

SOCIAL SECURITY ADVISORY BOARD

**STATEMENT ON THE SUPPLEMENTAL
SECURITY INCOME PROGRAM**

MAY 2006

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Public Law 104-193 requires that members of the Social Security Advisory Board be given an opportunity, either individually or jointly, to include their views in the Social Security Administration's annual report to the President and the Congress on the Supplemental Security Income (SSI) program. We appreciate the opportunity to present our perspectives on this important program, and we have asked the Social Security Administration (SSA) to include the following statement in this year's annual report.

The impetus for this statement came out of our renewed study of the disability program. During the course of this most recent work it has become clear that there is a need to strengthen our national policies relative to youth with disabilities. In presenting our views this year, we want to focus on the impacts of the SSI age-18 redetermination policy and how it affects the transition of youth from SSI benefits to the world of work and adulthood.

SSI applicants under age 18 have to meet different disability standards from those for applicants ages 18 and above. Beginning in 1996, all SSI beneficiaries who turn 18 have had to have their cases redetermined under the adult standards. Between 1996 and 2004, more than 400 thousand beneficiaries have had these age-18 redeterminations. About one-third of these redeterminations result in termination of benefits. The Board believes that it is crucial that parents and children be made aware of this so that they can better prepare for this eventuality. The job of children is to learn and grow and the role of the educational system is paramount. Schools play a large part in preparing SSI youth, especially those who will be able to work as adults, for their transition to adulthood. We will recommend some steps that SSA can take that can help make that preparation more effective.

SSI: TRANSITION FROM CHILDHOOD TO ADULTHOOD

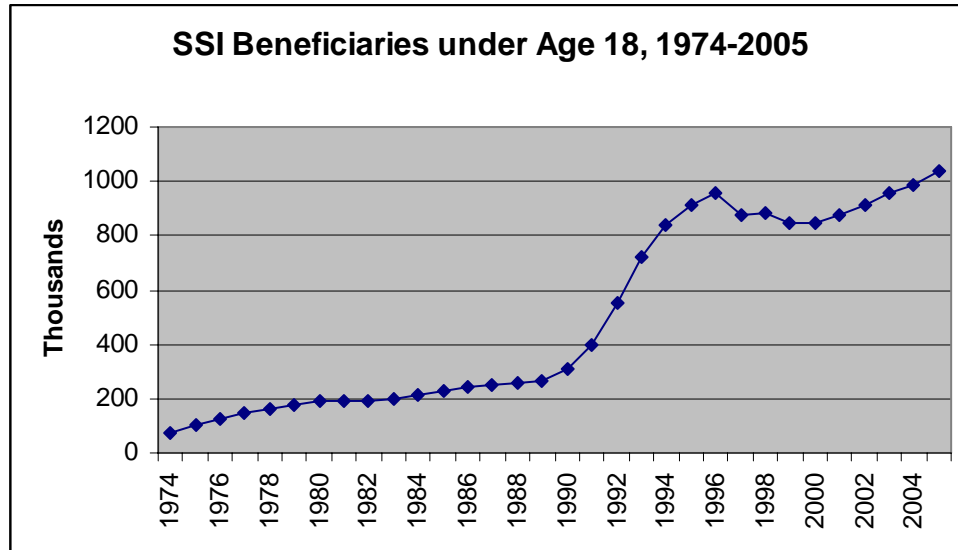
Age-18 Redeterminations

The number of SSI beneficiaries under age 18 grew slowly from the program's inception until the early 1990s, when it began to increase rapidly. (See Chart 1.) This rapid growth has been attributed mainly to a Supreme Court decision that loosened the eligibility requirements for children. A recession in the early 1990s, changes in State welfare programs, and efforts by disability advocates may also have been factors in the growth of the child SSI rolls.

