# Implementation and Analysis of Public Law 98–460—Section 1619 (The Social Security Disability Benefits Reform Act of 1984)\*

The following is a reprint of the report to Congress on section 1619 of the Social Security Act prepared by the Department of Health and Human Services in response to a provision of the Social Security Disability Benefits Reform Act of 1984 (Public Law 98–460). It also includes some of the report's appendix material. In addition to calling for an evaluation of the provision's effectiveness, that legislation extended the temporary authority of the provision through June 30, 1987. Section 1619 was originally enacted in 1981 as a demonstration project to remove work disincentives to supplemental security income (SSI) recipients by providing special benefits to those who work despite disabling impairments. It extends cash and Medicaid benefits to individuals whose earnings are too high to permit eligibility for regular SSI payments (section 1619(a)), and provides Medicaid coverage to persons whose earnings are high enough to preclude eligibility for regular SSI payments and special payments under section 1619(a), but which may not be sufficient to provide for adequate medical care (section 1619(b)). Before these provisions were enacted, SSI recipients who were disabled could lose SSI eligibility and Medicaid protection if they engaged in substantial gainful activity. As of August 1985, 2.6 million blind and disabled individuals were on the regular SSI eligibility rolls. Of these, 132,155—or 5 percent—had at least some earnings. Average earnings for the SSI disabled working population in 1985 were \$112 a month, compared with \$475 a month for individuals covered by section 1619(a) and \$674 monthly for those covered by section 1619(b).

#### Overview

#### **Background**

Section 1619 of the Social Security Act was enacted as a 3-year demonstration project effective January 1, 1981, to remove work disincentives for recipients of supplemental security income (SSI) disability benefits who work despite continuing disabling impairments. Prior to enactment, disabled recipients could lose eligibility for cash benefits and Medicaid coverage if they engaged in substantial gainful activity (SGA) (as evidenced by specified levels of earnings from work or self-employment). Section 1619 comprises two basic provisions:

• Section 1619(a) extends cash and Medicaid benefits

\*For an unabridged copy of the report, containing all the appendices in their entirety, specify the above title and direct your request to the Office of Public Inquiries, Social Security Administration, Room 4100 Annex, 6401 Security Boulevard, Baltimore, Maryland 21235. Orders may also be initiated by calling (301) 594-7700.

- to individuals whose earnings preclude eligibility for regular SSI cash benefits (as income increases, cash benefits are reduced); and
- Section 1619(b) extends Medicaid coverage to individuals whose earnings, although high enough to preclude eligibility for SSI and section 1619(a), may not be enough to provide for medical care.

Public Law 98-460 extended the temporary authority of section 1619 through June 30, 1987. At the request of the House Committee on Ways and Means, the Department of Health and Human Services (HHS) conducted a study to evaluate the effectiveness of section 1619 in reducing work disincentives and to determine the characteristics of individuals benefiting from its protection. This report is an outgrowth of the data collection and analysis activities performed by HHS during 1985 and 1986.

#### Training and Outreach

In addition to undertaking a study of the impact of sec-

tion 1619, HHS, in cooperation with the Department of Education and State and local vocational rehabilitation agencies, set in motion a vigorous campaign to increase public awareness and understanding of section 1619 and the other work incentive provisions of the Social Security Act. A number of specific outreach efforts, put in place during the spring and summer of 1985, have been integrated into HHS's ongoing program of public information. Many of these initiatives evolved as byproducts of an equally vigorous campaign to heighten the awareness of Social Security Administration (SSA) interviewing staff by means of intensive and specialized training on work incentives. The specific training and outreach initiatives are listed and discussed on pages 18–20.

As of August 1985, 2,611,900 blind and disabled individuals were on the SSI rolls. Of these, 132,155 (5.0 percent) had some earnings. Also as of August 1985, 816 individuals were participating in the section 1619(a) program (an increase of 101 percent over August 1984); and 7,954 were participating in the section 1619(b) program (an increase of 16.9 percent over August 1984). These increases appear to be, at least in part, the result of intensified training and outreach efforts.

#### **Data Sources and Study Methodology**

Although several sources of data were used in conducting the HHS study, the following major sources were used in developing this report:

- SSI administrative files—which allowed SSA to look beyond current section 1619 participation levels at individuals who had participated in the program at any time during the period between May 1981 and May 1985;
- The 1985 SSI Medicaid Recipient Survey ("The Survey")—designed to elicit specific demographic data as well as facts and attitudes toward disability and disability as it relates to employment and the desire to work. A total of 1,660 Survey questionnaires were tabulated and analyzed. (A full report of the Survey methodology and findings is attached as Appendix C of this report); and
- A Health Care Financing Administration (HCFA) study of Medicaid utilization in 11 States (representing nearly half of the section 1619 population). (A report of the HCFA study is attached as Appendix E.)

## Costs and Savings From the Section 1619 Program

Section 1619 reduces program costs only to the extent that SSI savings exceed Medicaid costs. SSI savings are calculated on the basis of an attitudinal survey of section 1619 participants. These results are subjective and the actual behavior of future 1619 participants may vary considerably from the survey results. This leaves room for substantial variation in projected SSI savings, and savings could be less than the estimated Medicaid costs.

#### **Study Findings**

Study results highlight the high turnover rate of participants in the section 1619 program. Although point-in-time participation levels are low compared to more broadly based programs, approximately 55,000 individuals had been covered by section 1619 for some period since the program's inception in 1981. Within 3 years, turnover was such that participants' program status was as follows:

• 1619(a) participants

—62.3 percent were no longer covered by SSI (regular program or section 1619(a) or (b))
—15 percent were again covered by the regular SSI program.

• 1619(b) participants

—58.3 percent were no longer covered by SSI (regular program or section 1619(a) or (b)) and —24.3 percent were again covered by the regular SSI program.

Although there have been many individual successes, the program's potential for reducing dependency among the entire disabled population is limited to a very small fraction. In 1985 average monthly participation was 7,300, or less than 0.2 percent of all SSI disabled individuals.

• Characteristics of the section 1619 population. Results of the Survey showed section 1619 participants to be significantly younger than the SSI disabled population as a whole. More often they are white and male, and a large portion (over 40 percent of those in section 1619(a)) are mentally retarded. Psychiatric disability was the second most common impairment. The following chart provides details of these findings:

Percent 1619(a)	Percent 1619(b)	Percent all SSI disabled
84.0	79.0	39.0
<del></del> 70	.0	60.0
58	.0 0.	40.0
64.0	48.1	47.6
40.5	18.7	22.0
8.6	11.7	2.6
	84.0 	1619(a) 1619(b) 79.0

- Income from work. The Survey showed that average monthly earned income was \$475.00 for section 1619(a) participants and \$674.00 for section 1619(b) participants. These figures compare to an average of \$112.00 for the entire SSI disabled working population and \$1,169.00 for all working United States residents ages 18-39.
- Work experience. For both section 1619(a) and (b) participants, "service occupations" represents the largest single employment category (54.0 percent of those under section 1619(a) and 39.9 percent of those under section 1619(b)).

Most participants were employed in private industry (67.5 percent of those under section 1619(a) and 50.7 percent of those under section 1619(b)). Almost twice as many section 1619(b) participants engaged in sheltered work as compared to section 1619(a) participants (26.7 percent vs. 14.8 percent).

- More than two-thirds (66.8 percent) of section 1619(a) participants worked at least 12 full months. About one-half (50.7 percent) of section 1619(b) participants did so.
- Health care coverage. Approximately one-third of section 1619(b) participants responding to the Survey reported having some type of private health insurance. For about half of the section 1619(a) participants and 28 percent of the section 1619(b) participants, Medicaid was the only type of health care coverage. The chart below summarizes specific combinations of coverage reported by both groups:

Type of coverage	Percent 1619(a)	Percent 1619(b)
Medicaid only	50.5	27.6
Medicaid and Medicare	16.5	20.4
Medicaid and private plan	12.8	11.5
Medicaid, Medicare, and private plan	4.5	6.3
Medicare only  Medicare and private plan	•••	6.0
Deinite also sale	4.8	14.4
Private plan only	11.0	12.9

Although the study did not gather individual data on catastrophic coverage, 10 percent of section 1619(b) participants were residents of Medicaidsupported institutions. (This group would usually be eligible for Medicaid without section 1619 protection.)

- Medicaid utilization. Based on HCFA research, Medicaid utilization by section 1619 participants is relatively low compared with the SSI disabled population at large. The per capita expenditure rate for all disabled SSI recipients is 2.3 times greater than the expenditure rate for section 1619 participants.
- Motivational impact of section 1619. Survey results suggest that the majority of section 1619 participants would not lessen work efforts in order to retain Medicaid eligibility. (Only 30 percent of 1619(a) participants and 21 percent of 1619(b) participants would reduce work activity without section 1619 protection.)

Survey results also suggest that many participants either have Medicare at the time they begin work and for some time thereafter or have private health insurance through employment.

The logical conclusion is that retention of Medicaid eligiblity is not as significant an incentive as is commonly believed. However, Survey findings suggest room for further research into the relationship between health care coverage and work effort.

#### Introduction

#### Purpose and Scope of the Report

Section 1619 of the Social Security Act is a temporary provision, originally enacted as part of the "Social Security Disability Amendments of 1980" (Public Law (P.L.) 96-265). The provision provides a continuation of special supplemental security income (SSI) payments and/or

Medicaid coverage for recipients of SSI disability benefits who work despite the continuation of their impairments. The demonstration was originally effective through December 31, 1983, but has been extended twice; first administratively, under section 110 of the Act, and shortly thereafter by P.L. 98-460, the "Social Security, Disability Benefits Reform Act of 1984," enacted October 9, 1984. P.L. 98-460 extended the section 1619 provisions through June 30, 1987.

P.L. 98-460 directed the Secretary of Health and Human Services (HHS) and the Secretary of Education to "jointly develop and disseminate information and establish training programs for staff personnel, with respect to the potential availability of benefits and services for disabled individuals under the provisions of ..." section 1619. The Secretary of HHS was further directed to "... provide such information to individuals who are applicants for, and recipients of, benefits based on disability under this title ..." and to establish training programs for the staffs of the Social Security Administration (SSA) district offices.

During the deliberations prior to enactment of P.L. 98-460, it was agreed that additional data collection and analysis would be essential to a complete evaluation of the section 1619 program. It was agreed also that SSA and the Health Care Financing Administration (HCFA), as well as State agencies, would further study a number of factors that may influence participation in the section 1619 program. Data concerning the characteristics of individuals benefiting from section 1619, the effects on work effort, and health care utilization were to be obtained and analyzed. (See excerpt in Appendix D, House Committee Report 98-618, for a further description of the suggested data collection.)

SSA and HCFA used a number of data collection and evaluative techniques to produce the information contained throughout the report. They included:

Analysis of characteristics of section 1619 participants contained in SSA administrative files including: point-in-time data pertaining to State of residence, age, race, sex, types and amounts of earned and unearned income, institutional status, and types of impairments. The point-in-time data show the growth in program participation.

Health care services data for section 1619 participants gathered partly from Medicaid Management Information Systems (MMIS) in four States for the most recent year available (1981 or 1982) and aggregate recipient, utilization, and expenditure data for fiscal year 1984 collected from Medicaid agencies in seven States with a relatively high pro-

portion of section 1619 enrollees.

An SSA mail Survey covering four groups: section 1619(a) participants; section 1619(b) participants; disabled SSI recipients with low earning levels; and disabled SSI recipients who had no earnings. The survey was designed to obtain data not available in administrative files and was directed at 3,256 individuals. SSA obtained a 60-percent response rate with 1,660 questionnaires, 84 percent of which were suitable for tabulation and evaluation.

— An indepth review by SSA of program experience for a small sample of participants over the period 1981-85. SSA administrative files were used to follow over 400 section 1619(a) and (b) participants and their eligibility status as earnings increased, decreased, or stopped between May 1981 and May 1985.

 Anecdotal information collected by SSA field staff in face-to-face interviews with program

participants.

The purpose of this report is to describe implementation of P.L. 98-460 and to provide further data as specified in the committee report. The report provides first a brief overview of the SSI program and work incentives, including effects of the "Social Security Disability Amendments of 1980." It then discusses implementation of the training and outreach provisions of P.L. 98-460, and presents detailed information on the characteristics of section 1619 program participants—their employment, and work.

The report attempts, where possible, to present analyses and conclusions drawn from study data or other available information. In the interest of objectivity, it was not always possible to explain or rationalize the findings. In these latter instances, the information is presented without comment to avoid leading the reader to conclusions not fully supported by the available evidence.

#### Work and the SSI Program

The basic program. Prior to enactment of the Social Security Disability Amendments of 1980 (P.L. 96–265), an individual who received SSI on the basis of disability and who worked faced a substantial risk of losing SSI benefits. Loss of SSI eligibility also frequently meant the loss of Medicaid benefits, since Medicaid eligibility is, in many instances, tied to SSI cash payment eligibility. Before the 1980 amendments; the only work incentive provisions available to assist disabled SSI recipients in their attempts to enter the workforce were income exclusions, the trial work period (TWP), and provisions for individualized plans to achieve self-support.

The SSI program was designed to provide a minimum level of support to recipients by supplementing other means of financial livelihood. Income received from other sources results in a reduced need for assistance from the SSI program. SSI recipients who work and have earnings have their SSI benefits partially offset to adjust for this additional source of income. Earnings exclusions that are applied before the offset is made result in the recipient losing less than one dollar in benefits for each two dollars of earnings. <sup>1</sup> These exclusions recognize the additional costs

associated with employment and assure that a recipient will always have higher gross income when he or she works than if he or she does not.

Prior to the 1980 amendments, income received by an SSI recipient in a sheltered workshop was considered earned income only if an employment relationship was found to exist between the recipient and the workshop. If an employment relationship did not exist, the income was treated as unearned income subject to a dollar-for-dollar offset, after application of the general \$20 per month income exclusion. Therefore, the earned income exclusions associated with other forms of earnings were not always available to disabled recipients who worked in sheltered workshops.

The income exclusions served to protect an individual's SSI benefits if he or she had limited earnings. However, individuals whose SSI benefits were based on disability could lose SSI eligibility if their earnings increased to the substantial gainful activity (SGA) level.<sup>2</sup>

Then, as now, a severely impaired individual (who is not eligible for SSI based on age or blindness) may qualify for SSI disability payments only if he or she is unable to engage in SGA by reason of a medically determinable physical or mental impairment. An individual who is determined to be disabled, then later works and earns at the SGA level after a trial work period (TWP)<sup>3</sup>, is considered able to engage in SGA, and hence no longer meets the definition of disability contained in the law.<sup>4</sup> Prior to 1981, loss of disability status meant a loss of status as an "SSI recipient" which, in turn, frequently meant loss of Medicaid eligibility.

Work and earnings prior to the 1980 amendments were treated similarly under the SSI and the social security disability insurance (SSDI) programs. SSDI beneficiaries did not lose benefits due to earnings below the SGA level since SSDI does not have an income test. An SSDI beneficiary who returned to work and had average earnings at the SGA level after a TWP also faced benefit cessation. For concurrently eligible disabled individuals, the two programs generally operated in tandem with an individual experiencing similar effects on eligibility for SSI and SSDI benefits.

<sup>&</sup>lt;sup>1</sup>The first \$65 of a recipient's monthly earnings and one-half of the earnings in excess of \$65 are excluded in computing the SSI benefit payable. An additional general \$20 income exclusion can be used to offset earnings if not already used to offset any other income a recipient may have. An SSI benefit in the amount of \$336 (the full Federal benefit for an individual effective January 1986) is subject to total offset when an individual has monthly earnings with no other income in the amount of

<sup>&</sup>lt;sup>2</sup>SGA is the performance of significant physical and/or mental activities in work for pay or profit, or in work of a type generally performed for pay or profit. Because earnings provide an objective and feasible measure of work, an employee's earnings and a self-employed individual's earnings and/or activity are used as the measure of SGA. The SGA level has been \$300 in average earnings per month since 1980, however, under some limited circumstances, earnings under \$300 constitute SGA.

<sup>&</sup>lt;sup>3</sup>A trial work period provides individuals with 9 months (not necessarily consecutive) in which they can test their ability to work without the fear of losing eligibility because they are determined no longer to be disabled. A trial work month is one in which an employee earns \$75 or more, or a self-employed individual earns \$75 or more or works more than 15 hours. After 9 months of trial work, an individual's continued disability is evaluated.

<sup>&</sup>quot;If an individual is found capable of performing SGA, his or her disability is ceased; however, the disability benefits continue for the month of disability cessation and the 2 following months (referred to throughout this report as the 3 additional months of benefits).

While the TWP applies both to SSDI and SSI, and has been a part of the SSI program since its inception, another work incentive applies only to SSI recipients. This provision permits a disabled or blind SSI recipient who has an approved plan for achieving self-support (PASS) to set aside income (and resources) for a work goal such as education, vocational training, starting a business, or purchasing work-related equipment. Income and resources set aside under a PASS are excluded from the SSI income and resources tests but do not influence the determination of ability to engage in SGA.

Work and the SSI and SSDI programs as modified by the "Social Security Disability Amendments of 1980." The Social Security Disability Amendments of 1980 contained a number of work incentive provisions for the SSDI and the SSI programs in addition to the section 1619 provisions. They are:

- Extended Medicare coverage: SSDI program only—Section 104 provided for extended Medicare coverage for SSDI beneficiaries whose entitlement terminated because of ability to engage in SGA. Previously, Medicare coverage stopped when SSDI entitlement ended. The new provision extended coverage for 24 months after SSDI termination.
- Continuation of payments, impairment-related work expenses, and special reentitlement: Both the SSDI and SSI programs—Section 301 provided for continuation of SSDI and SSI payments to individuals after their disability ceased due to medical recovery if they are participating in approved vocational rehabilitation plans and SSA determines that completion of the programs will increase the chances of permanent removal from the disability rolls. This provision assists individuals whose medical improvement occurs before completion of vocational training.

Section 302 provided for the exclusion from earnings of the cost of items and services needed in order to work that were paid for by the individual. These impairment-related work expenses (IRWE's) are excluded from earnings used in the determination of SGA and earned income used to compute ongoing SSI monthly payments. The IRWE exclusions are not applied in the determination of income for purposes of initial SSI eligibility.

Section 303 provided for a period of 15 consecutive months following the TWP during which SSDI or SSI disability payments that ceased due to SGA can be reinstated if the disabling impairment continues and work at the SGA level stops.<sup>5</sup> This provides a reentitlement period during which individuals can attempt to work without having to reestablish disability status if the attempt is unsuccessful (i.e., earnings fall below the SGA level).

Sheltered workshop earnings: SSI program only—Section 202 provided that remuneration for services performed in sheltered workshops or work activities centers will be treated as earned income. This change makes it possible to apply the earned income exclusions to earnings that previously would have been subject to a dollar-for-dollar offset.

The impact of section 1619 cannot be assessed without acknowledgement that the 1980 disability amendments as a whole acted to broaden work incentives for SSI disability recipients. These increased work incentive provisions presented the framework for section 1619 implementation. The other legislated work incentive provisions interact with both the section 1619 program and a heightened public interest in providing a meaningful work climate for disabled individuals to create a backdrop for the section 1619 demonstration.

Section 1619. There had been concern about the application of the SGA test in the SSI program for the needy disabled since the program's inception. The need to apply the test in the SSI program stems from the fact that the SGA concept is an integral part of the definition of disability used in the SSDI program and adopted in its entirety for the SSI program. The level of earnings used to determine whether a person is able to engage in SGA has always been lower than the level of earnings used to determine whether a person is in financial need for purposes of SSI eligibility.<sup>6</sup> This created a situation where an individual who has physical or mental impairments that are so severe that, absent earnings from work, he or she would be found by SSA to be disabled. The earnings, however, (if they constitute SGA) preclude SSI eligibility even though they are lower than the needs level used for the other two components of the SSI population—the blind and the aged-where SGA is not a factor. The same level of earnings that, by one definition are insufficient to preclude eligibility based on need, are also by definition, high enough to preclude a finding of disability for an individual with severe mental and/or physical impairments.

Viewed from the perspective of defining disability for the broad purposes of the SSDI and SSI programs, it has seemed reasonable to use a definition that relates the professional evaluation of the individual's physical and/or mental impairment(s) to the question of whether the person is unable to work as a result of the impairments. Thus, when a person has substantial earnings from current work despite impairments, there is clearly some point at which the person cannot be considered to be unable to engage in SGA because of a physical or mental condition. The issue more properly becomes one of defining SGA.

In the debate leading to enactment of the 1980 amendments, the Congress explored how SGA should be defined

<sup>&</sup>lt;sup>5</sup>The 15-month reentitlement period commences with the month immediately following the ninth month of trial work. The 15-month reentitlement period commences whether or not a recipient is found to be capable of performing SGA after completing the TWP. The 15 months are consecutive and the first 3 months of the reentitlement period may overlap the 3 months of additional disability benefits, when disability is determined to have ceased after the TWP due to the ability to perform SGA. See footnotes 3 and 4 for a discussion of the TWP and the 3 months of additional benefits.

<sup>&</sup>lt;sup>6</sup>Over the period 1974-79, the SSI breakeven level (for a person with earned income but no unearned income) was roughly \$200 higher than the SGA level; since 1979 the differential (now \$457) has grown sharply. Beginning in 1983, the basic Federal SSI standard (without application of any disregards) has exceeded the SGA level.

for the SSI program. The House-passed bill would have set the SGA level at the SSI breakeven level, thus retaining the definition of disability as the inability to engage in any SGA but nullifying its effect with respect to SSI recipients. This provision had substantial projected cost and raised basic concerns about the use of a different measure of SGA in the SSI and SSDI programs.

