CHAPTER IV
DISABILITY & WORK INCENTIVES

A. PREAMBLE TO CHAPTER

The historical perspective. National policy has moved slowly but steadily in the direction of providing broad-based help in solving the problems of people with disabilities-- including problems related to employment. This chapter is devoted to changes in practice and law which the experts believe will contribute to the solution of vital problems.

The first Federal step toward assisting those with disabilities came with the 1950 enactment of a Federal/State grant program called Aid to the Permanently and Totally Disabled. This program, under title XIV of the Social Security Act, had a minimum age limit of **18**. Title XIV was followed in 1956 by enactment of the original title II disability social insurance provisions; those provisions covered only disabled workers who were age 50-64 and had substantial recent work histories, plus coverage for certain disabled adult children.

The following years saw legislation to eliminate the age requirement in the insurance program and eventually to establish SSI. The latter had the effect of joining SSI to the social insurance programs to form a national income maintenance safety net for the aged and blind as well as for those with disabilities. As recently as 1990, the U.S. Supreme Court, by its decision in Zebley v. Sullivan, ensured inclusion in the SSI program of all needy children with disabilities while Congress's passage of the Americans with Disabilities Act, which prohibits discrimination against persons with disabilities, closed many of the remaining gaps.

The experts have endeavored to express their views in a manner that is consistent with the ever-broadening approach taken in congressional and judicial actions over the years and especially within the past decade.

More recent legislative/judicial actions and their effects. By law, State agencies (called disability determination services), under contract to SSA, make medical determinations of disability. During the Chairman's visit to some of these agencies, their staffs reported significant

changes in the adjudication of disability cases. They said that, when the SSI program began in 1974, they were taught to adjudicate claims with the presumption that a claimant was eligible when the preponderance of evidence so indicated. They also reported that subsequently it had become the responsibility of the claimant to establish eligibility beyond any doubt.

It is true that data reflect a decrease in SSI program disability allowance rates between 1977 and 1982. However, in 1982, the allowance rates began to rise and by 1991 were nearly back to their 1977 levels. (See Appendix i to this chapter for actual figures.) Although specific causes of these variations have not been identified with certainty, the continuing upward trend of the period 1982-1991 is consistent with a series of Federal court decisions and congressional actions which took an increasingly comprehensive view of the meaning of disability and of how to arrive at decisions concerning its existence. It is a trend endorsed by a majority of the experts.

The Federal courts. The period from 1982-1991 saw a number of U.S. district and circuit (appeals) court decisions which had such significant results as legislation on medical improvement; a ruling clarifying agency policy on evidence of pain: new regulations on evaluating disability in children and in widows/widowers; expedited processing of claims based on AIDS/HIV infection; and changes in the way SSA evaluates mental impairments.

Court decisions, combined with legislative history, also resulted in SSA's becoming the first Federal agency ever to publish regulations governing its policies on formal acquiescence with U.S. circuit court decisions which are not consistent with existing national policy. Under regulations signed by Secretary Sullivan, "acquiescence rulings" apply within the circuit(s) involved in the litigation. This can result in different policies in different parts of the country, a situation which can be resolved judicially only if the Supreme Court takes jurisdiction. The situation can also be resolved by the Secretary's declaring that one of the circuit court decisions will become national policy. The experts heard some public testimony on acquiescence and, as a result, it is believed to be important that all concerned understand that a new policy is now in effect. The experts are supportive of all efforts to clarify and formalize SSA's acquiescence policy.

The Congress. Some of the litigation described above was relevant to significant congressional actions over this same decade:

The Social Security Disability Amendments of 1980. Important provisions included work incentives, some of which applied to initial claims (and so may **have** affected allowance rates) while others were restricted to SSI posteligibility situations. One provision established a new section 1619 of the Social Security Act which allows working SSI recipients to maintain eligibility for SSI and/or Medicaid despite performance of substantial gainful activity. (For more information, see Part C below.) The 1980 amendments also modified the requirements for "deeming" parental income and resources to be available to a blind or disabled child and authorized the government to pay for medical evidence and certain travel expenses incidental to required medical examinations.

The Social Security Disability Benefits Reform Act of 1984. These amendments established new requirements relating to cases involving mental impairments, consultative examinations, and medical records. They also established **a** new medical improvement standard for determining continued disability. In addition, the conference report on these amendments was instrumental in the formalization of SSA's policy on acquiescence, described above under "The Federal courts".

B. DISABILITY

Background Information:

Disability **caseloads** in SSI. The category of "disability" is the largest and fastest growing of the three SSI eligibility- categories (the other two being "age" and "blindness"). Since the program began in 1974, there has been an overall growth of approximately 169 percent in its disability caseload. For 1993, the President's budget projects an increase in SSI disability claims of nearly 59 percent just since 1989. It also projects a backlog of 1.4 million SSI and social insurance disability cases by the end of 1993. While the growth began early in the program, there has been a recent surge. One result of that surge is a substantial backlog, due in large part to lack of adequate staff, in many of the State disability determination services which, by law, make medical determinations for SSA for which they are reimbursed solely with Federal funds.

Relationship of SSI disability to disability social insurance. As enacted in 1972, the SSI disability program rested on the same basic concepts which underlay the disability social insurance program enacted nearly two decades earlier. Specifically, it was intended that the "disability test" for SSI and for the disability insurance program be essentially the same so that SSI payments could more easily serve to supplement income for those persons whose disability insurance benefits, in the absence of significant other income, were low or nonexistent.

Despite the intended overlap, the two disability programs serve what are often significantly different segments of the population with disabilities. The social insurance disability provisions relate to people who have significant work histories. The SSI disability program, on the other hand, assists persons who are disabled and are in need, regardless of their work histories. Therefore, while conformity between the two programs is desirable in many respects, total parallelism may not be appropriate. Nevertheless, as testimony pointed out, differing rules can be confusing, particularly for those who may be eligible under both programs. For example, SSI offers special assistance and incentives to people who work despite being blind or disabled, while work at a substantial level can result in complete loss of benefits under the disability insurance program.

Some characteristics of the SSI population with disabilities. The nature of the SSI population whose eligibility is based on disability (but not blindness) has changed significantly over the program's eighteen years of operation. For example, children under age 18, none of whom would have been eligible under the pre-1974 Federal/State programs unless they were blind, now constitute 13 percent of SSI recipients with disabilities. In addition, more than 2 in 3 of all adult recipients are under age 50 (compared with 1 in 5 in 1976). This means that, on the average, adult recipients under 65 have become younger.

Areas Where Issues Arise:

Definitions. The statute defines "disability" as the inability to engage in any "substantial gainful activity" by reason of any medically determinable physical or mental impairment(s) which can be expected to result in death or which has lasted or is expected to last for a continuous period of not less than 12 months.

NOTE: The SSI statute categorizes the blind separately from those with other disabilities: therefore, discussions of "disability" in the SSI program do not apply to the blind unless specifically stated otherwise.