Concerns over this rapid growth and over media reports of children being coached to meet eligibility requirements led to restrictions on program access. In 1996 Congress tightened the child disability requirements and ordered SSA to redetermine the cases of SSI children whose eligibility might be affected by the new requirements. Congress also added a requirement that all 18-year-old SSI beneficiaries have their eligibility

redetermined to see if they meet the adult disability criteria. These redeterminations are different from continuing disability reviews (CDRs) that beneficiaries go through from time to time. Instead of determining whether the beneficiary's medical condition has improved to the point that he or she no longer meets the definition of disability, as is the case with CDRs, medical improvement is not a factor in the age-18 redeterminations. Rather, the age-18 redeterminations measure against adult disability criteria beneficiaries who had earlier been approved based on the childhood criteria.

Chart 1

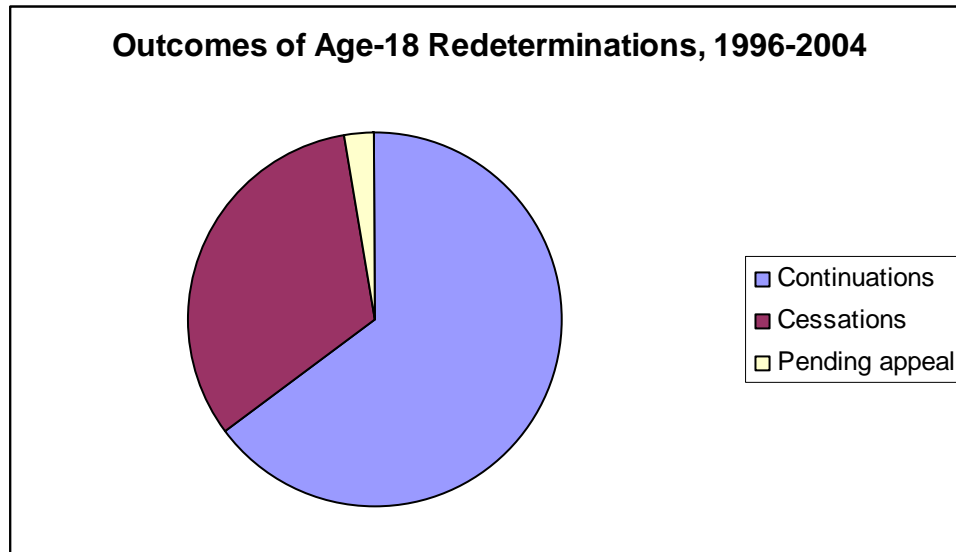


Outcomes of Age-18 Redeterminations

The age-18 redeterminations are conducted by the State agencies that make disability determinations for SSA. Between 1996 and 2004 those State agencies made more than 400 thousand such redeterminations. Of those determinations, 56 percent were decisions to continue benefits, and 44 percent were to cease benefits. Beneficiaries who received a decision to cease benefits could ask for a reconsideration of that decision by the State agency. Those who still received a cessation decision at the reconsideration level could request a hearing by an SSA administrative law judge. Those who received a cessation decision at the hearing level could ask for a review by SSA's Appeals Council. Those dissatisfied with the outcome at that level could take their case to the Federal courts. After appeals (as shown in Chart 2), 65 percent of these 1996 through 2004 age-18 redeterminations resulted in continuation of benefits, and 33 percent resulted in a cessation of benefits. (Two percent were still awaiting an appeal decision in January 2005).¹ By contrast, more than 90 percent of SSI adult beneficiaries whose cases received a full medical review over the same period had their benefits continued.

¹ There is considerable State-to-State variation in cessation rates by States. See Appendix.