The Senate adopted, in what became section 1619, a 3-year "demonstration" that would test the effects of the House approach—in particular the work incentive effects. Thus, under section 1619(a), as under the House bill, a person with a disabling impairment remains eligible for SSI and Medicaid until countable income (earned and unearned) exceeds the breakeven level. The Senate provision, as finally approved by the Congress, made no change in the initial eligibility requirements and, as indicated above, the same definition of disability (including SGA) used in the SSDI program was retained for the SSI program. In other words, section 1619 attempts to reduce work disincentives by continuing SSI cash payments and Medicaid coverage (in some States) regardless of the fact of the impaired individual's ability to perform SGA or having income in excess of the Federal (or State) income standard.

1619(a)—The statutory requirements for section 1619(a) participation are that the individual continue to have the disabling impairment on which disability was established and that he or she has received regular SSI benefits, but lost this eligibility because of engaging in SGA. The individual must also continue to meet the nondisability SSI eligibility requirements. The significant effect of section 1619(a) is that it permits a recipient to continue to receive cash payments beyond the usual 3 additional months of benefits following a determination that eligibility has ceased based on performance of SGA. This includes months during the 15-month reentitlement period when regular SSI disability benefits are not paid because earnings are at the SGA level, as long as the other conditions of eligibility are met. Under 1619(a), disabled SSI recipients can attempt employment or increase their earnings without being left worse off because of the loss of SSI and Medicaid eligibility when their earnings constitute performance of SGA.

Since loss of eligibility for a regular SSI disability benefit due to SGA is a prerequisite, section 1619(a) does not apply to recipients who are eligible based on blindness or age, or to disabled recipients who are in their TWP or are receiving the 3 months of additional regular SSI disability benefits when their disability has ceased.

There are no special payment amounts for section 1619(a) benefits; the regular SSI cash payment computation applies. The only difference between the regular SSI benefit rules and the special section 1619(a) rules is that the special rules allow a severely impaired person to be eligible for cash benefits even if he or she is performing SGA.

Initial eligibility for special section 1619(a) cash benefits is possible only if the recipient was eligible to receive a regular SSI disability benefit in the prior month. Then, special section 1619(a) benefits may be paid for consecutive months until the recipient becomes eligible again under the regular SSI disability rules or is otherwise ineligible.

States that currently supplement SSI disability benefits may elect to supplement the special section 1619(a) cash benefit. Twenty-eight States currently do so. The States (including the District of Columbia) that have elected to have supplemental payments continue under section 1619(a) are:

Alaska	Kansas	Oregon
California	Kentucky	Pennsylvania
Connecticut	Maine	Rhode Island
Delaware	Massachusetts	South Dakota
District of Columbia	Michigan	Tennessee
Georgia	Minnesota	Utah
Hawaii	New Jersey	Vermont
ldaho	New Mexico	Virginia
Illinois	New York	Wisconsin
lanna		

1619(b)—Even if an individual loses cash benefit eligibility (whether regular SSI benefits or special section 1619(a) benefits) because his or her countable income exceeds the "breakeven" point under SSI income counting rules, 7 the individual may be eligible for continued Medicaid coverage if he or she continues to work. Section 1619(b) authorizes continuing SSI recipient status for Medicaid purposes to qualified individuals who work. Although section 1619(b) was designed as a work incentive provision, performance of SGA is **not** a factor of eligibility. Individuals may also qualify for section 1619(b) during their TWP if total countable income makes them ineligible for regular SSI benefits. Likewise, individuals with relatively low earnings may still meet all the requirements of section 1619(b) because total countable income (work and nonwork) is high. The statutory requirements for section 1619(b) par-

The Statutory requirements for section 1019(b) participants are that they be under age 65 and recipients, for the prior month, of either regular SSI benefits based on disability or blindness or special section 1619(a) cash benefits. An individual must continue to have the disabling impairment or be blind, and must meet all nondisability requirements for SSI eligibility except for earnings. There are two statutory limits on income. First, an individual cannot have unearned income that would preclude eligibility for regular SSI cash benefits. Second, the individual cannot have earnings sufficient to provide the equivalent of SSI and State supplementary benefits and Medicaid for himself or herself. A final statutory requirement for section 1619(b) eligibility is that loss of Medicaid would seriously inhibit the individual's ability to continue working.

SSA uses the "threshold" concept to measure whether an individual has sufficient earnings to provide (for himself or herself) the equivalent of SSI and State supplementary benefits and Medicaid. The threshold is calculated for each State by starting with the annualized gross earnings amount which would reduce SSI cash benefits to zero for an individual with no other income (taking into account

<sup>&</sup>lt;sup>7</sup>See Appendix A, table A-1, for a State-by-State distribution of breakeven points.

that State's supplementary payment level, if any), and adding the State's average annual per capita Medicaid expenditures. These thresholds are published in chart form in SSA operating instructions. The median threshold level in 1985 was \$13,010. If the individual's gross earnings are equal to or less than the threshold amount shown on the chart, the threshold requirement is met. If the individual is not eligible according to this chart, SSA considers whether the individual has medical expenditures that are higher than the average Medicaid expenditures for the State of residence. If so, an individualized threshold is calculated using the individual's actual Medicaid expenditures.

To determine whether the loss of Medicaid would inhibit an individual's ability to continue working, SSA assesses the individual's use of Medicaid. This requirement is met by documenting actual use of Medicaid within the prior 12 months. Actual Medicaid use in the past year is indicative of expected future use. If there was no actual use, SSA accepts the individual's allegation that usage is expected in the future.

Interaction of section 1619(a) and section 1619(b) with Medicaid and regular SSI cash payments—Changes in eligibility factors move section 1619 program participants back and forth between the section 1619(a) and 1619(b) categories and the regular SSI program. The sequencing of these moves can be quite complicated. Given the specific requirements of section 1619(a) and the interaction of all the other statutory provisions with which it coexists (e.g., TWP, SGA, 15-month reentitlement period), there are limited sets of circumstances and time frames within which section 1619(a) eligibility is possible. The earliest month that section 1619(a) can apply is the individual's thirteenth month on the disability rolls (i.e., 9-month TWP plus the 3 months of additional payments must elapse before regular SSI disability benefits stop). During the remaining 12 months of the 15-month reentitlement period, payment eligibility can shift back and forth between the regular SSI rules and section 1619(a) depending on an individual's earning levels (i.e., SGA months versus non-SGA months). In addition, there may be some months where there may be no eligibility for either SSI disability benefits or section 1619(a) benefits, and section 1619(b) may apply or the individual

Even after the 15-month reentitlement period, if the individual does not perform SGA, eligibility may continue under the regular SSI disability rules indefinitely. When the individual performs SGA after the reentitlement period, regular SSI disability benefits may still continue for the 3 additional months if this is the first time SGA was performed by the individual.

may be ineligible for any benefit at all.

Once an individual is receiving section 1619(a) benefits, regular SSI disability benefits are reinstated if earnings drop below the SGA level during the 15-month reentitlement period. After the 15-month reentitlement period, if earnings drop below the

SGA level, the individual is reevaluated for a new period of eligibility based on disability under the regular SSI rules (payments are continued under section 1619(a) pending this determination). If any nondisability factor of eligibility is not met at any time, eligibility for payment under section 1619(a) is suspended (as it would be under the regular SSI program) although eligibility for Medicaid may continue under section 1619(b) if excess earnings caused the loss of cash benefits. If a section 1619(a) recipient recovers medically, benefits terminate immediately except when the vocational rehabilitation (VR) provision contained in section 301 applies (see page 15).

Unlike section 1619(a), continuing recipient status for Medicaid purposes under section 1619(b) is potentially available to any disabled or blind SSI recipient after the first month of SSI eligibility. Section 1619(b) eligibility can occur at any time provided the individual was eligible in the prior month under either regular SSI rules or sections 1619(a) or (b).

Once eligible for section 1619(b), an individual can be reinstated to cash benefit status only through the regular SSI rules, which means reintroduction of the SGA test for disabled individuals. If reinstatement is attempted beyond the 15-month reentitlement period, a new disability determination is required to begin benefits anew. This means the current SSI program connection is broken and current program eligibility is terminated; a new period of eligibility must be established.

The foregoing illustrates that determining eligibility for section 1619 program participation is at times a complex undertaking. The interaction of section 1619(a) and (b) between each other when overlaid with SSI cash payments, Medicaid eligibility, and other work incentive provisions of the law, coupled with fluctuating earnings from work and other income sources, can make individual determinations of eligibility quite difficult.

Further discussion of implementation of the section 1619 program will be offered in succeeding sections of this report. As a backdrop, however, the number of SSI blind and disabled recipients with earnings has increased steadily over time both in actual numbers and percentage

Table 1.—Number and percent of blind and disabled workers, 1976-85<sup>1</sup>

				d disabled kers
Month/Year	Total SSI caseload	Total blind and disabled	Number	Percent of total
December 1976	4,235,939	2,088,242	70,719	3.4
December 1977	4,237,692	2,186,771	83,697	3.8
December 1978	4,216,925	2,249,025	87,697	3.9
December 1979	4,149,575	2,277,859	92,270	4.1
December 1980	4,142,017	2,334,241	99,276	4.3
December 1981	4,018,875	2,340,785	102,632	4.4
December 1982	3,857,590	2,308,849	102,288	4.4
December 1983	3,901,497	2,386,097	108,734	4.6
December 1984	4,029,333	2,499,046	119,256	4.8
September 1985	4,127,557	2,611,900	132,155	5.1

<sup>&</sup>lt;sup>1</sup>SSI cash recipients only, including section 1619(a) participants but not section 1619(b) participants.

<sup>&</sup>lt;sup>8</sup>See Appendix A, table A-2, for a State-by-State comparison of "threshold" amounts.

of the SSI caseload. In December 1976, about 71,000 blind or disabled recipients (3.4 percent of the total) had earnings from wages or self-employment. By September 1985, 132,155 blind or disabled recipients (5.1 percent of the total) had earnings from work. Although this is still a fairly small percentage of SSI recipients working at any given point in time, the percentage having had some earnings since applying for SSI payments is much larger. According to SSA administrative records, over half a million SSI disabled recipients (approximately 20 percent of the current SSI disabled caseload) have had some earnings posted to their records since applying for SSI. Table 1 provides information that illustrates the increased participation of SSI disabled and blind recipients in the workforce.

## Implementation of P.L. 98-460—Section 1619(c)

## Training and Public Information Initiatives—General

The clear expression of congressional intent contained in P.L. 98-460, section 1619(c), resulted in a reintensification of HHS' efforts to publicize the work incentives provided in section 1619(a) and (b), as well as the other incentives contained in P.L. 96-265 and in the basic SSI program. The Administration on Developmental Disabilities (ADD) in the Office of Human Development Services (OHDS) joined forces with SSA in mounting a vigorous outreach and training campaign to assure, in particular, that the section 1619 demonstration was given maximum exposure and that SSI work incentives across the board were both understood by SSA interviewing staff and communicated to the public. Although the topics of training and outreach are discussed separately below, the two became pragmatically inseparable because a number of training efforts led to outreach activities and, conversely, SSA's outreach efforts identified external training needs that were fulfilled in later sessions held with interested groups, both public and private.

#### **Program Training**

During the brief period between the original expiration

date for the section 1619 provisions (December 31, 1983) and enactment of P.L. 98-460, the Secretary of HHS used the demonstration authority in section 1110 of the Act to test further the work incentive assumptions underlying section 1619. The administrative extension itself became a vehicle for heightened awareness of the section 1619 work incentives—on the part of both the SSA executive staff and SSA field office employees.

SSA headquarters teletyped messages to all of its field offices (FO's ) to convey transitional case processing instructions and to inform FO's of the strong probability of a further extension of section 1619 demonstration authority. Preparations were begun for expanding in-service training of SSA interviewing employees upon enactment of continuing authority. This heightened training activity, preceded by several executive staff announcements and directives, began shortly after enactment. The training is ongoing with continual quality monitoring conducted by SSA management from both headquarters and regional offices. Section 1619 program training represents one of the largest training efforts mounted by SSA in recent years. Followup audits have revealed that SSA FO employees are keenly aware of both the section 1619 program and SSI work incentives in general, with the training cited by individual employees as instrumental in this awareness. Individual employees have noted, however, that retention of technical knowledge regarding section 1619 is difficult because of program complexity and the relatively small number of work incentive cases encountered.

Although the various work incentive provisions were already covered in the Agency's comprehensive program training designed for new employees, SSA decided that a special effort was needed to further highlight the Agency's commitment and to provide refresher in-service training to experienced employees. A multidisciplined internal SSA task force developed and distributed a specially prepared national training package on work incentives. The training course consisted of multiple segments covering: TWP; SGA; reentitlement period; expanded Medicare coverage; extended eligibility for vocational rehabilitation participants; IRWE; PASS; and emphasized SSI benefits for people who work (section 1619). As pointed out previously in this report, utilization of the section 1619 provisions depends, in large part, on a thorough understanding of section 1619's role in relation to the other SSI and SSDI work incentive provisions. Because of the interrelationships among the several incentive provisions, SSA decided that, to comply with not only the letter of the law but the spirit as well, an across-the-board training effort on the full range of work incentives was essential.

The in-service training course consisted of:

- A 25-minute videotape overview of work incentives;
- Lesson plans for each work incentive provision;
- Student exercises: and
- Additional reminder charts for continued employee

Section 1619(c), as added by section 14(b) of P.L. 98-460, reads: "(c) The Secretary of Health and Human Services and the Secretary of Education shall jointly develop and disseminate information, and establish training programs for staff personnel, with respect to the potential availability of benefits and services for disabled individuals under the provisions of this section. The Secretary of Health and Human Services shall provide such information to individuals who are applicants for and recipients of benefits based on disability under this title and shall conduct such programs for the staffs of the district offices of the Social Security Administration. The Secretary of Education shall conduct such programs for the staffs of the State Vocational Rehabilitation agencies, and in cooperation with such agencies shall also provide such information to other appropriate individuals and to public and private organizations and agencies which are concerned with rehabilitation and social services or which represent the disabled."

A minimum of 2 hours of training (many offices did more) was mandated for all SSA public contact personnel and their supervisors. Local managers were required to certify that the training had been completed. The initial train-up exercise was completed in all SSA field facilities by mid-June 1985, with additional refresher training continuing as employees take on public contact responsibility. Several SSA regional offices have expanded the nationally prepared material and/or adapted it for use with outside groups.

Upon completion of the intensified in-service training, SSA took a fresh look at the work incentive lesson plans used for new claims representatives. Those lessons have also been enhanced to assure that all SSA interviewers are fully technically proficient as they handle potential work incentive cases.

SSA management is not sanguine that because the train-up effort conducted for P.L. 98-460 has been completed, the emphasis on work incentive training can be relaxed. The complexity of the work incentive provisions as they interact with one another requires continual refresher training. This is being accomplished on a daily basis through SSA's ongoing field in-service training program.

The almost uniform conclusion drawn by SSA managers throughout the organization is that while the train-up effort was a success, even the most experienced SSA employees find the section 1619 program difficult to understand and technically complex.

#### Outreach

A broad outreach campaign was begun by SSA in cooperation with the Department of Education (DE), other HHS components, State and local VR agencies, and numerous community-based private groups shortly following enactment of P.L. 98–460. The Agency used a multifaceted approach to assure the work incentive message was carried to the public at large. SSA went beyond "public information" by committing its staff resources to a targeted effort to enlist the support of public and private organizations serving disabled individuals. The outreach initiative, although begun at the national level, quickly fanned out through SSA's network of FO's to deliver work incentive information nationwide.

Some of the techniques and tools used to publicize section 1619 and its related provisions were:

- Use of 35 national "umbrella" organizations as intermediaries for communication with affiliated community-based service providers, agencies, professionals, and consumers. Examples:
  - —The Association of Retarded Citizens furnished material to over 2,000 affiliated State and local chapters and their membership of parents, professionals, and others.
  - —Goodwill Industries of America distributed materials throughout its nationwide network of 174 affiliated VR workshops.

- —The National Association of Rehabilitation Facilities prepared and distributed a booklet on work incentives as a reference for rehabilitation facilities and service providers.
- A cooperative venture with the ADD of the OHDS in conducting a series of special briefings to assist State developmental disabilities councils in their employment advocacy initiatives.
- Parallel regional campaigns that led to use of SSA staff in local level meetings of agencies serving disabled and blind people.
- Providing technical support to DE in reaching State VR agencies. SSA's in-service training material was shared with, and used by, VR directors at the State and local level. Shared SSA/VR training sessions were held in many locales.
- Expanding development and distribution of public information materials including:
  - —Distributing to SSA FO's 2.1 million copies of Publication No. 10375, Improvements in the Social Security Disability Program, a one-time leaflet summarizing the 1984 disability amendments. It was printed both in English and Spanish.
  - —Developing a new leaflet, Publication No. 10095, Disability Benefits and Work, and distributing it to the public through SSA FO's. This leaflet, which describes section 1619 and the other work incentive provisions, is now a regular publication and is currently being updated for 1986.
  - —Providing information about section 1619 in the following regular SSI publications: SSI for Aged, Disabled, and Blind People, which is for potential recipients; A Guide to SSI, which is for groups and organizations that serve the SSI population; and What You Have to Know About SSI, which is enclosed with award notices to SSI recipients.
  - —Producing a new "work incentives" poster, designed to encourage disability recipients to contact their social security office if they want to work. The poster was given wide internal and external distribution
  - —Inserting a stuffer into the November 1985 benefit check to each SSI recipient highlighting potential section 1619 eligibility.
  - —Producing model newspaper columns and news releases on section 1619 and other work incentives in the Monthly Information Package, which is distributed to SSA FO's for use with the local media.

    —Providing articles on section 1619 and other work incentives in SSA's monthly newsletter, Information Items, which is distributed to 5,000 groups and organizations nationally.
  - —Taping radio public service spot announcements in English and Spanish on section 1619 and other work incentives and providing them to 3,000 radio stations
  - —Distributing a package of information materials on section 1619 and other work incentives to every congressional office.
  - —Developing a model presentation on work incentives for use by SSA's regional and field offices for public presentations by SSA staff.
  - —Adapting the SSA training package to serve as a training aid for VR counselors. It was distributed to all VR agencies. The training aid was also given wide distribution among advocacy groups and, as a result of the positive reception, later revised to give

#### a broader perspective in future printings.

The outreach efforts continue. The initial wave of activity was conducted in the spring and summer of 1985. The increased availability of ongoing information materials accompanied by strong SSA management emphasis on work incentives assures that they will continue to be publicized for the duration of the section 1619 demonstration. The considered judgment of SSA management is that the work incentives outreach efforts were warmly received; and, coupled with other factors, can be credited with an enhanced public awareness of the availability of incentives that enable SSI recipients to work without fear of loss of all program benefits.

#### **Current Program Participation**

The following sections of this report provide detailed data on section 1619 participant characteristics. To conclude the discussion of implementation, tables 2 and 3 below are presented as pictures of increased participation in the section 1619(a) and (b) programs.<sup>10</sup>

While the numbers are realtively small compared to more broadly based programs, the percentages of increased participation in section 1619 are substantial. Section 1619(a) participation more than doubled between August 1984 and August 1985. The trend for section 1619(b) is not as dramatic, but participation has grown.

#### Selected Characteristics of Section 1619 Program Participants

#### **Data Sources and Presentation Format**

The data described in this section are, in most instances, given in far greater detail in the Appendices to this report—especially Appendix A. The data were gathered from two main sources: the 1985 SSI Medicaid Recipient Survey, 11 and SSA's SSI administrative files. The findings presented below reflect considerable research by SSA staff into the array of factors that may influence section 1619 program participation. The data are discussed in synopsis

Table 2.—Number of 1619 (a) participants

	Participants	
Month/year	Number	Percentage change over previous report period
December 1982	287 392	+ 36.6
August 1984	406	+3.5
August 1985	816	+ 101.0

Table 3.—Number of 1619(b) participants

	Participants	
Month/year	Number	Percentage change over previous report period
December 1982	5,515	
December 1983	5,165	-6.4
August 1984	6,804	+31.7
August 1985	7,954	+ 16.9

form in the subsections below; and, in the case of the 1985 SSI Medicaid Recipient Survey (hereinafter "the Survey"), some of the significant data are presented in the body of the text. The data are divided into three main groupings. They are: demographics; impairments and disability; and employment and work.

#### **Demographics**

#### Age, race, and sex of section 1619 participants:

- Age: Program participants are younger than the general population of SSI disabled, cash-payment recipients. Only 39 percent of the SSI disabled are under age 40. By contrast, almost 84 percent of section 1619(a) program participants are under age 40 and approximately 79 percent of the 1619(b) group is under that age.
- Race: There is a higher percentage of section 1619
  participation among whites than in the general SSI
  disabled population. Whites constitute 70 percent of
  section 1619 participants, but represent only 60 percent of all individuals on the SSI disability rolls.
- Sex: A higher number (58 percent) of section 1619 participants are male than among the SSI disabled at-large population (40 percent).

#### State of residence and living arrangements:

- Residence: A complete State-by-State breakdown of program participation is given in Appendix A, tables A-3 and A-4. California had the largest number of participants in both section 1619(a) and (b) with a combined total of 1,207 participants or 13.8 percent of all 1619(a) and (b) participants. New York was second with 934 participants or 10.2 percent. California and New York's percentage of the total SSI disabled and blind population are 15.9 and 9.2 percent, respectively.
- Living arrangements: Data from the Survey provide detail on the variety of dwellings in which program participants live. As would be expected, the vast majority live in houses, apartments, or mobile homes. Table 4 provides further detail.