The Secretary defines substantial gainful activity as any significant physical or mental activity in employment or self-employment. Generally, earnings above a specific amount function to delineate whether a person is able to work and, therefore, whether s/he is disabled. Originally a flat $50 per month, the substantial earnings figure is now $500 after deducting the cost of impairment-related work expenses and disregarding the value of earnings subsidies. For purposes both of disability social insurance and of SSI disability initial claims, work at or above the specified level means that the worker is not disabled. Thus, a person who is working and earning above $500 cannot become eligible in the first place under either program.

Unlike the disability social insurance program, once SSI eligibility has been established on the basis of disability (and assuming medical improvement has not occurred), work has a direct effect on SSI posteligibility situations only from the standpoint of benefit offset due to countable income. That is, SSI payments are offset **$1** for every $2 of earned income after applying appropriate income exclusions. However, work can be a sign of medical improvement and may trigger a review of continuing disability.

Disability claims process. Claims for SSI disability benefits are usually initiated through applicant contact with a teleservice center. The teleservice center, in most instances, mails a Disability Report form to the claimant for completion and schedules an interview at the local field office. A field office claims representative conducts the interview in person or by telephone. The interview consists of completing the basic application forms, reviewing them with the claimant, and obtaining permission to contact any treating sources. The claims file then goes to the State disability determination services for review and a determination concerning disability. Although they are State organizations, the disability determination services are funded by SSA and use SSA rules on disability.

Presumptive disability. It is possible to make SSI payments based on a presumption of disability or blindness, even though a formal medical determination has not yet been made, provided the claimant meets all other eligibility requirements. This cannot be done under the social insurance, or title II, provisions of the Act. These payments can be made for no more than 6 months. They do not

have to be repaid even if the later formal determination is that the presumption was erroneous and the claimant is not disabled or blind.

A presumption of disability may be made by a field office claims representative when there are readily observable severe impairments such as amputation of extremities. The field offices also have the authority to make a finding of presumptive disability for claimants with HIV infection whose disease manifestations are of a severity listed in the regulations. In addition, presumptive disability findings may be made for any claimants by the examiners in the State agencies when available medical and other evidence indicates a high probability of disability.

Very-young children. In establishing medically determinable impairments in very young children, SSA gives greater weight to the functional impact of impairments than to a precise definition or naming of their causes. Some children are too young to be tested formally to establish laboratory findings (e.g., to establish a precise reading of visual acuity), and it may not even be possible to attach a specific diagnosis to a recognized medically determinable impairment. For these children, medical findings are often presented in terms of the child's functioning in relation to age. In these cases, once it is established that there is a medically determinable impairment, SSA makes a disability determination based on all available evidence about the child's development and functioning, on knowledge of the course of the disease or disorder (if a diagnosis has been established), and on informed clinical observation and judgment.

As of May 1992, under new childhood disability regulations (to implement the Supreme Court's decision in Zebley), the initial allowance rate for children age 5 and under was 65.1 percent of the applications filed for those in this age group. Children under age 1 (the hardest to test) were being paid at the initial decision level at a rate of 75.6 percent.

Appeal of disability decisions. Each time a decision is made on an initial claim for benefits, or on continued eligibility, a written notice is sent to the individual. An individual who does not agree with the decision has the right to appeal. There are three appeals steps in the administrative review process and an individual usually has 60 days from receipt of a notice to appeal the decision.

1. If dissatisfied with the medical decision made by a State agency, an individual can request reconsideration. This is a review of all available

evidence by State employees other than the team who made the initial decision. Reconsideration usually does not involve a personal interview with the individual.

2. An individual who is not satisfied with reconsideration results may request a hearing before an administrative law judge. Such a hearing does involve a face-to-face interview and may also involve a representative for the individual as well as witnesses and new evidence.

3. The third step for a dissatisfied individual is to request a review of the administrative law judge's decision by the Appeals Council. If the request is granted, the Appeals Council will issue a decision or will remand the case to the administrative law judge. Also, the Appeals Council, on its own motion, may decide to review a hearing decision which is not appealed. Whatever it does, the Appeals Council sends the individual a notice explaining the action. If still dissatisfied, the individual may bring action in Federal district court.

Time limits on disability claims and appeals. There are no statutory time limits applicable to SSA actions with respect to initial disability decisions or to most decisions on claims under appeal. Claimants, who have 60 days to file appeals at each of the three levels described above, may have a long wait for a final decision.

Experts' Discussion of Disability Issues:

Definitions. All of the experts who took a position in this area agreed with public commenters that, for SSI purposes, the definition of "substantial gainful activity" should be changed to recognize that persons with disabilities may work and also become eligible for SSI. The experts said that an SSI individual who works by virtue of receiving significant support services should not be viewed as engaging in substantial gainful activity. However, the SSI means tests (limits on income and resources) would remain in place and earnings could result in ineligibility if countable income (or resources) exceeded the limit. While the experts cited on-the-job attendant care and job-related support services as examples of "significant support services", they did not wish to limit the scope of the term by suggesting a specific definition.

One of the experts submitted for consideration an option addressing the definition of "disability" itself. (For more information, see Appendix ii at the end of this chapter.)

This option urged use of functional measures of mental/physical impairments--not substantial gainful activity--to define disability in both the SSI and the social insurance programs.

The expert offering the option pointed out that this is essentially what SSI already does in determining childhood disability as well as blindness and said it should be viewed as important to have a better parallel between the SSI and social insurance programs in order to deal equitably with the "notch" effect. This effect, which occurs under current rules when a social insurance program beneficiary (under title II) works, is as follows. So long as the beneficiary's earnings are below the substantial gainful activity level, there is no reduction in insurance benefits. However, if the beneficiary completes a trial work period and begins to work at a level that constitutes substantial gainful activity, s/he loses all social insurance cash benefits rather than encountering a gradual reduction as would be the case under SSI.

A number of the experts agreed with the phil'osophy outlined above but were concerned about the possible impact on the administration of the disability social insurance program. They pointed out that, unlike SSI, the social insurance disability program does not apply any means limitation in the form of an "income" test or other mechanism. Most of them agreed that a feasibility study would be a better course. By way of clarification, one of them noted that it should be made clear that this option does not contemplate relying solely on medical listings to establish disability since that could be a more rigorous test than applies under current policy.

In their discussion, the experts took particular note of repeated testimony concerning the need to update medical criteria used to determine disability of persons with Parkinson's disease. The experts learned that SSA was reviewing its neurological Listing of Impairments and that the expert group established for that purpose included a specialist in Parkinsonian syndrome. Therefore, the modernization experts concluded that further consideration on their part was not necessary.

In response to some public comments on the July **31, 1991** FEDERAL REGISTER issue paper publication, the experts considered a change in the definition of disability to encompass those not fully functional but not fully disabled. Most of the experts said they were not prepared to endorse such a program. A number of the experts, however, indicated their strong support for a "functional" test of whether or

not a person is disabled as contrasted with the continuation of a "work" test.

Disability claims process. The experts acknowledged the many public comments concerning need for specially-trained staff to conduct informed, sensitive initial disability claims interviews in order to provide the State agencies with claims information that is both complete and accurate. The experts said that this kind of specialized staff would contribute significantly to faster, more accurate disability determinations. In this context, the experts considered whether it would be better for such staff to be attached to the SSA field offices or to the State disability determination services and whether the actual interviews should be moved from field offices to State agencies.