Chart 2



Characteristics of Beneficiaries

Recent data from the National Survey of SSI Children and Families (NSCF) provides a snapshot of who the SSI childhood beneficiaries are. The NSCF is a nationally representative survey – the first since 1978 – of noninstitutionalized children and young adults who currently or formerly received SSI. It was funded by SSA, and data were collected between July 2001 and July 2002. The following description of SSI beneficiaries between the ages of 14 and 17, the years immediately before the age-18 redetermination, is based on NSCF data:²

- 37 percent are female, 63 percent male.
- 25 percent live in a 2-parent family, 60 percent in a single-parent family, 14 percent live with another relative or guardian, and 1 percent live alone or in an institution.
- Parent’s education level is less than high school for 43 percent, high school or GED for 36 percent, and more than high school for 22 percent.
- In 51 percent of the households, at least 1 parent is working.
- The total average monthly household income, including SSI, is \$1,528. Average household income is 6 percent above the poverty level, and 38 percent of households are below the poverty line.
- Household income sources other than earnings and SSI payments include welfare (17 percent of households), Social Security benefits (21 percent), child support (19 percent), and pensions and annuities (2 percent).
- Non-cash benefits include Food Stamps (31 percent of households), Medicaid (93 percent), and housing assistance (11 percent).
- Almost 6 percent had dropped out of school.

² Pamela Loprest and David Wittenburg, “Choices, Challenges, and Options: Child SSI Recipients Preparing for the Transition to Adult Life,” Urban Institute, May 2005.

- Of those who had not dropped out, 32 percent had been suspended or expelled in the last 12 months.
- Of 17 year olds, 16 percent reported ever having been arrested.

Another rich source of data on youth with disabilities is the National Longitudinal Transition Study-2 (NLTS2), sponsored by the Department of Education. That study looks at a nationally representative sample of students who were 13 to 16 years old and received special education in December 2000. The study will follow them until 2010 to understand their experiences as they transition into adulthood. A report on early findings from that study makes the point that youths from low-income families, as SSI youth are, are different from those from wealthier families in some important respects. Youths from low-income families are less likely to have had their disabilities identified at an early age or to have received services to ameliorate the negative impacts of those disabilities. Low-income youth are more likely to have limitations in communication and social skills and to have vision problems even when they use glasses or contact lenses. They are less likely to have mastered basic functional cognitive skills such as reading common signs and counting change.

Over the last 40 years, the transition to adulthood in American society has become longer and more difficult. Young people are more likely to depend on parents for financial help, health insurance, or a place to live between jobs. Not all parents can provide such help, and supports from other sources often end at 18 or 21. Youth with disabilities are often the least able to assume adult responsibilities. They may lack work skills, or maturity, or life skills, or may have limitations that affect their work. They are more likely to be unemployed, to have children outside of marriage, to be socially isolated, to commit crimes, and to live in poverty.³

The transition to adulthood can be challenging, and is more challenging for youth with disabilities. The picture of SSI youth that emerges from survey data indicates that the transition to adulthood is especially challenging for them.

Impact on Beneficiaries

The NSCF sheds light on what happens to beneficiaries after their redetermination. Loprest and Wittenburg look at a group who were receiving benefits in 1996 and were ages 19 to 23 in 2000, a group they refer to as their post-transition cohort. They divide that group into 2 subgroups, those remaining on SSI and those who were cut off or left SSI at the age-18 redetermination. They find that some of the group off SSI found other sources of income, but many are struggling to get by. Both those remaining on SSI and those removed from the SSI rolls have incomes, on average, only a little above the poverty line. Following are some of Loprest and Wittenburg's findings about these subgroups:

³ D. Wayne Osgood, E. Michael Foster, Constance Flanagan, and Gretchen Ruth, "Programs and Policy Goals for Helping Vulnerable Youth as They Move into Adulthood," *Network on Transitions to Adulthood Policy Brief*, Issue 18, February 2005.