Additional data from SSA administrative files indicate that almost 10 percent (769 out of 7,954) of the section 1619(b) participants reside in "Medicaid facilities." This was unexpected because: only 6

<sup>&</sup>lt;sup>10</sup>See Appendix A, tables A-3 and A-4 [in the full report] for more detailed national and State data on section 1619(a) and (b) participation.

<sup>&</sup>lt;sup>11</sup>For a full discussion of the 1985 SSI Medicaid Recipient Survey, its methodology and results, see Appendix C [of the full report].

<sup>&</sup>lt;sup>12</sup>See Appendix A, tables A-5 and A-6 [in the full report], for additional demographic information.

<sup>&</sup>lt;sup>13</sup>Medicaid facilities include hospitals, skilled-nursing facilities (also known as extended-care facilities or skilled-nursing homes), nursing homes and intermediate-care facilities in which substantial payments (over 50 percent of the cost of care) are made under the State Medicaid program. The Federal benefit rate for SSI recipients who reside in Medicaid facilities is limited by law to \$25 per month.

Table 4.—Living arrangements of 1619 participants

Living arrangement	1619 (a)	1619 (b)
Total respondents	393	341
Total percent	100.0	100.0
Hotel or motel	.5	.3
Rooming or boarding home	3.1	4.4
House, apartment, or mobile home	87.0	80.6
Hospital, convalescent, or nursing home	.8	1.5
Retirement or rest home, foster care, personal		
care, or residential care home	6.1	10.6
School, rehabilitation, or training center	2.0	2.1
Other	.3	.6

percent of the SSI disabled population reside in Medicaid facilities and, more significantly, residents would be viewed as unlikely candidates for earnings. There are no section 1619(a) beneficiaries residing in Medicaid facilities.

The most plausible explanation for this seeming anomaly derives from the interaction of earned and unearned income and the \$25 payment cap placed on Medicaid facility residents. Section 1619(a) participants who are not self-employed are, by definition, engaging in SGA and have work-related earnings of at least \$300 per month. Since the \$25 per month payment cap applies to Medicaid facility residents, earnings at the SGA level (\$300 per month) make section 1619(a) status and residence in a Medicaid facility mutually exclusive. <sup>14</sup>

A recipient who resides in a Medicaid institution and is subject to the \$25 payment cap (making him ineligible for cash benefits due to countable income) can be eligible for SSI recipient status under section 1619(b) if income other than earnings is less than the Federal benefit rate. The section 1619(b) participants residing in Medicaid facilities do not receive cash payments but do retain their program connection because their combined unearned and earned income does not exceed \$336. The average earned income from this group is significantly lower than that of section 1619(b) participants as a whole (\$157 per month vs. \$674 per month). Unearned income is also lower (\$69 per month vs. \$134 per month).

There is some geographic concentration of the section 1619 population in Medicaid facilities. The heaviest concentrations of section 1619(b) participants in Medicaid institutions are in Minnesota (12 percent), Louisiana (12 percent), Texas (11 percent), and Illinois (11 percent). A closer look at the job types of these individuals indicates sheltered work. Of 24 section 1619(b) Survey respondents residing in Medicaid facilities, 18 listed sheltered workshop activities as the kind of work they did.

It should be noted that the section 1619(b) participants in Medicaid facilities would be, in almost all cases, eligible for Medicaid benefits without the section 1619(b) designation. These individuals have never lost categorical eligibility by reason of having performed SGA. In most States, these same

institutionalized individuals would be Medicaid eligible under State rules.<sup>16</sup> They would also be eligible for SSI cash payments if they left the institution and were no longer subject to the payment cap and, thus, again categorically eligible for Medicaid.

The practical effect, in the case of a section 1619(b) participant residing in a Medicaid facility, is that his or her section 1619(b) status confers no immediate benefit.

#### Impairments and Disabilities

Blindness. Blind persons receiving SSI cash payments are, by law, not subject to the SGA test in determining their eligibility. Blind recipients do not need the protection of section 1619(a) but qualify for section 1619(b) protection. In August 1985, 342 blind individuals were covered under section 1619(b). This represents 4.3 percent of all section 1619(b) participants and less than 1 percent of all blind recipients under age 65. Blind section 1619(b) participants had more income—both earned and unearned—than did the section 1619(b) group as a whole.<sup>17</sup>

Other disabilities and impairments. Disabled SSI recipients suffer from some form of mental disorder in 47.6 percent of all cases. The percentage is substantially higher for section 1619(a) participants (64 percent), with section 1619(b) participants marginally higher at 48.1 percent.

Mental impairment diagnoses differ between section 1619(a) and section 1619(b) participants with section 1619(a) participants carrying primary diagnoses of mental retardation in 40.5 percent of the cases, as opposed to 18.7 percent in the section 1619(b) category. Twenty-two percent of all SS1 disabled recipients are diagnosed as mentally retarded. The majority of the mentally retarded section 1619 participants (both (a) and (b)) had earnings below \$400. Those with either psychoses or neuroses were able to earn substantially more than participants diagnosed as mentally retarded.

<sup>16</sup>SSI recipients have categorical eligibility for Medicaid under whichever one of the Medicaid eligibility options his or her State follows:

—The State determines Medicaid eligibility using all SSI eligibility criteria. SSI recipients must file separate Medicaid applications with the State (5 States).

—The State determines Medicaid eligibility for the aged, blind, and disabled using more restrictive criteria than SSI's. Those criteria may not be more restrictive than those in effect on January 1, 1972 (14 States).

Termination of SSI payments does not necessarily mean loss of Medicaid coverage; title XIX provides States with several coverage options. For example, 40 States have elected an option to provide coverage to their aged, blind, and disabled who would be eligible for SSI or State supplementary payments if they were not residents of title XIX institutions. In 1985, 28 States and the District of Columbia also had medically needy programs for aged, blind, and disabled people who did not meet categorical eligibility standards.

<sup>17</sup>See Appendix A, tables A-10, A-11, and A-12 [of the full report] for further information on income, State of residence, and demographics

of the blind.

<sup>&</sup>lt;sup>14</sup>This occurs because a section 1619(a) recipient who is not selfemployed must be earning at the SGA level (i.e., \$300 a month) but countable income of \$25 or more does not permit any payment to a resident of a Medicaid institution.

<sup>&</sup>lt;sup>15</sup>See Appendix A, tables A-7, A-8, and A-9 [of full report] for more details concerning section 1619(b) participants residing in Medicaid institutions.

<sup>—</sup>The State accepts all SSI eligibility criteria as Medicaid eligibility criteria and SSA determines Medicaid eligibility for the State in accordance with an agreement under section 1634 of the Act (31 States and the District of Columbia).

Nonmental impairments among the section 1619(b) participants are diagnosed most frequently among the diseases of the nervous system or a sense organ. More than half of this group is hearing-impaired, compared with a much smaller group in the SSI population as a whole. The majority of hearing-impaired individuals had earnings above \$400 per month.

A further discussion of impairments and work is included in a succeeding section of this report.<sup>18</sup>

#### **Employment and Work**

Earned income (work income). Section 1619(a) participants' incomes normally range from the SGA level (\$300 per month) to the "breakeven point" (see Appendix A, table A-1). It is possible for some section 1619(a) participants to have earnings temporarily below the \$300 level (see footnote 2, page 14). Such a drop in earnings does not automatically mean that the participant is no longer capable of SGA and requires a disability review by SSA before reinstatement to regular SSI cash payments. In August 1985, 13.2 percent of section 1619(a) participants had monthly earnings below \$300. Earnings of section 1619(a) participants can also rise as high as the "breakeven point," the level at which cash benefits are reduced to zero because of countable income. Incomes for section 1619(a) participants are distributed throughout the possible income ranges, with the largest group (23.3 percent) earning between \$400 and \$499.19

When the combination of earned and unearned incomes rises beyond the "breakeven level," a recipient may be eligible for section 1619(b) participation if his or her income would be below the "breakeven level" without the earned income. Even though a section 1619(b) participant's total income exceeds the SSI" breakeven level," earnings may be very low when unearned income is present. Over 22 percent of all section 1619(b) participants had earnings from work below \$300 in August 1985. While some section 1619(b) participants have low earnings, 45.6 percent of the 1619(b) group earned more than \$700 per month. Over 30 percent of the section 1619(b) participants have sufficient earnings to exceed the breakeven point on work income alone.

Unearned income. Unearned income is a much more important part of the total income picture for section 1619(b) participants than it is for section 1619(a) participants. In August 1985, 54.5 percent of section 1619(b) participants had some unearned income. Of those with unearned income, 82 percent were receiving SSDI benefits. The remaining 18 percent were receiving income from interest, dividends, rents, or royalties. By contrast, only 18 percent of the section 1619(a) participants were receiving

any unearned income. Fifty-eight percent of this latter group were receiving income from interest, dividends, etc. Twenty-six percent were receiving SSDI benefits, presumably under the "3 additional months of benefits" provision.

The primary difference between unearned income distribution among section 1619(a) and (b) participants is the high entitlement rate of the section 1619(b), group to SSDI benefits.

Place of employment. Although SSA administrative records provide some employment data, the Survey was used to obtain specific information about the nature of the work performed by section 1619 participants. The answers to the employment questions on the Survey provided, depending on the individual question, an average of 700 responses for tabulation. Table 5 depicts the major groupings of work settings for program participants.

Most participants were working in competitive employment. The most prevalent employers for both section 1619(a) and (b) participants were private companies or businesses. Lesser percentages were employed by the government (State, local, or Federal) or were working in sheltered workshops. There is, however, a significant difference among section 1619(a) and (b) for competitive vs. sheltered work. Almost twice as many section 1619(b) participants were working in sheltered workshops as section 1619(a) participants.

It should be noted that the relatively high incidence of sheltered work performed by section 1619 program participants may be significant in assessing the degree of health care coverage and other benefits usually associated with employment. Sheltered workshops, as a group, generally do not provide the same employee benefit packages found in competitive employment, i.e., benefits are usually restricted to vacation and sick leave.<sup>20</sup>

Occupation. Section 1619 participants were also asked what kind of work they did. The results are displayed in table 6. The largest job category for both groups was by

Table 5.—Place of employment

Place of employment <sup>1</sup>	1619(a)	1619(ъ)
Total respondents <sup>2</sup> Total percent	373 100.0	337 . 100.0
Working in a private household	2.4	3.0
individual	67.5	50.7
government	14.3	18.4
Working in a sheltered workshop	14.8	26.7
Self-employed on your own farm	•••	.3
sional practice	1.1	.9

<sup>&</sup>lt;sup>1</sup>Source: 1985 SSI Medicaid Survey.

<sup>&</sup>lt;sup>18</sup>For complete data on impairments of section 1619 participants, see Appendix A, tables A-13, A-14, and A-15 [of the full report].

<sup>&</sup>lt;sup>19</sup>See Appendix A, tables A-16, A-17, A-18, and A-19 [of the full report] for the complete ranges of income for section 1619(a) and (b) participants.

<sup>&</sup>lt;sup>20</sup>W. Grant Revell, Jr., Susan Arnold, and Paul Wehman, "Supported Work Model of Competitive Employment for Persons With Mental Retardation: Implications for Rehabilitative Service," Competitive Employment for Persons With Mental Retardation: From Research to Practice, vol. 1, 1985, page 50.

<sup>&</sup>lt;sup>2</sup>Number of persons responding to any given question may be less than total respondents for that sample stratum.

Table 6.—Occupation of section 1619 program participants

Occupation	1619(a)	1619(b)
Total respondents	346	293
Total percent	100.0	100.0
Professional, technical, managerial	5.8	4.4
Clerical and sales	19.4	24.2
Service occupations	54.0	39. <b>9</b>
Farming, fishing, forestry	.9	2.0
Processing	.6	1.0
Machine trades	2.9	4.1
Bench work	10.1	19.1
Structural work	.3	.3
Miscellaneous	6.1	4.8

<sup>&</sup>lt;sup>1</sup>The occupation groupings displayed were recoded from the original survey forms and are based upon a common Department of Labor coding scheme.

far the "service occupations." Many section 1619 participants were engaged in some aspect of food preparation—cook, stocker, table cleaner, dishwasher, etc. Others performed janitorial duties, cleaned parks, did laundry, or worked as laborers. The second largest category was "clerical and sales." Typical jobs for section 1619 participants in this category were office clerks, stock clerks, mail clerks, and sales people. The third largest category, "bench work," encompasses those types of assembly operations normally associated with sheltered workshops.

Assistance in locating employment. Given the other characteristics of section 1619 participants, it appeared logical to assume that many of them required some degree of help in finding jobs. SSA designed the Survey to shed further light on the sources of employment assistance to would-be workers. Table 7 displays the results.

About two-thirds of each group received assistance in job location. The dominant source of help was from the combined assistance of VR and social services agencies. Roughly 40 percent of both groups received assistance from these sources. Significantly, one-third of the participants reported they found jobs on their own.

Duration of employment. One of the points sometimes voiced in criticism of the operation of the section 1619 incentives is their lack of recognition of the sporadic nature of employment of disabled individuals. The Survey provides objective data on length of work among disabled section 1619 program participants. The results are in table 8. The summarized responses relate to the number of

Table 7.—Sources of assistance for job placement

Provider of assistance	1619(a)	1619(b)
Total respondents	381	329
Total percent	100.0	100.0
Vocational rehabilitation agency	25.5	25.8
Social services agency/social action program	14.2	14.9
Family member/friends	9.7	14.0
Sheltered workshop staff	2.1	.9
Teacher/school	5.5	2.4
Other	3.9	1.5
Not reported	7.3	6.7
Did not receive help	31.8	33.7

months in the past year.

Over two-thirds of the section 1619(a) participants worked the full year; only half of the section 1619(b) participants did so.

#### Motivational Factors and Section 1619 Program Participation

There are many factors that go into an individual's decision to begin working or to increase his or her earnings. Some of these factors (e.g., parental attitudes, local economic conditions, family support, etc.) go well beyond the scope of this report. To all appearances, the section 1619 programs should provide incentives for SSI receipients to work. SSA used the Survey to gather additional motivational data as it pertains to the section 1619 programs. The answers section 1619 participants gave to Survey questions may also bear on the broader subject of work incentives and motivation in general.

In an effort to attribute going to work and increased earnings of SSI disabled recipients to section 1619 provisions, the Survey asked questions of section 1619(a) and (b) participants that would supply this cause-and-effect relationship. Because some recipients, particularly those entitled to SSI benefits before enactment of the section 1619 legislation, were unaware of any specific work incentives, the questions used could not presuppose an awareness of section 1619.

The responses to the motivational questions were:

Question

•		
Have you ever stopped work or worked less thought your SSI checks might stop?	because	you
Total responses	375	320

1619(a) 1619(b)

ight your bor enecks hight stop.		
Total responses	375	320
Total percent	100.0	100.0
Percent yes	10.4	8.1
Percent no	89.6	91.9

Have you ever stopped work or worked less because you thought your Medicaid/Medi-Cal might stop?

ght your Medicaid/Medi-Cal might	stop?	
Total responses	386	324
Total percent	100.0	100.0
Percent yes	9.3	8.3
Percent no	90.7	91.7

Would you work less if that was the only way you could continue to receive an SSI check?

Total responses  Total percent yes	384) 100.0 22.7 77.3	not appli- cable
Percent no	77.3 )	

Would you work less if that was the only way you could

keep your Medicaid/Medi-Cal card?		
Total responses	374	318
Total percent	100.0	100.0
Percent yes	28.3	21.4
Percent no	71.7	78.6

**Table 8.**—Duration of employment of 1619 program participants

Number of months worked	1619 (a)	1619 (b)
Total respondents Total percent	386 100.0	335 100.0
Less than 3 months 3 months but less than 6 months 6 months but less than 12 months All 12 months	2.1 6.2 24.9 66.8	5.4 15.5 28.3 50.7

About 1 person in 10 claimed to have stopped or limited his or her work in order to retain SSI or Medicaid coverage. A somewhat larger proportion (21–28 percent) of section 1619 participants felt that their connection with SSI or Medicaid was important enough that they would limit their earnings, if necessary, to receive SSI checks and/or Medicaid coverage. The 21–28 percent range seems to belie the threat of loss of SSI and/or Medicaid coverage as the dominant motivational factor.

## Health insurance (or medical coverage) and section 1619.

Medicaid coverage: Since continued Medicaid eligibility is such an integral part of the section 1619 programs, and its threatened loss is believed to be a potential work disincentive, the Survey examined awareness of Medicaid coverage. In direct response to the coverage question, surveyed participants answered as follows:

Question	1619(a) 1619(b)
Do you have a Medicaid/Medi-Cal	• • • • • • • • • • • • • • • • • • • •
card?	

Total responses	398	346
Total percent	100.0	100.0
Percent yes	84.7	66.1
Percent no	15.3	33.9

About 15 percent of the section 1619(a) participants reported that they did not have Medicaid coverage. Over one-third of the section 1619(b) participants indicated that they did not have Medicaid cards. While it is possible (given the nature of the question) that some program participants lacked Medicaid coverage (see footnote 16, page 21), it is reasonable to assume that a number of them were unaware of their Medicaid coverage status. Why then did these section 1619 participants not utilize Medicaid? Were there other forms of health coverage available such as Medicare or private health insurance through the participants' employers? In order to shed light on the above questions, Survey participants were also asked if they had Medicare coverage or belonged to private health plans through their employers.

Multiple coverages—Interactions of Medicaid, Medicare, and private insurance: Combining responses to the health care questions provides a health care coverage picture for the section 1619 participants.

Health care coverage	1619(a)	1619(b)
Total respondents	400	348
Total percent	100.0	100.0
Medicaid only	50.5	27.6

Medicaid and Medicare	16.5	20.4
Medicaid and private plan	12.8	11.5
Medicaid, Medicare, private plan	4.5	6.3
Medicare only		6.0
Medicare and private plan		.9
Private plan only	4.8	14.4
None	4.5	6.0
None and no response	6.5	6.9

Twenty-one percent of the section 1619(a) group and 33.6 percent of the section 1619(b) group had Medicare coverage. Section 1619(a) participants dually entitled to SSDI benefits eventually lose Medicare coverage. Medicare coverage ends 24 months after the end of the extended period of eligibility. Section 1619(b) participants may retain Medicare coverage indefinitely since, unlike section 1619(a)'s, they may not be engaging in SGA. For many of the section 1619(b) participants, Medicare coverage was combined with Medicaid. For participants with dual Medicare/Medicaid coverage, Medicare is the first payer on overlapping coverages, and Medicaid pays for any cost sharing and for expenses not covered by Medicare. The exact percentage of medical costs paid by Medicare in dual coverage cases is not known; but a 1984 study done for HCFA, estimated that 57 percent of the medical costs for aged dual enrollees was borne by Medicare.27

Slightly over 22 percent of the section 1619(a) group and 33.1 percent of the section 1619(b) group had private health coverage through employment. Most participants also had Medicaid coverage. Most private plans are like Medicare in that they pay before Medicaid in overlapping coverage cases. Slightly over half of the section 1619(a) participants and only 27.6 percent of the section 1619(b) participants relied entirely on Medicaid coverage. This may bear on the responses to the motivational question regarding fear of Medicaid loss, discussed in the previous section. A small percentage of both groups claimed to have no health coverage at all (see footnote 16, page 21, for an explanation of why some section 1619 participants do not have Medicaid coverage).

About 75 percent of section 1619 program participants worked for private employers or governmental entities where, in most cases, private health care coverage could be expected to be available. However, 27.7 percent of the participants reported having private coverage. Although the reasons for this disparity are not completely clear, several participants interviewed as part of the Anecdotal Study (see Appendix B) indicated that, while their employers generally provided health care coverage, they either were specifically excluded from the coverage or the cost of coverage was prohibitive.

Health coverage as a motivator. Although overall health insurance utilization by section 1619 program participants is not available, research done by HCFA<sup>22</sup> on Medicaid utilization in 11 States (representing almost half of the section 1619 population) indicates that Medicaid

<sup>&</sup>lt;sup>21</sup>Short Term Evaluation of Medicaid: Selected Issues, Urban Systems Research and Engineering, Inc., Cambridge, Massachusetts.

<sup>22</sup>For a full report of the HCFA research, see Appendix E.

utilization is relatively low. The per capita health expenditure levels of section 1619 program participants were consistently lower than those of the SSI disabled population at large. The lower expenditure levels among section 1619 participants were present in all Medicaid service categories with the across category expenditure rate for the SSI disabled averaging 2.3 times higher than for section 1619 participants. How much the demographic composition of section 1619 participants may influence expenditure levels cannot be stated with certainty absent further research. Section 1619 program participants are younger and consist of a higher percentage of males than recipients of regular SSI disability benefits (see Demographics, page 20). Even when section 1619 is not a pertinent factor, young males entitled to Medicaid, as a group, utilize Medicaid less than females and those over age 45. The significant degree of overlapping health coverage among section 1619 participants undoubtedly also affects Medicaid utilization, since Medicaid is the payer of last resort. While the precise reason(s) for the lower Medicaid utilization rate of section 1619 participants has not been isolated in the current research, it is an important factor in estimating the cost of a program extension and in assessing the incentive value of Medicaid continuation for working SSI disabled individuals.

