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# MEDICAID BUY-IN OPTIONS: HELPING PERSONS WITH SEVERE DISABILITIES AND CHRONIC CONDITIONS TO WORK


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## EXECUTIVE SUMMARY

*"It is difficult to measure completely the impact that having a job makes in a person's life. It gives people a sense of personal value and identity, and there is something very powerful about being able to support oneself."*

--Rep. Nancy Johnson, (Connecticut), Statement before the Subcommittee on Social Security, Committee on Ways and Means, Hearing on Barriers Preventing Disability Beneficiaries From Returning to Work, March 11, 1999.

## INTRODUCTION

For many Americans, a job and a paycheck are central to their sense of independence and self-worth. For people with severe disabilities and chronic conditions, the desire for independence and employment is perhaps even stronger. Yet because of their unusual health needs and their difficulties in getting the full-time jobs that offer comprehensive health benefits, even those people with severe disabilities and chronic conditions who want to and can work may depend on government health benefits—more specifically, Medicare and Medicaid.

Medicare and Medicaid eligibility for people with disabilities and chronic conditions, however, has long been tied to the Social Security cash benefits system—Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI). SSI and SSDI provide cash for people too disabled to work and earn much salary. Even though gaining or losing the capacity to support oneself economically is not the same thing as gaining or losing health insurance, the process of qualifying for disability health benefits is the same as qualifying for Social Security cash benefits. The central part of qualifying for Medicaid or Medicare as "disabled" has been to show that one cannot and does not work.

Concerned that this structure was keeping people who wanted to work trapped in the cash assistance system because they could not afford to lose critical health benefits, Congress passed the 'Medicaid buy-in' options in 1997 and 1999. These were intended to allow people who meet the Social Security definition of disability to go to work and still get Medicaid, 'buying in' by paying a small premium. But the options still left in place the longstanding Social Security requirement that people with disabilities and other chronic conditions be “unable to work” in order to be eligible for Medicaid.

The first provision, passed in 1997, allows states to provide Medicaid coverage to those who would be eligible for Social Security cash assistance and Medicaid, but earn more than those programs ordinarily permit—up to 250 % of poverty. A second optional Medicaid extension, a provision of 1999 Ticket to Work law, allows states to establish their own income and resource standard, including the option to have no income or resource standards at all. It also adds a new eligibility category in which states can cover employed individuals with a medically improved disability who lose Medicaid eligibility because their medical conditions have improved to the point where they are no longer disabled under the SSI definition of disability. In addition, the law provides for a limited demonstration for people with 'potentially disabling conditions'.

These politically popular provisions were expected to have modest impacts, but were viewed as steps toward removing the health insurance barriers to work and independence for people with severe disabilities and chronic conditions. Their impact, however, has been even more modest than expected: many states have not adopted the buy-in option at all, while most of those who have adopted it have had low enrollments. Nevertheless, information from several of

the higher-enrollment buy-in states suggests that the Medicaid buy-in may be an important program for promoting employment for a demonstrable number of people, particularly those with work histories that predate the onset of their disability or illness.

This paper describes the Medicaid buy-in programs and the states' experience with them. It then offers options to make the buy-in options more attractive to states and beneficiaries and to broaden the impact of the program. Our findings were derived from interviews with national and state disability advocates, state and federal buy-in program administrators, state legislators, and researchers. We conducted interviews in fifteen states representing a range of program enrollments and designs, including states that did not have buy-in programs at the time.

**FINDINGS**

- The critical element in the political attractiveness of and support for Medicaid buy-in programs was as a work incentive. The dominant rationale for the Medicaid buy-in was and remains as a vehicle for removing barriers to work for those already eligible for Medicaid because they are SSI recipients or qualify as 'medically needy'.
- Only 15 states have implemented the Medicaid buy-in options[1] and about 85% of the national enrollment of 17,000 is in just 4 states – Connecticut, Iowa, Minnesota, and Wisconsin. (Massachusetts, which has operated a program much like a Medicaid buy-in since 1988, currently has 5700 enrollees.)

[1] Since Spring of 2002 when our research was conducted, an additional six states have brought Medicaid Buy-In plans into operation, with Florida's Medicaid buy-in also established but, at least temporarily, eliminated during 2002.

- Many expected the program to serve primarily working-aged people on SSI and Medicaid (and to a lesser extent those receiving Medicaid through the medically needy program) who would work if they could keep their Medicaid coverage. Two other populations—people working without comprehensive insurance or any insurance despite a disability or chronic condition severe enough to meet the Social Security standard and people newly on SSDI and in the 24-month waiting period for Medicare coverage—also were expected by some to participate.
- Surprisingly, the principal source of national buy-in enrollment thus far has been beneficiaries already receiving both Social Security Disability Insurance (SSDI) and Medicare. The unanticipated heavy participation of this group in some states has not resulted in reduced political support in those states, but fear of the associated costs has led other states to largely bar the participation of SSDI/Medicare beneficiaries or to forego buy-in programs altogether.
- In some states, the buy-in has provided SSDI/Medicare participants the ability to obtain needed pharmacy and personal assistance benefits that are not offered in Medicare and had been available previously in Medicaid only after financial impoverishment through "spend-down" requirements. In two other states, the buy-in has been open to SSDI/Medicare participants but only for the purpose of encouraging work—those states have maintained a spend-down on SSDI income, but enabled individuals to retain their work earnings and buy into Medicaid with a small premium. A third group of states has barred those with substantial SSDI income from participating in the buy-in either as a work incentive or as an alternative to spend-down. Two states—Massachusetts and Mississippi—have implemented a fourth alternative, imposing a monthly work and earnings requirement for buy-in program

participants but alleviating spend-down requirements by raising Medicaid income eligibility dramatically.

- States can largely target who and how many will enroll in their programs through their eligibility and premium design.
- Although formal standards are the same, using a process or staff for determining eligibility for Medicaid buy-in that is different than that otherwise used for SSI and SSDI may generate larger enrollments.
- **Participation by states** has been limited for a number of reasons:
  1. *Fear of uncontrollable or unpredictable costs*. States are afraid that the buy-in will be used by people not currently on Medicaid, who are either on SSDI or not receiving cash benefits at all, adding to state costs.
  2. *Concern about large-scale and expensive shifts from the 'medically needy' eligibility category into the buy-in program*. Most of the 15 states with programs, however, have used special income eligibility limits on those with SSDI income to address this concern.
  3. *Insufficient time*. The buy-in options are relatively new and it takes states time to pass authorizing legislation, particularly if their legislatures meet infrequently. In the meantime, the availability of state funds has diminished considerably.
  4. *Focus on SCHIP program*. The buy-in options became available at the same time that most states were focused on authorizing and implementing State Children's Health Insurance programs (SCHIP).
- **Participation by beneficiaries** has been limited for a number of reasons:
  1. *Extremely stringent eligibility criteria*. There is a basic tension in a program for working people that retains a disability eligibility test based on inability to work. The Social

Security disability definition and the multi-step process for meeting it are extraordinarily rigorous. It seems there are simply a limited number of people who can meet this definition and work, at least without a more comprehensive set of supportive services than is currently available.

2. *Exclusion of potential beneficiaries*. In order to hold down state spending, six of the 15 current buy-in states bar those with SSDI income above the SSI maximum from participating in Medicaid buy-in at all. Those six states all have what appear to be exceptionally low enrollments. They have addressed the SSI work disincentive, but not the Medicaid spend-down work disincentive for those with SSDI income.
3. *Most eligible workers already insured*. Potential participation from those not already on cash assistance is also limited. People who can meet the SSI/SSDI disability criteria but still manage to work would have been unlikely to do so if it meant going without any or adequate insurance – their health care needs are too severe.
4. *Fear of losing benefits*. Those who have been through the often-lengthy ordeal of proving that they cannot work in order to receive income support and health insurance are reluctant to begin working, seeming to disprove what they worked so hard to prove. This fear of jeopardizing their benefits may be especially acute for SSDI beneficiaries in the 24-month waiting period for Medicare, who have only recently qualified for benefits.

