planners included that they were current SSI or SSDI beneficiaries, or had been beneficiaries within the past 5 years, that they had experience with work, and could bring diverse perspectives to the process. From August 2006 to February 2007, the summit planning committee (which included members of the Beneficiary Voice Subcommittee) designed, planned and implemented the summit. They met in person and on regular teleconferences to develop the summit themes, plan the sessions, select delegates, and review and critique read-ahead materials. In addition, they met with delegates to prepare them for attendance at the summit. The beneficiary planners are listed in Appendix A.

### **2.2 The Role of the Panel’s Subcommittees**

The Beneficiary Voice Subcommittee undertook the Beneficiary Summit in order to obtain beneficiary input on improvements to existing SSA programs and work incentives that would enable more beneficiaries to work. Under the leadership of the Beneficiary Voice Subcommittee, the other Panel subcommittees provided input in the design and content of the summit theme areas. The Continuous Improvement Subcommittee sought input on utilization and improvement of the Ticket to Work, other work incentives, health care, long term services and supports, as well as beneficiaries' experiences with other programs serving people with disabilities. The Transformation Subcommittee sought input on a series of ideas focused on transforming current systems to better support people with significant disabilities who want to work.

### **2.3 Focus, Themes, and Session Planning**

The overarching focus of the summit was to raise the beneficiary voice, as well as incorporating that voice into recommendations.

As a result of conversations between the summit planning committee and Panel subcommittees, three major theme areas emerged:

- Theme #1 – Employment and Work Incentives
- Theme #2 – Health Care and Long Term Services and Supports
- Theme #3 – Improving Program Communication, Procedures and Service Delivery

Workgroup sessions were identified in each theme area, and were designed to meet the objectives of the planners as well as the needs of the Panel to learn directly from beneficiaries. Summit workgroup sessions included:

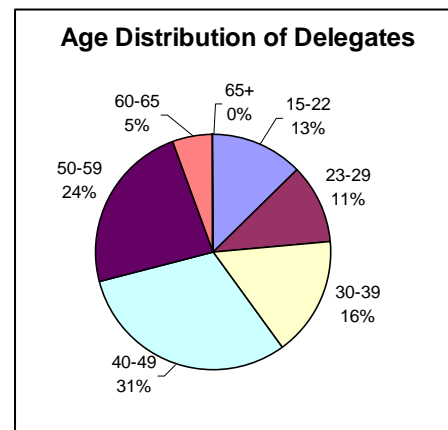
- ◆ Ways to Improve Current SSA Programs and Work Incentives
- ◆ Ideas for a New Work Support Program
- ◆ Employment for Youth with Disabilities and Adults with New Disabilities
- ◆ Medicare, Medicaid, and Private Health Insurance
- ◆ Long Term Services and Supports, Including Personal Assistant Services
- ◆ Getting the Right Information to the Right People at the Right Time
- ◆ Improving Service Delivery to Beneficiaries: How the Program Works in the Real World
- ◆ Improving Interaction between SSA and Other Programs.

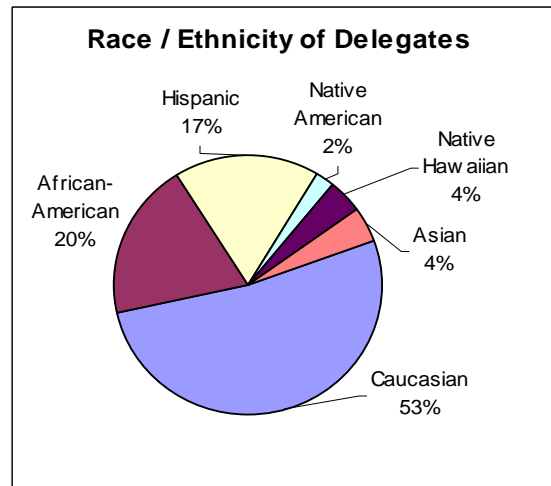
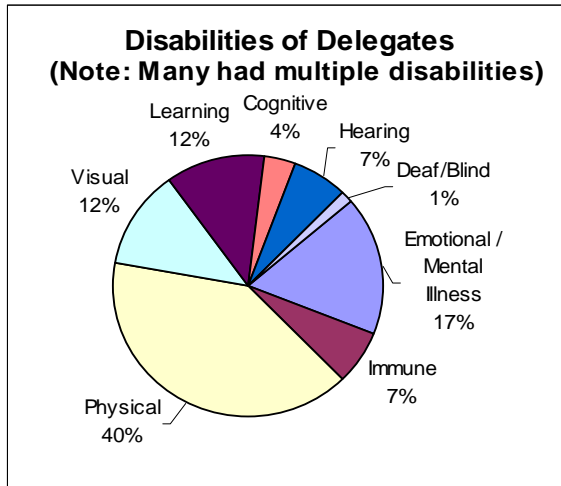
## 2.4 Selection of Delegates

Delegates were selected from a pool of over 300 applicants to achieve the broadest possible diversity in disability, culture, age, race, and gender, and represent all 50 U. S. states, the District of Columbia, Puerto Rico, U.S. Virgin Islands, American Samoa, and the Commonwealth of Northern Mariana Islands. The list of delegates is provided in Appendix A. Delegates ranged in age from 15 to 64, and were relatively evenly distributed across all working age groups.

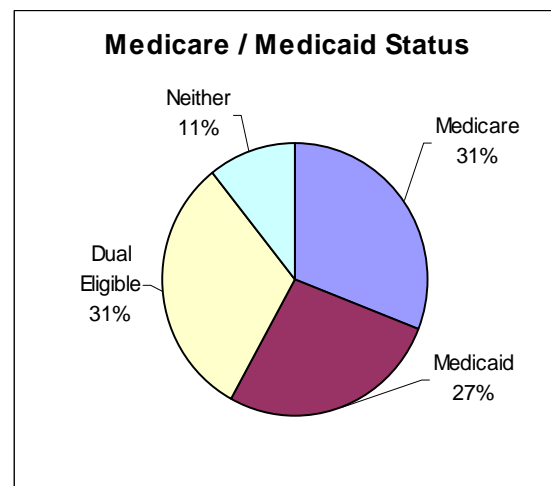
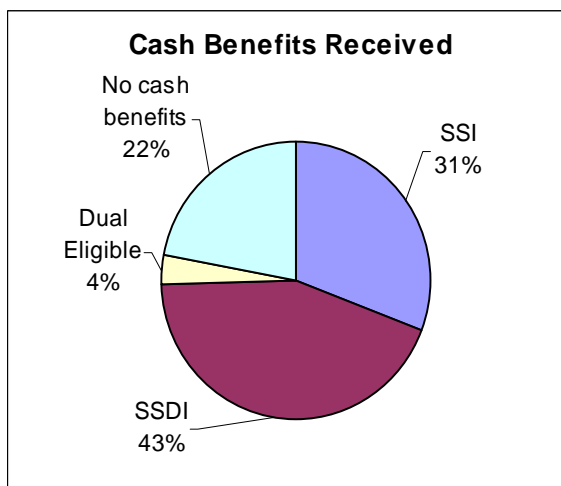
Disability types represented included: emotional/mental illness, intellectual, cognitive (traumatic brain injury, etc.), immune system, hearing, deaf/blind, visual, and physical. Many of the delegates had multiple disabilities.