A number of the experts expressed the view that the real problem was the budget-driven underfunding of agency operations. This, they concluded, results in a chronic lack of resources necessary to do a quality job. These experts said that, without added resources, lasting improvements are not possible no matter how much effort is directed toward altering administrative processes or reassigning priorities which, in turn, can only reduce backlogs at the expense of other program necessities. (For more information, see Chapter VI.)

A majority of the experts favored keeping responsibility for initial disability interviews in the field offices provided funding were made available for intensive training of their staffs in disability claims-taking. The experts preferred use of field offices because this would keep intact their traditional responsibility for maintaining a full and continuing relationship with each claimant whereas the State agency responsibility is that of making medical determinations. They pointed out, too, that the greater number of field offices makes them more easily accessible to the public. The experts also noted that, prior to SSA's staff downsizing, field offices had had disability specialists, similar to the kind of staff under discussion, and concluded that a return to such staffing would be the most appropriate route to faster, more accurate disability determinations.

A majority of the experts also said that using State agency staff to perform the interview function, even if those staff were outstationed in SSA field offices, could further overextend State staffs and change their long-standing basic role of making medical determinations. One expert, who preferred the majority view but found use of State agency personnel acceptable, said that the most important thing was

having sufficient personnel with adequate specialized expertise, and not whether these staff are assigned to field offices or State units. One expert who disagreed with the majority was concerned that the workload would be too much for field offices to absorb without funding for a new, specialized staff and questioned the need to build the disability determination services' kind of expertise at some other level of the organization.

Very young children. The experts considered a number of public comments concerning the need for disability criteria that would more easily permit an assumption of disability in very young children, thus providing early access to Medicaid in most States. They recognized that SSA does not necessarily follow the same process used to determine disability in adults because the emphasis for children is on whether their functioning is age-appropriate. A majority of the experts concluded that SSA should develop appropriate criteria for making an assumption concerning the existence of disability in children under the age of 4. They said that payments based on such an assumption should not be limited to the 6-month period allowed under the existing "presumptive disability" provision but, like the existing presumptive payments, they would not be overpayments when and if the children were found not to be disabled based on later testing and diagnosis.

Appeal of disability claims. A number of the experts expressed support for the principle of offering a claimant a face-to-face interview prior to denying a claim based on disability; they also supported the concomitant elimination of the reconsideration level of appeal. These experts were strongly opposed to the current procedures which do not provide claimants with the opportunity to be seen. One expert stated that it was "morally unacceptable... that there are people who are eligible for this program who are not getting it simply because the procedures basically freeze them out."

Time limits on disability claims and appeals. A majority of the experts favored establishment of 90-day time limits, not only for completing SSI cases under appeal, but also for making initial determinations on new SSI claims based on disability. They agreed that failure to reach a decision within the prescribed time should mean that SSI payments would begin without a final determination and that any benefits paid on this basis would not later become overpayments even if an individual were later determined not to be disabled.

One expert proposed, and most of the others agreed, that any time limits enacted should be studied after four years of experience with them.

Recapitulation of Experts' Opinions on Disability:

Option	Experts Supporting
Definitions.	
1. Change the definition of "substantial gainful activity" in the SSI program to recognize that persons who work by virtue of substantial support services (such as on-the-job attendant care, use of a job coach in a sheltered employment situation, or employer accommodations which create a highly specialized environment) are not performing substantial gainful activity and so are still disabled.	19
2. Study the feasibility of: (a) eliminating use of substantial gainful activity for determining disability in both the SSI and the disability insurance programs: and (b) formulating disability criteria in terms of being disadvantaged in participating in major life activities, of which work may be one. This study would be undertaken immediately and completed as soon as possible.	17
3. Change the definition of "disability" to cover those neither fully functional nor fully disabled under existing rules.	1
Disability claims process.	
1. Use specially trained disability experts assigned to field office staffs to conduct initial disability claims interviews.	16
2. Use State disability determination services staff, outstationed in SSA field offices, to conduct initial disability claims interviews. (This would provide claimants with a face-to-face interview as described below in connection with appeals.)	2

Very young children.

1. Develop appropriate criteria for making an assumption concerning the existence of disability in very young children. Permit continued payment, based on such an assumption, up to the age of 4 without creating an over-payment even if later testing and diagnosis result in a finding that the children are not disabled. 14

Appeal of disability decisions.

1. In both the SSI and the insurance programs: (a) eliminate the reconsideration level of appeal; and (b) provide claimants the opportunity for a face-to-face interview with the decisionmaker prior to issuing a denial based on a disability issue. 17

2. In both the SSI and the insurance programs, eliminate the reconsideration level of appeal in disability issues but without adding a face-to-face predenial interview. 1

   Comment: One expert, who did not take a position on this issue, suggested, as a means of controlling backlogs and costs, giving applicants written notice of pending denials and offering the opportunity to present additional medical evidence within a specified timeframe.

Time limits on disability claims and appeals.

1. Establish 90-day time limits which, if exceeded, would result in benefit payments which would not be considered overpayments even if the recipient were later found ineligible. Study the effects after four years of experience. Apply such limits to:

   a. making initial determinations on new SSI claims on the basis of disability. 13

   b. completing cases at the administrative law judge level of appeal. 15

      Comment: One expert, who supports a time limit but does not support this option, says that considered action at this level of appeal requires 120 days.

c. completing cases at the Appeals Council level of appeal 15

C. WORK INCENTIVES

Background Information:

Role of work incentives. Work incentives play a dual role in the SSI program. First, they offer the working individual emotional and psychological reward in the form of a sense of independence and self-worth. In addition, they seek to provide a meaningful net increase in the worker's income thereby reducing or eliminating reliance on public and private assistance. In order to be successful, work incentives must overcome work disincentives in the form of fear of losing needed assistance before someone is secure in believing that s/he has the capacity for self-support. The beneficiary must also be assured that, if his/her job terminates, s/he will not, in many instances, go through the long process of reestablishing eligibility for disability payments.

While less than 3 percent of SSI recipients (almost none of them disabled) received income from working in 1974, by September of 1991 the figure had risen to more than a quarter of a million representing 6.3 percent of all recipients with disabilities. Of the disabled who were working in 1991, some 50,000 were benefiting from special work incentive provisions passed by the Congress and available figures show a strong upward trend in this area.

Section 1619 provisions. The SSI statute has certain work incentives which do not affect the benefit amount. The most significant of these provisions appear in section 1619 of the Social Security Act and allow working SSI recipients to maintain eligibility for SSI and/or Medicaid. In 1982, the first year in which the provisions were effective, approximately 5,800 people benefited fom them. In September 1991, the number had risen to 40,443--an eightfold increase.

To establish SSI eligibility on the basis of disability, a person cannot be performing substantial gainful activity (see Part B above). However, a person who has received at least one month of "regular" SSI benefits can qualify to receive "special" benefits under section 1619(a) when earnings indicate substantial gainful activity--provided s/he has not recovered medically and still meets all other SSI requirements.