## OPTIONS TO INCREASE PARTICIPATION

- In any program that depends upon optional state financial participation, there is a tension between adding incentives for people to participate and adding incentives for states to

participate. Given the very limited purpose of this program, however, there are still several incremental strategies available to increase participation:

1. Launch a federal information campaign geared to assuring beneficiaries that they will not lose their benefits if they work and participate in this program.
2. Provide federal technical assistance to states to help them design their program to reach the population they wish to target.
3. Under existing rules, a person cannot receive vocational rehabilitation benefits if they state they are unable to work. This requirement is inconsistent with other disability benefit requirements and should be changed.
4. Provide specific statutory authority and encouragement for limited state demonstrations. This may give states a better understanding of potential costs and encourage greater state participation.
5. The biggest inhibiter to state participation is costs. Increasing the Federal match, perhaps similar to that in the SCHIP program, may induce more states to participate.
6. One of the greatest disadvantages of the American health system is its failure to cover millions of people with serious chronic health problems and disabilities. While the Medicaid buy-in was not intended to address this problem, it had the potential to alleviate it in its initial 1999 formulation—a version that included an optional eligibility expansion to those with 'Potentially Disabling Conditions'. Uninsured people already in the workforce who have costly disabling and chronic conditions have poor access to individually purchased health insurance, yet, may become unable to work without insurance. Providing insurance to them may be the biggest work incentive of all.

Defining the criteria for eligibility would be extremely difficult and controversial, but the potential benefits from such a policy justify the risk.

**MEDICAID BUY-IN OPTIONS: HELPING PERSONS WITH SEVERE DISABILITIES AND CHRONIC CONDITIONS TO WORK**

> ***"….we must make sure our efforts do not prohibit Americans with disabilities from living up to their full potential. After all, these programs were designed as safety nets, not iron cages."***
>
> Rep. Jim Ramstad (R) Minn., Statement before the Subcommittee on Social Security, Committee on Ways and Means, Hearing on Barriers Preventing Disability Beneficiaries From Returning to Work, March 11, 1999

## Introduction

More than 9 million working-aged people are living today with a severe long-term disability.[2] Medical and other technological advances have changed what that means, allowing people with disabilities and chronic conditions to live much longer and potentially more productively than they could have just a few decades ago. Unfortunately, society's efforts to support those with severe disabilities and chronic conditions have not kept up with those technological advances, and there are many barriers that prevent people with disabilities and chronic conditions from achieving independence and going to work, barriers that extend well beyond a person's medical condition. Together, these barriers have been simply too high for all but a relative few to scale. Employers are often reluctant to invest in the special accommodations or the higher health insurance premiums that employment of people with severe disabilities and chronic conditions would likely necessitate. Potential employees with these conditions may not have the training and skills, transportation, confidence, or other supportive services necessary to enter and remain in the workplace.

Lack of health insurance is also an important barrier to work for people with disabilities and severe chronic conditions in the United States. Many may not be able to work full-time and obtain

[2] Jack Meyer and Pamela Zeller, "Profiles of Disability: Employment and Health Coverage", Kaiser Commission on Medicaid and the Uninsured, September 1999.

employment in jobs offering health insurance—insurance they cannot survive or function without. And public health insurance programs for people with severe disabilities and chronic conditions (Medicare and Medicaid) have been tied to the Social Security cash assistance system, a system in which the central part of qualifying for benefits has been to show that one cannot and does not work.

In the Balanced Budget Act of 1997 and in the Ticket to Work and Work Incentives Improvement Act of 1999, Congress began to address the concern that this tie between Social Security income support and health benefits was keeping people who wanted to work trapped in the cash assistance system and unemployment. These new laws give states the option to offer Medicaid coverage to people with severe disabilities and chronic conditions who go to work and whose earnings would otherwise disqualify them from Medicaid. These provisions are known as the "Medicaid buy-in". While the buy-in program was by no means considered a panacea – maintaining health insurance is a necessary but not sufficient predicate toward independence for people with disabilities – its supporters believed it would be a significant step forward.

This report describes the basics of Medicaid buy-in options. Based on several dozen interviews, it examines the buy-in's original rationale, how it has operated in practice, why some states have adopted it and some have not, and why some beneficiaries have participated and some have not, and concludes with some possible approaches to extending its reach.

## METHOD

The core of the research was dozens of interviews with advocates, state and federal buy-in program administrators, state legislators, and disability policy and health policy researchers. Structured interviews were conducted with individuals in all the states that had significant buy-in

enrollment at the time of the study (Connecticut, Iowa, Minnesota, Wisconsin, and Massachusetts[3]), some states that had moderate or relatively low enrollments (Arkansas, California, Maine, Mississippi, New Jersey, and Vermont), in New York, where we conducted interviews during the long political struggle that preceded passage of a buy-in, in Florida, where a proposed buy-in was the subject of volatile budgetary politics throughout late 2001 and early 2002, and in Georgia, which has considered Medicaid buy-in and not passed it in recent legislative action. The Medicaid buy-in program and the issues surrounding its design and implementation intersect with a number of complex disability and health programs, each of which has important state-to-state operational differences. It was only through the generosity of our interviewees, often involving multiple follow-up sessions, that we were able to derive a national picture of Medicaid buy-in.

## BACKGROUND

Medicare and Medicaid for People with Disabilities: Broadly speaking, the federal government provides cash and health insurance benefits to people with disabilities and chronic conditions who meet strict medical or functional standards for being unable to work. Former workers (or children of deceased, disabled or retired workers) who have paid taxes into the Social Security system and who meet the disability criteria may receive Social Security disability payments (referred to as Social Security Disability Insurance or SSDI payments) and, after a 24-month waiting period, are eligible for Medicare health benefits. Extremely low-income people (incomes less than $500-$800/month) who meet the same disability test are guaranteed a minimum income through Supplemental Security Income (SSI) payments, regardless of work history, and they generally

[3] Massachusetts has a Medicaid buy-in program that dates to the late 1980s and operates under somewhat different rules than those authorized by the federal buy-in legislation in 1997 and 1999. While Massachusetts's program is not a product of the federal options we are analyzing as such, it bears important lessons and we have incorporated it into our analysis at several points.

receive Medicaid. If they do have sufficient work histories, they also receive SSDI and Medicare. (SSDI beneficiaries with low Social Security benefits may also receive SSI and Medicaid together with Medicare.) Medicaid offers a more comprehensive set of medical benefits than Medicare, often including personal care aides for the physically disabled and drug coverage, but it is a safety-net program, so it is usually available only to beneficiaries who have sufficiently low incomes to be receiving SSI. Thirty five states also have 'medically needy' programs, in which people with disabilities can also qualify for Medicaid if their income net of medical expenses is very low—below a state-specified amount that is typically significantly lower than the $800/month maximum for SSI.

The Social Security Administration is responsible for disability determinations for these two sets of programs—SSDI and Medicare, SSI and Medicaid—contracting with the states or their agents to carry it out. As Figure 1 demonstrates, the central part of qualifying for these programs as disabled has been to show that one cannot and does not work. The first part of qualifying for both of these sets of programs has traditionally been to show that one does not earn a substantial income. To become eligible one must also have either one of a list of chronic, disabling conditions or an equally severe condition; and the condition must make it impossible to work in one's previous job or to learn a different job.

**Figure 1**

**SSA's process for determining disability: five steps, each one about work**

**1. Are you working?**
If you are working in 2001 and your earnings average more than $740 a month, you generally cannot be considered disabled. If you are working in 2002 and your earnings average more than $780 a month, you generally cannot be considered disabled. If you are not working, we go to Step 2.
**2. Is your condition "severe"?**
Your condition must interfere with basic work-related activities for your claim to be considered. If it does not, we will find that you are not disabled. If your condition does interfere with basic work-related activities, we go to the next step.
**3. Is your condition found in the list of disabling conditions?**
For each of the major body systems, we maintain a list of medical conditions that are so severe they automatically mean that you are disabled. If your condition is not on the list, we have to decide if it is of equal severity to a medical condition that is on the list. If it is, we will find that you are disabled. If it is not, we then go to Step 4. [Inability to work is the underlying threshold for severity in most of these medical condition listings.]
**4. Can you do the work you did previously?**
If your condition is severe but not at the same or equal level of severity as a medical condition on the list, then we must determine if it interferes with your ability to do the work you did previously. If it does not, your claim will be denied. If it does, we proceed to Step 5.
**5. Can you do any other type of work?**
If you cannot do the work you did in the past, we see if you are able to adjust to other work. We consider your medical conditions and your age, education, past work experience and any transferable skills you may have. If you cannot adjust to other work, your claim will be approved. If you can adjust to other work, your claim will be denied.