The Survey suggests that the majority of section 1619 participants would not lessen their work efforts to retain Medicaid eligibility. It also sugests that many participants have Medicare at the time they begin work and for some time thereafter, depending on whether they achieve SGA or have private health insurance through employment. The logical conclusion from the Survey is that the retention of Medicaid eligibility is not as significant an incentive as is commonly believed. Conversely, the threat of Medicaid loss may not be the universal work disincentive that some believe. Certainly, the Survey respondents were not influenced in their decision to work or not to work by Medicaid eligibility alone. The Survey findings suggest room for further research on the relationship between health coverage and work efforts.

Program knowledge: A look at the nonearner and low earner. The most obvious reason why disabled SSI recipients do not work is because they believe they cannot. Since many of the severely impaired do, however, SSA's research was directed at potential participants in the section 1619 provisions in addition to those already benefiting from the program. Despite strenuous outreach and broad publicity, the fact is that many potential recipients do not know about the provisions of section 1619, or at least profess no knowledge of them. SSA asked the following questions of nonearners in the Survey:

Do you know you can work and still get an SSI check? Do you know you can work and still get a Medicaid/ Medi-Cal card?

Almost 47 percent of the nonearning respondents (or other persons answering the questions) said they did not know

they could work and get SSI checks. Fifty percent said they did not know they could work and get Medicaid cards.

A similar question was asked of the low earners:

Do you know that you may be able to earn more money and still keep your Medicaid/Medi-Cal card?

About 64 percent of the respondents said that they did not know that.

It is evident that a sizeable portion of potential program participants is not aware of, or does not or cannot comprehend, the relationship between work and SSI/Medicaid eligibility. Many of the low earners are simply not capable of absorbing the complex interrelationships between their work and their program benefits. The Survey revealed that the health limitations of the low and nonearners made many approachable only through third parties. Continued outreach and third party assistance may, over time, fill in some of this knowledge gap.

Impairments, health, and work effort. The nature of the SSI program for disabled individuals is such that each section 1619 program participant is, by definition, quite severely disabled. The Survey collected information about the impairments of individuals to create a picture of relationships among diagnostic categories. Again, some comparisons were struck among nonearners, low earners, and section 1619 program participants (see Appendix C [in the full report] for a further description of the Survey methodology). Table 9 divides low earners, section 1619(a), and 1619(b) participants into impairment-related groups and compares these groups with the general SSI disabled recipient population.

Low earners are more likely to be mentally retarded than their section 1619 program counterparts. Contrasting the above three categories with the SSI disabled population at large, the following overall mental impairment rates (psychosis, neurosis, and mental retardation) are found in ascending order: SSI disabled, 47.6 percent; section 1619 (b) participants, 48.1 percent; section 1619(a) participants, 63.9 percent; and low earners, 79.8 percent. These findings tie in closely with the types of jobs among the three categories. Table 10 provides further detail.

Almost all low earners work in sheltered workshops. Average earnings in sheltered workshops are usually well below the \$300 per month SGA level.

The following data present an interesting picture of "desire" to work more and individual self-assessment of work ability (table 11).

If desire to work and individual self-assessments of ability are given credence, low-earning SSI recipients do not represent a substantial pool of prospective section 1619 program participants.

The other, much larger, group of potential section 1619 program participants is composed of SSI disabled nonearners. This group, too, shows some differences from the section 1619 participants. The nonearners are much

Table 9.—Work and impairment groupings

Primary diagnosis	Low earners	1619(a)	1619(b)	SSI disabled
Total percent	100.0	100.0	100.0	100.0
Mental disorders				
Psychosis/neurosis	27.5	23.4	29.4	23.5
Mental retardation	52.3	40.5	18.7	24.1
Diseases of nervous system	6.4	16.1	21.4	12.2
All other diagnoses	13.8	20.0	30.5	40.2

**Table 10.**—Comparison of low earners and section 1619 participants—place of employment

Place of employment	Low earners	1619(a)	1619 (b)
Total respondents	316	381	329
Total percent	100.0	100.0	100.0
Working in a private household Employee of a private company,	2.4	2.4	3.0
business	3.2	67.5	50.7
government	1.5	14.3	18.4
Working in a sheltered workshop.	92.3	14.8	26.7
Self-employed on own farm			.3
Self-employed in own business	.6	1.1	.9

**Table 11.**—Comparison of low earners and section 1619 program participants—desire and ability to work

Desire and ability to work	Low earners	1619(a)	1619(b)
Do you want to work more?			
Total respondents	301	380	314
Total percent	100.0	100.0	100.0
Percent yes	41.9	56.1	54.1
Percent no	58.1	43.9	45.9
Are you able to work more?			
Total respondents	316	365	304
Total percent	100.0	100.0	100.0
Percent yes	24.6	44.4	43.4
Percent no	75.3	55.6	56.6

older than the section 1619 group. Nonearners also show slightly higher rates of respiratory, circulatory, and endocrine disorders than section 1619 participants (see Appendix A, table A-13 [in the full report], for more detail).

Nonearners were asked if they had ever worked. Almost 55 percent of the respondents replied that they had worked at some time. Those former workers were then asked for the reason they stopped working. The answers:

Total respondents	320 100.0
Employer thought health was too poor Poor health/not well enough to work Spouse's health Other family responsibilities Too old/wanted to retire Disliked job/boss Company closed down/job discontinued To get back on SSI Other	9.1 73.4 .3 5.3 .3 .3 5.3 .3 5.6

The primary reasons (82.5 percent) for stopping work were related to the nonearners' health as self-assessed or as assessed by the employer. Only one respondent reported stopping work to get back on SSI.

The 45 percent of the nonearners who never worked were asked why. The results:

Total respondents	301
Total percent	100.0
Injury/disability/illness	79.1
Going to school/training	4.0
Not enough experience/training/schooling	5.3
Could not find work	2.7
Jobs did not pay enough	
Did not want to work	
Taking care of home or family	6.0
Afraid of losing SSI check or Medicaid	.7
Other	2.3

Again, poor health was given as the main obstacle to working. All nonearners were then asked the following two questions:

354
100.0
44.1
55.9
480
100.0
13.8
86.2

While over 44 percent of the nonearners said there was some type of work they would like to do, only 13.8 percent believed they were able to work. On the positive side, the Survey disclosed that there are (even though not a high percentage) a number of potential section 1619 participants who deem themselves both able to work and interested in performing some type of work.

#### 

A look at methodology. SSA conducted an intense review of its administrative files in order to determine the nature of section 1619 program experience. An indepth study of 421 (121 section 1619(a) and 300 section 1619(b)) cases was conducted to look at "before and after" factors in section 1619 participation. The Case Review Study followed cases from May 1981 to May 1985.

A major finding of this research is: The section 1619 rolls are volatile. Turnover is **dramatic**, while the point-in-time data disclose the current number of section 1619 participants, extrapolation from the Case Review Study indicates that some 55,000<sup>23</sup> recipients have participated in

<sup>&</sup>lt;sup>23</sup>Based on the SSI 1-percent sample file. At the 95-percent confidence limit, the actual number of such participants may range from 50,400 to 59,600.

the section 1619 program since its inception in 1981.

Initial SSI eligibility and earnings. A substantial number of the sample participants had been SSI recipients for a long time. Exactly 57 percent of the section 1619(a) participants, and 47.4 percent of the section 1619(b) participants became eligible for SSI payments in 1974 or 1975.<sup>24</sup> Many, however, did not begin to work until much later. Over 51 percent of the section 1619(a) participants and 54 percent of the section 1619(b) participants began their work in 1980 or later. The reason for beginning work may not relate entirely to the section 1619 work incentives, since a large portion of the participants began to work in 1980, before the January 1981 effective date of section 1619. The most plausible explanation for this is the changed definition of sheltered workshop earnings resulting from another provision in the 1980 disability reform amendments. An SSI recipient who previously could earn only \$20 at a workshop before it reduced his or her check dollar-for-dollar, could now have his or her benefit reduced by only half of the amount of earnings over \$65 (\$85 if there was no unearned income).

Since about 15 percent of the section 1619(a) participants and about 27 percent of the section 1619(b) participants worked in sheltered workshops (see page 22), it may be that some of these participants were originally encouraged to begin their employment by the sheltered workshop provision, and then later benefited from section 1619. It is also possible that some of the sheltered employees' salaries were raised after the 1980 change in the treatment of workshop earnings.

Changes in eligibility status. Most section 1619 sample participants changed eligibility categories between May 1981 and May 1985. Within a year, 62.8 percent of the May 1982 participants in section 1619(a) had left that status. An even greater percentage (72.6) of the section 1619(b) participants left that status by the following year. Obviously, very rapid turnover for section 1619 categories is masked by the relatively steady point-in-time caseload figures. Most participants stay for a few months before leaving. A few later return. By May 1985, 62.3 percent of the original group of section 1619(a) sample participants no longer had a program connection. Another 15 percent returned to the regular SSI program. A very few (3.3 percent) of those who remained in the section 1619(a) category later became section 1619(b) participants.

Of the original section 1619(b) sample participants, 58.3 percent had no program connection by May 1985. Another 24.3 percent were back in the regular SSI program. Only 19 percent of those in section 1619(a) status and 17.3 percent of those in section 1619(b) status remained in their original section 1619 category throughout the period.

There are several reasons why section 1619 participants leave that status. Appendix A, table A-22 [in the full report], shows the reasons why 98 sample section 1619(a)

cases left that status between May 1982 and May 1985. About 7 percent of the cases returned to the regular SSI program because their earnings fell or stopped. The largest group (about 58 percent) was terminated from the SSI program. The most common reason (21.4 percent) for termination was the loss of disability status as the result of a medical determination that the recipient's disability had ceased (due to medical recovery). Approximately one-third of the section 1619(a) cases moved into section 1619(b) status because their combined countable earned and unearned incomes rose above the "breakeven levels."

The section 1619(b) sample cases showed a much different pattern. Almost half of the participants returned to the regular SSI program.<sup>26</sup> The reasons for the return were fairly evenly divided between those whose earnings fell and those whose earnings stopped altogether. The remainder of the cases were terminated. About 12 percent were terminated because their uncarned incomes rose. Another 8.5 percent failed the "use test" (were not seriously inhibited in continuing employment if Medicaid coverage was lost). Only 2.8 percent were terminated because they had earnings high enough to purchase their own equivalent medical benefits. This last group could be considered the "graduates" of the section 1619 program. Most section 1619(b) participants, however, did not sustain their earnings.

#### A Retrospective on the Research

The research undertaken by SSA to compile the data given throughout this report was done to add to the knowledge of the many factors that influence participation or nonparticipation in the work incentive programs available to disabled and blind SSI recipients. The research, although narrow in scope, adds to a growing body of knowledge of the factors that influence impaired individuals to work. It is hoped that the additional knowledge gained will serve both its primary purpose and prove useful to other research endeavors as well.

While the data given in this and the preceding sections of this report provide the reader with a quantified look at numerous factors, it is suggested that the Case Summaries contained in Appendix B not be overlooked. SSA spent many workhours collecting section 1619 participants' "own stories" so that the human side of the program would not be lost among the numbers.

#### Interprogram Factors That May Influence Section 1619 Program Participants

#### Introduction

The interrelationship between the section 1619 program and broader work incentive programs has been stressed

<sup>&</sup>lt;sup>24</sup>See Appendix A, table A-20 [in the full report].

<sup>&</sup>lt;sup>25</sup>See Appendix A, table A-21 [in the full report].

<sup>&</sup>lt;sup>26</sup>See Appendix A, table A-23 [in the full report].

throughout this report. Section 1619 is obviously only one of several legislated incentive programs that may influence a recipient of SSI disability or blindness cash payments in his or her decision to work or not to work.

#### State Supplementation and Section 1619

Not all States that supplement regular SSI cash benefits pay a supplement to section 1619(a) program participants. Nine States that have federally administered mandatory or optional State supplements do not supplement section 1619(a) program participants. The States are:

Arkansas	Maryland	Nevada
Florida	Mississippi	Ohio
Louisiana	Montana	Washington

Another 12 States have State administered supplementation of the basic SSI program but do not supplement section 1619(a) participants. They are:<sup>27</sup>

Alabama	Missouri	North Dakota
Arizona	Nebraska	Oklahoma
Colorado	New Hampshire	South Carolina
Indiana	North Carolina	Wyoming

SSA data indicate that the 21 States without supplementation of the section 1619(a) category represent 38.5 percent of the SSI disabled and blind population at large.<sup>28</sup> To whatever degree section 1619(a) program participation is influenced by loss of State supplementation, it is present in these 21 States.

## Section 1619 Participation and Medicaid Rules

As previously indicated (see page 21, footnote 16), in 14 States, representing approximately 20 percent of the SSI population, SSI eligibility is not used by the State as its sole criterion for Medicaid eligibility. Section 1619 participants in these States may be subject to more restrictive Medicaid eligibility requirements either by virtue of the disability eligibility test or the income and resources eligibility criteria. The States are:

Connecticut	New Hampshire
Hawaii	North Carolina
Indiana	North Dakota
Illinois	Ohio
Minnesota	Oklahoma
Missouri	Utah
Nebraska	Virginia

Section 1619 participants in these States are not auto-

matically eligible for Medicaid. They may, however, be Medicaid eligible under State criteria. Section 1619 participation does not appear to be disproportionally affected by the States' decisions to use definitions other than SSI eligibility for their Medicaid determinations. Further data would have to be collected and analyzed to determine conclusively the section 1619 program effects of differing Medicaid and SSI standards on a State-by-State basis.

#### Other Factors—Interprogram/ Intraprogram

Eligibility for Medicaid is not the only entitlement that can be lost through the work efforts associated with section 1619 program participation. In an informal survey of the States, SSA's regional personnel identified nine States where continued eligibility for such programs as home support services or attendant care could be affected by section 1619 program participation. Whether these extra program influences bear on section 1619 participation rates is, at best, speculative. It appears logical that they might, in at least a few cases.

It is not possible to quantify the effect of the limited life of the section 1619 provisions. Has the temporary nature of section 1619 unduly influenced participation rates? Certainly some believe it has. Two recent State-prepared reports stemming from State analyses and research have recommended extension of section 1619 to remove any possible disincentive created by the temporary nature of the program.<sup>29</sup>

SSA, in its implementation of section 1619, has had to walk a fine line in carrying out its outreach and public information responsibilities by providing encouragement to interested program participants without obscuring the fact that the program has an expiration date.

#### Note on Appendices

The preceding material is a reprint of the Report to the Congress on the 1619 program required under a provision of the Social Security Disability Benefits Reform Act of 1984. Because the material appears here verbatim, it contains references to all of the appendices that were prepared to augment the report.

The appendices section, which follows, contains only selected appendices. Some of the appendices that appear are not reprinted in their entirety. Copies of the complete report, including all the appendices in their entirety, are available from the Office of Public Inquiries, Social Security Administration, Room 4100 Annex, 6401 Security Boulevard, Baltimore, Maryland 21235 or by calling (301) 594-7700.

<sup>&</sup>lt;sup>27</sup>Based on latest available information. Because States frequently change State-administered supplementation categories without informing SSA, the number should be viewed with some caution.

<sup>&</sup>lt;sup>28</sup>It should be noted that two States (Texas and West Virgina) have no State supplementation of the basic SSI cash benefit and, therefore, no supplementation of the section 1619(a) cash benefit. The other 28 States (including the District of Columbia) that provide a supplement to the section 1619(a) cash benefit are listed on page 16.

<sup>&</sup>lt;sup>29</sup>Michigan Interagency Task Force on Disability, "Work: The Real Social Security," December 1985, and Bob Griss, Report on Health Care Coverage for Working Aged Persons With Physical Disabilities: A Key to Reducing Disincentives to Work, Department of Health and Human Services, Madison, Wisconsin, December 1985.

Table A-1.—SSI income guarantee and "breakeven" levels for section 1619 participants in independent living arrangements, January 1985.

Į	Individ	ual	Couple		
	SSI		SSI		
	monthly	1	monthly		
	income	Break-	income	Break	
Type of administration	guarantee	even	guarantee	eve	
of optional supplement	level	level <sup>1</sup>	level	leve	
Alabama (State)	<b>\$</b> 325	\$735	<b>\$</b> 488	\$1,06	
Alaska (State)	586	1,257	859	1,80	
Arizona (State)	325	735	488	1,06	
Arkansas (none)	325	735	488	1,06	
California (Federal)	504	1,093	936	1,95	
Colorado (State)	325	735	488	1,06	
Connecticut (State)	325	735	488	1,06	
Delaware (Federal)	325	735	488	1,06	
District of Columbia				•	
(Federal)	340	765	518	1,12	
Florida (State)	325	735	488	1,06	
Georgia (State)	325	735	488	1,06	
ławaii (Federal)	330	745	497	1,07	
daho (State)	383	851	514	1,11	
Ilinois (State)	<sup>2</sup> 325	735	<sup>2</sup> 488	1,06	
ndiana (State)	325	735	488	1,06	
owa (Federal)	325	735	488	1,06	
Cansas (none)	325	735	488	1,06	
Kentucky (State)	325	735	488	1,06	
ouisiana (none)	325	735	488	1,06	
Maine (Federal)	335	755	503	1,09	
Maryland (State)	325	735	488	1,06	
Massachusetts (Federal)	439	963	668	1,42	
Michigan (Federal)	352	789	528	1,14	
Minnesota (State)	360	805	554	1,19	
Mississippi (none)	325	735	488	1,06	
Missouri (State)	325 325	735	488	1,06	
Montana (Federal)	325	735 735	488 488	1,06 1.06	
Nebraska (State)	325	735	488	1,06	
New Hampshire (State)	325	735	488	1,06	
New Jersey (Federal)	356	797	513	1,11	
New Mexico (State)	325	735	488	1,06	
New York (Federal)	386	857	564	1,21	
North Carolina (State)	325	735	488	1,06	
North Dakota (State)	325	735	488	1,06	
Ohio (none)	325	735	488	1,06	
Oklahoma (State)	325	735	488	1,06	
Oregon (State)	325	735	488	1,06	
Pennsylvania (Federal)	357	799	537	1,15	
Rhode Island (Federal)	379	841	590	1,26	
South Carolina (State)	325	735	488	1,06	
South Dakota (State)	340	765	503	1,09	
Tennessee (none)	325	735	488	1,06	
Texas (none)	325	735	488	1,06	
Jtah (State)	335	755	508	1,10	
Vermont (Federal)	378	841	555	1,19	
Virginia (State)	325	735	488	1,06	
Washington (Federal)	325	735	488	1,06	
West Virginia (none)	325	735	488	1,06	
Wisconsin (Federal)	325	735	488	1,06	
Wyoming (State)	325	735	488	1,06	
Northern Mariana Islands	325	735	488	1,06	

<sup>&</sup>lt;sup>1</sup>The point at which countable earnings result in reduction of Federal SSI and State payments to zero. This assumes no unearned income.

<sup>2</sup>State budgets each case individually regardless of living arrangements. Note: "None" indicates no optional State supplementation. Where optional supplementation is indicated but the Federal level of \$325 and \$488 are shown, the State optional supplementation does not apply because the State elected not to supplement recipients under section 1619 and/or individuals or couples in independent living arrangements. Nevada does not supplement disabled SSI recipients. Section 1619 supplementation may also apply for certain individuals who were previously on State programs (Arkansas, Louisiana, Mississippi, Ohio, Tennessee) in effect prior to January 1974 and are receiving mandatory supplements. Optional State sup-

plementation may also apply for other living arrangements.