If a working SSI recipient's total income becomes too high to allow a payment, the recipient may continue to qualify for Medicaid under section 1619(b). To qualify for Medicaid, the person's unearned income must be low enough that the person would receive an SSI payment if s/he were not working. The person must also need Medicaid in order to work and not have enough earnings to replace certain benefits s/he would receive absent the earnings (i.e., SSI, Medicaid, and publicly-funded attendant care).

Special income and resources provisions. In addition to the SSI work incentives described above, there are many others which take the form of exceptions to the regular income and resource counting rules. Under the work incentive rules, portions of a working recipient's income and resources are excluded. Specifically, the Act allows for exclusion of:

The earned income of a child who is a student, subject to limits set by the Secretary (currently $400 per month and $1,620 per year).

The first $65 of a person's earned income, plus any portion of the $20 general income exclusion not applied to the person's unearned income.

Amounts of the earned income, of a person who is disabled, used to pay for certain work expenses the person has because of the disability. These expenses are known as impairment-related work expenses and may include things like special equipment or certain transportation costs.

Half of a person's remaining earned income after the above exclusions are applied.

Any portion of the earned income, of a person who is blind, which is used to pay expenses related to earning the income. These are called blind work expenses. The expenses do not have to be related to the person's blindness; they only have to be work-related. Examples of these expenses include taxes, dog guide expenses, meals bought during work hours, etc.

Income (earned or unearned) and/or resources, which a person who is blind or disabled, uses to fulfill an approved plan for achieving self-support. This is a plan written specifically for the individual. The plan allows the person to set aside income or resources for a period of time to pay for things needed to reach a job goal. A plan may be used to pay for things like training, education, job coaching, equipment, etc.

Areas Where Issues Arise:

State Medicaid rules and 1619. In most states, SSI eligibility, including eligibility under section 1619, automatically makes a person eligible for Medicaid. However, a few States make their own determinations of Medicaid eligibility using criteria that are more restrictive than those used under SSI. In such States, a working recipient could lose Medicaid eligibility because of earnings before those earnings reach the substantial gainful activity level. Such States are only required to continue Medicaid under section 1619 if the person was eligible for Medicaid under State rules in the month prior to attaining 1619 eligibility. Therefore, the 1619 provisions offer only limited protection to residents of these States.

Deeming rules and Medicaid eligibility under 1619(b). n determining continued Medicaid eligibility under section 1619(b), SSA uses the same methodologies-that apply to regular SSI and Medicaid eligibility determinations. Therefore, a working person's unearned income is considered to include any income deemed available from an ineligible spouse. In some cases, this means that the worker who is blind or disabled does not qualify for continuation of Medicaid even though his/her own income alone is low enough to meet the requirements.

State supplementation and 1619. States are not required to make supplementary payments to someone who receives benefits under section 1619(a). Currently, most States which supplement regular SSI payments also supplement section 1619 **(a)** payments. Eight do not.

Disability definition and 1619. The discussion of definitions under Part B above explains the "notch" effect which occurs when a person's social insurance disability benefits result in too much income for him/her to receive SSI payments. If this person should begin to work **at** a level considered indicative of substantial gainful activity, s/he would no longer be disabled and would lose all disability insurance benefits. At the same time, s/he could not become SSI eligible because the SSI statute does not permit use of section 1619 provisions in adjudication of initial claims; the provisions apply only in posteligibility situations.

Experts ' Discussion of Work Incentives Issues:

Need for expanded work incentives: A majority of the experts said that SSA should begin at once to seek legislation authorizing use of expanded work incentives

(detailed below under option 1). An even larger majority favored SSA's conducting a national demonstration in order to make the expanded incentives available as quickly as possible. Most of these experts also supported seeking legislation to make the incentives permanent--ideally without any "moratorium" on the incentives between completion of the demonstration and implementation of permanent provisions. They said that demonstration results should be helpful in establishing the value of such legislation.

Recognizing that it may take more time to obtain legislation than would be possible to devote to a demonstration, most of these same experts also favored some kind of "grandfathering" arrangement so that earnings would not cause demonstration participants to lose benefits when the project ended. One expert commented that, without grandfathering, the demonstration cannot truly test the incentive value of the prospect of retaining the incentives.

Time limits for approval of self-support plans. One of the experts said that, all too often, SSA field offices do not make timely decisions on plans for achieving self-support which are submitted for approval. The result can be inordinate delays in eligibility. All of the experts taking a position on work incentives agreed that there should be a 30-day time limit for such decisions and that, lacking a decision, the proposed plan should be deemed approved; i.e., resultant payments, which should begin at once based on application of the plan exclusions, would not become overpayments if the plan were subsequently disapproved.

State rules and Federal "disability" definitions. A majority of the experts expressed concern over, and supported correction of, two technical problem areas involving other programs. One of these problem areas was national while the other was limited to certain States. The areas were: (a) loss of social insurance disability benefits due to work which also prevents initial SSI eligibility, despite having little or no income; and (b) lack of State supplementation or Medicaid eligibility for persons who are, or are considered to be, SSI-eligible under section 1619(a) or (b). All of the experts who expressed a view on work incentives said that efforts to work should be encouraged as much as possible. A majority of them concluded that there was a need for changes in the rules governing interprogram relationships to permit initial SSI eligibility despite performance of substantial gainful activity and to provide Medicaid and State supplementation to eligibles under section 1619.

Nonselected options. The experts considered, but did not support, the idea of establishing **a** work attempt period during which all of an individual's earnings would be excluded. It **was** their view that recipients who work should recognize the effect of that work and earnings on their benefits.

There was also discussion of allowing a working recipient to put some earnings in an excluded "independence account" which could be used only for specified purchases, such as a home or a vehicle. Two experts supported this idea but the others who took a position said that it was not necessary in light of the options for increasing the resource limits (see **Chapter** III).

Recapitulation of Experts' Opinions on Work Incentives:

Option	Experts Supporting
1. Begin **at** once to seek legislation, where needed, to authorize permanently all of the following work incentives:	12
a. Raise the earned income exclusion from $65 to $200 and reduce the SSI benefit by $1 for every $3 (instead of the current $1 for every $2) of earned income over $200. The increased exclusion amount would be intended to compensate the recipient for his/her work expenses. Therefore, this exclusion would replace all of the existing earned income exclusions except for the student earned income exclusion and plans for achieving self-support. Individuals whose actual work expenses are more than the amount of earnings excluded (i.e., more than $200 plus two-thirds of the remaining income) could have an individual exclusion computed which would consider the person's actual work expenses. All work-related expenses would be excluded, regardless of whether they are disability related, similar to the current blind work expense exclusion, and this exclusion would be available to all working SSI recipients.	

b. Eliminate continuing disability reviews triggered by work activity and defer scheduled medical reviews for working recipients for 3 years after beginning work.

c. Treat unemployment compensation, workers' compensation, sick pay, and other similar benefits received because of recent work activity as earned income rather than as unearned.

Comment: Some experts question whether treating these kinds of benefits as earned income would be an incentive to work.

d. Eliminate the regulatory time limit for completing a plan for achieving self-support.

e. Make individuals who receive benefits based on age eligible for all work incentives.