-- From SSA's Publication, "How We Decide If You Are Disabled"

The Buy-in Program and Its Relationship to Existing Medicaid Rules: With the passage of the Medicaid buy-in options in the late 1990s, states can drop the first "Are you working?" portion of this qualification process for people with disabilities who work. Since 1999, states may offer Medicaid buy-in to anyone who meets the disability criteria at whatever income level the state chooses up to $75,000 a year, with wide state discretion over cost-sharing and premiums. States may also offer the buy-in to people on SSI whose medical condition improves to the point where they would no longer meet the definition of "disabled".

Nevertheless, the Medicaid buy-in program still leaves the other four parts of disability determination intact—that is, it leaves "ability to work" in place as the main criterion for Medicaid eligibility for people with disabilities. The Medicaid buy-in rests on a seeming contradiction—

making benefits available to those who ostensibly cannot work but encouraging them to work once they qualify for disability-related benefits. This contradiction has been an implicit part of American disability benefits for some time. SSI and Medicaid have long given beneficiaries who begin to work and earn incomes some financial and health coverage advantages over those who receive money from other sources, such as Social Security or personal savings. SSI beneficiaries have been able to retain Medicaid coverage even if they get a job and earn a modest income, as allowed under Section 1619 of the Social Security Act. In 2000, this provision allowed 83,000 people with disabilities to receive Medicaid after their income disqualified them for SSI.[4] Medicaid buy-in expanded on Section 1619 in a variety of ways, as detailed in Figure 2 below.

[4] Quarterly Report of the Social Security Administration, Office of Policy, Office of Research, Evaluation and Statistics, *SSI Disabled Recipients Who Work*, December 2000.

**Figure 2**

## FEDERAL WORK INCENTIVE PROVISIONS FOR PEOPLE WITH DISABILITIES

**Section 1619 (b) of the Social Security Act (1980**) – Once qualified for SSI, beneficiaries can retain Medicaid coverage even if they work and earn a modest income: Medicaid coverage must continue for employed former SSI recipients if their income is below state specific limits, ranging from $13,792 in Arizona to $34,125 in Alaska. The provision applies in all states.

**Section 4733 of the Balanced Budget Act of 1997 (BBA)** – A state can provide Medicaid coverage to working individuals with disabilities who meet SSI disability medical criteria and whose net family incomes are below 250 % of poverty. They need not be receiving or have ever received SSI cash assistance to be eligible. States may impose premiums or other cost-sharing charges on a sliding scale based on income. As of early 2002, 11 states have implemented this provision.

**Ticket to Work and Work Incentives Improvement Act of 1999 (TWWIIA) –** The Ticket to Work law established two optional coverage groups and a demonstration category. <u>Basic Coverage Group</u>: similar to section 4733 of the BBA except states are free to establish their own income and resource standard, including the option to have no income or resource standards at all. States are limited to premiums of no more than 7.5% of income for those with incomes under 450% of poverty, and there is no Federal match for individuals with annual adjusted gross incomes that exceed $75,000. As of early 2002, 4 states have implemented this provision, with several more scheduled to begin operations soon. <u>Medical Improvement Group</u>: a new eligibility category in which states can cover employed individuals with a medically improved disability who lose Medicaid eligibility because their medical conditions have improved to the point where they are no longer disabled under the SSI definition of disability. If a state wants to cover this group, it must also cover the Basic Coverage Group. As of early 2002, only Connecticut had implemented this operation, although several legislated but as-yet unimplemented state programs will incorporate this group. <u>Potentially Disabling Conditions Demonstration</u>: Another state option to offer the buy-in to people with "potentially disabling conditions" was considered and then dropped because of potential costs; appropriations for a limited demonstration were included instead. Four states have been approved for demonstrations.

Although Medicaid buy-in legislation gave states freedom to set income and asset requirements, it restricted them in other notable areas. With the exception of the "medically-improved" group, states are prohibited from establishing a definition of work or employment that sets a minimum standard for number of hours worked during a period of time or a minimum level of earnings.[5] Thus, people working few hours can participate in the buy-in program. This has important implications. Some disability advocates consider it an important work incentive provision for people experimenting with their capacity to work. It also increases the possibility that SSDI beneficiaries can use nominal work to access the buy-in as a way to obtain Medicaid's comprehensive benefits, otherwise available to them only if they spend almost all of their income on medical expenses to qualify as Medically Needy (a process known as 'spend-down'). The legislation also requires states to include a personal assistance benefit for beneficiaries in the buy-in program even if it is not otherwise part of the state's Medicaid plan.

The Political Rationale: The dominant rationale for the Medicaid buy-in was and is as a vehicle for removing barriers to work for those already receiving Medicaid through the SSI or medically needy programs. This is affirmed by stakeholders at all levels of involvement in the program: at the federal level, among the national organizations working with federal and state officials to coordinate state buy-in program development; by advocates who have worked or are working to pass and promote buy-in programs in the states; by the legislators in both parties who shepherded buy-in bills through state legislatures; and by the state Medicaid and rehabilitation administrators who are running the programs. The people with disabilities who testified in Washington and in state capitals in support of Medicaid buy-in were always people who wanted to

[5] People in the medically-improved group, however, must earn at least the federally required minimum wage and work at least 40 hours per month unless the state designates an alternative work definition.

work but could not, either for fear of losing their Medicaid benefits when they lost SSI eligibility, or in a smaller number of cases for fear of losing Medicaid eligibility as medically needy. Advocacy groups, following a national template, conducted and publicized informal surveys in a series of states reporting that thousands of people on SSI wanted to work but could not because they would lose their

> "Medicaid buy-ins are about work. It is not a health-insurance expansion."
> *Administrator at a non-profit organization with national oversight role in Medicaid buy-in options.*
>
> "Everyone understands the buy-in as an employment program. This is also definitely how it has been sold to state legislatures."
> *-State Human Services Administrator*
>
> "We're spending all this money on [people with disabilities] now. Maybe this would save the state money."
> *-Senior State Legislator describing motives for sponsoring that state's buy-in law*
>
> "The main impetus of our survey was: If you're not working, why are you not working? What are the government disincentives?"
> *-Advocate instrumental in passing Medicaid buy-in program*
>
> "This is all about self-sufficiency."
> *-State Human Services Administrator*

health benefits, and interviews with key players confirm that those surveys were critical to passing Medicaid buy-in programs in most of the 15 states that now have them. Moving people with disabilities into employment was also thought to have broader economic implications in some states, in which the tight labor markets of 1998-2000 made this potential new source of workers very appealing.

Possible Categories of Participants: Although the primary legislative purpose of Medicaid buy-in at the federal level and in almost all the states was to help the Medicaid population to work, the buy-in provisions can reach other populations both in principle and practice. Several different

categories of people with disabilities who can do at least some work can benefit from a buy-in program:

1. **People with disabilities on SSI who want to earn more than the amount allowed under their state's Section 1619 limits**.

2. **People on SSDI and Medicare who currently spend-down SSDI and/or work income in order to qualify for Medicaid, and would like to work and to make more income, retain their earnings and continue to receive Medicaid benefits.**

   These first two categories of individuals are the prototypical buy-in groups, trapped into unemployment or underemployment by their need for Medicaid benefits.

3. **People who are not receiving SSI or Medicaid, but who meet the disability definition under the SSI program**.

   This population is working without comprehensive insurance or any insurance despite a disability or chronic condition severe enough to meet the Social Security standard.

4. **People with disabilities on SSI whose medical condition improves to the point that they would lose eligibility.**

   If a state wishes to cover this category, they must also cover those in the "Basic Coverage Group"—the three categories described above.

5. **People on SSDI in the 24-month waiting period for Medicare.**

   Social Security law requires eligible people with disabilities to wait for 24 months after passing the disability determination process before receiving Medicare benefits. There are 900,000 individuals in this category at any one time, and the Centers for Medicare and Medicaid Services

(CMS) projected 5%, or up to 45,000, would take advantage of a buy-in if their state implemented the option.[6]

6. **People on SSDI and Medicare who do not live in spend-down states or who do, but would have to impoverish themselves through a spend-down in order to also receive Medicaid.** To receive Medicaid, SSDI beneficiaries either have to have SSDI payments low enough to meet the state's income standards, or, in 35 states, "spend down" to qualify for Medicaid as Medically Needy. (The spend-down/Medically Needy states offer Medicaid eligibility to people with disabilities with incomes higher than the SSI level, but whose medical expenses bring their remaining income down to a level set by the state, typically the SSI level or lower.) Both those currently meeting a spend-down requirement and those who are not or cannot could now potentially buy into Medicaid for a small premium at most—if they work.