The race/ethnicity of the delegates included: African American, Hispanic, Asian, Native Hawaiian, Native American and Caucasian.





Delegates' experience with Social Security programs included SSDI, SSI, Medicaid, Medicare, and dual eligible for both cash and health benefits.



## 2.5 Delegate Commitment

By agreeing to participate, summit delegates committed to do a great deal more than just attend a conference and listen to speakers. Prior to the summit, they read briefing papers to prepare them for the workgroups, and participated in teleconferences to ensure that all participants were educated about the programs and issues to be discussed. At the summit, delegates worked together to develop recommendations and reach consensus on a broad range of issues. They also committed to continue their work after the summit by sharing information in their states and working collectively towards furthering the recommendations they developed at the summit.





### 3 The Summit

#### 3.1 Day One -- Development of Workgroup Recommendations

The delegates participated in morning and afternoon workgroup sessions. Prior to the summit, the delegates were asked to choose the two sessions in which they wanted to participate.

Workgroups were assigned a facilitator, topic leader, scribe, note taker, and listener. These groups also included delegates, Panel members and Panel staff. Each workgroup selected a spokesperson, discussed the issues surrounding its topic and formulated recommendations, which were reported back to the entire group.



Delegates Participating in a Workgroup

Later, delegates participated in a dot poll to prioritize the recommendations from the morning and afternoon workgroups. Recommendations were arranged on a wall by theme area, and similar recommendations were grouped together. Each delegate was given 35 sticky dots to use as “votes” on the wall. Recommendations receiving more than 36 votes were organized by theme and posted on the recommendations wall, which summarized the results of the summit.

#### 3.2 Day Two – Raising the Beneficiary Voice in Public Policy

The second day began with a group photo, and then the results of the dot polling were briefed to the entire group and agreed to by delegates.

The delegates split into six workgroups, which focused on developing recommendations for raising and incorporating the beneficiary voice. The workgroup recommendations were briefed back to the entire group, and resulted in numerous areas of similarity. A self-selected group of beneficiaries and facilitators synthesized the



Jack Mindrup, Deanna Greene-Rogalski and Kim Allen Prioritizing Recommendations Using a Dot Poll

recommendations and posted the results to the recommendations wall. The results were reported to the group, and next steps were discussed.

At the end of the summit, a closing ceremony was conducted, during which beneficiary delegates placed their signatures on the recommendations wall indicating their agreement and support of the issues presented. The signatures represented delegate unity and commitment to the future.

Following the summit, the delegate recommendations were reported to representatives from:

- The Panel
- The White House
- The Senate Committee on Finance
- The SSA Office of Ticket Operation and Provider Support
- The SSA Atlanta Regional Office
- The Centers for Medicare and Medicaid
- The Department of Labor Office of Policy, Development and Research, Employment and Training Administration
- The National Council on Disability
- The Social Security Advisory Board



Katie Beckett, Natalie Alden, Chris Clasby, and Jessica Lehman Brief Results of Summit

Following the reporting of results, beneficiary delegates had the opportunity to talk to the representatives present. Delegates told of their desire to work and experiences trying to go to work and provided the unique personal perspective of individuals navigating the maze of programs.

### 3.3 Keynote Speakers

On the first day of the summit, Nancy Ward, self-advocate and Information Coordinator for the Medicaid Reference Desk gave the luncheon keynote presentation. She recounted her story of trying to achieve community-based employment for herself and others.

Nancy explained that she used to work in a sheltered workshop and would sometimes fill in for her boss. When her boss quit, Nancy was not promoted to the job and was told that she had to train her boss's replacement.

Instead, she left the workshop and got a job helping people learn how to advocate for themselves. Based on her own work experience, Nancy's advice to the delegates was:

- Raise your expectations and believe in yourself
- Advocate for yourself and each other
- You can do more than others think you can

She also told the story of Sally, who, because of her disability and the types of benefits she received, was forced to live in a nursing home. Her messages for the delegates from this experience included:

- Just because somebody doesn't communicate with words doesn't mean that they have nothing to say
- Everyone deserves and has a right to respect, and everyone needs to be respected
- Everyone needs to have friends
- Be a friend and be there for others
- Teach others, both those in the community and those involved in caring for people with severe disabilities; what disability is and that people with disabilities deserve respect and friendship.

On the second day, Julie Reiskin, the Executive Director of the Colorado Cross-Disability Coalition, delivered a keynote presentation which provided delegates with ideas for organizing themselves to continue the effort begun at the summit. She provided guiding principles:

- (1) Involve everyone, cross-disability
- (2) Support those who are already working
- (3) Stay focused on a unified national solution with shared leadership
- (4) And most important, have high expectations

Julie suggested that the delegates:

- Form an initial leadership team of 5 to 10 people in each state, who set up meetings, keep the database, do the outreach, and talk to the press, to begin building their base
- Develop an action plan of how to reach their elected officials
- Conduct events to promote their issues
- Meet with the editorial board of their newspaper

She stressed that the summit was a historic opportunity because there was someone at the summit from every state, the District of Columbia, Puerto Rico, U.S. Virgin Islands, American Samoa, and the Commonwealth of Northern Mariana Islands.

### 3.4 Graffiti Wall and Video Testimony

During the summit, wall space was made available where delegates could post personal stories, recommendations, or other issues and items of interest. Items received in advance of the summit from beneficiaries not able to attend were also posted to the wall.

The Graffiti Wall was organized into the following sections:

- ◆ Tell Your Story
- ◆ Barriers to Work
- ◆ Ideas for Theme #1 – Employment and Work Incentives
- ◆ Ideas for Theme #2 – Health Care and Long Term Services and Supports
- ◆ Ideas for Theme #3 – Program Communications, Procedures, and Service Delivery
- ◆ Ideas for Theme #4 – Raising the Beneficiary Voice
- ◆ What's Your Dream Job



Maricela Hernandez and Wayne Ross Post Ideas on the Graffiti Wall

Summit participants posted a wide variety of personal stories, recommendations, and suggestions that resulted in over 50 pages of material. These materials will be provided in a separate document.

Ten delegates provided video testimony (identified in Appendix A). The Panel will use this testimony to formulate its final recommendations. A DVD containing the video testimony is being prepared. Key points from the video testimony included:

- ◆ People with disabilities want to work and participate in their communities.
- ◆ It is difficult to get clear, accurate, consistent information about how to use Social Security and other government programs for people with disabilities, particularly if you are interested in working. Information should be accessible and culturally appropriate.
- ◆ Existing work incentives are complicated, poorly understood, and underutilized, but they can be an effective tool to return to work and pursue a career and self sufficiency.
- ◆ Self employment can be an effective strategy to overcome job discrimination and pursue work you enjoy.
- ◆ People with disabilities are willing to take responsibility for their lives and are able to do amazing things with the right supports.