Comment: The experts recognize that, even under present conditions, the nation is confronted with worker shortages in certain occupations which could be filled by older persons. These shortages are likely to increase in the future.

2. Simultaneous with the legislative effort in option 1, conduct a national demonstration of the work incentives listed in that option. Use the demonstration results to reinforce legislative efforts. 18

Comment: Six of those who support a work incentives demonstration are withholding judgment on specific legislative proposals until demonstration results are available. Another expert favors seeking legislation without a demonstration.

3. Provide a "grandfathering" arrangement for demonstration participants so they can continue to receive benefits upon expiration of the project (assuming that legislation is not yet in place). 14

Comment: Five of the experts who support a demonstration do not support a grandfather provision while another expert, who does not favor a demonstration, views a grandfather provision as essential if a demonstration were to be conducted.

4. Disregard deemed income of an ineligible spouse when determining continued Medicaid eligibility under section 1619(b). 18

5. Require SSA to make a decision on a plan for achieving self-support within 30 days. Lacking a decision within that time, assume the plan to be acceptable. 18

6. Require States which supplement regular SSI payments to supplement payments under section 1619(a). 18

7. Provide Medicaid under section 1619 to all working persons who are blind or disabled in States not using SSI criteria for Medicaid eligibility purposes. 17

8. Provide SSI benefits for individuals who lose their social security benefits due to substantial gainful activity. 17

9. Do not permit States to count resources set aside under a plan for achieving self-support when determining Medicaid eligibility using their own rules. 14

D. SUMMARY OF OPTIONS PREFERRED BY A MAJORITY OF EXPERTS

Many persons who are truly disabled fail to qualify for disability benefits. Many who are on the disability rolls fail to have the opportunity of realizing their highest possibilities in the work force.

The changes in this chapter which are supported by a majority of the experts deal with both problems. They are designed both to add to, and to subtract from, the beneficiary rolls numbers of persons with disabilities.

The options that the experts favor on the definition of disability support both goals.

The experts favor a change in the definition of "substantial gainful activity" which the SSI law requires as a test of disability. This change would recognize that working persons are disabled if they are unable to work without support services such as on-the-job attendant care or job-related support services such as those furnished through transitional employment programs for persons with mental illness.

The experts want to encourage persons with disabilities to work. The present "substantial gainful activity" definition is seen as detrimental to that objective. These experts see it as highly desirable to encourage work, particularly on the part of persons with disabilities so severe that they are able to work only by virtue of special supportive services. The experts want to see these people qualify for, and continue receiving, disability payments until such time as their total income exceeds the SSI standard, assuming there is no medical recovery before that time. Therefore, they support encouraging persons with disabilities to use their abilities at work instead of encouraging them not to work.

In addition to the SSI change described above, a majority of the experts would like to see the Social Security Administration undertake a study of the feasibility of eliminating "substantial gainful activity" as a test of disability in both the SSI and disability insurance programs. In place of ability to work, they wish to see tested a disability standard based on inability to perform certain mental or physical processes in order to participate in major life activities, of which work may be one. Such a change in definition might add some persons to the disability rolls. This study should begin immediately and be completed as soon as possible.

Next, the preferred options deal with a consideration of the manner in which applications from disabled persons are handled. They are changes which, if adopted, would undoubtedly add persons to the beneficiary rolls.

A majority of the experts supports the view that claims interviews should be conducted initially by trained disability experts who are SSA field office employees rather than by State disability determination services interviewers outstationed in field offices. These experts are convinced that it is sound procedure to equip the 1,300 SSA field offices with trained personnel who are able to deal with the full range of the SSA-administered income maintenance programs.

While conducting initial disability interviews in field offices is the procedure currently in use, the experts are concerned that the lack of adequate staff prevents SSA from conducting in-depth, high quality interviews with individuals who have disabilities.

A majority of the experts favors a requirement for a face-to-face interview before a claim at the initial level can be denied on the basis of disability. Such an interview can prevent the rejection of a claimant who is clearly eligible and would establish an essential step in providing due process.

The same majority of experts has paired the face-to-face interview prior to a denial with the elimination of the reconsideration level of appeal which would no longer serve a significantly useful purpose. An appeal of a denial after a face-to-face interview would go directly to an administrative law judge.

A majority of the experts concludes that SSA should develop appropriate criteria for assuming the existence of disability in a very young child. These experts favor continuing payments based on such an assumption (until the child reaches four or, if sooner, until a formal disability determination is possible) without creating an overpayment. These experts believe that early access to cash benefits and to medical care is essential in helping these children become adults who are, as much as possible, healthy and productive.

The experts are very much concerned with the current backlog of 762,000 disability cases. This is estimated by the President in his budget message for the fiscal year 1993 to be 1.4 million at the end of that year. The experts want to commend Commissioner King for the increase in the

processing rate for these cases. However, if the estimate in the 1993 budget proves valid, they see it as a reasonable assumption that a doubling of the backlog would have a material effect on processing time.

The experts are aware that Commissioner King, in testimony before the Congress, has stated that prevention of the projected significant backlog increase would require the processing of an additional 500,000 claims. That, in turn, would take 5,000 workyears at a cost of $500 million. This supports the experts' view (see Part B of Chapter VI) that the Social Security Administration staff should be increased, as a first step, by 6,000 people.

A majority of the experts believes that, if a claim on the basis of disability has not been decided within 90 days of filing, payments should begin. Such payments would not be regarded as overpayments should the applicant ultimately be found ineligible. The 90-day rule would apply to cases at the administrative law judge and Appeals Council levels of appeal as well.

Those favoring this option believe that it would encourage Congress and the Administration to obtain adequate staff, thereby preventing situations such as currently exist with large backlogs leading to significant delays in many claims for disability benefits.

Long delays often occur in appeals that are made to administrative law judges and to the Appeals Council. These delays are frequently due to a lack of resources. The procedures should be examined very closely to see if they can be shortened without affecting the high quality of decisions made by administrative law judges and the Appeals Council. The experts pointed out that justice delayed can be justice denied.

The number of appeals and the time it takes to handle them should be affected favorably by the Secretary's policy on acquiescence. The Chairman has examined the agreement in the Stieburger case in New York dealing with the policy of acquiescence. He believes the Department was wise in entering into the court-approved agreement with the plaintiffs. He believes further that the agreement is consistent with the Secretary% policy and could be applied to the rest of the country.

In addition to the change in the definition of disability, experts discussed how people could ultimately earn enough income to leave the rolls by providing an increasing number of the beneficiaries with the incentives they need to join the workforce. Here are some of the options.

A majority of the experts favors beginning at once to seek legislation to provide expanded work incentives in the form of increasing the monthly earned income exclusion to $200 plus two-thirds of dollars earned over $200; eliminating continuing disability reviews triggered by a return to work even on a part-time basis, and deferring scheduled medical reviews for workers for three years after work begins; treating benefits received because of recent work activity (e.g., unemployment compensation, worker's compensation, sick pay, etc.) as earned income rather than unearned income; eliminating the time limit for completion of a plan for achieving self-support and requiring action on a plan within 30 days or else the plan would be assumed to have been approved.