It was difficult to predict both how many states and how many people in each category would participate. The federal government projected a substantially higher enrollment than what has occurred to date, particularly from the first four groups, while some states with buy-in programs seriously under-estimated enrollment. According to our interviews, both federal and state projections of who would enroll were off-target in one significant respect: the lion's share have been SSDI/Medicare beneficiaries, some of whom may have enrolled primarily to obtain Medicaid's pharmacy and personal assistance benefits without first impoverishing themselves through Medicaid spend-down. We discuss the heavy participation of this group in detail below.

[6] Personal Communication, Centers for Medicare and Medicaid Services.

## FINDINGS

### State Participation

As of the beginning of 2002, fifteen states had implemented some form of Medicaid buy-in program (see figure 3) and several more are scheduled to start during the year.[7] About 85% of the estimated 17,000 enrollees are in just four states—Connecticut, Iowa, Minnesota, and Wisconsin. Additionally, Massachusetts' pre-existing buy-in for adults with disabilities has about 5700 enrollees. (Since Massachusetts' program predates the federal buy-in options and operates under its own rules, we have not included it in the count of buy-in participation.)

The buy-in is an extremely popular program among legislators in the states that are participating. Despite the widespread pressure on state Medicaid budgets in 2001-2002, no state has proposed substantially cutting back its Medicaid buy-in as of this writing, not even those states in which the buy-in is significantly over-budget. One such state affirmed that it was last on their list of potential Medicaid eligibility cuts, while the medically needy program is at the top of the list.

Although the Medicaid buy-in is politically strong where it has passed, less than half of the states have implemented the program or passed bills to do so. State participation has not been more widespread for several reasons. First, it is very rare for Medicaid eligibility options to be quickly and universally adopted by states. Furthermore, a rare exception to that pattern took place just as the buy-in options were introduced: buy-in became available at the same time that almost all of the states were focused on authorizing and implementing the State Children's Health Insurance Program (SCHIP), leaving less money and political capital for another health care eligibility expansion. A

[7] Since Spring of 2002 when our research was conducted, an additional six states have brought Medicaid Buy-In plans into operation, with Florida's Medicaid buy-in also established but, at least temporarily, eliminated during 2002.

significant number of state legislatures meet for only a few months every other year, and it can take multiple biennial sessions for authorizing legislation and accompanying appropriations to be passed. As deliberations on Medicaid buy-in were deferred into 2001, worsening budgets compromised any Medicaid expansions in some states.

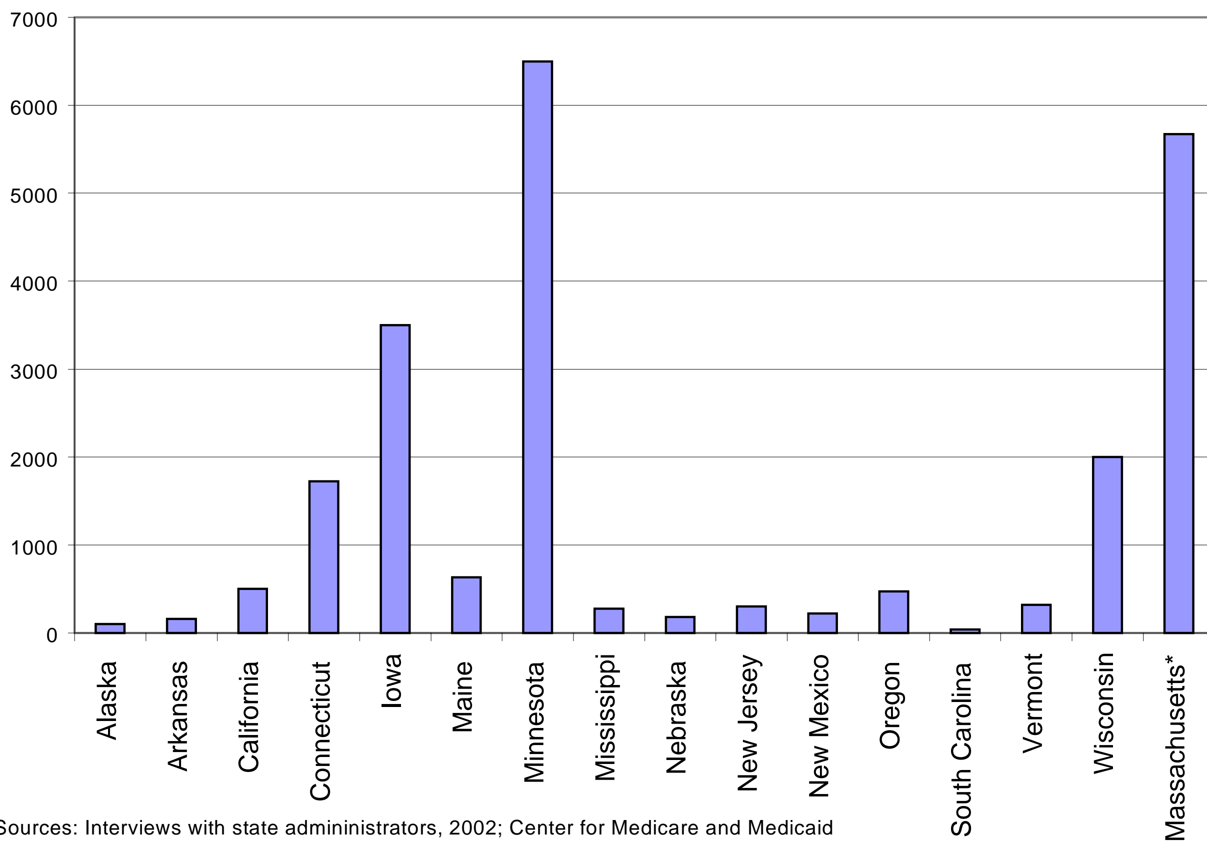
In addition to these broader factors, states have feared uncontrollable and unpredictable costs if they adopt buy-in programs, a fear that has only grown with weakening state budgets. Many states have doubted their ability to project enrollment accurately. As we discuss in the next section, some of the early buy-in states were surprised by large enrollments from the SSDI beneficiary population. With the exception of the Massachusetts buy-in—a state whose program now has several thousand participants— there were neither state examples nor smaller-scale demonstrations on which to base projections. Some states have raised the possibility of avoiding this concern by capping their program enrollment formally—similar to the enrollment limits and waiting lists permitted in the home and community-based waiver program—but there is no separate waiver mechanism for the buy-in. Some states have also expressed concern about the potential expense of the required personal assistance services. Georgia (along with 19 other states) does not offer Medicaid beneficiaries personal assistance services in its state Medicaid plan, and it is afraid it will be pressured to offer the benefit to all for the sake of the buy-in. But this fear may be misplaced: three states have already implemented the program without making personal assistance part of their state plan and have offered it to the buy-in participants only.

## Beneficiary participation

Enrollment has differed by orders of magnitude in participating states: enrollment can be counted in the dozens in four states, in the hundreds in seven, and in the thousands in Wisconsin, Connecticut, Iowa, and Minnesota (which by itself has over 40% of national enrollment).

**Figure 3**

**Medicaid Buy-In Enrollment, most recent figures available**




Sources: Interviews with state admininistrators, 2002; Center for Medicare and Medicaid Services

[*] Massachusetts has a Medicaid buy-in program that dates to the late 1980s and operates under somewhat different rules than those authorized by the federal buy-in legislation in 1997 and 1999. While Massachusetts's program is not a proof the federal options we are analyzing as such, it bears important lessons and we have incorporated it into our analysis at several points.

These programs differ significantly in their design, which partly explains their different enrollment levels. Figure 4 summarizes these structural differences.