	On SSI	Off SSI
Gender		
Female	44.9%	32.6%
Male	55.1%	67.4%
Living Arrangement		
2-parent family	27.0%	17.1%
Single-parent family	37.3%	40.1%
Other relative/guardian	23.9%	26.4%
Alone/institution	10.6%	15.3%
Ratio of total household income to poverty level	1.17	1.10
Percent below poverty	37.0%	28.7%
Sources of household income		
<u>Earnings</u>		
Parental earnings	41.1%	35.0%
Own earnings	13.2%	38.4%
Any earnings	46.3%	61.7%
<u>Government transfers</u>		
Welfare	13.5%	8.0%
General assistance	1.1%	1.9%
Other SSA benefits	19.0%	11.4%
Any government transfer	30.9%	19.4%
<u>Other income</u>		
Child support	9.6%	10.9%
Pension and annuity	3.3%	4.3%
<u>Other supports</u>		
Food Stamps	29.4%	29.2%
Housing assistance	7.7%	10.9%
<u>Health insurance</u>		
Medicaid	92.5%	24.8%
Any private insurance	10.5%	15.3%
No insurance	3.5%	55.2%
Education		
Graduated, in post-secondary school	7.0%	4.4%
Graduated secondary school	41.2%	45.3%
In secondary school	16.7%	2.1%
Dropout	35.0%	48.2%
Current activities		
Employed full-time	1.9%	21.9%
Employed part-time	10.1%	15.1%
Enrolled in school	23.7%	6.5%
In vocational training	13.6%	9.1%
None of the above	59.3%	51.7%
Ever arrested	18.6%	31.8%

While more of the group off SSI are working and a smaller percentage of the group off SSI are in households below the poverty level, their total household income is below

that of the group still on SSI and is only slightly above the poverty level. More than half have no health insurance. Only half of them have graduated from secondary school. More than half of the off-SSI group are neither employed, enrolled in school, nor in vocational training. Nearly a third of them have been arrested.

The NSCF also provides data on the health and disability of the post-transition group. Those off SSI have fewer health care needs than those still on SSI, but they still have a significant level of needs.

	On SSI	Off SSI
Has a special care need	88.3%	71.4%
Needs or uses more services compared with children of same age	66.5%	43.6%
Needs or uses medicine prescribed by a doctor	56.4%	36.3%
Limited in ability to do things like most children of same age	69.7%	48.7%
Needs or gets special therapy	27.2%	13.8%
Needs or gets mental health treatment or counseling	41.5%	33.0%
Uses special medical equipment	16.1%	7.8%
Needs help with personal care needs (eating, bathing, dressing, getting around inside home)	28.9%	5.4%
Needs help with handling routine needs (preparing meals, managing money, doing housework, managing medication)	74.8%	41.1%

THE ROLE OF THE EDUCATIONAL SYSTEM

The cash benefits that SSI youth receive, and the Medicaid health insurance that almost all of them also receive, are clearly important to them and to their families. But those benefits do not themselves prepare SSI youth for adulthood. Other institutions, particularly the educational system, play a greater role in that preparation.

Individuals with Disabilities Education Act Requirements

The Individuals with Disabilities Education Act (IDEA) establishes school systems' responsibilities for special education students. IDEA was passed in 1975 and became effective in 1978. Major amendments were passed in 1997. Congressional findings accompanying those amendments state: "Disability is a natural part of the human experience and in no way diminishes the right of individuals to participate in or contribute to society. Improving educational results for children with disabilities is an essential element of our national policy of ensuring equality of opportunity, full participation, independent living, and economic self-sufficiency for individuals with disabilities."

IDEA guarantees that all students with disabilities aged 3 through 21 have the right to a "free and appropriate public education," ending when a student graduates with a regular high school diploma. IDEA applies to students who have a disability resulting in a need for special education and related services. The written Individualized Education Program (IEP) is the focal point of the IDEA. Developing the IEP begins with a comprehensive

individual evaluation. The IEP is to set out in detail the nature of the student's educational needs, the services to be provided, and specific goals for the student. The IEP must also include provisions to assist students in making the transition from school to adult living. Beginning at 16, the IEP is to include a full transition services plan, including identifying the responsibilities of agencies other than the schools to provide services.

The Individuals with Disabilities Education Improvement Act, passed in 2004, reauthorized IDEA. It clarified that one of the primary purposes of the law is to ensure a free appropriate public education designed to meet each student's unique needs and to "prepare them for further education, employment and independent living." Schools were required to set clear and specific transition goals beyond secondary school.