A majority of the experts also favors extending all work incentives to older persons as well as to the blind and disabled.

A larger majority of the experts supports conducting a national demonstration involving the work incentives described above while legislative efforts are under way. Most of the experts also support permitting demonstration participants to retain their demonstration incentives when the project ends if new legislative provisions are not yet in place.

With respect to Medicaid coverage in all States, a majority of the experts supports mandating the disregard of income of an ineligible spouse when determining Medicaid eligibility under section 1619(b). A majority also supports requiring States using more restrictive eligibility criteria than those applicable to the SSI program to disregard resources set aside under a plan for achieving self-support. They also support the provision of Medicaid to all working individuals who are eligible under section 1619.

In addition, there is majority support for required supplementation, by States which supplement benefits to recipients of regular SSI benefits, of those who receive **special** SSI benefits under section 1619(a). Finally, a majority of experts supports provision of SSI disability benefits to workers who lose their social insurance disability benefits due to substantial gainful activity, provided they have not recovered medically and that they meet the SSI income and resources limits.

All of the preceding opinions further reinforce the experts' support of the proposition that it is good public policy to encourage persons with disabilities to work. The disability program should have written into it incentives, not disincentives, for work.

E. COST ESTIMATES ON OPTIONS PREFERRED BY A MAJORITY OF EXPERTS

Disability: definitions.

1. Change the SSI program's definition of "substantial gainful activity" to recognize that persons who work by virtue of substantial support services are not performing substantial gainful activity and so are still disabled.

Estimated Cost
(In millions)

Fiscal Year	SSI Program	SSI Administrative	Medicaid Program
All	(a)	(a)	(a)

(a): Unable to estimate.

* * * * *

2. Study the feasibility of: (a) eliminating use of substantial gainful activity for determining disability in both the SSI and the disability insurance programs: and (b) formulating disability criteria in terms of being disadvantaged in participating in major life activities, of which work may be one. This study is to be completed as soon as possible.

Estimated Cost
(In millions)

Fiscal Year	SSI Program	SSI Administrative	Medicaid Program
All	None	(a)	None

(a): Unable to estimate.

* * * * *

Disability: claims process. Use specially trained disability experts assigned to field office staffs to conduct initial disability claims interviews.

Estimated Cost
(In millions)

Fiscal Year	SSI Program	SSI Administrative	Medicaid Program
1993	(a)	(20)	Negligible
1994	(a)	(20)	Negligible
1995	(a)	(20)	Negligible
1996	(a)	(30)	Negligible
1997	(a)	(30)	Negligible

(a): Unable to estimate.

* * * * *

Disability: very young children. Develop appropriate criteria for making an assumption concerning the existence of disability in very young children. Permit continued payment, based on such an assumption, up to the age of 4 without creating an overpayment even if later testing and diagnosis result in a finding that the children are not disabled.

Estimated Cost
(In millions)

Fiscal Year	SSI Program	SSI Administrative	Medicaid Program
1993	$ 8	$ 0	$ 5
1994	31	10	20
1995	35	0	20
1996	38	0	25
1997	42	0	25

* * * * *

Disability: appeal of decisions. In both the SSI and the insurance programs: (a) eliminate the reconsideration level of appeal: and (b) provide claimants the opportunity for a face-to-face interview with the decisionmaker prior to issuing a denial based on a disability issue.

Estimated Cost
(In millions)

Fiscal Year	SSI Program	SSI Administrative	Medicaid Program
All	(a)	(a)	(a)

(a): Unable to estimate.

* * * * *

Disability: time limits on claims and appeals. Establish a 90-day time limit which, if exceeded, would result in benefit payments which would not be considered overpayments even if the recipient were later found ineligible. Apply this time limit to making initial determinations on SSI disability claims as well as to completing cases at the administrative law judge and Appeals Council levels of appeal.

Estimated Cost
(In millions)

Fiscal Year	SSI Program	SSI Administrative	Medicaid Program
All	(a)	(a)	(a)

(a): Unable to estimate.

* * * * *

Work incentives: legislation. Seek legislation, where needed, to authorize permanently: (1) increasing the earned income exclusion to $200 plus two-thirds; (2) eliminate continuing disability reviews triggered by work and defer scheduled medical reviews for 3 years after beginning work; (3) treat as earned income unemployment compensation, worker's compensation, sick pay, and similar benefits received because of recent work; (4) eliminate the regulatory time limit for completing a plan for achieving self-support; and (5) extend all work incentives to the aged.

Estimated Cost
(In millions)

1. **Increase earned** income exclusion:

Fiscal Year	SSI Program	SSI Administrative	Medicaid Program
1993	$ 149	$ 80	$ 140
1994	328	200	510
1995	351	20	605
1996	370	20	695
1997	388	20	805

2. Modify requirements for continuing disability reviews and scheduled medical reviews.

Estimated Cost
(In millions)

Fiscal Year	SSI Program	SSI Administrative	Medicaid Program
All	(a)	Negligible	(a)

(a): Unable to estimate.

3. Treat certain work-related benefits as earned income.

Estimated Cost
(In millions)

Fiscal Year	SSI Program	SSI Administrative	Medicaid Program
1993	$ 10	Negligible	Negligible
1994	14	Negligible	Negligible
1995	15	Negligible	Negligible
1996	16	Negligible	Negligible
1997	16	Negligible	Negligible

4. Eliminate time limit for completing a self-support plan.

Estimated Cost
(In millions)

Fiscal Year	SSI Program	SSI Administrative	Medicaid Program
All	(a)	Negligible	(a)

(a): Unable to estimate.

5. Extend all work incentives to the aged.

Estimated Cost
(In millions)

Fiscal Year	SSI Program	SSI Administrative	Medicaid Program
All	(a)	(a)	(a)

(a): Unable to estimate.

* * * * *

Work incentives: demonstration.

1. Conduct a national demonstration project involving all of the incentives listed above while seeking legislation.

Estimated Cost
(In millions)

Fiscal Year	SSI Program	SSI Administrative	Medicaid Program
All	None	(a)	Negligible

(a): Unable to estimate.

2. Permit demonstration participants to retain incentives.

	Estimated Cost (In millions)		
Fiscal Year	SSI Program	SSI Administrative	Medicaid Program
All	(a)	(a)	(a)

(a): Unable to estimate.

* * * * *

Work incentives: additional legislation.

1. Disregard deemed income of an ineligible spouse when determining Medicaid eligibility under section 1619(b).

	Estimated Cost (In millions)		
Fiscal Year	SSI Program	SSI Administrative	Medicaid Program
All	None	Negligible	Negligible

2. Require SSA to make a decision on a proposed self-support plan within 30 days or else assume it is acceptable and begin payments accordingly.

	Estimated Cost (In millions)		
Fiscal Year	SSI Program	SSI Administrative	Medicaid Program
All	None	Negligible	Negligible

3. Require States which supplement regular SSI payments to supplement section 1619(a) payments.

Estimated Cost
(In millions)

Fiscal Year	SSI Program	SSI Administrative	Medicaid Program
All	(a)	Negligible	Negligible

(a): No Federal program cost and negligible State cost.