#### Appendix A

Table A-2.—Threshold amounts effective January 1, 1985<sup>1</sup>

Alabama \$10,622 Alaska 25,071 Arizona 8,820 Arkansas 11,493 California 16,790 Colorado 16,596 Connecticut 15,488 Delaware 12,621 District of Columbia 11,341 Florida 11,341 Georgia 11,481 Hawaii 12,436 Idaho 12,673 Illinois 13,790 Indiana 14,693 Iowa 13,010 Iowa 13,010 Iowa 10,744 Louisiana 12,740 Maryland 11,580 Massachusetts 15,849 Michigan 13,468 Minestota 19,647 Mississippi 10,423 Missouri 10,424 Missouri 10,424 Missouri 10,423 Missouri 10,464 Montana 11,362 Nevada 15,056 New Hampshire 13,560 New Jersey 13,455 New Mexico 12,272 New Hampshire 13,345 New Mexico 12,272 Oregon 11,345 New Mexico 12,272 Oregon 11,344 North Dakota 15,044 Ohio 13,394 North Carolina 12,441 North Dakota 15,044 Ohio 13,394 North Carolina 12,441 North Dakota 15,044 Ohio 13,394 New Mexico 11,362 New Pennsylvania 13,332 Rhode Island 13,757 South Carolina 10,677 South Dakota 15,448 Tennessee 11,1300 Texas 12,849 Utah 15,346 Verrmont 15,446 Tennessee 11,1300 Texas 12,849 Utah 15,346 Verrmont 15,440 Verrmont 15,461 Washington 19,726 West Virginia 9,901 Wisconsin 15,610 Wyoming 13,157	State	Threshold amount
Alaska         25,071           Arizona         8,820           Arkansas         11,493           California         16,590           Connecticut         15,488           Delaware         12,621           District of Columbia         13,485           Florida         11,341           Georgia         11,481           Hawaii         12,436           Idaho         12,673           Ilinois         13,790           Indiana         14,693           Iowa         13,010           Iowa         13,010           Kentucky         10,744           Louisiana         12,771           Maryland         11,580           Massachusetts         15,849           Michigan         13,468           Minnesota         19,647           Mississippi         10,423           Mississippi         10,423           Mississippi         10,423           Mississippi         10,424           Mortana         11,362           New Hampshire         13,560           New Hexico         12,128           New York         16,092           N	Alahama	\$10.622
Arizona         8,820           Arkansas         11,493           California         16,596           Conceticut         15,488           Delaware         12,621           District of Columbia         13,485           Florida         11,341           Georgia         11,481           Hawaii         12,436           Idaho         12,673           Illinois         13,790           Indiana         14,693           Jowa         13,010           Kansas         12,145           Kentucky         10,744           Louisiana         12,740           Maine         12,771           Maryland         11,580           Massachusetts         15,849           Michigan         13,468           Minnesota         19,647           Mississippi         10,423           Missouri         10,424           Mortana         11,362           Nebraska         15,056           New Hersey         13,455           New Hersey         13,455           New Hexico         12,128           New York         16,092           North Caro		_ •
Arkansas         11,493           California         16,790           Colorado         16,596           Connecticut         15,488           Delaware         12,621           District of Columbia         13,485           Florida         11,341           Georgia         11,481           Hawaii         12,436           Idaho         12,673           Illinois         13,790           Indiana         14,693           Jowa         13,010           Kansas         12,145           Kentucky         10,744           Louisiana         12,740           Maryland         11,580           Massachusetts         15,849           Michigan         13,468           Minnesota         19,647           Mississippi         10,423           Missouri         10,423           Mississippi         10,423           Mississippi         10,423           Mortana         11,362           New Hampshire         13,560           New Hersey         13,550           New Mexico         12,128           New York         16,092		
California         16,790           Colorado         16,596           Connecticut         15,488           Delaware         12,621           District of Columbia         13,485           Florida         11,341           Georgia         11,481           Hawaii         12,673           Illinois         13,790           Indiana         14,693           Jowa         13,010           Kansas         12,145           Kentucky         10,744           Louisiana         12,740           Maine         12,071           Maryland         11,580           Massachusetts         15,849           Michigan         13,468           Minnesota         19,647           Mississippi         10,423           Missouri         10,423           Missouri         10,423           Missouri         10,423           Missouri         10,423           Mevada         14,619           New Hampshire         13,506           New Hexico         12,128           New Wexico         12,128           New York         16,092           No		
Colorado         16,596           Connecticut         15,488           Delaware         12,621           District of Columbia         13,485           Florida         11,341           Georgia         11,481           Hawaii         12,673           Idaho         12,673           Illinois         13,790           Indiana         14,693           Iowa         13,010           Kentucky         10,744           Louisiana         12,071           Maryland         11,580           Massachusetts         15,849           Michigan         13,468           Minnesota         19,647           Mississippi         10,423           Missouri         10,464           Montana         11,360           New Hampshire         13,560           New Hampshire         13,560           New Hexico         12,128           New York         16,092           North Carolina         12,128           New York         16,092           North Carolina         12,441           North Carolina         12,441           North Carolina         13,332     <		
Connecticut         15,488           Delaware         12,621           District of Columbia         13,485           Florida         11,341           Georgia         11,481           Hawaii         12,436           Idaho         12,673           Illinois         13,790           Indiana         14,693           Jowa         13,010           Kansas         12,145           Kentucky         10,744           Louisiana         12,740           Maine         12,071           Maryland         11,580           Massachusetts         15,849           Michigan         13,468           Minnesota         19,647           Mississippi         10,423           Missouri         10,464           Montana         11,362           Nevada         15,056           Nevada         14,619           New Hampshire         13,560           New Jersey         13,455           New Mexico         12,128           New Mexico         12,128           New Mexico         12,128           New Mexico         12,241           Nort		
Delaware         12,621           District of Columbia         13,485           Florida         11,341           Georgia         11,481           Hawaii         12,436           Idaho         12,673           Illinois         13,790           Indiana         14,693           Iowa         13,010           Kansas         12,145           Kentucky         10,744           Louisiana         12,071           Maryland         11,580           Massachusetts         15,849           Michigan         13,468           Minnesota         19,647           Mississiippi         10,423           Missouri         10,464           Montana         11,362           Nebraska         15,066           New Hampshire         13,560           New Hampshire         13,560           New Jersey         13,455           New York         16,092           North Carolina         12,241           North Dakota         15,044           Ohio         13,394           Oklahoma         12,722           Oregon         11,362 <t< td=""><td></td><td></td></t<>		
District of Columbia         13,485           Florida         11,341           Georgia         11,481           Hawaii         12,436           Idaho         12,673           Illinois         13,790           Indiana         14,693           Iowa         13,010           Kansas         12,174           Kentucky         10,744           Louisiana         12,740           Maine         12,071           Maryland         11,580           Massachusetts         15,849           Michigan         13,468           Minnesota         19,647           Mississipi         10,464           Montana         11,362           Nebraska         15,056           New Hampshire         13,560           New Hampshire         13,550           New Mexico         12,128           New York         16,092           North Carolina         12,441           North Dakota         15,044           Ohio         13,394           Oklahoma         12,722           Oregon         11,364           Pennsylvania         13,332 <td< td=""><td></td><td></td></td<>		
Florida		
Hawaii       12,436         Idaho       12,673         Illinois       13,790         Indiana       14,693         Iowa       13,010         Kansas       12,145         Kentucky       10,744         Louisiana       12,740         Maine       12,071         Maryland       11,580         Massachusetts       15,849         Michigan       13,468         Minnesota       19,647         Mississippi       10,423         Missouri       10,464         Montana       11,362         Nebraska       15,056         Nevada       14,619         New Hampshire       13,550         New Jersey       13,455         New Mexico       12,128         New York       16,092         North Carolina       15,044         Ohio       13,394         Oklahoma       12,722         Oregon       11,364         Pennsylvania       13,332         Rhode Island       13,757         South Dakota       15,418         Tenas       12,849         Utah       15,346		
Idaho         12,673           Illinois         13,790           Indiana         14,693           Iowa         13,010           Kansas         12,145           Kentucky         10,744           Louisiana         12,740           Maine         12,071           Maryland         11,580           Massachusetts         15,849           Michigan         13,468           Minnesota         19,647           Mississippi         10,423           Missouri         10,464           Montana         11,362           Nebraska         15,056           New Hampshire         13,550           New Hampshire         13,455           New Mexico         12,128           New York         16,092           North Carolina         12,441           North Dakota         15,044           Ohio         13,394           Oklahoma         12,722           Orgon         11,364           Pennsylvania         13,332           Rhode Island         13,757           South Carolina         10,677           South Dakota         15,418	Georgia	11,481
Illinois         13,790           Indiana         14,693           Iowa         13,010           Kansas         12,145           Kentucky         10,744           Louisiana         12,740           Maine         12,071           Maryland         11,580           Massacchusetts         15,849           Michigan         13,468           Michigan         19,647           Mississippi         10,423           Missosuri         10,423           Montana         11,362           Nebraska         15,056           New Hampshire         13,560           New Hampshire         13,560           New Jersey         13,455           New Mexico         12,128           North Carolina         12,128           Nowth Carolina         12,441           North Dakota         15,044           Ohio         13,394           Oklahoma         12,722           Oregon         11,364           Pennsylvania         13,332           Rhode Island         13,757           South Carolina         10,677           South Dakota         15,418	Hawaii	12,436
Indiana     14,693       Iowa     13,010       Kansas     12,145       Kentucky     10,744       Louisiana     12,740       Maine     12,071       Maryland     11,580       Massachusetts     15,849       Michigan     13,468       Minesota     19,647       Mississippi     10,423       Missouri     10,464       Montana     11,362       Nevada     14,619       New Hampshire     13,560       New Hampshire     13,455       New Mexico     12,128       New York     16,092       North Carolina     12,441       North Dakota     15,044       Ohio     13,394       Oregon     11,364       Pennsylvania     13,332       Rhode Island     13,757       South Carolina     10,677       South Dakota     15,418       Tennessee     11,130       Texas     12,849       Utah     15,346       Vermont     14,945       Virginia     12,041       Washington     19,726       West Virginia     9,901       Wisconsin     15,610	Idaho	12,673
Iowa         13,010           Kansas         12,145           Kentucky         10,744           Louisiana         12,740           Maine         12,071           Maryland         11,580           Massachusetts         15,849           Michigan         13,468           Minnesota         19,647           Mississippi         10,464           Montana         11,362           Nebraska         15,056           Nevada         14,619           New Hampshire         13,560           New Jersey         13,455           New Mexico         12,128           New York         16,092           North Carolina         12,441           North Dakota         15,044           Ohio         13,394           Oklahoma         12,722           Oregon         11,364           Pennsylvania         13,332           Rhode Island         13,757           South Carolina         10,677           South Dakota         15,418           Tennessee         11,130           Texas         12,849           Utah         15,346 <td< td=""><td>Illinois</td><td>13,790</td></td<>	Illinois	13,790
Kansas       12,145         Kentucky       10,744         Louisiana       12,740         Maine       12,071         Maryland       11,580         Massasachusetts       15,849         Michigan       13,468         Minnesota       19,647         Mississippi       10,423         Missouri       10,464         Montana       11,362         Nebraska       15,056         Newada       14,619         New Hampshire       13,560         New Jersey       13,455         New Work       16,092         North Carolina       12,128         New York       16,092         North Dakota       15,044         Ohio       13,394         Ohio       13,332         Rhode Island <td< td=""><td>Indiana</td><td>14,693</td></td<>	Indiana	14,693
Kentucky       10,744         Louisiana       12,740         Maine       12,071         Maryland       11,580         Massachusetts       15,849         Michigan       13,468         Minnesota       19,647         Mississippi       10,423         Missouri       10,464         Montana       11,362         Nebraska       15,056         Newdada       14,619         New Hampshire       13,550         New Jersey       13,455         New Work       16,092         North Carolina       12,128         New York       16,092         North Dakota       15,044         Ohio       13,344         Oklahoma       12,722         Oregon       11,364         Pennsylvania       13,332         Rhode Island       13,757         South Carolina       10,677         South Dakota       15,418         Tennessee       11,130         Utah       15,346         Vermont       14,945         Virginia       12,041         Washington       19,701         West Virginia       9,90	Iowa	
Louisiana       12,740         Maine       12,071         Maryland       11,580         Massachusetts       15,849         Michigan       13,468         Minnesota       19,647         Mississisppi       10,464         Montana       11,362         Nebraska       15,056         Nevada       14,619         New Hampshire       13,560         New Jersey       13,455         New Mexico       12,128         New York       16,092         North Carolina       12,441         North Dakota       15,044         Ohio       13,394         Oklahoma       12,722         Oregon       11,364         Pennsylvania       13,332         Rhode Island       13,757         South Carolina       10,677         South Dakota       15,418         Texas       11,364         Vermont       14,945         Virginia       12,849         Vest Virginia       9,901         Wisconsin       15,610		
Maryland       11,580         Massachusetts       15,849         Michigan       13,468         Minnesota       19,647         Mississisppi       10,423         Missouri       10,464         Montana       11,362         Nebraska       15,056         Nevada       14,619         New Hampshire       13,560         New Jersey       13,455         New Mexico       12,128         New York       16,092         North Carolina       12,441         North Dakota       15,044         Ohio       13,394         Oklahoma       12,722         Oregon       11,364         Pennsylvania       13,332         Rhode Island       13,757         South Carolina       10,677         South Dakota       15,418         Tennessee       11,130         Texas       12,849         Utah       15,346         Vermont       14,945         Virginia       12,041         Washington       19,726         West Virginia       9,901         Wisconsin       15,610	•	
Maryland       11,580         Massachusetts       15,849         Michigan       13,468         Minnesota       19,647         Mississippi       10,423         Missouri       10,464         Montana       11,362         Nebraska       15,056         Nevada       14,619         New Hampshire       13,560         New Jersey       13,455         New Mexico       12,128         New York       16,092         North Carolina       12,441         North Dakota       15,044         Ohio       13,394         Oklahoma       12,722         Oregon       11,364         Pennsylvania       13,332         Rhode Island       13,757         South Carolina       10,677         South Dakota       15,418         Tennessee       11,136         Utah       15,346         Vermont       14,945         Virginia       12,041         Washington       19,726         West Virginia       19,726         West Virginia       19,901         Wisconsin       15,610		
Massachusetts         15,849           Michigan         13,468           Minnesota         19,647           Mississippi         10,423           Missouri         10,464           Montana         11,362           Nebraska         15,056           New Hampshire         13,560           New Jersey         13,455           New Mexico         12,128           New York         16,092           North Carolina         12,441           North Dakota         15,044           Ohio         13,334           Oklahoma         12,722           Oregon         11,364           Pennsylvania         13,332           Rhode Island         13,757           South Carolina         10,677           South Dakota         15,418           Tennessee         11,130           Texas         12,849           Utah         15,346           Vermont         14,945           Virginia         12,041           Washington         19,726           West Virginia         9,901           Wisconsin         15,610	Maine	12,071
Massachusetts         15,849           Michigan         13,468           Minnesota         19,647           Mississippi         10,423           Missouri         10,464           Montana         11,362           Nebraska         15,056           New Hampshire         13,560           New Jersey         13,455           New Mexico         12,128           New York         16,092           North Carolina         12,441           North Dakota         15,044           Ohio         13,334           Oklahoma         12,722           Oregon         11,364           Pennsylvania         13,332           Rhode Island         13,757           South Carolina         10,677           South Dakota         15,418           Tennessee         11,130           Texas         12,849           Utah         15,346           Vermont         14,945           Virginia         12,041           Washington         19,726           West Virginia         9,901           Wisconsin         15,610	Maryland	11.580
Michigan       13,468         Minnesota       19,647         Mississippi       10,464         Montana       11,362         Nebraska       15,056         Nevada       14,619         New Hampshire       13,550         New Jersey       13,455         New Mexico       12,128         North Carolina       16,092         North Carolina       15,044         Ohio       13,394         Oklahoma       12,722         Oregon       11,364         Pennsylvania       13,332         Rhode Island       13,757         South Carolina       10,677         South Dakota       15,418         Texas       11,304         Texas       11,349         Utah       15,346         Vermont       14,945         Virginia       12,041         Washington       19,726         West Virginia       9,901         Wisconsin       15,610		
Minnesota       19,647         Mississispipi       10,423         Missouri       10,464         Montana       11,362         Nebraska       15,056         Nevada       14,619         New Hampshire       13,560         New Jersey       13,455         New Mexico       12,128         New York       16,092         North Carolina       12,441         North Dakota       15,044         Ohio       13,394         Oklahoma       12,722         Oregon       11,364         Pennsylvania       13,332         Rhode Island       13,757         South Carolina       10,677         South Dakota       15,418         Tennessee       11,136         Utah       15,346         Vermont       14,945         Virginia       12,041         Washington       19,726         West Virginia       9,901         Wisconsin       15,610		
Mississippi       10,423         Missouri       10,464         Montana       11,362         Nebraska       15,056         New da       14,619         New Hampshire       13,560         New Jersey       13,455         New Mexico       12,128         New York       16,092         North Carolina       12,441         North Dakota       15,044         Ohio       13,394         Oklahoma       12,722         Oregon       11,364         Pennsylvania       13,332         Rhode Island       13,757         South Carolina       10,677         South Dakota       15,418         Tennessee       11,1364         Utah       15,346         Vermont       14,945         Virginia       12,041         Washington       19,726         West Virginia       9,901         Wisconsin       15,610		
Missouri       10,464         Montana       11,362         Nebraska       15,056         New Adada       14,619         New Hampshire       13,560         New Jersey       13,455         New Mexico       12,128         New York       16,092         North Carolina       12,441         North Dakota       15,044         Ohio       13,344         Oklahoma       12,722         Oregon       11,364         Pennsylvania       13,332         Rhode Island       13,757         South Carolina       10,677         South Dakota       15,418         Tennessee       11,130         Texas       12,849         Utah       15,346         Vermont       14,945         Virginia       12,041         Washington       19,726         West Virginia       9,901         Wisconsin       15,610		
Nebraska       15,056         Nevada       14,619         New Hampshire       13,560         New Jersey       13,455         New Mexico       12,128         New York       16,092         North Carolina       12,441         North Dakota       15,044         Ohio       13,394         Oklahoma       12,722         Oregon       11,364         Pennsylvania       13,332         Rhode Island       13,757         South Carolina       10,677         South Dakota       15,418         Tennessee       11,130         Texas       12,849         Utah       15,346         Vermont       14,945         Virginia       12,041         Washington       19,726         West Virginia       9,901         Wisconsin       15,610	Missouri	10,464
Nevada       14,619         New Hampshire       13,560         New Jersey       13,455         New Mexico       12,128         New York       16,092         North Carolina       12,441         North Dakota       15,044         Ohio       13,394         Oklahoma       12,722         Oregon       11,364         Pennsylvania       13,332         Rhode Island       13,757         South Carolina       10,677         South Dakota       15,418         Tennessee       11,130         Texas       12,849         Utah       15,346         Vermont       14,945         Virginia       12,041         Washington       19,726         West Virginia       9,901         Wisconsin       15,610	Montana	11,362
New Hampshire       13,560         New Jersey       13,455         New Mexico       12,128         New York       16,092         North Carolina       12,441         North Dakota       15,044         Ohio       13,394         Oklahoma       12,722         Oregon       11,364         Pennsylvania       13,332         Rhode Island       13,757         South Carolina       10,677         South Dakota       15,418         Tennessee       11,130         Texas       12,849         Utah       15,346         Vermont       14,945         Virginia       12,041         Washington       19,726         West Virginia       9,901         Wisconsin       15,610	Nebraska	15,056
New Jersey       13,455         New Mexico       12,128         New York       16,092         North Carolina       12,441         North Dakota       15,044         Ohio.       13,394         Oklahoma       12,722         Oregon.       11,364         Pennsylvania       13,332         Rhode Island       13,757         South Carolina       10,677         South Dakota       15,418         Tennessee       11,130         Texas       12,849         Utah       15,346         Vermont       14,945         Virginia       12,041         Washington       19,726         West Virginia       9,901         Wisconsin       15,610	Nevada	14,619
New Mexico         12,128           New York         16,092           North Carolina         12,441           North Dakota         15,044           Ohio         13,394           Oklahoma         12,722           Oregon         11,364           Pennsylvania         13,332           Rhode Island         13,757           South Carolina         10,677           South Dakota         15,418           Tennessee         11,130           Texas         12,849           Utah         15,346           Vermont         14,945           Virginia         12,041           Washington         19,726           West Virginia         9,901           Wisconsin         15,610	New Hampshire	13,560
New Mexico         12,128           New York         16,092           North Carolina         12,441           North Dakota         15,044           Ohio         13,394           Oklahoma         12,722           Oregon         11,364           Pennsylvania         13,332           Rhode Island         13,757           South Carolina         10,677           South Dakota         15,418           Tennessee         11,130           Texas         12,849           Utah         15,346           Vermont         14,945           Virginia         12,041           Washington         19,726           West Virginia         9,901           Wisconsin         15,610	New Jersey	13,455
New York         16,092           North Carolina         12,441           North Dakota         15,044           Ohio.         13,394           Oklahoma         12,722           Oregon.         11,364           Pennsylvania         13,332           Rhode Island         13,757           South Carolina         10,677           South Dakota         15,418           Tennessee         11,130           Utah         15,346           Vermont         14,945           Virginia         12,041           Washington         19,726           West Virginia         9,901           Wisconsin         15,610		
North Carolina         12,441           North Dakota         15,044           Ohio         13,344           Oklahoma         12,722           Oregon         11,364           Pennsylvania         13,332           Rhode Island         13,757           South Carolina         10,677           South Dakota         15,418           Tennessee         11,130           Texas         12,849           Utah         15,346           Vermont         14,945           Virginia         12,041           Washington         19,726           West Virginia         9,901           Wisconsin         15,610		
Ohio       13,394         Oklahoma       12,722         Oregon       11,364         Pennsylvania       13,332         Rhode Island       13,757         South Carolina       10,677         South Dakota       15,418         Tennessee       11,130         Texas       12,849         Utah       15,346         Vermont       14,945         Virginia       12,041         Washington       19,726         West Virginia       9,901         Wisconsin       15,610		
Oklahoma       12,722         Oregon       11,364         Pennsylvania       13,332         Rhode Island       13,757         South Carolina       10,677         South Dakota       15,418         Tennessee       11,130         Texas       12,849         Utah       15,346         Vermont       14,945         Virginia       12,041         Washington       19,726         West Virginia       9,901         Wisconsin       15,610	North Dakota	15,044
Oregon.         11,364           Pennsylvania         13,332           Rhode Island         13,757           South Carolina         10,677           South Dakota         15,418           Tennessee         11,130           Texas         12,849           Utah         15,346           Vermont         14,945           Virginia         12,041           Washington         19,726           West Virginia         9,901           Wisconsin         15,610	Ohio	13,394
Pennsylvania       13,332         Rhode Island       13,757         South Carolina       10,677         South Dakota       15,418         Tennessee       11,130         Texas       12,849         Utah       15,346         Vermont       14,945         Virginia       12,041         Washington       19,726         West Virginia       9,901         Wisconsin       15,610	Oklahoma	12,722
Rhode Island       13,757         South Carolina       10,677         South Dakota       15,418         Tennessee       11,130         Texas       12,849         Utah       15,346         Vermont       14,945         Virginia       12,041         Washington       19,726         West Virginia       9,901         Wisconsin       15,610	Oregon	11,364
South Carolina         10,677           South Dakota         15,418           Tennessee         11,130           Texas         12,849           Utah         15,346           Vermont         14,945           Virginia         12,041           Washington         19,726           West Virginia         9,901           Wisconsin         15,610		
South Dakota         15,418           Tennessee         11,130           Texas         12,849           Utah         15,346           Vermont         14,945           Virginia         12,041           Washington         19,726           West Virginia         9,901           Wisconsin         15,610	Rhode Island	13,757
Tennessee     11,130       Texas     12,849       Utah     15,346       Vermont     14,945       Virginia     12,041       Washington     19,726       West Virginia     9,901       Wisconsin     15,610		
Texas       12,849         Utah       15,346         Vermont       14,945         Virginia       12,041         Washington       19,726         West Virginia       9,901         Wisconsin       15,610		
Utah       15,346         Vermont       14,945         Virginia       12,041         Washington       19,726         West Virginia       9,901         Wisconsin       15,610	_	
Vermont       14,945         Virginia       12,041         Washington       19,726         West Virginia       9,901         Wisconsin       15,610		
Virginia       12,041         Washington       19,726         West Virginia       9,901         Wisconsin       15,610		
Washington       19,726         West Virginia       9,901         Wisconsin       15,610		
West Virginia         9,901           Wisconsin         15,610		
Wisconsin		
wyoming		
	wyoming	13,157

<sup>&</sup>lt;sup>1</sup>A person can exceed the threshold if his gross earnings for the 12-month period beginning with the month that 1619(b) applies go above the amounts shown. Threshold amount is based on a summation of a Federal portion, 2 times the State supplement, and the State Medicaid projection.