- ◆ People should prepare for the future, developing the skills and credentials needed to pursue their jobs of choice; volunteer work can be a good way to develop skills and experience.
- ◆ Social Security programs should consider the role of the family as well as the person with a disability; for example, the marriage penalty should be removed.
- ◆ Social Security beneficiaries have the potential to be a powerful voice for change. The summit is an exciting first step in creating that voice.



## 4 Summit Recommendations

The sections below present the highest priority recommendations resulting from the summit, sorted by number of votes received. These sections reflect minor editing and consolidation of similar items and, as a result, are slightly different from the recommendations briefed at the summit. A high priority recommendation that emerged, but had not been briefed was providing peer-to-peer training and mentoring by beneficiaries for beneficiaries and by youth for youth.

The dot poll results by session topic are provided in Appendix B. The appendix contains all of the recommendations that the full delegation considered. Many of the recommendations that were not included in the high priority recommendations are important and warrant further consideration.

### 4.1 Employment and Work Incentives

#### 4.1.1 People with disabilities should be able to work and retain access to their health care and other necessary benefits

This recommendation was among those most strongly supported by the delegates. The opportunity to work to one's capacity and desire is an inherent part of the American dream, yet people with disabilities frequently limit their work to avoid losing benefits essential to their lives.

The potential solutions to this problem are varied, ranging from specific changes to SSA programs such as extending eligibility by raising the substantial gainful activity (SGA) level, to expansion of State Medicaid Buy-in programs, to improvement of or better communication about existing work incentives, etc. Other summit recommendations address some of the specifics.

**“Most people with disabilities know that even though they want to work, they know they really can't because of health care.”**

**Robin Renshaw  
Delegate, Nevada**

#### 4.1.2 Develop and implement a Work Support Program (WSP) that would:

- **Be voluntary**
- **Have no income or asset limits**
- **Provide a health care buy-in**
- **Provide transitional cash benefits**
- **Involve beneficiaries in the development and implementation of any new program, including the WSP**

**“If we had the Work Support Program... we would know we would have some support to fall back on. I wouldn't... feel like I am standing out alone.”**

**Paula Stockdale  
Delegate, Tennessee**



A workgroup session was conducted on ideas for a new program to support the transition of beneficiaries from benefits to work and self-sufficiency. This recommendation came out of that workgroup and was received with great interest by the delegates. The delegates felt that retaining access to health care was a major requirement, that participation in a work support program should be voluntary, and that the transition to self-sufficiency would be aided by removing limitations on income and assets.

#### **4.1.3 Raise the SSI resource limit to today's dollars (at least double -- \$7,000 to \$10,000), indexing it with a cost of living adjustment (COLA), with more asset exclusions (allow asset development, savings, and retirement)**

In general, eligibility for the SSI program is limited to individuals with no more than \$2,000 and couples with no more than \$3,000 in assets. There has not been an increase in these resource limits in more than a decade, while the cost of living has increased dramatically. The delegates felt that increasing and indexing the SSI resource limits should be a priority.

Some assets, such as the beneficiary's home, reasonably valued household goods and personal items, and a car are not counted in this resource limit. The delegates felt that, although the SSI program is a means-tested program, allowing SSI beneficiaries to set aside money for housing, medical expenses not otherwise covered, emergency savings, and for retirement would help them to escape poverty. Solutions might include raising the resource limit, allowing higher limits on individual development accounts (IDAs), and excluding retirement accounts from countable resources.

#### **4.1.4 Change the SSDI extended period of eligibility (EPE) to not be time-limited if the beneficiary continues to be medically disabled**

The SSDI extended period of eligibility (EPE) is a period of 36 consecutive months following the end of a trial work period (TWP). The current rules allow disability benefits to be reinstated during the EPE without a new application for any months in which the beneficiary is unable to work at the SGA level. The beneficiary must continue to have a disabling impairment in addition to having earnings below SGA for that month.

Effectively, if the individual is not medically recovered, and does not work above SGA throughout the EPE and thereafter, he or she is eligible for benefits, but if they work above SGA they will lose those benefits.

The problem, as viewed by the delegates, is that many disabilities are episodic or recur at unpredictable times. An individual may be able to work at SGA during some periods, exhaust the TWP and EPE, and still need to have benefits for another period of disability without undergoing a new eligibility determination. The solution should include making the EPE not time limited for those beneficiaries who continue to be medically disabled regardless of their work attempts.

#### **4.1.5 Remove the SSI marriage penalty**

There are several aspects of SSI that result in a marriage penalty. In general, when a person who is eligible for SSI benefits lives with a spouse who is not eligible for SSI benefits, SSA counts some of the spouse's income in calculating the SSI benefit. The government may reduce SSI benefits or end them if the beneficiary, the spouse, or anyone contributing to their support has significant income or resources. If the person becomes ineligible for SSI, Medicaid may also be terminated, which ends coverage for needed medical care and supports such as personal assistance. Benefits for a married couple, both of whom receive SSI and have no other income, amount to about 25 percent less than the total they would receive if they were living together but not as husband and wife.<sup>1</sup> Additionally, the student earned income exclusion is only available to unmarried students, which is a significant marriage penalty. Many of the delegates felt strongly that SSA programs should not have the effect of discouraging people with disabilities from marrying.

**“My girlfriend and I are unable to get married because I am dependent upon Medicaid... Does this mean that I don’t love her? No, it means I love her enough not to make her dependent on the same things I am.”**

**Chris Clasby, Summit Planner, Montana**

#### **4.1.6 Raise the Substantial Gainful Activity (SGA) to \$1200, and index it to provide a cost of living adjustment (COLA). A related recommendation was: Index SGA to allow for local variability in cost of living, and raise SGA limits**

Rules took effect January 1, 2001, increasing SGA for people with an impairment other than blindness to \$740 a month and establishing that SGA will be automatically adjusted annually based on increases in the national average wage index. For 2007, the SGA amount is \$1500 for people who are blind and \$900 for people with other significant disabilities.

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<sup>1</sup>*Treatment of Married Couples in the SSI Program*, Issue Paper 2003-1, is available at <http://www.ssa.gov/policy/docs/issuepapers/ip2003-01.html>.

The SGA amount is used by SSA to determine whether or not an individual is considered to be disabled, and eligible for benefits. The delegates felt strongly that the current SGA level is inadequate, that it did not keep pace with changes in the cost of living, and that it does not adjust for local variability in the cost of living.

#### **4.1.7 Impose a statute of limitation on overpayments (e.g., 12 months or “no fault” if reported)**

Benefit eligibility and payment amounts for SSI and SSDI beneficiaries are determined by factors such as an individual’s income, resource levels, and living arrangements. Individual circumstances often change, requiring reassessment. In many cases beneficiaries have experienced overpayments, despite accurate reporting of income, because of the unwieldy nature of program administration. In some cases, amounts and demands for repayment have been extreme. SSA already considers overpayments to be a significant problem and has focused its resources on reducing overpayments.

The delegates felt that imposing a statute of limitations on overpayments would further incentivize SSA to develop ways to avoid overpayments and resolve overpayment situations promptly. If a beneficiary had correctly reported their income, and the overpayment was valid, they would only be liable for a certain period of overpayment, for example a year, and would not be liable for any additional amount.