**Figure 4**
**The Structure of Existing Medicaid Buy-In Programs**

| State | Date Imple ment. | Most recent available enrollment | Income Maximum (with exclusions that vary by state) | Treatment of SSDI Income | Premiums |
|---|---|---|---|---|---|
| **Alaska** | 7/99 | **99** | 250% FPL | Ineligible if it is above SSI income limits | Sliding scale above 100% FPL |
| **Arkansas** | 2/01 | **159** | 250% FPL | Ineligible if it is above SSI income limits | Additional co-payments: above 100% FPL. |
| **California** | 10/99 | **500** | 250% FPL | The same as earned income* | $20-$250/mo. Premium based on income |
| **Connecticut** | 10/00 | **1722** | Up to $75,000 | The same as earned income* | 10% of marginal income over 200% poverty |
| **Iowa** | 3/00 | **3500** | 250% FPL | The same as earned income* | Premiums over 150% FPL |
| **Maine** | 8/99 | **633** | 250% FPL | Ineligible if above 100% of FPL | $10-$20/mo. between 150-250% FPL |
| **Minnesota** | N/a | **6500** | None | The same as earned income* | 10% of marginal income over 200% poverty |
| **Mississippi** | 99 | **276** | 250% FPL (Must work >40 hours a month) | Ineligible if above 135% of FPL | None |
| **Nebraska** | 6/99 | **183** | Up to 250% FPL | Ineligible if it is above SSI income limits | Sliding scale b/w from 200-250% FPL, 2-10% of income |
| **New Jersey** | 10/00 | **300** | Up to 250% FPL, unearned up to 100% | Eligible with any amount of SSDI income | Premium $25-50 over 100% FPL |
| **New Mexico** | 1/01 | **223** | 250% FPL | Ineligible if it is above SSI income limits | Co-payments (up to a max. based on income) |
| **Oregon** | 2/99 | **472** | 250% FPL (unearned income not counted) | Eligible with any amount of SSDI income, but all above SSI level is taken as premium | Premium for income above $2200 per month (All unearned income above $532/ month) |
| **South Carolina** | 10/98 | **40** | 250% FPL | Ineligible if it is above SSI income limits | None |
| **Vermont** | 1/00 | **320** | 250% FPL | The same as earned income* | Above 185% FPL, $12-25 monthly premium |
| **Wisconsin** | 3/00 | **2000** | 250% FPL | Eligible with any amount of SSDI income, but all above SSI level is taken as premium | Above 150%, 3% of earned income (100% adjusted unearned inc.) |

*(except for standard 50% earned income disregard)

There are two particularly striking facts about Medicaid buy-in enrollment. The first is its apparent low level overall, particularly when compared to the numbers of participants in the few higher-enrollment states. The second is that a large majority—some four-fifths—of national buy-in enrollment thus far has been from Medicare beneficiaries receiving SSDI. We discuss each of these phenomena below.

Limited Overall Enrollment: A principal reason for this limited enrollment may be the basic tension in a program for working people that retains a disability test based on inability to work. The Social Security disability definition and the multi-step process for meeting it are extraordinarily rigorous. The five-step Social Security process is, as a Florida advocate put it, the strictest legal definition of disability we have. It may be that there are simply a limited number of people who can meet this definition and work, or recover enough to work, particularly without access to the necessary training and skills and other supports needed to sustain employment. Relatively few people, largely those with a prior work history, may be able to overcome all of the immense health and other problems associated with severe disability.

Another important reason for limited participation is the fear many people with disabilities have of losing their hard-won benefits. Medicaid buy-in is a new coverage category gradually being offered by the states, and without much marketing in most of those states. Advocates have told us that many people who have been through a difficult process of proving that they cannot work in order to get income support and health coverage are reluctant to start working. This has been a particularly big factor for those in the 24-month waiting period after qualifying for SSDI before becoming

eligible for Medicare, who have not enrolled in significant numbers. For many who have just qualified for SSDI, the last thing they are thinking about is how to start working.

There are also more specific reasons the buy-in options have not drawn more enrollment from SSI recipients and those not in the Social Security cash assistance system at all. The SSI population was one of the main projected sources of enrollment for the buy-in—indeed for many involved with advocating and passing the Medicaid options, the prototypical buy-in participant was someone with SSI looking to work and earn an income. Advocates also emphasized that buy-in participants would almost all be existing Medicaid beneficiaries for whom states would incur little or no incremental cost. Yet for the most part, relatively few people receiving SSI have participated in the buy-in. This is in part because there already are existing, though limited, work incentives in the SSI program—Section 1619—that allow beneficiaries to keep Medicaid coverage even after they earn enough to move off cash assistance, as long as their income is below state-specific limits ranging from $14,000-34,000 a year. In addition, people receiving SSI without SSDI generally have limited or no work history. This affects both their marketability and their willingness to push the limits of their severe disabilities in the workplace. The buy-in provides health benefits, but little else in the way of supportive services. As one advocate suggested, "You can't pass a law and suddenly expect them to work. They're afraid they can't do it."

Another group that has so far failed to participate in appreciable numbers is people with disabilities who are not receiving Social Security payments but are disabled, working, and uninsured. Some states—particularly those without buy-ins—have worried about a large 'employed and uninsured' enrollment (a "woodwork effect") that has not materialized. This working, disabled but uninsured population is hard to describe and estimate. First, since this is the one potential population

that has not been through a Social Security disability determination, they would have to become eligible by passing the disability tests with adjudicators implementing the inherently problematic 'working but is too disabled to work' eligibility standard. Second, there are limited population-level data on who would meet the Social Security definition of disabled, with existing surveys referring to functional limitations that map imprecisely to the more elaborate tests for government benefits.[8] Among states that passed buy-ins, however, none of their projections showed much participation from those currently working and not previously a part of SSI or SSDI, with the exception of Mississippi, where this group was primary target, referred to as 'working and uninsurable'. Government officials in several states did raise the possibility of unpredictable and large enrollment from this group, a concern advocates minimized. No state except Massachusetts has more than 200 of these 'employed and uninsured' buy-in participants, although the approximately 125 in Mississippi represent half of that program's enrollment. Several states, particularly those with larger buy-in enrollments, did project (and, in states such as Connecticut and Iowa, subsequently recruit) some enrollment from those who had been on SSI/Medicaid and lost eligibility when they began earning wages, but these individuals had already been through a disability determination.

Disability advocates are generally not surprised that so few people in the working, disabled and uninsured category are participating in the buy-in. People who can meet the very rigorous SSI/SSDI disability eligibility requirements, but are working, are unlikely to be able to do so without already having comprehensive health insurance benefits. Their conditions would deteriorate to the point where they would be unlikely to survive or remain productive without the benefit of health insurance. Nevertheless, both Massachusetts and Wisconsin have attracted a small cadre of buy-in

[8] For existing estimates, see Gerard Anderson and James Knickman, "Changing the Chronic Care System to Meet People's Needs", Health Affairs, Vol. 20 No. 6; cf. Jack Meyer and Pamela Zeller, "Profiles of Disability: Employment and Health Coverage", Kaiser Commission on Medicaid and the Uninsured, September 1999.

participants not previously on cash assistance. This may be because of their unique approaches to disability determination procedures, described below.

Disability determination for SSI and SSDI is performed by state or non-profit agencies under contract to the Social Security Administration; that is not necessarily true for those seeking Medicaid without Social Security cash assistance, including those applying for Medicaid as Medically Needy or through a Medicaid buy-in. How buy-in disability determinations are conducted and in particular whether they are done by the same people who do Social Security disability determinations appears to have an impact on enrollment from the working, disabled and uninsured population. In Massachusetts (whose buy-in goes back to 1988), different people do disability determinations for the buy-in program and for SSI/SSDI. The group of 'adjudicators' determining disability for the buy-in wind up using a slightly looser standard of disability than those working for Social Security, according to one Massachusetts advocate. (The advocate added that the buy-in disability definition seems to get more or less broad depending on the state's fiscal circumstances.) In Wisconsin, where the same agency does all disability determinations including the buy-in, the most experienced adjudicators were selected for the buy-in with the expectation that they would know how to look closely at the circumstances of employment for working people with disabilities to see if they were only able to work because of 'extraordinary circumstances'. A program administrator in Mississippi confirmed the need for special disability determination treatment if its buy-in—specifically intended to reach those working in substantial jobs who have not been on cash assistance—is to be viable, and she saw the lack of such special treatment as a central cause of that state's current low enrollment.