#### Appendix B

The case histories contained in this appendix were gathered by SSA personnel to supplement the statistical data contained in the basic report. The study, internally known as the "1619 Anecdotal Study," consisted of home or worksite interviews with selected section 1619 program participants and/or their representative payees. Although a degree of randomness was used to select the cases, the anecdotal study was not designed as a scientific exploration of the program universe.

The interviews were conducted by SSA field staff trained in interviewing skills but not necessarily in preparation of case summaries. Interviewers were encouraged to follow a suggested outline (Appendix B, Exhibit 1) for gathering information but were free to deviate from the outline as circumstances dictated. The interviewers were not aware of the disabling impairment and described people in their own words. Thus, these write ups are not intended to be judgments on the severity of a participant's disability.

The section 1619 program participants that cooperated with SSA in making their stories available are to be thanked. While the case histories have been minimally edited to preserve individual confidentiality, they are presented in their entirety with criticism of SSA or the program(s) left intact.

The case histories, perhaps better than all of the data, illustrate the heterogeneity of section 1619 program participants.

## Appendix B, Exhibit 1: 1619 Interview Outline for Anecdotal Study

(Note to interviewer: We are looking for some detailed information on supplemental security income (SSI) individuals participating in the 1619 demonstration. Below is a list of topics with a few suggested questions that should be covered in the interview. During the court of the interview, you may want to explore some of these areas in greater detail. The primary objective of this activity is to obtain "human interest" information for Congress.)

#### Socio/Demographic

What is the individual's age, sex, and race? What early childhood information is the individual able to recall?

What is the composition of the individual's family? What is the highest level of education the individual completed? Parents completed? Siblings completed?

Has the individual ever been enrolled in vocational rehabilitation or other special training? Where? How long?

#### Living Arrangement/Social Support

What is the individual's living arrangement? How long

has he/she lived there? How many in the household? What is the individual's social support network?

#### **Current Employment**

Does the individual work? Where?
What kind of work does the individual do?
Is the work full-time or part-time? Seasonal? Temporary or permanent?

How many hours per week does the individual work? Does the individual want to work more? What is the hourly salary?

How long has the individual worked at present job? How did he/she find this job?

Does the individual have any problems with job that are related to his/her impairment?

#### **Past Employment**

What is the longest length of time that the individual held a job? Type of work? Why did the individual leave that job?

When did the individual first begin to work; i.e., age? Type of work? Salary? Length of time worked? Full/part-time? Temporary/permanent? Seasonal?

What is the longest length of time that the individual did not have a job? Why?

#### Health

How does the individual rate his/her overall health? Does the individual take any medication regularly? What is an estimate of monthly health costs?

How does the individual feel about the Medicare/ Medicaid card? How long has the individual had the card? How often is it used? For what services is it used?

If employed, does the employer have a health plan? Is individual covered under such a plan?

Does the individual participate in any other private health plan (beside employer) that he/she pays for?

#### **Impairment**

How does the individual cope with the impairment? How does the individual believe others feel about his/ her impairment?

Does the impairment influence activities and work or cause any job-related problems?

#### SSA/Other Program Experience

What is the individual's experience with SSA?
When the individual applied for SSI, did he/she know that SSI/Medicaid benefits/coverage could be retained while working?

Does the individual participate in any other social welfare program?

When he/she began working, did anyone advise about the impact on SSI benefits? Medicaid?

How does individual let SSA know about amount of monthly earnings?

#### Appendix B, Exhibit 2

DEPARTMENT OF HEALTH & HUMAN SERVICES Social Security Administration Baltimore MD 21235 Refer to: SJB-5-2

in order to better acquaint the people of the United States with the Social Security Act, with the benefits provided by that Act, and with the services performed by the Social Security Administration, consent to the Social Security Administration's release for publication any information which may be taken in this connection."

"I understand and agree that such information may be published at any time and may appear in a report, periodical, newspaper, or other news media, but no personal identifying information will be used."

Date	Signed For	
	Address	
Witness:		
		<del></del>

#### Case Summary A

Miss Monica A. is 22 years old. She was an SSI beneficiary until 16 months ago. She recalls very little of early childhood so her mother provided some information on that.

The family consists of her mother, age 50, and a sister, age 24. The father, age 50, "deserted" them when Miss A. was 7 days old. He has provided some child support over the years but not on a regular basis nor the full amount set by court order. The inconsistency of the child support payments caused frequent overpayments. She was an AFDC beneficiary for a very short period many years ago, probably before her mother became an SSA beneficiary. Her father no longer contributes and has very little contact with the family.

Miss A.'s mother said that her daughter was very delicate as a baby, but became a very active child. She learned things quickly and was very anxious to go to school. She caught the school bus one day with her sister when she was 4. Her mother was unaware of this until she finally found her at school in the middle of her sister's class, the center of attention. She attended kindergarten and was ahead of most children her age in math and reading. Miss A. recalls having frequent severe headaches

from childhood, becoming so severe in junior high school that she had to have a homebound teacher for a while. She also "fell out" a lot during that time. Friends, relatives, teachers, and some doctors tried to get her mother to have Miss A. placed in the State mental hospital, but her mother said she knew her daughter was not "crazy."

About this time (1978), when Miss A. was age 15, they filed for SSI and she received that until about September 1984. Her mother also took her to a doctor who diagnosed her illness as hypoglycemia. Miss A.'s mother said that the SSI benefits made it possible for them to buy the food that her daughter needed and this helped her health condition greatly. She was also able to get the medication she needed.

Miss A.'s mother said she completed high school and took a cosmetology course. She has operated a small beauty shop in her home for many years when she was able but has been disabled much of her life. She received disability benefits for a number of years but the amount was rather low. She was terminated some time ago "while in the hospital flat on her back." She feels badly about that. Miss A.'s father returned to school after he left the family and got a college degree. He works in the security force of an art gallery. Miss A. and her sister earned college degrees in 1984. Miss A. is a graduate of a highly rated liberal arts college in the south.

Miss A. has been living in her present home with her mother and sister since 1968 when her mother built it "a little at a time" as she could. Prior to then, they had lived in a very dilapidated house owned by Miss A.'s grandmother.

Miss A.'s social activities are pretty much confined to her family and school activities. Before Miss A. got her degree, she began contacting the principal of the public school she had attended. Just before school started in September 1984, she was hired as a teacher in a Chapter I program. This is "slow learner" students and the classes have a maximum of 15. She said she teaches 7th grade math and English at the junior high school. Her job is full-time, 35 hours a week. She helps some with other school activities but does not receive any extra pay for that. Her salary is \$14,550.00 a year for 9 months teaching, but the salary is paid over a 12-month period. This is Miss A.'s first job. She contacted the social security office to have her SSI stopped as soon as she got her first paycheck but had to repay the SSI for that month. She knew of the effect of work, but did not understand Medicaid continuation.

Miss A. still has some health problems due to the hypoglycemia but is able to work nearly every day as long as she eats frequently. She said she has to eat a snack or drink some juice at least one or two times between meals to avoid the severe headaches and blackouts. However, tension sometimes causes these headaches and she cannot eat sweets. She sometimes goes a week to two without a severe headache. She is optimistic about her chances of continuing work. She is not on any prescribed medication, but takes vitamins and Tylenol. She goes to the doctor 3-4 times a year and her health costs are about \$20-\$30 a month. She has not used the Medicaid card since SSI stopped as she was afraid she would have to repay any benefits from it. She apparently has had the Medicaid card since her State became a buy-in State for SSI benefits.

The employer has a health insurance plan but Miss A. said that she cannot afford the premium cost of about \$200.00 a month. She has no other health insurance. Miss A. and her mother feel that the Medicaid card was of considerable help when she really needed it.

She has no long-range plans regarding marriage or family. She was hurt very much by her father's actions.

#### Case Summary B

Mr. Mark B. is the 23-year-old son of Mr. John B., a meat cutter, and Mrs. Clara B., a hotel maid. He is the youngest of six children. Except for the father, the entire family lives in the same city.

Mr. B. was born mentally retarded and will probably never be able to live alone. He currently lives with his 48-year-old mother, his 26-year-old brother, and his 75-year-old grandmother. His father left the family when Mr. B. was only 4 years old. The family knows where the father is, but only occasionally hears from him. Mr. B. never really knew his father since he left when Mr. B. was so young.

Mr. B. has always attended special schools operated by the County Board of Mental Retardation. He went to school full-time until 1983 when he began working part-time in a special workshop operated in coordination with the special school. He continued working half-days in the workshop and went to school half-days until he graduated in 1985. Two of his sisters have graduated from high school. His mother has a tenth grade education and his father has a ninth grade education.

Currently, Mr. B. works 25 to 30 hours per week in a workshop doing such tasks as folding bags, bagging small parts, and assembly work. During the warm months, he works in a special program which does landscaping work around various public buildings. Mr. B. runs a power mower and also pulls weeds. This program is run by the same workshop that he has always worked for. His winter wages are \$130 to \$170 per month. In the summer, he makes up to \$310 a month for longer hours of work. He is able to ride public transportation to work since having been trained to do so. He has no problem taking the bus to work and often stops on the way home to do his personal shopping. Many other workshop workers must ride a special bus because they are unable to ride public transportation. Mr. B. cashes his own paycheck and puts a small amount in the bank. He uses the rest to buy clothing and record albums. He also buys cigarettes and personal items for himself with the money he has earned. Mr. B. seldom misses work (only 5 days in 1 year) and says he likes the work. He does sometimes complain to his mother a little

about the boss. He likes the outside work (lawn mowing) better than the indoor workshop work since it pays more money and he likes the outdoors.

Mr. B. is in good physical health and only goes to the doctor for checkups. He occasionally goes to the dentist. He takes no medication. He has a health card provided by the County Welfare Department which pays for his doctor visits.

He has a few noticeable problems, primarily slurred speech and unusual mannerisms. He doesn't have many friends, but does play volleyball and some softball at the neighborhood school. He has won two swimming medals in the Special Olympics.

The interview was conducted with Mr. B.'s mother, who is also his payee. She did not realize that her son benefited from the disability amendments in question. She indicated, however, that his benefits enable him to live more independently than he would otherwise be able to.

#### Case Summary C

Mrs. Mary C., age 57, grew up in the Dallas area as one of eight children. Her siblings include two brothers and five sisters. Her parents emigrated from Italy and later became naturalized citizens. Her mother never attended school, while her father completed the fourth grade. None of her siblings attended college, but one brother graduated from high school. Mrs. C. completed 2½ years of high school; did not graduate but believes this entitles her to a GED—although she did not receive a diploma. She later completed a 6-week secretarial course.

Mrs. C. currently resides in her own home with one of her six children. She has lived there for approximately 29 years. She is divorced and her son is her representative payee.

Mrs. C. is currently working at a fast food restaurant. She has been there about 2 years. Her job duties consist of cooking. It is a permanent, part-time position. She works 4 days per week, 4 hours per day, at \$4.00 an hour. Because of her disability this is the most she can work. She decided to return to work for two reasons: (1) she needed the money and (2) she felt that returning to work would benefit her health. She needed to keep moving and work provides exercise. The only problem she is experiencing at the present is exhaustion related to walking to work (as she cannot afford transportation) and being on her feet. She felt the exercise of working far outweighs the exhaustion factor.

The longest length of employment was as assistant manager at a luncheonette. She worked 2½ years and quit because of her health.

Mrs. C. first went to work at age 21 at a discount department store. She earned \$2.00 an hour, or minimum wage. She worked about 1½ years. It was a full-time, permanent position at 40 hours per week. She quit because of her health.

She then took a 6-week secretarial course and obtained a

job with an insurance company. She became pregnant and quit. She was a housewife from about 1952-67, raising six children. She held a job working counter at a donut shop for a while. She worked at a minimum wage and quit because of her health.

Mrs. C. rates her overall health as "not too good." She is a diabetic and must have daily insulin shots, as well as take insulin by mouth. She also takes medication for depression since she has had a nervous breakdown. She attributes this to her children. She must see her doctor twice monthly at \$35.00 a visit. She must have urinalysis and blood tests frequently, ranging from \$25.00 to \$50.00 a month. She must, of course, have medication and insulin but the druggist bills Medicaid so she doesn't know the costs. Mrs. C. buys needles and alcohol for about \$10.00 a month.

She has had Medicaid/Medicare for about 4 years and uses her Medicaid monthly, but is not too sure about the amount of use of Medicare. She uses it for her medication and doctor's visits.

She doesn't know about her employer's health plan—it may be with Blue Cross/Blue Shield, but is not sure whether she is covered.

When asked about coping with her impairment she replied, "I just have to accept it." Because her impairments are not visible, she doesn't mention her disability to others and most people just do not say anything to her about it. The only time it comes up is when she is offered sweets and must turn them down saying she is diabetic.

Basically, she just keeps going. Some days she doesn't feel good, but overall feels it's better to get out of the house and work. Except for frequent bouts of exhaustion, she has no job-related problems because of her disability.

According to Mrs. C., SSA has done a nice job for her. She was not aware she could work while receiving benefits but did remember receiving some sort of pamphlet about working. She decided to return to work on her own, basically because she needed the money. She does not participate in any non-SSA programs. When Mrs. C. reported her work to SSA, she was told it would not make a difference in her check. She reported her return to work, as well as a later raise in salary. Her only problem was that although she reported timely, SSA did not adjust checks for about 6 months. She was assessed an overpayment which is still being withheld from her social security check. She also alleged that the SSA representative told her she would always be on Medicaid as long as she received "SSA" checks. She apparently is confused or unaware of the difference between DI and SSI. When asked for a final comment about her experience with SSA she replied, "If it hadn't been for social security, I wouldn't have made it."

#### Case Summary D

Mr. David D. is 22 years old. His father died when he was about age 12 but had not worked enough for his family to receive social security benefits. Most of his work

was odd jobs and yard work. Mr. D. helped his father with some yard mowing. After his father's death, Mr. D. earned money for himself and gave some to his mother by mowing yards when the work was available. The family received AFDC after his father's death.

Mr. D. was not a good student in school, being retarded to some extent. He was placed in a special education group in school by the time he was in upper elementary grades. He got to the tenth or eleventh grade. Mr. D. lives with his mother (age 52) and his older brother (age 29). His mother completed seventh grade in school. She has filed for SSI on the basis of disability but was denied. His brother also attended special education classes in school and received SSI benefits for some time, but it stopped because of his working and then receiving unemployment benefits.

Mr. D.'s first real job was at a sheltered workshop making bed frames for about \$1.00 an hour. He said he worked there about 4 months. He later worked for a firm that provides workers where needed on a contract basis. He said he worked there for about a year—working for the city most of that time under contract. He made minimum wages (\$3.35 an hour). He then went to work directly for the City Water Department turning water meters off and on and installing water meters. He now works 40 hours a week and earns \$4.71 an hour. He said he works a little overtime when asked to do so. He said he has been working for the City Water Department "going on 2 years." This is the longest he has had one job. He thinks he was off work about a year between the sheltered workshop job and the job with the contract firm. He said he handles the job pretty well and gets along all right with his boss.

Mr. D. feels that his health is all right except for his nerves. He said he goes to a mental health clinic every other month and takes medication regularly. His only health care cost is \$3.00 for each visit to the clinic and \$1.00 for each prescription. Medicaid pays the balance. He said he gets along all right with other people and they don't seem to think anything about his condition.

He sometimes gets upset he said over serious matters, but his mother indicated this happens fairly frequently though not as often as in the past.

Both of them said that he has not had any contact with the social security office—his mother handling all business for him as his payee. Neither of them understand much about the correlation of SSI, Medicaid, and work. His speech is not very clear and he is slow in responding.

He has an automobile about 5 years old and drives. He plays cards, pool, and sometimes attends a ball game.

His employer has group insurance. He said he has a \$10,000 term life insurance policy but does not have health insurance through the employer.

#### Case Summary E

Mrs. Connie E. is a young woman of 25 years, very polite and cooperative. She grew up in a middle-class family

of six children—four girls and two boys. Mrs. E. was the fourth child and completed high school, as have all her siblings.

Mrs. E. lived at home with her parents until October 1985, when she moved into an apartment with her husband. She and her husband are not very active socially—other than a handful of friends, they keep to themselves at home. Their main entertainment is watching television and Mrs. E. is fond of soap operas.

At present, Mrs. E. is on a leave of absence from her job and is receiving State disability insurance while recuperating from surgery she received on December 13, 1985. The surgery was for "female problems" and she is eager to return to her job as soon as possible. She works for a large retail store selling home improvement supplies, tools, gardening equipment, etc. Mrs. E. has worked in the warehouse there since October 1984, pricing merchandise and moving it out to be shelved. She is a full-time employee and earns \$5.80 an hour. She has been offered overtime on occasion but has declined as she feels 40 hours is enough to work in 1 week. She got her present job by responding to an advertisement in the local paper. She completed an application for employment and then kept calling repeatedly to find out if they had a job for her. Her persistence paid off as she was eventually given an interview and was then hired. She had trouble learning her job at first and was given extra attention by her supervisor, who was aware of Mrs. E.'s mental limitations. Eventually Mrs. E. was matched with work that suited her abilities and her supervisor has been pleased enough with her work to dissuade her from quitting over a personality conflict with another employee a few months ago. Mrs. E. herself feels very competent in her job and describes herself as a good worker. She is obviously proud of the increased responsibilities she has been given and has even helped to train new workers in the warehouse. She readily agrees that her work has added greatly to her self-image and sense of worth.

Mrs. E.'s present job is her longest period of steady employment, though she did have several previous attempts at working. Shortly after high school she went to work at a sheltered workshop that helps disabled persons train for the job market. She left after a few months because she felt she didn't fit in. The other workers had more severe disabilities and the program was too slow and boring for her. After several months of unemployment Mrs. E. tried a couple of jobs in the fast food business. At a local fast food restaurant she was a full-time employee at minimum wage for about 4 months before quitting due to the fast pace and excess pressure. At another fast food restaurant she subsequently had a very similar experience, where her part-time job ended after only a few weeks. For several months afterward, she was not able to find work, though she applied for jobs at several places. Finally she obtained her present job.

As her current condition illustrates, Mrs. E.'s overall health has been mediocre for her entire life. Her early

childhood was plagued by ear infections and surgical problems with a cleft palate. As her mother puts it, "there was always something going on, health-wise," though Mrs. E. has also had long periods without illness and does not regularly take any medications. Thus, her average health costs vary greatly depending on the period in question. Over the past couple years she has had over \$3,000 in dental services due to needing caps installed on all her teeth, but otherwise she has not had any real health problems for many months before the December 1985 surgery. Although she still has the Medi-Cal coverage that comes with SSI eligibility, Mrs. E. does not use it because the physicians she sees do not participate in Medi-Cal. She was not pleased with the physicians that she had to go to when Medi-Cal was her only health coverage, so she has found others to help her now that she has health coverage from her employer.

Mrs. E. does not really feel that she is imparied now—she has a job she likes and does well at, has a new residence, a marriage, and feels her life is generally "coming together." She feels people see her as normal unless she is exposed to tasks that exceed her mental limitations, which is not often as such tasks are avoided both at work and in outside activities.

Mrs. E. has not yet dealt directly with SSA much, as her mother has been her payee. Mrs. E. has now applied as her own payee. Her mother feels the local SSA office has generally provided good service, though she has had conflicting information from different workers. Mrs. E.'s mother sees the local workers as helpful but not always well informed.

Work was not an issue for Mrs. E. when SSI was first applied for since she had just graduated from high school and no employment was imminent. When she did begin working, the local office advised that the SSI benefits would be affected by her earnings. Changes in earnings or work activity have always been reported promptly, and often in person by her mother. The only other social program (besides Medi-Cal) that Mrs. E. has benefited from is the Crippled Childrens Fund, which helped with therapy when she was younger.

When SSI was applied for, there were no 1619 provisions but her mother was very determined that Mrs. E. work if able to, as her mother feels the psychological benefits of working are more important than the SSI benefits. Despite this, her mother readily agrees that the continued financial and medical support that Mrs. E. has received has been important for her sense of security and has reduced the burden on the family.

#### Case Summary F

Mr. Scott F. is presently 22 years old and the child of middle-class parents. He has two full sisters, both younger, and several half-sisters and bothers. I gathered that his parents divorced when Mr. F. was in his teens and both remarried. He was clearly reluctant to talk about the

split in his family or the siblings that resulted from the remarriages. As he phrased it, "I don't remember the things that I don't like to remember." Apparently he blocks many memories that make him unhappy.