#### **4.1.8 Create a short-term disability status that provides wage replacement when a prior beneficiary temporarily loses or reduces employment (possible enhancement to the expedited reinstatement (EXR) for SSI/SSDI)**

The delegates felt strongly that many people have disabilities which cause their work capacity to vary over time and that SSA’s rules are “all or nothing”. Thus, a short-term disability status would allow these individuals to receive benefits during a period of incapacitation, without having to go through the application process and prove once again that they are unable to work at the SGA level. This could be used instead of EXR, even if the reason they need it, is not the same as the disability on the original claim.

Effective January 1, 2001, an SSI or SSDI recipient who loses benefits due to wages can apply for reinstatement and have benefits reinstated (without a new application), if they apply within 60 months of the last month of eligibility, and they meet all eligibility requirements. EXR permits up to six months of provisional benefits while the request is processed. The individual’s disability must be the same as (or related to)

the disability for the original claim and the disability must have rendered the individual incapable of performing SGA. The six months of provisional benefits is insufficient because, in many cases, SSA takes too long to send the necessary files to the state disability determination service (DDS). In addition, the delegates felt that SSA should not be allowed to apply provisional benefits to overpayments.

#### **4.1.9 Improve the Plan for Achieving Self-Sufficiency (PASS) Program:**

- **Federal or State matching funds.**
- **Allow continuation of a successful PASS when completed, enhancing it to work toward greater self-sufficiency and expanded business opportunity.**
- **Better communication between PASS specialists and applicant during application (appeal/denial) process.**
- **Increase the number of trained PASS specialists available.**
- **Increase communication with youth about work incentives including PASS.**
- **Simplify and streamline PASS application forms and process.**

The PASS is a work incentive that SSI beneficiaries can use to set aside income and/or resources for a specified time for a work goal. The PASS can be used to fund college degree programs, technical training, equipment purchases, starting or equipping small businesses, etc. It is very underutilized at present.

The delegates supported improving communication about the PASS, increasing the number of PASS specialists available, and improving the PASS application, appeal, and denial process.

Today, when the education or business goal of the PASS is completed, the PASS ends. For SSI beneficiaries, the PASS allows income to be applied toward the goal and protects resources (such as gifts toward college tuition), avoiding the loss of benefits due to exceeding income or resource limitations. For SSDI beneficiaries, the PASS can be used to apply cash benefits toward the goal and protect resources, making the recipient eligible for SSI benefits. When the PASS ends, the ability to protect benefits ends. The delegates supported allowing the continuation and enhancement of a successful PASS for the same goal; to work toward greater self-sufficiency and expanded business opportunity.

In addition, the delegates supported enhancing the PASS through programs to match PASS contributions with Federal or State funds. This would allow education or work goals to be achieved more quickly.

#### **4.1.10 Involve beneficiaries in the development and implementation of any new program, including the proposed Work Support Program (WSP)**

In line with the disability rights slogan, “Nothing about us without us”, the delegates strongly supported hands-on involvement of beneficiaries in the development of any new program, including the Work Support Program. The delegates expressed the desire to be part of the Panel’s dialog on the WSP.

## **4.2 Health Care and Long Term Services and Supports**

### **4.2.1 Offer payments, tax deductions and/or credits for family caregivers who provide personal assistant services and other supports for a person with a disability to go to work, to recognize the economic hardship on a family of a spouse or parent not working or working reduced time**

The spouse or parent of a person with a disability who provides personal assistant services and other supports that allow a person with a disability to go to work often stops working themselves or reduces their work. These caregivers support countless numbers of people with disabilities. They and their families endure economic hardship but receive little recognition or support. The delegates overwhelmingly supported some form of economic assistance for these caregivers and their families. This assistance could be provided through additional payments, tax deductions, or tax credits.

“It would be nice if they would pay family members. There are several reasons for that. Family members care, they give the best support. Sometimes they give up their entire careers, like my wife did, and keep you out of a nursing home. And I believe the government should recognize that; especially, if they are helping that person to maintain employment.”

**Brian Bard  
Delegate, Delaware**

### **4.2.2 Ensure that beneficiaries have access to a health care package that they can take to work, including self employment**

The delegates strongly supported this recommendation. The biggest fear expressed by the delegates was that of losing their health care coverage when they went to work. Ongoing access to an appropriate and portable health care package, whether provided as a benefit or at an affordable premium that would support work or self-

“Imagine the incentive for employers if you walked in with a healthcare package and there was no worry.”

**Monica Newton  
Delegate,  
New Hampshire**

employment, would greatly encourage more beneficiaries to go to work. In addition to basic health care and prescription coverage, the package should provide the personal assistant services and durable medical equipment needed for work. Although work incentives provide part of the solution, their complexities, limitations, and ambiguities make the transition to work practically insurmountable for many beneficiaries because losing their coverage would endanger their life or put them in a nursing home.

### **4.2.3 Remove the 24-month waiting period for Medicare**

Under current law, people with new disabilities who qualify for SSDI must wait an additional 24 months before becoming eligible for Medicare. They have already waited through the disability determination process and the five month waiting period for SSDI. Many beneficiaries' SSDI benefits and resources do not allow them to qualify for SSI and Medicaid, and they are unable to obtain other health care coverage at an affordable price or at any price. Lack of insurance comes at the very time when they need it most, and many people are forced to delay treatment, skip medications, or otherwise compromise their recovery. Often, getting timely medical treatment is a stepping stone back to work. The delegates strongly supported removal of the 24-month waiting period for Medicare.

## **4.3 Program Communication, Procedures, and Service Delivery**

### **4.3.1 Empower beneficiaries by making SSA policies and procedures easier to find, understand and accessible**

- **Minimize “SSA Speak”, and use plain language all can understand.**
- **Ensure that all materials are accurately translated, in accessible formats, and reviewed by a diverse ethnic and disability committee.**
- **Provide beneficiaries with a clear and understandable handbook or information packet.**
- **Provide information and training to parents and students on rights and responsibilities.**
- **Simplify and streamline application forms.**

**“Information and referral is the first service any agency provides. People with disabilities will feel more secure if all agencies are speaking the same language.”**

**Emilio Gandara  
Delegate,  
Puerto Rico**

The delegates overwhelmingly supported making SSA policies and procedures easier to find, understand, as well as more accessible. This would include using plain language

(minimizing “SSA Speak”), explaining all acronyms, and ensuring that all communication is correct and accurately translated, with clear explanations of all acronyms. All material should be reviewed by a diverse ethnic and disability community, perhaps by these delegates or a similar group.

Specific recommendations include providing individuals with an easy-to-understand handbook or information packet in a timelier manner, providing information and training to parents and students on their rights and responsibilities, and simplifying and streamlining the application forms.

**Provide funding for paid peer-to-peer training and mentoring to beneficiaries to encourage work and help them navigate the programs.**

- **Use people working with disabilities to train people with new disabilities, and former beneficiaries to train current ones.**
- **Use youth to train youth on independent living skills and supports, individualized education programs (IEPs), VR, etc.**
- **Create a Multi-Agency Work Advocacy/Mentor Link to help people through the process, and work with employers and/or employment agencies.**
- **Hold service fairs for dissemination of information by people with disabilities**

“I learned about the work incentives and that I could go to work, and now I help other people go to work too.”