4. Provide Medicaid under section 1619 to all working persons in States not using SSI eligibility criteria.

Estimated Cost
(In millions)

Fiscal Year	SSI Program	SSI Administrative	Medicaid Program
1993	None	Negligible	$ 10
1994	None	Negligible	15
1995	None	Negligible	15
1996	None	Negligible	15
1997	None	Negligible	15

5. Provide SSI benefits to those who lose disability social insurance benefits due to substantial gainful activity.

Estimated Cost
(In millions)

Fiscal Year	SSI Program	SSI Administrative	Medicaid Program
All	(a)	(a)	(a)

(a): Unable to estimate.

6. When States determine Medicaid eligibility using their own rules, do not permit them to count any resources set aside under a self-support plan.

Fiscal Year	Estimated Cost (In millions) SSI Program	SSI Administrative	Medicaid Program
All	None	(a)	Negligible

(a): Unable to estimate.

* * * * *

DISABILITY ALLOWANCE RATES--SSI ONLY

Fiscal Year	Percent Allowed		
	Initial	Reconsideration	ALJ
1977	47.7	21.1	45.0
1980	32.5	14.4	51.0
1982	29.4	11.2	46.0
1985	37.5	15.3	47.0
1990	41.1	18.9	56.0
1991	44.8	19.2	60.0

NOTE: The data do not reflect rates applicable to concurrent claims for SSI and disability social insurance benefits.

DEFINITION OF DISABILITY
by Elizabeth M. Boggs

The July 1991 FEDERAL REGISTER issue paper included no specific reference to the disability definition used in the SSI program. However, two of the topics in that paper have direct bearing on the matter: Work Incentives and Substantial Gainful Activity.

In approaching this topic, it is well to recall Commissioner King's request that we review present practice in the light of the original intent of the SSI program. In doing so, a posture similar to that taken toward the Constitution may be helpful: Maintain the principles but interpret them in terms of contemporary conditions.

PRINCIPLES UNDERLYING 1974 LEGISLATION

Among the relevant principles are:

1. Social insurance programs should increasingly become the basic universal guarantees of income replacement for workers and their dependents when they are not expected to work because of age or incapacity.

2. SSI should supplement social insurance for those among the elderly and disabled for whom social insurance benefits (together with other resources) are insufficient to assure a minimally acceptable standard of living.

3. The supplement should be sufficient to keep recipients out of "poverty? This would be the standard for individuals or couples having no other income.

4. For those retired or disabled workers who have contributed to their own retirements, whether through savings or through a public or private retirement system (including social insurance), a higher allowance would be effected through an unearned income disregard.

5. In principle, SSI was to complete a basic nationally uniform, uncomplicated underlying system of cash benefits (with associated medical benefits), with the States retaining authority and responsibility for fine tuning allocations to meet individual special needs, whether for cash or social services.

At that time and until the 1980s, Federal financial participation **(FFP)** in the States' costs of social services was closely tied in with eligibility for federally-supported means-tested programs; these were locally administered with a substantial targeted Federal subsidy. Such State assistance, whether in cash or in kind (e.g., social or medical **services),** if based on need as State determined, was not to be counted as income for SSI purposes. In recent years this rule has been generalized so that contributed in-kind goods and services that cannot be applied or converted to food, clothing or shelter are disregarded regardless of source. The block granting of Title XX in the early '80s deprived SSI recipients both of their priority for federally-funded social services and of the open ending that permitted States to expand those services in proportion to evident need in the growing younger population.

SIGNIFICANT CHANGES SINCE 1974

Overall, the SSI system as set up in 1974 was designed primarily for people over 65. The manuals were written with them in the forefront. Seniors were then in the majority (58 percent) of all SSI recipients. The disability program was seen as largely composed of people over 50 who had found it necessary to retire early because of chronic illnesses, such as heart disease and arthritis. For them, as for those somewhat older, replacement of income and access to medical care appeared to be the highest priorities.

Today those receiving SSI (including federally-administered State supplements) based on being age 65 or older constitute only 28 percent of the total number of recipients. The median age of adults under 65 on SSI has declined significantly. In 1976 only one in five of all adult recipients was under 50 whereas today more than two in three fall in the younger group. The majority of those under 35 have been disabled since childhood and have little or no work history or credits: they represent an increased survivorship among children with conditions such as spina bifida, traumatic brain injury, and certain syndromes associated with moderate, severe, or profound mental retardation. In addition, the distribution of other etiologies of later onset has shifted significantly, with spinal cord injury and adult traumatic brain injury survivors being more numerous than in 1974. Chronic mental illness among young adults and, more recently, AIDS have further changed the picture. These younger people are not only not looking for nursing home care, they are actively resisting it. They would rather have a relatively small amount of cash in hand with which to purchase supportive social services

such as personal assistance than depend on Medicaid for an institutional package. Clearly, stereotypes have to be changed to include new images while recognizing that the traditional populations are still with us.

MODERNIZING THE DEFINITION

The postulates laid down in 1974 required, among other things, that the definition of disability used in the new Title XVI (SSI) be the same as that used under Title II for Social Security Disability Insurance (SSDI). They have remained very similar but not identical. Although some people believe that the definition of disability should be more liberal for SSI than for SSDI, this discussion recognizes the merits of a single definition and seeks to remedy the dilemmas it creates in either system. When SSI was implemented in 1974, replacing the myriad State definitions with a uniform Federal one, there were already 15 years of Federal experience with the disability insurance (DI) definition and some revisions of it. These years have been followed by a further 15 years of refinement through regulation to interpret the statutory language concerning "physical or mental impairment" and "substantial gainful activity" (SGA). The former has provided us with a viable tool for an alternative definition using functional capacity; the latter (SGA) has become less and less useful as actual gross wages have become more and more distorted as measures of productive capacity.

The inappropriateness of both the concept of SGA and the use of a monetary value as an index has been increasingly apparent in the last decade as attempts have been made to adjust SGA (expressed as dollars of earnings) in the light of various forms of support or wage subsidy or accommodation for a person with a severe continuing disability who (with accommodation) can make a net contribution to the gross national product (GNP). These problems will only become worse as The Americans with Disabilities Act (ADA) is implemented. While the intentions are laudable, the rules for carrying them out have become a jungle, a direct challenge to the "simplicity principle? In addition, the levels of SGA that have been set over the years by a succession of DHEW and DHHS Secretaries have been well below the minimum wage, creating real problems for those who attempt to make a transition from no work to full employment. The disengagement of SGA as a criterion for an individual on SSI who attempts work while continuing to meet the medical criteria has been a major improvement in both principle and practice but it has not gone far enough.