Mr. F. was in San Jose, California, for his early child-hood, though the family moved to Phoenix, Arizona, when he was in high school. They lived there only 3 years before returning to San Jose, but Mr. F. graduated from high school before they returned. Mr. F.'s first recollection of his childhood was that he could not learn to read in school, and is still not able to read. He feels that he was passed from grade to grade despite his learning disability because the schools didn't want to take the trouble to deal with his problem. He was not willing to recall anything else about his early years, so I did not press the questioning. Mr. F. said that all his siblings completed high school except one half-brother that dropped out.

After returning to San Jose, Mr. F. was entered into a work training program. This is an educational/residential program that teaches basic living skills to persons with mental disabilities. He participated in this program for about 3 years, learning the basic skills of maintaining his own home such as: cooking, cleaning, paying bills, keeping a checking account, shopping, laundry, etc.

Mr. F. currently lives in a house with four other people—three men and one woman. Each person has his or her own bedroom and they all share the kitchen and living area. He has lived there almost a year, but wants to find a different living situation because he feels a lack of privacy and also feels he does more than his share of the housework and yardwork. Indeed, he says much of his spare time is spent in these pursuits, though he also has time to go to the beach and hang out with several buddies. He also has frequent visits with family, but could not recall any other recreational activities. He does not go to movies, bowl, watch TV, nor read, but has a car and driver's license so he gets around to visit people as he wishes.

Since December 1984, Mr. F. has worked for a small company that does custom cabinet installations and other interior finish work, mostly for residential customers. He works between 20 and 40 hours per week, depending on the work available for him, and is paid \$5.00 an hour. He was hired because his father is the owner of the company and manages it, though Mr. F. is supervised by another employee. His main duties are cleaning, maintenance, deliveries, and generally helping out wherever needed. He would like to work full-time and make more money, but this is apparently not feasible now, based on the work available.

The first job he had was for minimum wage at a fast food restaurant, where he worked for about 6 months back in 1983. He next worked as a maintenance and cleaning person for an auto repair and restoration company. He started there as a part-time employee in the evenings and, after a few months, went to full-time in the day. He was paid minimum wage all along, so was happy to go to

\$5.00 an hour when his father offered him the opportunity. Mr. F. Worked 14 months for the auto repair company.

Mr. F. enjoys excellent physical health and does not take any medications regularly. He believes that God can heal any illness or injury better than the medical profession, so he rarely uses the Medi-Cal benefits which are his only health care coverage. His employer offers a health care plan but he is not eligible due to his part-time status.

Other than his reading problem, Mr. F. does not feel that he is impaired and does not feel others see anything unusual about him.

In his dealings with SSA, Mr. F.'s main complaint is that he sometimes has to wait too long for service at the local office. He says the workers he has seen have been helpful and informative once the wait is over. At the time he originally filed for SSI he was advised on how work affects his benefits, and has been kept apprised all along. He currently reports his earnings every 3 months—this is done through his counselor at work training. Even though he no longer resides at this facility, his progress and welfare continue to be monitored by one of their social workers. He has not had experience with any other social or welfare programs.

#### Case Summary G

Ms. Anna G. is 47 years old, the second-born in a family of eight children, all of which are still living with the exception of Ms. G.'s older sister. Her childhood was unremarkable but pleasant until she graduated from high school and had to look for work. The graduation makes her something of an exception in her family, as only two other siblings got their diplomas. The parents also had very limited educations—they did mostly seasonal work in the agricultural industry or semiskilled assembly work. It seems that financial needs forced most of the children to follow suit before completing high school. Ms. G. has always lived in the Santa Barbara area and did not have any formal training or education after high school.

At present, Ms. G. is living in a house with several family members—a sister, niece, nephew, both parents, and her own son (16 years old). As the house is only a small three-bedroom, it makes things crowded, and Ms. G. is hopeful of getting her own place soon with the help of the housing authority. She did have more room in a prior situation but did not get along with the other residents and moved into her present quarters in mid-December 1985.

When not working, Ms. G. likes to knit and crochet, though she misses the sports that she used to enjoy. Her arthritis prevents most physical activities, so she has had to find other hobbies in the past few years. She also belongs to a fraternal club that has bingo games and other social activities, where she spends a few hours every week. She also visits often with several family members and enjoys television at home with family.

Ms. G. began working right after high school. Her first job was packaging orchids for shipment by a local grower. This job lasted only for one season and was for minimum wage. She was not rehired the following season, and was not able to get other employment for several years. Ms. G. has visibly swollen joints in her fingers and feels most employers would not hire her because of this clear sign of rheumatoid arthritis. After a long search for work, she was finally hired by a small manufacturing firm that made restaurant supplies such as napkin dispensers, salt shakers, and such. She enjoyed this job and did well at it. Since no great dexterity was needed, despite the low pay (minimum wage again), she would probably have stayed there indefinitely if not for the birth of her son. Since she had no husband to share the financial support of the child, Ms. G. had to leave work and subsist on social programs. She and the child were on AFDC for several years, though Ms. G. later became eligible for SSI benefits.

Ms. G. remained unemployed until 1981, though she did a lot of volunteer work at the schools her son attended (teaching aide type work), at which time she sought the services of a sheltered workshop that provides job training to the disabled. Her intent was to learn sewing skills and perhaps start a small home enterprise to make a few extra dollars, but she became on good terms with a supervisor and this led to her being hired as a "lead worker" in October 1981. The workshop has a lot of clients with severe mental limitations and Ms. G.'s job is to set up their work areas, tools, and supplies, with continued attention to insure the tasks are properly completed. The tasks are mostly assembly of simple components for telephone equipment and then packaging them for shipment. Ms. G. is paid \$4.95 an hour and works up to 40 hours per week, depending on how much work there is. She says she rarely works less than 30 hours per week and would not like to work more than 40 as she gets tired out.

The rheumatoid arthritis that Ms. G. suffers from affects her hands the most, though she also has some pain and weakness in her knees and feet. This is more pronounced in certain weather conditions. The loss of fine manipulation in her fingers has been the only job-related problem caused by her impairment, but she works around this and in general feels her work is not much affected by the disease. Because her place of employment has so many severely disabled people, the attitudes are very tolerant and her coworkers take no notice of her impairment. Other than the arthritis, her health has always been good. She does not take any regular medications nor receive any regular medical attention. She has her Medi-Cal coverage but does not like the physicians that she has to see if she uses this program so she would go to a private physician if services were needed. She isn't sure whether or not she has coverage under the health plan her employer carries. Since she hasn't needed any care recently, the issue hasn't arisen. She feels that staying active to keep her joints from stiffening is the most effective treatment of her disease at

its present stage.

When Ms. G. applied for SSI, she was told that working would affect her benefits, and her years of AFDC benefits also helped her in understanding the SSI program. When she began working, she was again advised of the impact on her benefits and she feels that SSA has generally kept her well informed. She said there was once "some kind of mix-up" regarding a report of wages and an overpayment resulted. This was resolved to her satisfaction and without hardship to her. She says her earnings are reported each year during her annual redetermination and the data is sent directly from her employer to the local SSA office. She also understands that any large changes in the amount she earns must be reported.

Ms. G. is a pleasant woman, though not very talkative and does not give the impression of a high school graduate. She understands only simple words and short sentences and seemed to have trouble concentrating, though she may have been tired or preoccupied. She is very short (about 5 feet) and has gnarled and bent fingers, but is otherwise unremarkable physically. She impresses me as a woman that would have trouble competing in the open job market but has found a niche where her impariment is not held against her.

#### Case Summary H

Mrs. Jan H. is a 39-year-old woman. She grew up with her parents and two sisters in a large extended and supportive family. She went to high school, got married in her senior year, and then divorced at age 21. She went back to high school nights to get her high school degree, which was attained in 1968. She earned an A.A. degree in business administration from a local community college.

She has had asthma and then epilepsy since early child-hood. The epilepsy began when she was 13 years old. She has had asthma since early childhood and believes it is hereditary.

Her parents are retired; she has a 19-year-old daughter who just moved out recently and got her own apartment. She helps her daughter pay for car repairs, as well as giving her other support when needed.

Mrs. H. lives in the home of her parents, helping by paying her own room and board to the extent that she can on her salary. Her two sisters live separately right now.

She was involved in vocational rehabilitation for close to 5 years. They sent her to the community college. She wants to go beyond this level of education when she can. Taking classes over and above her full-time job right now would be too taxing on her because her condition demands that she rest sufficiently.

Mrs. H. works full-time plus—until the job gets done. She works for an insurance company, a life and health insurance agency. She deals with people on the phone (clients); is into "broker relations;" she answers many questions. The employees are a close-knit group. She said she

is the oldest of all of them and feels like their "mom." Her salary is about \$11,000 per year, and she has been doing this job for 18 months. She found the job herself. Her only problem is "keeping everyone else healthy" so she won't catch anything from them.

This job has been the longest one she has held. Her other jobs have included being a bookkeeper and receptionist. She has lost her past jobs due to the business being sold, or one went bankrupt. All past jobs have ended due to circumstances beyond her control.

Mrs. H. rates her health as very good. She has to take a "handfull" of medication 3 times per day to control her asthma and epilepsy. Monthly costs of these medications are approximately \$172 as of 2 years ago. Maybe this would be \$200 at least per month in today's market.

Without Medicare/Medicaid cards she would be unable to work. With her salary of \$11,000 approximately per year, she would never be able to afford the medication she needs to control her asthma and epilepsy. She said the cost was much more than this but, due to improvements in the medications that she takes and adjustments to get the right dosages, it has come down to \$172-\$200 per month. Mrs. H. has had her Medicare/Medicaid cards since 1975. She uses Medicaid monthly for these medications, without which she could not function at work or anywhere.

Mrs. H.'s employer has a health plan (in fact they sell health insurance) but they would not insure her due to her illnesses. She inquired about health insurance with Blue Cross/Blue Shield, but they offered her a plan that would cost her \$262 per month. With this, plus her medications, her costs would be \$460 plus per month. This plan did not cover prescription drugs.

Mrs. H. does not like to call her illnesses "impairments." She balks at calling herself "impaired." She does not feel that her illnesses affect her ability to function at her job. The medications have her "symptoms" under control.

Her experience with the Social Security Administration has been an extremely positive one, except for an overpayment that occurred when she was working. Mrs. H. said that she kept calling, but someone told her she was able to keep the checks. She is now paying back this overpayment on a monthly basis at a rate she can afford.

Mrs. H. understands that her work could have ended both her SSI checks (which it has) plus her Medicaid and Medicare (which is still in effect). But her attitude is such that she felt she must do something and use her skills to earn a living. She is under no other social welfare programs. She is now earning more than she can to receive any SSI benefits, but she said she is contacted yearly to fill out a report about her earnings. At \$11,000 per year average she is not due any SSI.

Mrs. H. is extremely emphatic about how important Medicare/Medicaid is to her personally. She said she would be "on the street" possibly without her medications being paid for.

#### Case Summary I

Miss Roselyn I. is 38 years old, single and has never been married. She lives with her daughter, who is 15 years old. They live in subsidized housing. Her daughter also receives SSI benefits. They applied together in 1983. Miss I. also has a son who is 8 years old and does not live with her.

Miss I. suffers from severe depression. She occasionally attends a local church, but does not get out of her apartment to socialize very frequently. She graduated from high school via the G.E.D. program in 1974. She believes that her mother, who lives in a nearby town, also graduated from high school, as did her father. He died in June 1960 of cancer. Miss I. now receives title II childhood disability benefits and Medicare on her account number.

Miss I. was the seventh of 13 children. She has four sisters and eight brothers, all of whom are working. A younger sister and an older brother both have diabetes. To her knowledge, none of her siblings receive social security or any kind of public assistance benefits.

Miss I. began working at a sheltered workshop in 1975. Her transportation from her apartment to the workshop (12 to 14 miles) is provided by the County Department of Mental Health. Her working hours are 8:30 a.m. to 2:45 p.m. each day. The only break in her workday is the one-half hour she takes for lunch. In 10 years of work, she has had only one lengthy absence. She was off 3 to 4 months when her son was born in 1978.

She is 1 of approximately 30 people employed at the workshop. Earnings are based on piecework. Most of the contracts come from local industries, and call for simple repetitive types of work (e.g., packaging bow sights for a local archery equipment manufacturer; unwrapping bubble gum so that it can be reprocessed by the manufacturer; and janitorial work). Her only prior job experience was working in a kitchen of her high school when she attended classes there.

Miss I.'s earnings at the workshop have ranged from below \$65 per month to over \$235 per month during the last 2 years. These earnings, together with her title II benefits, generally make her ineligible for SSI cash benefits. Because of section 1619(b), however, she continues to qualify for Medicaid. She is in relatively good physical condition, but suffers from severe depression for which her doctor prescribes medication twice daily. The cost of this prescription is about \$20 per month. Although Miss I. has not used her Medicaid card to a great extent, she said that she appreciates the added security that it provides.

Miss I.'s experience with SSA has been satisfactory. She said that it is sometimes difficult for her to get into the district office for her redeterminations of eligibility, even though transportation is provided free-of-charge by the County Department of Social Services. She had lost her Medicare card, so arrangements were made to get her a new one.

#### Case Summary J

Miss Susan J. is age 27, a single female. She resides with her parents and one brother who is away at college. She has a sister who is married, attended college but did not graduate. Miss J. has a B.A. in Early Childhood Development. While in the Rehabilitation Institute she underwent vocational testing for about a month.

She is currently working for a bank as a Data Entry Supervisor. This is a full-time permanent position with lots of overtime exceeding 40 hours a week. Her salary is approximately \$1,200 per month. She first went to work in March 1985 and this is her first job. She had been working with the State Rehabilitation Commission but found her job through a family friend. She did have some part-time summer work at college before the onset of disability (a spinal cord injury resulting from an accident).

Miss J. said her overall health is good, although she is wheelchairbound, or in a "power chair." She takes very little medication except for occasional antibiotics. Her monthly medical bills are none at the moment. She hasn't used the Medicaid card since starting work. She must buy catheters, but Medicaid doesn't cover any of the costs. She did use the Medicaid prior to going to work but she now participates in her employer's health care plan, which also covers prescriptions. She needed the Medicaid for the initial medical costs in 1980 when her family insurance plan was exhausted.

She has adjusted to her handicap extremely well. At work, "everything is accessible." Miss J. does everything for herself, including driving. The only problems she has encountered because of her impairment is inability to reach high at work and the continuing nuisance of the public using parking designated for the handicapped. She believes that her impariment causes no problems in the interaction with coworkers, nor does it influence her activities. She feels she can go anywhere and do anything she wants, with no special problems.

Her first comment when asked about her experience with SSA was "a lot of red tape and hassles." She felt that she was treated better by SSA staff in California at the onset of her disability than by SSA staff in Texas after she moved. She received checks for at least 3 months after reporting earnings. At the first report she was advised that they did not know how it would affect her and they would get back to her. Her next contact with SSA was a past due notice on an overpayment. Miss J. called and asked about the continuing receipt of the Medicaid card and was again advised that they did not know whether she was entitled and would get back to her. As the card has kept coming, she assumed she was entitled. She did not remember at any time being advised by SSA about how work would affect earnings or Medicaid entitlement. In SSA's defense she said that her mother handled her initial application in California and could have been advised of the rules, etc., at that time.

Miss J.'s main complaint was that Medicaid does not

pay for the items that enable her to work: the batteries for her wheelchair at approximately \$200 a year and the catheters at \$150 to \$200 every 3 months. The medical program in California did a much better job of coverage, but also did not pay for the catheters.

Miss J. felt she could not give a valid opinion of the 1619(b) program as it has never been fully explained to her.

#### Appendix C: 1985 SSI Medicaid Recipient Survey Methodology

#### **Background**

The Committee on Ways and Means in its report on H.R. 3755, asked the Department of Health and Human Services to provide information about the effects of 1619 on the work effort of the SSI disabled population. SSA internal administrative records could not be used to provide a complete picture; therefore, a mail survey was used to supplement other available information on SSI disability recipients and work.

#### Sample Design

The populations studied were:

- (1) Participants in section 1619(a);
- (2) Participants in section 1619(b);
- (3) Disabled SSI recipients who were not working, and (4) Disabled SSI recipient workers not participating in either 1619(a) or (b), and earning less than \$75 per month.

A total of 3,324 questionnaires were mailed to the four groups of disabled individuals as follows:

(1) Participants in section 1619(a)	709
(2) Participants in section 1619(b)	932
(3) Disabled SSI recipients who were not	
working	916
(4) Disabled SSI recipient workers not	
participating in either 1619(a) or (b) and earn-	
ing less than \$75 per month	767

Of this number 2,007 were returned after an initial mailing and one followup mailing. The U.S. Postal Service returned 68 questionnaires as undeliverable because the individuals had moved or died. This reduced the total number of returnable questionnaires to 3,256. Of the 2,007 returned questionnaires, 347 were not included in the analysis because (1) they were incomplete or (2) the sample individual's status changed between the time of selection and the time the questionnaire was completed.

The number of questionnaires available for analysis were:

(1) Participants in section 1619(a)	400
(2) Participants in section 1619(b)	348

(3) Disabled SSI recipients who were not

### Appendix C, Exhibit 1: 1985 SSI Medicaid Recipient Survey

Please place an X in the box next to your best answer. Write in answers in the blank spaces. If you have trouble filling out this form, anyone can belp you answer the questions. Please return the completed form in the enclosed envelope. You don't need a stamp.

If	you are now working, Please answer the questions in Column A	If you are not working, please answer the questions in Colum	an B
Colum	N A WORKERS  (Answer questions in this column only)	Column B NON-WORKERS (Answer questions in this column only)	
A-1	Did you get an SSI payment this month?  Yes No	B-1 Did you get an SSI payment this month?  Yes No	
A-2	Do you have a Medicaid or Medi-Cal card?  Yes No	B-2 Do you have a Medicaid or Medi-Cal card?	
A-3	How often do you use your Medicaid/Medi-Cal card?  Less than once a month About once a month 2-3 times a month 4 or more times a month Don't have a Medicaid/Medi-Cal card Don't have a Medicaid/Medi-Cal card  What type of services do you usually use your Medicaid/Medi-Cal card for? (check all applicable) Prescription drugs (medicine) Doctor visits Hospital services (including clinic visits and services)	B-3 How often do you use your Medicaid/Medi-Cal card?  Less than once a month  About once a month  2-3 times a month  Never used my Medicaid/Medi-Cal card  Don't have a Medicaid/Medi-Cal card  B-4 What type of services do you usually use your Medicaid/Medi-Cal (check all applicable)  Prescription drugs (medicine)  Doctor visits  Hospital services (including clinic visits and services)	al card for
	☐ Transportation services ☐ Home health services ☐ Other services ☐ Never used my Medicaid/Medi-Cal card ☐ Don't have a Medicaid/Medi-Cal card	☐ Transportation services ☐ Home health services ☐ Other services ☐ Never used my Medicaid/Medi-Cal card ☐ Don't have a Medicaid/Medi-Cal card	
A-5	Do you have a red, white, and blue Medicare card?  Yes No	B-5 Do you have a red, white, and blue Medicare card?  Yes No	,
A-6	Which of the following is the kind of job you have?  Working in a private hosuchold?  An employee of a private company, business, or individual?  An employee of the local, Federal, or State government?  Working in a sheltered workshop?  Self-employed on your own farm? Self-employed in your own business or professional practice?  Please go on to question A-7	B-6 Have you ever worked?  Yes-skip to question B-8  No-go to question B-7  B-7 What was the main reason you never worked?  Injury/disability/illness Going to school/training Not enough experience/training/schooling Could not find work Jobs didn't pay enough Didn't want to work Taking care of home or family  Please skip to question B-11	
A-7	Did someone help you get this job?  Yes, who helped you?  (for example, vocational rehabilitation, or social service agency, social security, relative)  No	Afraid of losing SSI check or Medicaid/Medi-Cal card Other-please specify  B-8 In what year did you work last? 19	
A-8	Does your job or work offer you a health plan?  Yes, and I belong to the health plan at work  Yes, but I don't belong to the health plan at work  (Please explain why you don't belong to the health plan at work)  No, my job does not offer a health plan	B-9 What is the main reason you stopped working?    Employer thought health was too poor   Poor health/not well enough to work   Spouse's health   Other family responsibilities   Too old/wanted to retire   Disliked job/boss   Company closed down/job discontinued	,
A-9	What kind of work do you do (for example, food service, dishwasher, shoe salesman, assembler)?	To get back on SSI Other-please specify	
A-10	How much money do you usually earn each month?  \$74 or less \$75 to \$149 \$150 to \$299 \$300 to \$599 \$600 to \$899 \$900 to \$1,199 \$1,200 to \$1,499 \$1,500 or more	B-10 What kind of work did you do (for example, food service, dis salesman, assembler)?  B-11 Please answer "Yes" or "No" to the following questions.  a) Is there some type of work you would like to do? b) Do you believe you are able to work? c) Do you know that you can work and still get an SSI check? d) Do you know you can work and still get a Medicaid/ Medi-Cal card?	Yes No

#### Appendix C, Exhibit 1: 1985 SSI Medicaid Recipient Survey—Continued

Please place an X in the box next to your best answer. Write in answers in the blank spaces. If you have trouble filling out this form, anyone can help you answer the questions. Please return the completed form in the enclosed envelope. You don't need a stamp.