Natalie Alden  
Summit Planner,  
Florida

The delegates overwhelmingly supported<sup>2</sup> the use of peer-to-peer training and mentoring to encourage work. The training and mentoring should be institutionalized, funded, and implemented as part of ongoing programs, rather than done on a casual, volunteer basis. This recommendation applies to SSA programs, as well as other federal and state programs. One specific suggestion was the creation of a multi-agency program to link advocates/peer mentors with beneficiaries trying to go to work, like a One-Stop, but using peer advocates and mandating multiple agencies to collaborate.

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<sup>2</sup> The recommendation provided here combined two similar summit recommendations and their votes.

### **4.3.2 Provide and enforce minimum, universal standards and accountability for programs, personnel, benefits and services:**

- **For better outcomes for every student in school**
- **For coordinated youth transition**
- **For VR**
- **For SSA**

The delegates strongly recommended standards and accountability for better outcomes for every student with a disability, including mandating the necessary coordination for youth transition to work or higher education.

In other areas, accountability should be for better outcomes related to enabling people with disabilities to work. The delegates' concerns reflect a need for improvements in a number of areas, including a consistent level of knowledge among SSA and VR staff with whom beneficiaries actually interact, standards for training of field office staff, standards and checklists for agencies and programs to talk about with each beneficiary, documentation of referrals and documentation that SSA is communicating and coordinating service delivery with other agencies, and customer service surveys after interactions between beneficiaries and SSA staff.

## **4.4 Raising the Beneficiary Voice**

The recommendations for raising the beneficiary voice, and elevating and incorporating the beneficiary perspective in policy discussions and program improvements were very consistent from workgroup to workgroup and were consolidated by a group of delegates and facilitators at the summit.

### **4.4.1 The Panel should undertake the following actions:**

- **Assemble summary materials about the summit.**
- **Create summit press release and disseminate it.**
- **Write letter to elected officials about the summit and identify the delegates.**
- **Create a SSA website presence about the summit.**
- **Create a public service announcement about the summit.**

This report is one of the Panel's actions to advertise the results of the summit. A press release was disseminated to delegates for their use directly after the summit. The delegates felt that the Panel had an important role to play in advertising the results of the summit and disseminating the recommendations.



**4.4.2 The delegates should create a sustainable beneficiary organization to be a beneficiary voice, supporting internal and external communications, and advocate for needed changes:**

- **Operate on multiple levels (federal, regional, state, and local).**
- **Support internal communication among beneficiaries through teleconferences, creating an e-mail discussion list, website, and newsletter.**
- **Support external communication with other beneficiaries, the media/press, government decision makers, disability organizations, and employers.**
- **Advertise the results of the summit and recommendations made.**
- **Obtain seed money and ongoing, sustainable funding.**

**“Millions of us are using these programs, and no one knows how they work or how they could work better than the beneficiaries... We’ve got great ideas and insights.”**

**Jessica Lehman, Summit Planner, California**

The delegates have already begun to organize an ongoing beneficiary organization and advertising the results of the summit. For information, visit: [www.voicesforwork.org](http://www.voicesforwork.org).

**4.4.3 Establish a Beneficiary Voice within SSA, with a direct reporting relationship to the Commissioner and Congress, and develop a Memorandum of Understanding (MOU) between beneficiaries and SSA**

The delegates overwhelmingly supported creating a permanent mechanism to provide SSA with an ongoing beneficiary voice in both policy and ongoing operation.

- **SSA should fund, plan and conduct future beneficiary summits and conferences**
- **Multi-level (National, Regional, State, Local)**
- **Ongoing**

This beneficiary summit generated great enthusiasm for working for change and raising the voice of beneficiaries throughout the country. The delegates overwhelmingly supported making the summit an annual event.

## 5 Next Steps

The summit was a unique opportunity to bring together individuals who use the disability programs every day and to learn how those programs could be made better so that more individuals with disabilities can go to work. The Panel will use the results of the summit in formulating their recommendations and developing their final report to the President, Congress, and the Commissioner of SSA.

The delegates plan to maintain the momentum created at the summit and establish a sustainable beneficiary-led organization that can work with SSA and Congress to improve systems enabling work for people with disabilities.