On the other hand, the functional measures of mental/physical impairments now in use (funtional limitations plus consideration of age, education and vocational factors--see 20 CFR Part 404, Subpart P, Appendices 1--Listing of Impairments--and 2--Medical-Vocational Guidelines), although necessarily detailed (49 pages) and complex, are based on a relevant body of knowledge that has produced credible indicators of "work disability" derived from the (nonworking) individual's observable ability (or lack of it) to function in major life activities. These concepts have recently been validated in the successful compliance by SSA with the Supreme Court mandate to write the disability criteria for children in a manner equivalent to the "work disability" criteria used for adults. An additional example is provided in section 1614(a)(2) of the Social Security Act (Act) where blindness is considered separately from other disabilities and is defined entirely in terms of explicitly stated functional limitations, omitting any reference to SGA. (For purposes of Title II, earnings of blind beneficiaries are, in effect, limited by the same "retirement tests" that apply to the elderly.)

RECOMMENDATIONS

I propose to build on these findings to redefine disability (for both SSDI and SSI) in a way that will not significantly change the level of severity associated with the SSA programs but will permit and encourage more of the younger men and women with continuing severe impairments who want to work to do so without being worse off than when not working. While continuing on the rolls in some cases, they will draw down reduced benefits.

These incentives are made equally available to SSI recipients and applicants of all ages; however, experience has shown that people over 55 make relatively little use of them.

The effect of the proposal on the SSI program will be minimal in that it will adopt the same standard for initial eligibility as is now in effect for continuing eligibility of an individual who works despite continuing severe functional limitations. The extension of the same definition to initial and continuing eligibility for social security benefits based on disability will require some structural changes in title II as described below.

BASIC CHANGE

Eliminate references to "substantial gainful activity" in Title II and in Title XVI; reformulate the criteria for disability in terms of disadvantage in performing or

participating in major life activities--of which work may be one. This step has already been taken, in effect for SSI continuing eligibility purposes and is under consideration for initial award as well.

In order to secure adoption of this concept in the statutory definitions (sections 223(d) and 1614(a) of the Act), it will be necessary to consider the impact on SSDI. In the SSI program, as has already been demonstrated, even in the absence of a specified dollar limitation on SGA, benefits with earnings are self-limiting (by the formula for countable income) at a level that makes for a fairly smooth transition from reliance entirely on benefits to reliance entirely on earnings (or earnings plus other income). This effect is not found for substantial levels of SSDI benefits under Title II. One of the major obstacles experienced to date for putting work incentives into Title II comparable to those recently enacted for SSI (section 1619 of the Act) has been the recognition that the breakeven point (at which benefits are reduced to zero) for individuals with the highest earnings records would be unacceptably high unless a formula were introduced for gradual reduction in benefits as earnings increase, beginning well below the level protected by the presently specified SGA dollar limit. This would somewhat disadvantage some present SSDI beneficiaries who regularly earn something not far under $500 a month while concurrently receiving full tax-free SSDI benefits without any reduction; disadvantaging any present beneficiaries is a step which members of Congress consider "off the table". Furthermore, a high breakeven point would tend to produce "induced filers? "Induced filers" are people with disabilities (who may or may not have heavy extraordinary disability-related expenses) who are well situated in good primary jobs where they have already accumulated generous Social Security credits and who (it is assumed) would, in the absence of an SGA limit, be induced to apply for SSDI benefits while continuing to work at the same or a similar job. These cases, although relatively rare, would require rather complex rules of the kind that we seek to avoid imposing on SSA. To come to grips with this issue, it would be necessary to differentiate between gross salary and net disposable income after legitimate disability-related expenses are assessed on an individual basis.

It is suggested that the appropriate place to counter these inappropriate incentives can be found in the IRS environment. A precedent has already been set for taxing some Social Security benefits and for calculating refunds owed to SSA by a retiree who has significant earned income. Annual calculations of individual medical expenses are also an IRS routine and similar protocols could be used to

calculate disability-related costs that should be deductibe by a disabled taxpayer in order to equalize his net income as compared to his peers. This arrangement could alleviate what is likely to become an increasingly burdensome task for claims representatives: calculating "real" (net) earnings on a monthly basis.

ADDITIONAL OPTIONS

Option l--Use the disability determination process to gather and record needed data about the nature and extent of functional impairments of individuals who qualify as disabled under title II and title XVI: The processes presently in place for determining the extent and severity of functional impairments associated with specified physical or mental conditions or disorders readily lend themselves to identifying also the extent of need for personal or other ongoing assistance of a nonmedical nature. Following the models used in practice by the US Public Health Service, three levels can be established: a) most severe - those requiring ongoing (frequent) assistance of another person in the activities of'daily living; b) very severe - those requiring some personal assistance but less frequently or those who require special transportation, special equipment, devices, vehicles, pharmaceuticals, adapted housing, etc., where maintenance and ongoing operation involve expenses substantially in excess of those experienced by nondisabled people; and c) severe - those meeting the eligibility criteria currently in place as indicators of work limitation but who do not experience extraordinary need for ongoing nonmedical support.

Partly because of the increasing interest in maintaining people with disabilities in their own homes, the National Center for Health Statistics has in recent years given increased attention within its ongoing National Health Interview Survey to ascertainment of the prevalence of impairments in specific "activities of daily living" (ADL), primarily related to personal self care, and "instrumental activities of daily living" (IADL), primarily related to management of money, use of telephone, mobility outside the home and the like among people living in "households? Some of the results have been analyzed by Mitchell LaPlante (1988. Data on Disability from the National Health Interview Survey, 1983-1985. National Institute on Disability and Rehabilitation Research, U.S. Department of Education.) Among those age 18-69 reporting a limitation in amount or kind of work, about 7 percent reported that they needed personal assistance in IADL or ADL. These surveys also show different rates of prevalence of these impairments among persons of working age depending on age and income, along

lines that might be anticipated. Clearly people eligible for SSI, being poorer, can be expected to have higher rates of need for personal assistance. An additional supplement to the NHIS, focused on disability, will be included in the 1993 and 1994 waves. Valuable as these surveys are, however, the interpretations that we can put on the results are limited both by the survey methodology and by their reliance on self reporting without clinical verification as to diagnosis or impairment.

On the other hand, there are upwards of 5 million individuals between the ages of 18-64 who are receiving either social security benefits or SSI, or both, based on their own work disability, each of whom has been subject to a professional clinical evaluation as to both the medical condition and the extent of functional impairment. Medical conditions by age are regularly coded and reported, although there are some missing data in older records.

It is recommended that impairments that limit major life activities (including self care, self management, communication, mobility, personal planning and decision making, as well as working) be documented prospectively as they are identified in the course of carrying out the routines now prescribed for disability determinations, and that the data be made available for analysis.

Option 2--Give consideration to establishing a specified Federal supplement (a percentage of the benefit, whether SSI or SSDI/DAC) associated with each of the two higher classifications of need for assistance; i.e., "most severe" and "very severe? The supplement would recognize some part of the incidental extra cost of living experienced by these individuals in the ordinary course of life, without detailed accounting (e.g., the food for a guide dog, the taxi to the station). It is recognized that such a standard supplement (which resembles the federally-administered supplement given by some States to SSI recipients who live in boarding homes or similar non-Medicaid residential facilities) will not obviate the need of many recipients for substantial additional social services as indicated in the description of the "most severe" and "very severe" categories. These more costly services would continue to be allowed based on individual need and monitored for quality and cost under State and local supervision.