The requirements of IDEA are clearly of great potential benefit to SSI beneficiaries who receive special education as they approach the transition to adulthood. Not all SSI youth are in special education, but a large percentage are. It is estimated that about two-thirds to three-quarters of SSI youth ages 14 to 17 are in special education. Data from school staff in the NLTS2 indicate that transition planning does in fact take place for special education students and that 96 percent of 17 to 18 year olds have transition plans.

Individuals with Disabilities Education Act Performance

The quality of this planning, however, is probably not what Congress envisioned when it passed the IDEA legislation. School staff reported in the NLTS2 that nearly 20 percent of secondary school students have transition programs that are only somewhat well suited or not at all well suited to meet their transition goals. Research has shown that parent participation in transition planning is an important element in successful transitions. School staff reported in the NLTS2 that students in the lowest household income group were less likely to have parents that actively participated in transition planning. Parents reported that they were not as involved as they would like in IEP decisions. They said that the school mostly decides students' goals for about half the students.

The content of the IEPs is often defective. A National Council on Disability (NCD) report in 2000 stated that the Department of Education had found 20 States out of compliance with standards on the content of IEPs.⁴ For example, of 17 IEPs reviewed in a New Jersey school district, 16 showed identical goals and objectives. In Kentucky, 14 of 53 IEPs reviewed did not include goals and objectives to address each of the students' needs identified on the IEP. State violations of content requirements were often widespread, affecting a large percentage of IEPs in the State.

Whatever the quality of the planning process or the IEPs, the services themselves may not be available. SSI children, especially those in low-income areas, may not have sufficient supports available for their IEPs. This lack of availability, in turn, may reduce the expectations that parents and school staff have for many children. A student in a poor

⁴ National Council on Disability, *Back to School on Civil Rights*, January 25, 2000.

school district may not have access to needed services, reducing expectations for independent living and employment after age 18.

KNOWLEDGE GAPS IN THE TRANSITION PROCESS

Studies of the transition process have questioned whether school personnel have, or should be expected to have, the needed level of knowledge about SSI work incentives and the redetermination process to help youth and their families make informed decisions. Uncertainty about program rules is likely to make beneficiaries and families reluctant to take steps that they fear may jeopardize their eligibility for SSI or for Medicaid. Students and their families lack knowledge as well. The NCD's Youth Advisory Committee reported that students and their families lacked information about IDEA, preventing them from obtaining needed support services.⁵

Beneficiaries and their families also lack information about the transition process, work incentives, and the impact of work on benefits. The Benefits Assistance Resource Center at Virginia Commonwealth University reports that beneficiaries and their families ordinarily do not know that the age-18 redetermination is required or how it differs from regularly scheduled continuing disability reviews that they may have had under the childhood disability standard. The Center reports that folklore about disability benefits is very influential and that most of the information spread among families about disability benefits is either incomplete or incorrect. This misinformation is often reinforced, the Center says, by school personnel, vocational rehabilitation counselors, and even SSA employees.

Under the Ticket to Work and Work Incentives Improvement Act of 1999, SSA awarded cooperative agreements to community organizations in every State, known as Benefits Planning, Assistance, and Outreach (BPAO) projects. These BPAO projects were established to provide all disability beneficiaries, including transition-aged youth, access to benefits planning and assistance services. As of September 30, 2005, these projects had provided services to about 14 thousand persons between ages 14 and 22, only 7.3 percent of the total population served and a small fraction of the transition-aged population.⁶

Other observers have also commented on the lack of accurate information on the part of beneficiaries and caregivers. It has been reported that frequently misinformation and fear of losing benefits have led beneficiaries to limit work alternatives, refusing employment despite a desire to enter the workforce.⁷ Others speak of a need to "demystify" the age-18 redetermination process. "When the child or young adult is receiving SSI, the usual myths about benefits and work often persist, with parents often resistant to having their child work for fear of an immediate end to cash benefits and

⁵ *Perspectives on the Individuals with Disabilities Education Act: Youth with Disabilities and Others Respond*, November 20, 2002.