## Appendix A. Summit Participants

### Delegates

ALABAMA  
David Cox

ALASKA  
Scott Wheat

AMERICAN SAMOA  
Lauifi Tauilili

ARIZONA  
Rhonda Webb

ARKANSAS  
Dustin Shreve

CALIFORNIA  
Wayland Wong

COLORADO  
Mikelle Learned

CONNECTICUT  
F. Jay Sullivan

DELAWARE  
Brian Bard

DISTRICT OF  
COLUMBIA  
Yvonne Smith

FLORIDA  
Joseph Benito

GEORGIA  
Monique Butler

HAWAII  
Cavin Castaneda

IDAHO  
Rachel Quade

ILLINOIS  
Maricela Hernandez

INDIANA  
Nancy Ford Winters

IOWA  
Debra Hughell

KANSAS  
Joe Steffy

KENTUCKY  
Kevin Webb

LOUISIANA  
C. Wright

MAINE  
Doreen Stone

MARYLAND  
Kim Allen

MASSACHUSETTS  
Wayne Ross

MICHIGAN  
Brucina Tyler

MINNESOTA  
Kenneth Rodgers

MISSOURI  
Roger Crome

MISSISSIPPI  
Shanickey Kirkwood

MONTANA  
Jim Brown

NEBRASKA  
Jack Mindrup

NEVADA  
Robin Renshaw

NEW HAMPSHIRE  
Monica Newton

NEW JERSEY  
Rafael Rivas

NEW MEXICO  
Mary Rogers

NEW YORK  
Sharon Giovinazzo

NORTH CAROLINA  
Tracy Mixson

NORTH DAKOTA  
Marlene Warnke

N. MARIANA ISLANDS  
Jason Teregeyo

OHIO  
Jessica Norwood

OKLAHOMA  
Janice Oak

OREGON  
Lorie Szynal-Rich

TENNESSEE  
Paula Stockdale

WASHINGTON  
Maryann Matsuka

PENNSYLVANIA  
Glenn Koons

TEXAS  
Angelica Lopez

WEST VIRGINIA  
Zila Schemel

PUERTO RICO  
Emilio Gandara

UTAH  
Jonney Sanchez

WISCONSIN  
Michelle Martini

RHODE ISLAND  
Edward Allard

VERMONT  
Guy Doherty

WYOMING  
Richard Leslie

SOUTH CAROLINA  
Jim Sparks

VIRGIN ISLANDS  
Wanda Rosario

SOUTH DAKOTA  
Joy Tuscherer

VIRGINIA  
Michel Bagbonon

## **Summit Planners**

Natalie Alden  
FLORIDA

Jessica Lehman  
CALIFORNIA

Linda Speaker  
NEW YORK

Ardis Bazyn  
CALIFORNIA

James Meadours  
TEXAS

Chris Clasby  
MONTANA

Djuna Parmley-  
Mitchell  
MARYLAND

## **Delegates and Planners Providing Video Testimony**

Natalie Alden, Planner, FLORIDA

Ardis Bazyn, Planner, CALIFORNIA

Joseph Benito, Delegate, FLORIDA

Calvin Castaneda, Delegate, HAWAII

Chris Clasby, Planner, MONTANA

Emilio Gandara, Delegate, PUERTO RICO

Jessica Lehman, Planner, CALIFORNIA

Rachael Quade, Delegate, IDAHO

Jason Teregeyo, Delegate, NORTHERN MARIANA ISLANDS

Paula Stockdale, Delegate, TENNESSEE

## Members of the Panel

Berthy De La Rosa-Aponte, *Chair*  
Cheryl Bates-Harris  
Katie Beckett  
Libby Child  
J. Russell Doumas  
Loretta Goff  
Thomas P. Golden  
Frances Gracechild  
Andrew J. Imparato  
David Miller  
Dorothy Watson  
Torrey Westrom

## Panel Staff

Jill Houghton, *Executive Director*  
Michael Anzick  
Shirletta Banks  
Patricia Laird  
Jenn Rigger  
Debra Tidwell-Peters  
Tinya White-Taylor

## Facilitators

**Sharon Brent** is a national expert on multiple federal policy issues related to the employment and self-determination that improves economic status of youth in transition and adult individuals with disabilities. She is Director of Training and Technical Assistance for the National Disability Institute.

**Dorothy Firsching, PMP, CDP** is President of Ursa Major Consulting, LLC. She has over 25 years of experience in business and technology-related consulting for federal agencies and commercial firms, and has supported clients in the disability community since 1999.

**David M. Mank, Ph.D.** is the Director of the Indiana Institute on Disability and Community at Indiana University, Indiana's University Center for Excellence on Disabilities, and a Full Professor in the School of Education, Department of Curriculum and Instruction.

**Michael Morris** is the Director of the National Disability Institute where he works to advance the social and economic independence of persons with disabilities through strategic investment and technical assistance activities.

**Becky Roberts, CPF, PMP, Lead Facilitator**, is the President of Catocin Consulting, LLC. She designs individually tailored programs to help organizations define their business objectives, measure their performance against their objectives, develop strategic management processes, and implement the change necessary to reach their goals.

**Jonathan Young J.D., PhD** is an attorney with FoxKiser, a health law and policy firm in Washington, DC.

## Appendix B. Dot Poll Results by Session Topic

The delegates conducted a dot poll to roughly prioritize the recommendations that were developed by the workgroups. Each delegate received 35 sticky dots to place on the wall on the roughly 100 items to be prioritized. Delegates were asked to place at least 15 dots on items in theme area one, and at least five dots in each of theme areas two and three. Each delegate was able to vote their dots the way they chose, including voting more than once for a given item. The results of the dot poll were tallied at the summit. This section consolidates the recommendations made by multiple workgroups, prioritizes them in accordance with the dot poll, and reflects minor editing of recommendations posted.

Note that recommendations made by a workgroup that fell into a different theme area were moved to that area. For example, recommendations made in session 1A, Ways to Improve Current SSA Programs and Work Incentives, that concerned health care, were moved to the section on 2A, Medicare, Medicaid, and Private Health Care.

### Session 1A: Ways to Improve Current SSA Programs and Work Incentives

Ways to improve current SSA programs and work incentives were discussed in two workgroups, both of which briefed recommendations back to the full group. The recommendations of both groups were included in the dot poll. The recommendations garnering the most support in this area were:

Recommendation	Votes
1. People with disabilities on SSI and SSDI should be able to work and retain access to their health care and other necessary benefits.	62
2. Raise the SSI resource limit to today's dollars (at least double -- \$7,000 to \$10,000), indexing it with a cost of living adjustment (COLA)), with more asset exclusions (allow asset development, savings, and retirement).	58
3. Change the SSDI extended period of eligibility (EPE) to not be time-limited if the beneficiary continues to be medically disabled. (Note, 5. Change extended period of eligibility for people with significant disabilities gathered an additional 12 votes).	56
4. Remove the SSI marriage penalty.	51
5. Raise the Substantial Gainful Activity (SGA) to \$1200 and index it to provide a cost of living adjustment (COLA). (Note: a related recommendation was: "Index SGA to allow for local variability in cost of living and raise SGA limits", which received 20 votes.)	43



Recommendation	Votes
6. Impose a statute of limitation on overpayments (e.g., 12 months or “no fault” if reported).	42
7. Improve the Plan for Achieving Self-Sufficiency (PASS) Program: <ul style="list-style-type: none"> <li>o Federal or State matching funds</li> <li>o It would be “way cool” if a successful PASS could continue when completed and simply be enhanced to work toward greater self-sufficiency and expand business opportunity.</li> <li>o Better communication between PASS specialist and applicant during application (appeal/denial) process.</li> <li>o Increase the number of trained PASS specialists available.</li> <li>o Increased communication with youth about work incentives including PASS.</li> <li>o Simplify and streamline PASS application forms and process.</li> </ul>	40
8. Create a short-term disability status that provides wage replacement when a prior beneficiary temporarily loses or reduces employment (possible enhancement to the expedited reinstatement (EXR) for SSI/SSDI). Simplify EXR rules.	41

Other recommendations in this area included:

Recommendation	Votes
9. Provide more incentives for employers for hiring SSI/DI beneficiaries (e.g., Wage subsidy).	30
10. Exclude inheritance as a resource by the SSI Program.	29
11. Give beneficiaries their “Ticket” resources (front load) to hire their own provider.	27
12. SSA should work off of “net” income (after taxes), not gross income.	22
13. Index SGA to allow for local variability in cost of living and raise SGA limits.	20
14. Expand impairment-related work expenses (IRWE) to include “spend-down”.	18
15. Improve the way all SSI/SSDI work incentives work together across all federal programs.	17
16. Raise SSI earned-income disregard levels (pattern after the Florida demonstration project).	13
17. Change the extended period of eligibility for people with significant disabilities.	12
18. Improve the SSDI trial work period (TWP) by extending the length (e.g., 24 months), service month amount (e.g., SGA) and allow work incentive use during the TWP.	11

Recommendation	Votes
19. Prior to claiming a beneficiary is no longer disabled under SSI or SSDI, provide information and referral to create safety nets.	9
20. Address SGA parity between blindness and other disabilities.	9
21. No impact on food stamps, housing, and other programs.	8
22. Don't wait until the end – start with early intervention, then education, then services. Provide information and technical assistance.	7
23. The SSDI extended period of eligibility (EPE) should no longer be consecutive months (e.g., if a person needs to stop working – the EPE should stop). The problem is that SSA currently counts non-worked months in the EPE.	7
24. Create a more streamlined process for wage reporting by working beneficiaries in the SSI and SSDI programs.	6
25. Empower beneficiaries by ensuring that they have access to SSI/SSDI work incentive practitioners in sufficient numbers that they can provide substantive support (increase number of practitioners).	5
26. Remove the peril of losing benefits following the extended period of eligibility (EPE) by making SSI and DI more similar through building an SSDI \$2 for \$1 benefits reduction following the EPE.	5
27. Allow subsidies as a work incentive under SSI.	3
28. Assist states with Developmental Disabilities (DD) waiver services.	3

## Session 1B: Ideas for a New Work Support Program

The work group was briefed on the ideas of the Panel's Transformation Subcommittee for a new Work Support Program. The work group then discussed the features it would most like to see in a new program to support work, and formulated and presented its recommendations back to the entire group. The entire group participated in the dot poll to vote upon the workgroup's recommendations. The results are presented below.