If you are now working, Please answer the questions in Column A		If you	are not working, Please answer the questions in Column B						
Column A		WORKERS (Answer questions in this column only)					<del>-</del> '	Column B	NON-WORKERS (Answer questions in this column only)
A-11	How	many months have you worked in the last year? Less than 3 months 3 months but less than 6 months 6 months but less than 12 months All 12 months	٠.		B-12 Whi	ich of the following is where you live? Hotel or motel Rooming or boarding home House, apartment, or mobile home Hospital, convalescent home, or nursing home Retirement or rest home, foster care, personal care, or residential			
A-12	Was	last year a typical work year for you?  Yes, I usually work the same number of months each No, I just started working last year No, I usually work (check one of the following)  Less than 3 months  3 months but less than 6 months  6 months but less than 12 months  All 12 months	year		-	care home School, rehabilitation, or training center Other (where)  very much for your time and help.			
A-13	a) b) c) d) e) f)	Do you want to work more? Are you able to work more? Have you ever stopped work or worked less because you thought your SSI checks might stop? Have you ever stopped work or worked less because you thought your Medicaid/Medi-Cal might stop? Would you work less if that was the only way you could continue to receive an SSI check? Would you work less if that was the only way you could keep your Medicaid/Medi-Cal card? Do you know that you may be able to earn more money and still keep your Medicaid/Medi-Cal card?	Yes	∞□□□□□□□□					
A-14	0000000	ch of the following is where you live? Hotel or motel Rooming or boarding home House, apartment, or mobile home Hospital, convalescent, or nursing home Retirement or rest home, foster care, personal care, or care home School, rehabilitation, or training center Other (where)  a very much for your time and help.	or reside	ential					

working	563
(4) Disabled SSI recipient workers not	
participating in either 1619(a) or 1619(b) and	
earning less than \$75 per month	349
Total	1.660
earning less than \$75 per month	

Because of low response rates in several strata, a comparison of selected characteristics was undertaken to see if there were any significant differences between respondents and nonrespondents. Since there were no significant differences between these groups, SSA used 1,660 in its statistical analyses.

Table C-1 presents additional data on the characteristics and response rates from the four study populations. (Also see Exhibit E, table C-3 [in the full report], for a comparison of the characteristics of respondents and nonrespondents.)

**Table C-1.**—Number of sample cases and number of responses

Responses	Total	1619(a)	1619(b)	Non- earners	Low earners
Total sample mailed	3,324	709	932	916	767
Percent of universe		86.9	11.7	.04	1.0
Undeliverable <sup>1</sup>	68	10	26	26	6
Total returnable					•
questionnaires	3,256	699	906	890	761
Total returned	2.007	453	460	594	500
Excluded from study	347	53	112	31	151
Incomplete responses	37	3	19	6	9
Other <sup>2</sup>	310	50	93	25	142
Included in study	1,660	400	348	563	349
Response rate	51.0	57.2	38.4	63.3	45.9

<sup>&</sup>lt;sup>1</sup>Includes cases in which recipient/participant had moved with no forwarding address, and those who had died.

<sup>&</sup>lt;sup>2</sup>Includes those respondents whose status had changed between the time they were selected in the sample and the time they responded to the questionnaire.

## Appendix F: Supplemental Security Income Program—Cost And Caseload Estimates of the Section 1619 Program

#### **Background**

A major issue surrounding the section 1619 program is cost. When first introduced, the legislation recommended that the earnings level for substantial gainful activity (SGA) be established at an amount equal to the point at which an individual would no longer be eligible for SSI benefits. This proposal had serious cost implications for the disability insurance program and was not adopted. In response to congressional concerns, a special analysis was made to determine the costs/savings of the section 1619 program. Following are the major assumptions used, the methodology for developing the estimates, and finally the estimates themselves. Estimates for section 1619 involve two operating divisions in the DHHS-SSA and HCFA. SSA was responsible for the SSI cost and savings estimates, while HCFA estimated the Federal and State Medicaid costs. The estimates prepared by both agencies were derived from the same general assumptions about program participation.

#### **Assumptions Used in the Estimates**

Incentive effects of section 1619. The major question surrounding the section 1619 cost/saving estimates is, "How much does the program cost (or save)?" It is clear that, in the absence of the section 1619 program, some disabled SSI recipients would have gone to work or increased their earnings. This added work effort would have resulted in a reduction in, or termination of, their SSI benefits. Therefore, the major question is, "How many of the SSI disabled individuals who went to work (or increased their earnings) did so as a result of the section 1619 program?"

To answer this question, SSA undertook a survey to determine the work incentive effects of the section 1619 program. Answers to the following two questions—"Would you work less if that was the only way you could continue to receive an SSI check?" and "Would you work less if that was the only way you could keep your Medicaid/ Medi-Cal card?"—were used as indicators for the work incentive effects of section 1619. The combined positive responses to either question were used as a "work incentive proxy" for section 1619(a) participants, and positive responses to the second question were used as a "work incentive proxy" for section 1619(b) participants. Positive responses indicated that 30 percent of section 1619(a) and 21 percent of section 1619 program had not been enacted.

Defining SSI costs and savings. The purpose of the section 1619 program is to lessen possible disincentives that prohibit disabled individuals from working. Any sav-

ings realized as a result of the program can be attributable to the reduced expenditure of SSI benefits; reduced SSI expenditures result from increased earnings of individuals. The formula for computing an SSI benefit includes a provision that reduces the SSI payment by \$1 for every \$2 of earnings (after the first \$65 of monthly earnings). However, calculation of SSI savings attributable to section 1619 is not as simple as taking a person's earnings, subtracting \$65 a month, and then dividing the remainder by two. There were three problem areas that required decisions. The following is a brief discussion of the problem areas and their resolutions.

- Earned vs. unearned income. In addition to earned income, some section 1619 participants also have unearned income (e.g., social security benefits, unemployment compensation payments, private pensions, etc.). In determining eligibility for section 1619(b), the amount of earnings is the factor that precludes eligibility for SSI benefits. Therefore, the question became, "How much of the earnings should be counted as savings?" Savings are defined as the reduction in benefits after unearned income is counted. For example, if in 1985, an individual had unearned income of \$220 per month and earned income of \$565 per month. the individual would have countable income of \$200 in unearned income and \$250 in earnings and would not be eligible for an SSI payment. Even without the earnings, the individual would have received only \$125 in Federal SSI benefits (\$325 less \$200 countable unearned income). Thus, the savings are calculated as the reduction of SSI benefits after counting unearned income first. This is the most conservative approach for recognizing savings and assumes that earnings are the "last" dollars to be counted in the benefit computation.
- Incremental vs. impact value savings. The analysis of SSI case records revealed that some individuals had earnings long before they participated in the section 1619 program. The question became, "Should savings accrue based on all of the earnings or only that portion of the earnings that made the individual eligible for section 1619 participation?" A simple example illustrates the problem. In May, an individual had \$220 in unearned income and \$165 in earnings and was eligible for an SSI benefit of \$475. In June, the earnings increase to \$365, precluding SSI eligibility; the individual then becomes eligible for section 1619(b). The next question was, "What savings should be attributed to the SSI program because of section 1619?" Two methods of computing savings were considered. One can choose to count as savings the value of the reduction in benefits due to incremental earnings (\$75, using the example above), or the

impact value of actual earnings (i.e., \$125). The latter method was selected. While use of this value may, in a small number of cases, cause savings to be overstated: use of the alternative (incremental) method (given the wide fluctuations noted in individual earnings) would also be subject to a margin of error and would require individual month-bymonth computations of projected future earnings.

- (3) Savings and Overpayments. During the case record analysis, a number of individuals were found to have changes in earnings while they were participating in the section 1619 program. In these situations, overpayments resulted from increases in countable earned income. In computing the savings to the SSI program, the amount of recovered overpayments was included.
- (4) 1619(a) cases—a special situation. Section 1619(a) program participants present special problems in estimating SSI program savings. Prior to the section 1619 program, SSI recipients found to be engaging in SGA were terminated from the SSI program regardless of the amount of income. Under section 1619(a), participants who engage in SGA and have income below the SSI Federal benefit rate are entitled to special SSI cash payments. Comparing this group (current section 1619(a) participants) to similar groups in the pre-1619 days, the following rules were developed:
  - (a) For incentive cases (i.e., 30 percent of all section 1619(a) participants), only the savings attributed to earnings were counted. In the absence of section 1619, the assumption was made that these individuals would not have been working (and therefore would have been receiving full SSI benefits less any unearned income). Therefore, the actual earnings of these participants result in savings to the SSI program.
  - (b) For nonincentive cases (i.e., 70 percent of all section 1619(a) participants), only costs would be counted. The assumption here is that if it were not for the section 1619 program, these individuals would not be eligible for a cash benefit. Therefore, all of the special SSI cash payments to these individuals represent additional costs to the SSI program.

Spillover effects. Only a portion of the estimated SSI program savings accrue while individuals participate in the section 1619 program. A larger portion—approximately 80 percent—is directly attributable to assumptions made about individuals who no longer have section 1619 program connections. Although some 55,000 people participated in the section 1619 program at some time during the period under study (May 1981–December 1985), many of these left the section 1619 rolls because their earnings decreased or stopped. Others lost eligibility for section 1619

and SSI benefits (and Medicaid, as well) because of factors unrelated to earnings (e.g., increased countable unearned income or resources).

In still other cases, section 1619 ties were severed for one or more of the following reasons:

- Earnings increased to the point of exceeding the threshold limits applicable under section 1619(b);
- Medicaid was no longer needed (as evidenced by failure to meet the usage test); or
- Individuals voluntarily withdrew from program participation.

As a result of this latter group of cases—hereinafter referred to as "spillover" cases—savings accrue to the SSI program. The question is, "How much of the savings can be attributable directly to section 1619?" In answering this question, the incentive effects of section 1619 (as indicated by Survey responses to the two pertinent questions) were applied. This led to the assumption that section 1619 is responsible for SSI program savings in some (30 percent for section 1619(a) and 21 percent for section 1619(b)) of the spillover cases (i.e., those individuals who would not work if section 1619 had not been enacted and who, therefore, would have remained on the regular SSI rolls). The standard closing rate was used in arriving at estimated savings in these cases.

#### Methodology for SSI Estimates

The data source for estimates of SSI program cost/ savings was SSA's 1-percent sample file. There were three major steps in developing the estimates. Following is a brief description of each step:

- (1) Identifying cases ever in section 1619. The first step in the process was to identify each case that had a section 1619 program connection at any time. For the period July 1981 through December 1985, all cases on the 1-percent sample file (550) that had section 1619 indicators on the records were selected for this analysis. Information was gathered on the months in which individuals participated in section 1619 and the amount of cost and/or savings associated with each case. For cases that were no longer in section 1619, information was gathered on the reasons why such individuals were no longer participating in the program. The above information was compiled on a computer file, and summary counts were made of the number of cases in section 1619 by month and year, with benefit cost/savings by month.
- (2) Selecting incentive/nonincentive cases. All cases selected were divided into 2 groups: (1) those that entered the section 1619 program through the section 1619(a) provision and (2) those that entered through the section 1619(b) provision. Using a ta-

ble of random numbers, each case was assigned to either the incentive group or the nonincentive group. (For individuals entering through the 1619(a) provision, 30 percent were considered to be incentive cases and 70 percent were nonincentive cases. For individuals entering through the 1619(b) provision, 21 percent were classified as incentive cases and 79 percent were nonincentive cases. The rationale for these percentages is found in the assumption section above.)

(3) Projecting future caseloads, costs, and savings. As a result of the identification and selection activities described above, data were compiled in a series of computer files. Using a step-wise autoregressive technique, estimates of future caseloads, costs, and savings were computed. Costs and savings were computed both for the Federal SSI program as well as State supplementation programs. In addition, estimates were made of the actual cost impact of the section 1619 program for the first 5 years.

#### The Estimates

Two tables are included in this section to show the estimated cost/savings effects of section 1619 on the SSI program. Table F-1 shows the estimated program costs and savings from the beginning of the program through the end of the FY 1985. Table F-2 shows cost/savings and caseload estimates for FY's 1986 through 1990. For FY 1986, the costs and savings that are attributed to the section 1619 program do not represent additional savings, since these dollars are already included in the SSI program estimates for the 1987 Federal budget.

**Table F-1.**—SSI caseloads and estimated costs/savings resulting from the section 1619 provisions, fiscal years 1981–85

Caseloads and savings	1981	1982	1983	1984	1985
Total in section 1619					
program	3,310	4,015	5,395	6,610	7,330
Participants:1					
1619(a) cases	200	285	605	625	665
1619(b) cases	3,110	3,730	4,790	5,535	6,665
Spillover cases	200	585	1,205	2,275	3,090
Cost/savings (in millions): SSI costs:			·	•	
Federal Benefits	\$0.2	\$0.3	\$0.5	\$0.6	\$0.7
State benefits	(2)	(2)	.2	.3	.4
SSI savings:		•			
Federal benefits	.9	1.9	4.5	6.8	8.5
State benefits	.1	,4	.6	.9	1.2
Net SSI savings:					
Federal benefits	.7	1.6	4.0	6.2	7.8
State benefits	.1	.4	.4	.6	.8

<sup>&</sup>lt;sup>1</sup>Average monthly number of participants.

Table F-2.—Projected SSI caseloads and estimated costs/savings resulting from the section 1619 provisions, fiscal years 1986-90<sup>1</sup>

Projected caseloads and estimated savings	1986	1987	1988	1989	1990
Total of section 1619					
program	8,410	9,250	10,395	11,615	12,655
Participants: <sup>2</sup>					
1619(a) cases	730	900	1,140	1,295	1,405
1619(b) cases	7,680	8,350	9,255	10,320	11,250
Spillovers cases	3,735	4,520	5,285	6,025	6,760
Cost/savings (in millions):	•,	.,	• •	•	-
SSI costs:					
Federal benefits	\$0.8	\$1.0	\$1.1	\$1.3	\$1.4
State benefits	.4	.5	.5	.6	.7
SSI savings:					
Federal benefits	10.4	12.7	14.9	16.9	18.8
State benefits	1.4	1.6	1.9	2.3	2.5
Net SSI savings:					
Federal benefits	<sup>3</sup> 9.6	11.7	13.8	15.6	17.4
State benefits	1.0	1.1	1.4	.17	1.8

<sup>1</sup>Assumes that section 1619 authority, which expires June 30, 1987, is continued. <sup>2</sup>Average monthly number of participants.

<sup>3</sup>Net program savings already included in SSA's FY 1987 budget.

## Appendix G: Impact of Section 1619 on Medicaid Program Costs

#### **Background**

Estimates of the Medicaid costs and savings of the section 1619 program were prepared using the same general assumptions regarding program participants as used by SSA in estimating SSI program impact. (See Appendix F for a discussion of the SSI impact.) The total section 1619 population is viewed as consisting of two groups:

- (1) The incentive group—i.e., those for whom the section 1619 program was an incentive to work and who would not work in its absence; and
- (2) The nonincentive group, consisting of those participants who would have worked even without the continuation of benefits provided by section 1619.

The incentive group does not cost Medicaid anything since they would not have worked in the absence of section 1619 and hence would be receiving Medicaid anyway.

On the other hand, benefits paid to participants in the nonincentive group represent costs to the Medicaid program since this group would work (and not get Medicaid) without section 1619.

Another group which impacts the Medicaid program is that referred to as the "spillover" population in Appendix F—i.e., those individuals who leave the section 1619 program (e.g., because of increased earnings or voluntary withdrawal) and no longer receive SSI or Medicaid. Spillover cases in the incentive group save Medicaid money when their benefits cease since, in the absence of section 1619, they would not work and would continue to be eligible for Medicaid.

In summary, the nonincentive cases are a cost to Medicaid as long as they are in the section 1619 program,

<sup>&</sup>lt;sup>2</sup>Less than \$100,000.

and the incentive spillover cases save Medicaid money when they leave the section 1619 program.

#### **Derivation of Medicaid Cost Estimates**

Estimates of the Medicaid program costs/savings of section 1619 were derived in three steps:

- (1) Estimating annual numbers of Medicaid recipients in the groups which impact Medicaid program costs—i.e., the nonincentive and spillover cases;
- (2) Multiplying the results of step 1 by estimating percapita annual expenditures for each group; and
- (3) Calculating net Medicaid costs/savings as nonincentive costs minus spillover savings.

The estimates derived from these steps were converted to a cash expenditure basis by assuming that 20 percent of Medicaid bills incurred in a given fiscal year would be paid in the following year. In calculating Federal and State shares, an average Federal matching rate (FMAP) of 55 percent was used.

It should be pointed out that the subgroup of the section 1619 population residing in medical institutions was not included in the Medicaid estimates, since these individuals would be, in almost all cases, eligible for Medicaid benefits without section 1619 program participation.

- (1) Estimating Medicaid recipients. The underlying caseloads used to estimate Medicaid recipients were the same as the average monthly caseloads used in developing SSI estimates. These caseloads, representing Medicaid eligibles, were converted to annual ever-enrolled Medicaid recipients by assuming that individuals are eligible an average of 9 months per year and applying a ratio of recipients to eligibles obtained from the study of the section 1619 population prepared by HCFA's Office of Research and Demonstrations. (This study is discussed in Appendix E [of the full report].) The resulting ever-enrolled recipient counts are shown below with the cost estimates.
- (2) Per-capita annual Medicaid expenditures. Percapita Medicaid costs for the section 1619 program participants were estimated by using the HCFA/ ORD study to develop a ratio of Medicaid expenditures for section 1619 program participants to expenditures for the general disabled Medicaid recipient and applying this ratio to historical disabled recipient costs and projections done by HCFA's Office of the Actuary for the spring review of the fiscal year 1987 budget. (As mentioned above, costs for institutionalized recipients were not included in the calculations.) The resulting per-capita expenditures are about half of those for the general noninstitutional disabled Medicaid population and are shown with the cost estimates below.
- (3) Incentive vs. nonincentive costs. No data is avail-

Table G-1.—Summary of estimated Medicaid impact of section 1619, fiscal years 1981–85
[Numbers in thousands]

1981				
1981	1982	1983	1984	1985
2,971	3,366	3,936	4,490	5,552
107	171	363	373	400
2,864	3,195	3,573	4,117	5,152
213	624	1,285	2,427	3,296
\$425	<b>\$</b> 462	\$491	\$518	\$549
\$1 1	\$1 1	\$2 2	\$2 2	\$3 2
\$0 0	\$0 0	\$1 0	\$1 1	\$2 1
\$1 1	\$1 1	\$1 1	\$1 1	\$1 1
\$0	\$0	<b>\$</b> 0	<b>\$</b> 0	<b>\$</b> 0
	107 2,864 213 \$425 \$1 1	107 171 2,864 3,195 213 624 3425 \$462  \$1 \$1 1 1 \$0 \$0 0 0  \$1 \$1 1 1 \$0 \$0 0 \$0	107 171 363  2,864 3,195 3,573  213 624 1,285  \$425 \$462 \$491  \$1 \$1 \$2	107 171 363 373  2,864 3,195 3,573 4,117  213 624 1,285 2,427  \$425 \$462 \$491 \$518  \$1 \$1 \$2 \$2 \$1 1 2 2  \$0 \$0 \$1 \$1 \$1 \$1 \$1 \$1 \$1 \$1 \$1 \$1 \$1 \$1 \$1

<sup>1</sup>Net costs may not equal costs minus savings due to rounding.

Table G-2.—Summary of estimated Medicaid impact of section 1619, fiscal years 1986-90

[Number	s in thou:	ands]			
Estimated impact	1986	1987	1988¹	1989¹	1990¹
Annual Medicaid recipients:					
Total nonincentive cases	6,512	7,040	7,574	8,464	9,205
1619(a) nonincentive cases 1619(b) nonincentive cases	448 6,064	555 6,485	667 6,907	752 7,712	832 8,373
Spillover cases	3,984	4,821	5,637	6,427	7,211
Annual per-capita expenditures (Federal share)	\$589	\$625	\$660	\$697	\$732
Program costs/savings (in millions):  Medicaid nonincentive costs Federal	\$4	<b>\$</b> 4	<b>\$</b> 5	<b>\$</b> 6	\$7
State	3 \$2	<b>\$</b> 3	4 \$4	5 \$4	\$5 \$5
State	2	2	3	4	4
Net Medicaid costs (-savings) <sup>3</sup> Federal State	\$1 1	\$1 1	\$1 1	\$1 1	\$1 1
Net rounded program costs					
(-savings) nearest \$5 million): Federal	\$0 0	\$0 0	\$0 0	\$0 0	\$0 0

<sup>1</sup>Fiscal years 1988-90 assume continuation of section 1619 authority beyond June 30, 1987, expiration date.

<sup>2</sup>Most of the savings in fiscal year 1988 through fiscal 1990 is attributable to current law. The net cost of the proposed law extending section 1619 indefinitely cannot be determined exactly from available data, but probably would be about \$5 million (rounded) in each of fiscal year 1988 through fiscal year 1990.

<sup>3</sup>Net costs may not equal costs minus savings due to rounding.

able to analyze separately the utilization and costs of the incentive and nonincentive section 1619 program participants. Since the incentive group evidently places a higher value on their Medicaid benefits than the nonincentive group, their per-capita costs are likely to be higher than those of their nonincentive counterparts, but it is difficult to determine what the differential should be. Lacking any data on which to base such a determination, in calculating both nonincentive costs and spillover

savings, the estimated recipient to eligible ratio in step 1 and the per-capita cost ratio in step 2 were derived using data on the section 1619 population as a whole. Since this practice probably overstates the net costs of section 1619, results rounded to the nearest million dollars should be treated with caution. However, when rounded to the nearest \$5 million (the recommended rounding for all Medicaid estimates) net costs are unlikely to be affected.