⁶ *Social Security Disability Benefit Issues Affecting Transition Aged Youth*, January 2006.

⁷ Valerie Brooke, "Benefits Planning and Outreach Projects: Providing Beneficiaries with Information," in V. Gaylord, T.P. Golden, S. O'Mara, and D.R. Johnson (eds.), *Impact: Feature Issue on Young Adults with Disabilities & Social Security Administration Employment Support Programs*, Minneapolis: University of Minnesota, Institute on Community Integration, 2002.

Medicaid.”⁸ The National Center on Secondary Education and Transition lists myths that may discourage SSI youth from taking a job: that people who work are not eligible for SSI; that people who work will lose cash benefits and/or Medicaid; and that benefits will stop if they enter a training program.⁹ NSCF data support these statements about lack of information. Loprest and Wittenburg report that only 22 percent of pre-transition SSI recipients surveyed said that they had ever heard of SSA work incentives or discussed them with an SSA representative.

CLOSING THE KNOWLEDGE GAPS

SSA and its partners should implement an early notification process.

SSA has a limited but clear and important role in transitioning SSI youth to adulthood. The educational system must continue to play the leading role in the transition process, but SSA can help both educators and beneficiaries and their families by making information available. We have frequently stated that SSA’s disability programs should be more work-oriented. The experience of the age-18 redeterminations since 1996 has been that about a third of SSI youth have their benefits stopped at age 18 because it is determined that they do not have a disability that prevents them from working. Unfortunately, they are transitioning into a young adulthood in which recent data show only 22 percent of them employed full-time and 15 percent employed part-time. This represents a waste of their young lives and a waste of a valuable national asset.

The SSI youth transition process is an opportunity to change this gloomy picture by helping a portion of SSI youth make a transition to self-supporting employment. Beneficiaries and their families and the educators who assist them need good information in order to make good choices.

We recommend that SSA begin a process of early notification of SSI youth and their parents or caregivers on the subject of the age-18 redetermination. The first notice should be sent to beneficiaries when they turn 14, to let them know that the age-18 redetermination will take place and to inform them about IDEA and how an IEP can help them prepare for the transition to adulthood. The second notice should be sent at age 16, reminding them about the age-18 redetermination, giving them further information about the IEP process and the transition plan it should include, and providing information about SSI work incentives and the effect of work on SSI benefits. The notice should also tell them how to contact their local SSA work incentive liaison as a knowledgeable source of information on work and benefits.

SSA should also work with the Department of Education to identify appropriate persons in the educational system to receive information about the age-18 redetermination process, work incentives, and the effect of work on benefits. The

⁸ James R. Sheldon, Jr., and Thomas P. Golden, *Conducting Outreach to Transition-Aged Youth*, Cornell University Work Incentive Support Center, Policy and Practice Brief 25.

⁹ National Center on Secondary Education and Transition, *Parent Brief*, March 2003.

appropriate educators should also be told how to contact their local SSA work incentive liaison for further information or for consultation about specific cases.

ADDITIONAL RECOMMENDATIONS

A fresh look at work incentives for youth in transition is needed.

SSI work incentives are complex, and interactions with other means-tested programs make beneficiaries' decisions about work even more complex. The effect of SSI work incentives is reduced by potential reductions of benefits from other transfer programs, plus Federal, State, and local taxes, as well as the potential loss of medical insurance. This combination is equivalent to a high cumulative marginal tax rate for individuals receiving benefits from multiple programs. In our comments on the SSI program last year, we referred to a demonstration project known as Work Incentives for Participants in the Florida Freedom Initiative, which will end in March 2007. Participating SSI beneficiaries will have an earned income disregard of \$280, 4 times the amount in current law. This means that the first \$280 of earnings per month will have no effect on their SSI benefits. We look forward to the results of this demonstration project. Increasing work incentives for all program participants would be expensive, but the expense could be offset somewhat by some of the program simplifications we suggested last year in our statement on the SSI program. Other work incentives should also be re-examined. For example, the student earned income exclusion ends at age 22, but the average age of entry to postsecondary education for students with disabilities who receive SSI benefits is 40.¹⁰