Recommendation	Votes
1. Develop and implement a Work Support Program (WSP), that would: <ul style="list-style-type: none"> <li>○ Be voluntary</li> <li>○ Have no income or asset limits</li> <li>○ Provide a health care buy-in</li> <li>○ Provide transitional cash benefits</li> </ul>	60
2. Involve beneficiaries in the development and implementation of any new program, including the Work Support Program.	38

Additional recommendations with regard to a work support program included:

Recommendation	Votes
3. People should be given a grace period to move from traditional work incentives to the WSP when they receive a new job or wage increase.	25
4. Ensure that no beneficiary will be harmed by trying to work or save assets.	18
5. WSP participants should be able to save for retirement and access Medicaid as needed in retirement.	14
6. Protect assets earned under the WSP when WSP participants need to go back to SSI.	13
7. Facilitate a partnership between an individual beneficiary and SSA to plan for accessing community resources to transition to employment. Must be flexible and individualized.	11
8. Provide a work support account, possibly with matched savings and/or initial credit from SSA for WSP.	8
9. Apply the expedited reinstatement rules to the WSP.	8
10. Integrate the WSP with housing, food stamps, etc. (e.g., Wisconsin Making Work Pay initiative).	8
11. Make the WSP responsive to individual circumstances across a lifespan, including protections for short term income loss.	7
12. Make the WSP address the needs of ALL beneficiaries.	6
13. Make the WSP integrate ALL types of employment.	6
14. The WSP should provide for early access and planning for young people coordinating with schools and other youth-serving organizations.	5
15. The WSP should provide a health care buy-in to cover dependents.	2
16. Provide a framework for evaluating and improving participation in work support programs over time.	1

### Session 1C: Employment for Youth with Disabilities and Adults with New Disabilities

One work group discussed both employment for youth with disabilities and adults with new disabilities, which represented two topics. The group spent most of its time discussing employment for youth with disabilities; as the group had more interest in making recommendations concerning helping youth begin to work.

Many of the recommendations for adults with new disabilities involved changes to work incentives (e.g., payment for Personal Assistant Services (PAS), and PASS) or health care, and were consolidated with other recommendations in those sections.

Likewise, there was concern about providing better information to youth and parents; recommendations in that area were moved to 3A, Getting the Right Information to the Right People at the Right Time.

The recommendation receiving the most votes was:

Recommendation	Votes
1. Provide and enforce standards and accountability for providers: <ul style="list-style-type: none"> <li>○ In the schools for better outcomes for every student</li> <li>○ For VR</li> <li>○ For SSA</li> </ul>	55

Additional recommendations included:

Recommendation	Votes
2. Provide funding for peer training for youth, by youth, on independent living skills and supports, IEPs, VR, etc. (Note that this recommendation was combined with the peer-to-peer training recommended under 3A.)	31
3. Provide early intervention and youth activities at all ages, including youth actively participating and procuring employment results.	27
4. Increase VR counselors' skills and expectations. Fix performance measures for VR counselors especially working with youth with severe disabilities.	24
5. Independent living centers should have a greater focus on youth.	8
6. Provide benefits counselors in SSA, VR, schools, One Stops, and in the educational system.	8
7. VR transition counselors should be available across the country.	7
8. Expand independent living services to adults with new disabilities.	4
9. Scale disabilities for benefits similar to the way it is done in the Veterans Administration system (i.e., partial disability).	3
10. Provide a unified system of education.	0

## Session 2A: Medicare, Medicaid, and Private Health Insurance

Health care was clearly of primary importance to all. The topic came up in many of the workgroups; recommendations were consolidated and voted upon. In addition, recommendations were made in this workgroup concerning personal assistant

services (PAS); they were moved to section 2B, Long Term Services and Supports, Including Personal Assistant Services.

The recommendations concerning health care that received the most votes are listed below.

<b>Recommendation</b>	<b>Votes</b>
1. Ensure that beneficiaries have access to a health care package that they can take to work, including self employment.	62
2. Remove the 24-month waiting period for Medicare.	37

Additional recommendations include:

<b>Recommendation</b>	<b>Votes</b>
3. Make 1619(b) available to SSDI/SSI beneficiaries for Medicaid or Medicare to pay for assistive technology and durable medical equipment.	22
4. Make the Ticket to Work and Medicaid Buy-Ins work for individuals with significant disabilities.	21
5. Eliminate 80%; give 100% coverage for Medicare.	20
6. Improve healthcare benefits (e.g. dental and vision coverage).	16
7. Provide universal access to health care with a co-pay option, or offer some sort of alternative health care for people who are not Medicaid/Medicare eligible.	13
8. All health insurance premiums/payments should not be counted as income.	8
9. Medicare/Medicaid should cover pre-existing conditions when transitioning to private health insurance.	8
10. Provide dependent coverage through the Medicaid Buy-In.	7
11. Separate eligibility for cash benefits from health coverage.	6
12. Eliminate the penalty for refusing Medicare and applying at a later date.	6
13. Improve portability of Medicare/Medicaid.	2

## **Session 2B: Long Term Services and Supports, Including Personal Assistant Services**

The single recommendation that dominated the delegate voting and was of primary interest was:

Recommendation	Votes
1. Offer payments, tax deductions and/or credits for family caregivers who provide personal assistant services and other supports for a person with a disability to go to work, to recognize the economic hardship on a family of a spouse or parent not working or working reduced time.	80

Additional recommendations included:

Recommendations	Votes
2. Allow higher wages connected to personal assistant services (PAS) utilized for assistance in the workplace in order to remain employed.	13
3. Create minimum training standards for personal assistants and require adequate wages and benefits.	12
4. Create a health care buy-in option outside of SSI/DI eligibility standards that will include long term services and supports. Make the Medicaid Buy-In available in every state with consistent requirements.	11
5. Create a federal definition that provides a consistent scope of personal assistant services and long term supports regardless of which state you live in. The definition should include: consumer-directed services, personal assistance, transportation, service animals, job coaches, job developers, peer mentors, technology and training in how to use it, home and vehicle modifications, services in the home and the workplace.	11
6. Create a federal funding source to allow consistent coverage of long term supports regardless of income level and assets, but with cost sharing by the person with a disability once they earn above SGA.	11
7. Offer expanded tax incentives for employers who cover costs of PAS and long term supports that help a beneficiary transition off benefits.	8

### Session 3A: Getting the Right Information to the Right People at the Right Time

Improvement of communication of SSA policies and procedures was very important to the delegates. The following recommendation represents the combination of two similar items that each received a significant number of votes.