Massachusetts and Wisconsin have two of the largest buy-in programs, despite requirements that prevent use of the buy-in to avoid spend-down. The apparent enrollment success of states with separate personnel to conduct disability determination processes suggests that there may be a

significant number of people with disabilities and chronic conditions who are working, uninsured or underinsured, and at risk of reaching the level of severity inherent in the Social Security definition of disability. That risk is likely greatly exacerbated by their lack of health insurance, and some are likely to end up eventually on SSI or SSDI. Their precarious health situation thus jeopardizes both their physical well-being and their financial independence, and Medicaid buy-in can be about work for them as well as for those already on cash assistance. While some of these uninsured people on the margins of Social Security eligibility might use the buy-in, particularly in Massachusetts and Wisconsin, and a small number might take advantage of the as-yet unimplemented "potentially disabling conditions" demonstration mentioned earlier, this population is essentially out of luck in the current American health system.

The High Proportion of SSDI Enrollees: Our interviews indicate that the principal source of national buy-in enrollment – about 80% – thus far has been beneficiaries receiving SSDI and Medicare. The reasons are a combination of the financial vagaries of 'Medicaid spend-down' and the higher likelihood of employment for those with work histories.

Further background on the SSDI program and its relationship with Medicare and Medicaid is necessary to understand how SSDI participation has developed in the states with buy-in programs. The SSDI program provides cash benefits and, after a 2-year waiting period, Medicare, primarily to people with a substantial work history who meet the same disability criteria as people on SSI. Approximately 3.75 million people aged 18-64 qualify for Medicare as disabled, of whom about one million also receive Medicaid. Thus, there are more than 2 million people with severe disabilities and chronic conditions who must meet the same disability standard as SSI to receive Medicare, but

who do not receive Medicaid's benefits—including prescription drug and long-term care benefits—because their income is too high, principally their SSDI payments themselves.

In order for SSDI/Medicare beneficiaries to also qualify for Medicaid, either their SSDI payments would have to be low enough to meet the state's income standards, or, in 35 states, they could possibly "spend down" to the Medically Needy income eligibility level for Medicaid. Most medically needy adults with disabilities are SSDI recipients. Spend-down can be a financially devastating and onerous requirement, and it also can effectively render those who receive Social Security benefits because of a work history worse off than those without a work history when it comes to eligibility for Medicaid benefits. The amount of remaining income allowed those who spend-down to Medicaid eligibility is often very low, averaging only 50% of the federal poverty level.

The Medicaid buy-in, in contrast, can offer disabled people with low and middle incomes access to Medicaid at much lower costs—states may charge premiums of no more than 7.5% of income for those earning up to 450% of the federal poverty level. Needless to say, this is potentially very attractive to people paying a heavy price to maintain medically needy eligibility. The condition is that they must have some employment.

Two of the states with the highest enrollment were surprised by the large participation from SSDI beneficiaries. Notably, Minnesota, with one of the first and now the largest buy-in program, made an enrollment projection that overlooked those on SSDI who would enroll without first spending down to Medicaid eligibility, a population that is now 80% of their enrollment. This oversight led Minnesota to project 1200 enrollees rather than the current 6000. Iowa, the state with the second-largest buy-in, also drastically under-projected enrollment, estimating 400 as opposed to

its initial enrollment of over 2000 (current enrollment is 3500), with a great majority of them receiving SSDI and Medicare. Although no hard figures exist, some of these participants appear to use the buy-in principally as an alternative to Medicaid spend-down and only secondarily as a work incentives program, and we have heard some anecdotal examples from advocates and program administrators of nominal employment among Medicare-eligible buy-in participants for this purpose.

The unanticipated high enrollments in Minnesota and Iowa have not affected the strong political support for the buy-in programs in those states. The legislative committee chairmen in both parties who sponsored the buy-in in Minnesota continue to be strong supporters of it and see it as a successful program, and the Ventura administration has also proposed only slight modifications to the program (to how the buy-in will verify work income.) In Iowa, which like many states has been going through a wrenching debate over Medicaid costs in its budget process in early 2002, the buy-in was placed at the bottom of a list of potential eligibility cuts, while the medically needy program for adults was placed at the top of the list and was for a time recommended for elimination.

Outside of Minnesota and Iowa, though, most of the buy-in states have taken specific steps to limit the participation of those with substantial SSDI income. One method is to make ineligible those with SSDI income above the original Medicaid/SSI disabled income standard. This has the effect of strictly limiting the buy-in to those who would be eligible for SSI and Medicaid were it not for their work income. This method was employed in Alaska, Arkansas, Maine, Mississippi, Nebraska, New Mexico and South Carolina, and it is also about to be used in Florida's buy-in, which was scheduled to begin operating in April 2002. This program structure does not extend work incentives to those spending down SSDI payments to receive Medicaid: spend-down limits employment income as effectively as it limits Social Security income. Alaska, New Mexico, and South Carolina do not have

a medically needy program at all, and thereby exclude virtually all non-elderly disabled adults with substantial work histories from Medicaid regardless of their medical or employment situation.

A second method, adopted by Oregon and Wisconsin, allows people with SSDI income above the SSI standard to participate in the buy-in, but requires them to pay premiums that effectively amount to what they would have had to spend on medical expenses to qualify under the Medically Needy program. This approach thus extends work incentives to those with SSDI and other unearned income above the spend-down amount by allowing them to keep additional work income, but does not allow them to avoid the spend-down entirely by participating in the buy-in. (This approach also allows those on SSDI and in Medically Needy programs to take advantage of the more liberal asset maximums in the buy-in.)

The first method, by design, has held down SSDI enrollment in the states that have adopted it. And, in part because of their treatment of SSDI income, those states are all low enrollment states—six of the seven are the buy-in states with enrollment under 300. The exception is Maine, which has unusually high income eligibility levels for Medicaid for the disabled—100% of poverty—and therefore allows the 2/3 of SSDI beneficiaries with benefits up to that amount to participate in the buy-in and keep work earnings. Wisconsin and Oregon (which maintain a spend-down on SSDI income while allowing SSDI beneficiaries to enroll in the buy-in and keep earned income) have more substantial levels of participation, with several hundred people enrolled in Oregon and 2,000 people enrolled in Wisconsin. Notably, SSDI is still the main source of enrollment. Wisconsin's program has attracted more than 1,700 SSDI beneficiaries with the dominant attraction being work incentives rather than relief of spend-down requirements.

States are now highly attuned to this issue. They can pre-determine overall buy-in enrollment to a significant extent just with their treatment of SSDI income. For example, the legislative research arm in Washington State projected enrollment in the buy-in program as either 1,700 or 9,000 depending on the treatment of SSDI income relative to the buy-in premiums. (The state split the difference, charging half rather than all of SSDI income above the Medically Needy level of $571/month as a premium in its buy-in program, which begins operating in 2002.)

Yet there are stakeholders who want the buy-in program to remain available as a vehicle to avoid spend-down. One advocate described Medicaid buy-in as a "backdoor approach" towards addressing the punitive effect of low spend-down eligibility limits for those with work histories and modest social security pensions. Others were not as explicit, but several of those involved with the buy-in programs in Minnesota and Connecticut, both in and out of government, have noted the relief for those previously spending down and see it as a welcome development. The strategy—intentional or not—of advocating buy-in in the name of work incentives while incidentally making Medicaid benefits more affordable to Medicare beneficiaries has had mixed results. While it arguably succeeded in three to five states, it also led six of the fifteen states with buy-in programs to exclude those with SSDI income above $500-$700 a month from participating in the program at all, even as a work incentive.

We have discussed three options for handling those with SSDI income: (1) the Minnesota/Iowa alternative approach which includes spend-down relief; (2) the Wisconsin/Oregon method of keeping the buy-in open as a work incentive but leaving spend-down in place; and, (3) the six-state method of keeping those with SSDI income above SSI levels out of buy-in entirely. Massachusetts has developed a fourth option in its Common Health program for working-age adults

with disabilities, an expansive approach that has separately and explicitly addressed both work incentives and the spend-down issue. The program dates back to 1988, although it was expanded and folded into a Medicaid waiver in 1997. In Massachusetts, the Medicaid buy-in requires 40 hours a month of work, thereby excluding those who get nominal jobs in order to avoid spend-down. The 40-hour work requirement was a compromise between the state administration, which proposed a much higher work minimum, and disability advocates in the early 1990s. As part of a broad Medicaid waiver in 1997, the state initially sought to eliminate its Medicaid spend-down program, and as a substitute, increase overall income eligibility for the aged and disabled to 133% of poverty. Massachusetts subsequently agreed to continue a spend-down program together with the liberalized income eligibility and indeed to liberalize spend-down requirements dramatically. The state changed spend-down from an ongoing requirement to a one-time, up-front one, so that potential enrollees must only spend the required portion of their income on medical expenses over one initial six month period, rather than indefinitely for as long as they wish to retain Medicaid benefits.