SSA is currently conducting youth transition demonstration projects in 6 States: California, Colorado, Iowa, Maryland, Mississippi, and New York. The demonstration projects will provide empirical evidence on the impacts of changes in SSI rules and enhanced coordination of services on work activity and earnings. SSA has recently awarded a contract for a national evaluation of these projects. While we recognize that, because of the age of the target population, evaluating the implications for work for these young people will be a long process, we do believe that the ultimate findings will be valuable to researchers and public policymakers in the long term.

Publication and analysis of a broader range of data will foster better decisions by beneficiaries, families and policymakers.

The data on age-18 redeterminations published in the *Annual Report of the Supplemental Security Income Program* are helpful, but limited. To assist SSI youth, their families, and educators, SSA should add to the data it already publishes data on cessations and continuations by State and by type of disability. Given what we know about their health limitations, lack of health insurance, and low income, it is possible that the health of those

¹⁰ The National Postsecondary Student Aid Survey obtained information on 50,000 undergraduate students in 2000. The mean age of postsecondary enrollment for all undergraduates with disabilities was 33 years; for SSI beneficiaries it was 40 years of age. Hugh Berry, Megan A. Conway, and Kelly B.T. Chang, "Social Security and Undergraduates with Disabilities: An Analysis of the National Postsecondary Student Aid Survey," National Center on Secondary Education and Transition *Information Brief*, October 2004.

whose benefits are terminated at age 18 may worsen to the point that they are eligible for benefits. SSA should also include in the *Annual Report of the Supplemental Security Income Program* data on the extent to which those terminated at 18 later apply for and receive benefits again. Policymakers may want to consider options to assist that group in the transition process and prevent later dependence on benefits.

The NSCF is an important resource that can provide policymakers with a great deal of insight into the workings of the SSI program and how it can be improved. SSA is to be commended for funding the survey. It should encourage researchers to make use of the public use data from the survey. Linking administrative data to the survey data makes the NSCF an even more powerful resource. SSA should use this resource and publish results for use by the wider research community. It should also make linked survey and administrative data available to qualified researchers to the greatest extent possible, consistent with privacy concerns.

CONCLUSION

The age-18 redetermination is a critical time in the life of a vulnerable population. Data from the NSCF show that most of those ages 19 to 23 whose SSI benefits have been stopped are not employed nor are they enrolled in school or in vocational training. Nearly half of them have dropped out of secondary school. Many have a significant level of health needs, but a majority have no health insurance. The educational system has a major responsibility to prepare them for the transition to adulthood, but educators are not sufficiently informed about the SSI program and the advantages of work for SSI beneficiaries. Parents and caregivers also lack information.

By taking a more active role in informing educators, parents, and caregivers, SSA can help make an improvement in the lives of at least some of those who transition off benefits. We are aware that SSA is already hard-pressed to meet its current commitments. But we believe that the agency can help SSI youth transition to a more productive adulthood by taking on this more active role and that the Congress should support it in doing so.

Hal Daub, Chairman

Dorcas R. Hardy

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APPENDIX TO SOCIAL SECURITY ADVISORY BOARD STATEMENT

SSI Age-18 Redeterminations— Outcomes by State

Data on outcomes by State show a considerable variation in cessation rates among the States. The following chart displays the initial and ultimate cessation rates for each State for FY 2003. The national cessation rate for the initial decision was 40.8 percent, and the State rates varied from 13.2 percent in Vermont to 54.9 percent in Mississippi. The ultimate cessation rate is the cessation rate after all appeals. The national rate was 30.5 percent, and State rates ranged from 2.6 percent in Vermont to 43.7 percent in Delaware.

As with other aspects of decision making on disability, we are concerned by State-to-State variations in this national program. We hope that the Disability Service Improvement plan that SSA will soon begin to implement will reduce this variation.