Recommendations	Votes
1. Empower beneficiaries by making SSA policies and procedures easier to find, understand and accessible. <ul style="list-style-type: none"> <li>o Provide beneficiaries with a clear and understandable handbook or information packet.</li> </ul>	85

Recommendations	Votes
<ul style="list-style-type: none"> <li>○ Minimize “SSA Speak” and use plain language all can understand.</li> <li>○ Provide accessible format of choice.</li> <li>○ Provide information and training to parents and students on rights and responsibilities.</li> <li>○ Simplify and streamline application forms, including PASS.</li> <li>○ Ensure that materials are reviewed by a diverse ethnic and disability committee – could use this group of delegates.</li> <li>○ Ensure that all communication is accurately translated.</li> <li>○ Provide clear explanations of acronyms.</li> </ul>	

In addition, the following other recommendations were made in this area:

Recommendations	Votes
<p>2. Conduct a social marketing campaign to encourage employment, raise expectations, and reduce stigma.</p> <ul style="list-style-type: none"> <li>○ Provide success stories to the broader community.</li> <li>○ Get a celebrity to support the program (say through a song).</li> <li>○ Create a media blitz/PSA (public service announcements).</li> <li>○ Educate the community through public education and outreach. More information to everyone!! People can work!</li> <li>○ This could be done like they did with Medicare Part D and the “bus”.</li> </ul> <p>(Note that this combined two items and their votes.)</p>	29
<p>3. Provide SSI beneficiaries with more education and training about how to use Special Needs Trusts.</p>	20
<p>4. Provide information and education to employers on:</p> <ul style="list-style-type: none"> <li>○ Work incentives</li> <li>○ Reasonable accommodations</li> <li>○ Etiquette</li> <li>○ Extended workplace support (MOU) to maintain connections with employers</li> </ul>	18
<p>5. Provide information and education to VR service coordinators/case managers (through state agencies) that they can use to inform clients about work options. There should be no conflict of interest to keep them there.</p>	16
<p>6. Provide in-service training for personnel at One Stops for disability awareness, etiquette, and assistive technology.</p>	15
<p>7. To improve communication, require each state to provide a dedicated website, toll-free number and physical locations to provide information about all relevant systems and public benefits.</p>	13

8. Provide continuing education relative to people with disabilities for doctors/nurses/patient representatives, educators to sensitize them about disabilities and disability programs (all systems).	11
9. Provide regularly scheduled monthly meetings (or conference calls) with SSA in the community to provide general information about their programs/services.	7
10. Provide information and training outside SSA on work options <ul style="list-style-type: none"> <li>○ Do training in schools, rehabilitation centers, medical facilities, etc.</li> <li>○ Expand training services in rural areas.</li> <li>○ Target blind agencies</li> <li>○ Provide ADA rights training prior to job search, in hospitals and rehab centers.</li> </ul>	6
11. Provide SSA leadership with “face to face” recommendations from beneficiaries.	5
12. SSA should engage existing community groups (such as libraries and churches) to disseminate information on programs and services with validated information.	5
13. SSA should more quickly roll out findings from demonstration projects	1

### Session 3B. Improving Service Delivery to Beneficiaries: How the Program Works in the Real World

When the dot poll results were reviewed, it was possible to combine recommendations regarding peer-to-peer mentoring and information dissemination, which had not been recognized previously as receiving many votes. Peer-to-peer mentoring was also mentioned in other recommendations.

Recommendations around training also were able to be combined.

Recommendations	Votes
1. Provide funding for paid peer-to-peer training and mentoring to beneficiaries to encourage work and how to navigate the programs. <ul style="list-style-type: none"> <li>○ Provide training for youth, by youth, on independent living skills and supports, individual education programs (IEPs), VR, etc.</li> <li>○ Use former beneficiaries to train current ones.</li> <li>○ Use people working with disabilities to train people with new disabilities.</li> <li>○ Create an Advocacy/Mentor Link to help people through the process beginning with employers and/or employment agencies.</li> </ul>	83



Recommendations	Votes
<ul style="list-style-type: none"> <li>○ Hold service fairs for dissemination of information by people with disabilities.</li> </ul> <p>(Note that this combined two recommendations and their votes.)</p>	

Other recommendations in this area included:

Recommendations	Votes
2. Provide more benefit counselors.	31
<p>3. Create a uniform system of training that is carried out on an ongoing basis with a regional training team and is consistent across the country. Provide ongoing training for SSA staff and other agencies on SSA programs and non-SSA programs, and the connections to VR, One Stops, etc. Training should:</p> <ul style="list-style-type: none"> <li>○ Be specific to disabilities, so that trained staff can meet the needs of all people.</li> <li>○ Provide accurate information with compassion.</li> <li>○ Include self-employment support options.</li> <li>○ Include the options and programs available for beneficiaries.</li> <li>○ Provide access to people who can explain information and offer peer support.</li> <li>○ Document ongoing collaborations between SSA, VR, and education (transition), etc.</li> <li>○ Include collaborative development of PASS plans between SSA, VR, education, and other agencies. Collaboration must be documented.</li> </ul>	29
<p>4. Provide staff to specialize in work incentives and disability in each SSA field office.</p> <ul style="list-style-type: none"> <li>○ Provide a navigator/liaison in each SSA field office, preferably a person with a disability.</li> <li>○ Embrace cultural sensitivity through ongoing training and employing people with disabilities.</li> <li>○ Grantees should also employ people with disabilities/culturally diverse populations.</li> </ul>	24
<p>5. Provide accountability with sensitivity throughout intra and interagency programs, including personnel, benefits, and services from youth transition through the life of the disability. Key points include:</p> <ul style="list-style-type: none"> <li>○ Establish a set of core concepts SSA field office staff must understand.</li> <li>○ Conduct a customer service survey after every interaction between beneficiaries and SSA staff.</li> <li>○ Review resource options with each beneficiary, using a checklist of agencies and programs.</li> </ul>	15

Recommendations	Votes
<ul style="list-style-type: none"> <li>o Document referrals and that SSA is communicating and coordinating service delivery with other agencies.</li> </ul>	
6. Increase resources for protection and advocacy services (e.g., employment discrimination, and peer support network).	2

### Session 3C: Improving Interaction between SSA and Other Programs.

Many of the recommendations that surfaced from this work group concerned training and were moved under 3B, Improving Service Delivery to Beneficiaries: How the Program Works in the Real World. The top recommendation is listed below.

Recommendations	Votes
1. Enable veterans to be able to receive both SSDI and veterans benefits, without one offsetting the other.	42

Additional recommendations in this area include:

Recommendations	Votes
2. Improve collaboration between VR, CMS, and SSA. This could include creation of a multi-agency Advocacy Link (like a One Stop external agency) that uses peer advocates, where multiple agencies are mandated to collaborate.	16
3. Establish federal/state agency collaboration to remove disincentives between means tested programs.	5



## Contact Information

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Anyone requiring materials in alternate formats, or for further information regarding this document, or the Ticket to Work and Work Incentives Advisory Panel should contact the Panel.

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