The net effect of these expansions is that people with disabilities in Massachusetts can receive Medicaid if their income is under 133% of poverty, or they can still get Medicaid with an income above that level if they can meet a one-time spend-down requirement or if they work 40 hours a month and pay a modest premium. These policies have contributed to enrollment growth of about 40,000 in Massachusetts' adult, disabled Medicaid categories. Notably, Medicaid buy-in enrollment has grown strongly even with attractive alternative eligibility pathways to Medicaid and buy-in requirements that together strictly limit the buy-in to the work incentives population. Mississippi has adopted a similar structure to Massachusetts, except that Mississippi lacks a spend-down, so that the only way people with disabilities making more than 135% of poverty can receive Medicaid is if they work 40 hours a month. Mississippi's program still has a small enrollment. This

may be the result of limited outreach and a unified disability determination process where state agents conducting regular SSI/SSDI adjudications are asked to consider persons working more than 40 hours a month and making a working class income as "unable to work."

**SUMMARY OF FINDINGS**

Medicaid buy-in has had limited impact. Only 15 states have implemented the Medicaid buy-in options, national enrollment is only 17,000, and about 85% of that enrollment is in just four states – Connecticut, Iowa, Minnesota, and Wisconsin. Another 5,700 enrollees are in Massachusetts, a state with a Medicaid waiver that includes a buy-in like program. Still, a look at the experience of the buy-in states gives clear evidence that it is a valuable program. Information from several of the higher-enrollment buy-in states suggests that the Medicaid buy-in may be an important program for promoting employment for a demonstrable number of people, particularly those with previous work histories. Moreover, the buy-in is a positive step towards two broader goals: providing health coverage for those with serious chronic conditions, and giving fuller economic opportunities to people with disabilities.

State participation has been limited. For the states that have implemented it, the buy-in is extremely popular politically. For the remaining states, they now find themselves in a worsening budgetary climate and a worsening job market with less pressure to find new sources of labor. These states are afraid of uncontrollable or unpredictable costs, fearful that they cannot successfully target their programs, even though the experience of other states belies these fears. In addition, the buy-in is relatively new and it takes time for states to pass authorizing legislation. And almost all the states have been focusing time, money, and institutional attention on passing and implementing the State Children's Health Insurance Program (SCHIP).

For states that have implemented the buy-in, enrollment generally has also been both substantially smaller than was anticipated by the federal actuaries and composed of different beneficiaries than anticipated.[9] The Medicaid buy-in option was designed as a work incentive program. But inserted into government disability programs that retain "unable to work" as their definition of disability, it could have only a modest impact in supporting employment. Moreover, in all of the states, people who have been through the ordeal of proving that they cannot work in order to first receive income support and health insurance benefits are afraid to start to work and potentially jeopardize their benefits.

The goal of increasing employment for those on cash assistance is what makes the program politically attractive, and it was aimed at the limited group of working-age people with disabilities and chronic conditions who currently receive cash assistance but could work if they could keep their Medicaid. Based on these assumptions, Medicaid buy-in would have very limited costs (or even savings) since it would not expand Medicaid to an uncovered population.

However, even before the federal authorizing legislation was passed, a variety of other categories of possible program beneficiaries were identified for whom states could incur additional costs, including people with severe chronic conditions who were working but had no or insufficient insurance, and people receiving Social Security payments because of disability in the 24-month waiting period to receive Medicare coverage. Most of the buy-in states (and all of those with substantial enrollments) found that it primarily reached people who had a work history, were receiving Social Security disability benefits (SSDI), and were already receiving Medicare. About four-fifths of the total buy-in enrollment comes from the SSDI population. The availability of

[9] Personal communication, Centers for Medicare and Medicaid Services. Federal actuaries predicted state participation conservatively, with under 10 states participating by 2002, and still showed enrollment of 32,000 in the buy-in options.

Medicaid benefits, especially pharmaceuticals and personal assistance, the ability to retain work earnings, and, in some states, the ability to avoid a spend-down of cash benefits as well made the buy-in attractive.

In some cases, SSDI/Medicare beneficiaries needing drug and personal assistance benefits may perform a nominal amount of work to become eligible. But in many cases, participation in buy-in programs by people with SSDI is serving the program's intended, work incentive function. SSDI recipients already have a work history, and may have the confidence, skills, and job connections to make work an immediate possibility. Without the new buy-in, they also have no equivalent to SSI's Section 1619 program to maintain Medicaid benefits with a modest level of work income. Even though the SSDI population was not the main intended target population for the buy-in, the buy-in has been useful to that population and has shown that support for returning to work is important public policy. Several states that did not allow SSDI beneficiaries to avoid spending down their unearned income *still* drew enrollments of hundreds or thousands, dominated by SSDI enrollees using the buy-in to go to work: Oregon and Wisconsin, which maintained a spend-down requirement on SSDI income but not work income; Maine, which allowed all those with SSDI income up to 100% of poverty (about 2/3) to participate; and Massachusetts, which requires substantial employment to join Medicaid buy-in and provides alternative mechanisms to alleviate spend-down requirements. In contrast, six of the buy-in states designed their programs to avoid the SSDI population, and they enrolled relatively few people as a result. For people with severe disabilities without a work history, extremely poor health coupled with broad employment hurdles may be too difficult to surmount without further job-related assistance; the Section 1619 program already has served almost all of those who can overcome those barriers.

Low enrollment of the "working uninsured" group—people who can meet the rigorous Social Security disability criteria but have not been on cash assistance—in part reflects the fact that people with serious health problems could not work (and, in many cases, live) without comprehensive health insurance. Nevertheless, there are signs in the buy-in states that a larger problem of uninsured people with serious disabilities and chronic conditions does exist: in two states that acted indirectly to slightly loosen the procedures to be deemed “disabled,” there seems to be greater enrollment from those who have not been on cash assistance. This indicates that the “potentially disabling condition” eligibility group, dropped from the final buy-in legislation, might help to address a problem that threatens both the health and the employability of people with chronic conditions who lack health coverage.

## OPTIONS TO BUILD ON MEDICAID BUY-IN

There are two important limits on any initiatives to increase the impact of Medicaid buy-in. The first is that any expansion that increases costs is likely to limit future state participation—many of the states that have established buy-in programs did so with the expectation that they would not materially expand Medicaid coverage at all. The second is that health coverage is only one of a spectrum of supports that people with severe disabilities and chronic conditions may need to pursue employment. However, given these constraints, there are steps of varying cost and complexity that can build upon the Medicaid buy-in options and extend their reach. The following briefly describes a range of options:

### Education campaign

One of the reasons beneficiaries do not participate in the buy-in is fear: fear that if they go to work they will lose eligibility for SSI or SSDI, fear that they will be without work income or public

assistance if they go to work and then stop, fear that the program will eventually disappear and they will then lose eligibility for the health benefits they need. Given the critical role that inability to work plays in eligibility determination and redetermination, this fear is not at all unreasonable. But it may be ameliorated if confronted head-on in a federal education campaign. While the federal government cannot promise that states will always offer the program, it can promise that even if the program is discontinued, federal benefits such as SSI (and Medicaid) or SSDI (and Medicare) will not be jeopardized by having participated in the buy-in. This campaign would supplement the Social Security Administration Benefits Planning, Assistance, and Outreach Program that was authorized in The Ticket to Work Incentives Improvement Act of 1999. That Program awards cooperative agreements of between $50,000 and $300,000 per year to states to conduct outreach efforts to beneficiaries with disabilities and work with agencies and organizations that serve them to provide benefits planning and assistance services. Unlike that Program, however, the education campaign described here would be conducted by the Federal government. It would target persons with disabilities, as well as advocacy groups, Centers for Independent Living, client assistance programs, state vocational rehabilitation offices, and other points of access to the disability community. Using public service announcements, assurances from the President or other high-ranking officials, handouts by Social Security benefit specialists and eligibility workers, inserts in SSI and SSDI checks and other mailings, it would be geared to educating beneficiaries and advocates about the program and assuring them that their benefits will not be taken away if they go to work. It would require relatively minimal Federal funding.

**State Demonstration Authority**

Fear is also one of the reasons states do not participate in the Medicaid buy-in: fear that more people will participate than the state projected and appropriated funds for, fear that enrollees will

come from populations that they had not anticipated, and in some states fear that the required personal assistance benefit will be more costly than anticipated or will push the state toward including it in its state plan. Permitting and encouraging states to test this program in a limited geographic area, to test alternative designs in alternative areas, and to limit the number of persons served may be an important bridge to broader state adoption. Such demonstration authority may already exist, but to clarify authority and to provide encouragement to states, a specific statutory provision requiring the demonstrations is necessary. The statute should provide federal funds for the demonstration and evaluation and the government should be explicitly prohibited from imposing budget neutrality requirements. The demonstration should be time–limited, however; its purpose would be to learn about the impact of different design features and not to avoid the stricter requirements that pertain when the buy-in is made part of a state plan. This option would require a relatively minor federal investment.

**Increased Federal Match**

In any optional Medicaid expansion, the biggest inhibition to state participation is likely to be cost. As we have seen, if the buy-in is targeted to more than just the current SSI population, there will be additional state costs. Increasing the federal share for some or all groups of enrolless may provide the incentive states need to participate or expand their programs' reach. Given the relatively small number of potential enrollees overall, an increase in the federal share may not result in large additional spending, and it is consistent with the policy used successfully in the State Children's Health Insurance Program. In 1997, to provide additional incentives for state participation in SCHIP, Congress enhanced the federal share or match rate – the Federal Medical Assistance Percentage (FMAP) -- for this program, decreasing by 30% the difference between 100 and the previous FMAP. The increased federal match in SCHIP appears to have generated significant state interest and

participation: every state now has an SCHIP program of some kind in operation. While the cause of covering children was politically compelling in both Washington, D.C. and the states, insurance coverage that permits persons with severe disabilities and chronic conditions to become productive members of society may have a similar political draw.

## Eliminate Eligibility Inconsistencies in Vocational Rehabilitation

Because the Medicaid buy-in is a health insurance program, we have not discussed other supportive services that facilitate employment. But any work program for people with serious functional or cognitive limitations must address assistive and educational supportive services to be successful. With that in mind, one major inconsistency between eligibility for state vocational rehabilitation services and eligibility for other disability supports bears repeating and addressing: to receive governmental vocational rehabilitation services, participants are required to be definitively able to work. This inconsistency was pointedly described by a disability advocate: "People with disabilities coming out of a hospital and the newly injured go to the Social Security Administration and they are asked, 'Can you work?' And they have to say no to get benefits. The same individuals then return to the vocational rehabilitation agency and are asked, "Can you work?' They are told to say, 'yes, I can,' in order to receive benefits. What is the point of that?" Denial of vocational rehabilitation benefits can mean denial of a college education, hand controls or a lift on a van, or a specially tailored wheel chair. The "unable to work" eligibility requirement is unlikely to be dropped entirely from SSI or SSDI; but the absolute yes/no "Can you work?" can feasibly be dropped from the application process for vocational rehabilitation benefits. While vocational rehabilitation agencies must make decisions about allocating their resources, the basic premise of vocational rehabilitation should be that employability is a dependent variable, not an independent variable. It should be an aspiration, if not an assumption, that anyone who applies for those benefits can be

capable of working with the proper assistance; more flexible eligibility rules should govern access to vocational rehabilitation services.

**Expansion to Those With 'Potentially Disabling Conditions'**

One of the greatest disadvantages of the American health system is its failure to cover millions of people with serious chronic health conditions and disabilities. While Medicaid buy-in was not intended to address this problem, with the exception of Mississippi's program, it had the potential to alleviate it in its initial 1999 formulation—a version that included an optional eligibility expansion to those with 'Potentially Disabling Conditions'. While this involved an unambiguous health insurance expansion, it is not out of place in a work incentive program. Lack of health insurance is a clear risk factor for deteriorating health and later dependence on public programs for those with chronic conditions. One of the more compelling work programs one could provide for persons with severe disabilities and chronic conditions is to assure that those already in the workforce stay healthy enough to remain there. This means providing coverage to uninsured working persons with disabilities and chronic conditions who do not (yet) meet the current "unable to work" criteria now in place. The Ticket to Work legislation included authorization and funds for a demonstration to test coverage of the "potentially disabled", but it has been designed to have an extremely narrow reach. This Demonstration to Maintain Independence and Employment applies to workers with physical or mental impairments that, without medical intervention, have the potential to result in disability. However, each participating state is limited to covering no more than three potentially severe physical or mental impairments. To date, demonstration grants have been awarded by the Centers for Medicare and Medicaid Services (CMS) to only four states, and they each cover only one

medical condition – two cover HIV/AIDS, one covers multiple sclerosis, and one bi-polar schizophrenia.

The population of people who have severe and potentially disabling chronic conditions but cannot meet a work-based disability definition is difficult to define. Estimates of the number of uninsured, working age persons with two or more serious chronic illnesses range from 2.6 - 3.1 million, while an additional 4.8 - 6.1 million have one chronic condition and no insurance.[10] An estimate based on functional disability approximated that 2.2 million employed and uninsured people have a chronic disabling condition in the United States.[11] Clearly, a national program covering those who have severe and potentially disabling chronic conditions could help hundreds of thousands of individuals struggling to remain productive and struggling to pay for their health care.

A number of basic questions accompany any planning for such a health coverage expansion. First, what conditions would qualify as potentially disabling? While CMS provided a list of conditions for the demonstration, states are not limited to them as long as the state provides evidence that the condition is likely to lead to disability and will respond to early intervention. Should there even be a list of specific conditions? Should coverage be confined to persons with a certain number of chronic or disabling conditions or to a level of functional impairment? There is no agreement on what constitutes "potentially severe" or even how many people are in each group.

A second set of basic questions revolve around financing and administration. Should Medicaid expansion be the vehicle, and if so, as a state option? As we have seen, such an expansion

[10] Ha Tu and Marie Reed, "Options for Expanding health Insurance for People with Chronic Conditions", Center for Studying Health System Change, Issue Brief No. 50, 2/2002; Jane Horvath, unpublished manuscript based on 1998 Medical Expenditure Panel Survey, Partnership for Solutions: Better Lives for People with Chronic Conditions.
[11] Meyer and Zeller, "Profiles of Disability: Employment and Health Coverage"; cf. Anderson and Knickman, "Changing the Chronic Care System to Meet People's Needs".

would have limited take-up, particularly in the current budgetary climate. Or, should the criteria for eligibility for Medicare be broadened, delinking it from SSDI eligibility? This would add Federal costs for the increased Medicare population, and potentially state costs as well if Medicaid relies in whole or in part on a newly expanded disability definition. A full discussion of these questions would be, to say the least, a paper unto itself, but it is clear they engage very basic and sweeping questions about large-scale resources and basic obligations to members of our society with serious health problems.

## CONCLUSION

The last few decades have witnessed unparalleled medical and technological breakthroughs in extending the lives of persons with severe chronic conditions and disabilities and assisting them to participate in the workforce. However, this population is caught in a disability-support system that has not been updated to match those biotechnological advances and is only starting to change to match the aspirations of people with disabilities to participate fully in the economy and the broader society. Working-age persons with severe disabilities can only receive government cash assistance and health care coverage if they are declared “unable to work”. The Medicaid buy-in represents a small step towards a suite of policies in which disability pensions, a health care safety net, and functional, educational, and other supportive services encourage employment and integrated community living for people with severe disabilities and chronic conditions. It may also, more speculatively, be a step towards extending health insurance coverage to the hundreds of thousands of uninsured Americans who risk disability and death because they have no way to pay for care of serious chronic illnesses. In the 15 states that have adopted the buy-in, it has helped some 17,000 persons. But hundreds of thousands more still need help. Both as a step towards economic

integration and a step towards health insurance coverage of those with disabilities and other chronic conditions, the agenda opened up by the Medicaid buy-in could not be more compelling.