Review of Alaska-specific Work Disincentives for Individuals with Significant Disabilities

submitted to the:

Governor's Council on Disabilites and Special Education

by:

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Executive Summary
Review of Alaska-specific Disincentives to Work for Individuals with Significant Disabilities

The Problem

The number of individuals receiving disability benefits from the Social Security Administration (SSA) has increased dramatically since the late 1980s. This trend is occurring throughout the country. Nationally, the number of Social Security Disability Insurance (SSDI) beneficiaries increased from 2.8 million in 1988 to almost 4.2 million in 1995. During the same time period, the number of Supplemental Security Income (SSI) recipients increased from 2.6 million to 4 million (with approximately 700,000 individuals under age 65 receiving both SSDI and SSI).

In a 1994 report issued by the Social Security Administration, the following program growth trends were noted:

1. The number of beneficiaries with disabilities and program expenditures grew steadily over a ten year period and are expected to continue at an equal rate as baby boomers age.
2. There is a significant increase in younger people coming onto the disability rolls. Between 1989 and 1993, the number of SSDI beneficiaries under the age of 30 increased 43% -- a 57% increase is projected through 1998.
3. The earlier individuals become beneficiaries, the longer they are likely to stay on the rolls.
4. Less than one-half of 1 percent of beneficiaries with disabilities leave the SSDI rolls to go to work and less than 10 percent of SSI recipients are gainfully employed.

In Alaska, the problem is no different. The Adult Public Assistance (APA) caseload, the program that supplements federal SSI payments, has witnessed equally dramatic increases. Between 1990-97, the APA caseload increased 49%, while the SSI-only caseload increased between 7-8% annually during the same period. A significant issue related to the APA caseload is the lack of data on enrollee characteristics, an issue that will be discussed in the *Recommendations* section of this report.

We do know that as of March 1998, of the 6,464 disabled SSI recipients in Alaska, only 491 (2.8%) were working. More specifically, that 56 recipients were working under the 1619(a) work incentive provisions of the Social Security Act, and an additionally 94 were working under 1619(b). Alaska ranks 25th in the country for number of SSI disabled recipients between the ages of 18-64 who are 1619 participants -- a total of 2.69 percent.

Of Alaska's fifty-six 1619(a) participants, the average March, 1998 earnings were $794/month (slightly higher than the national average of $775). Alternatively, the average monthly earnings for the ninety-four 1619(b) participants were $941 (the national average being $918). Only three Alaska SSI recipients were on record as having benefited from a PASS plan, six others had used IRWEs, and two used Blind Work Expenses (BWEs).

To put this problem in a policy context, the federal Department of Education recently described it in terms of the specific work disincentives that exist in current laws and public program practices (Federal Register, June 3, 1998).

- There is a lack of adequate health insurance options for people with disabilities who want to return to work and therefore the fear of loss of public health benefits is a major disincentive to work.
- Existing SSA work incentives (e.g., Section 1619 of the SSA, PASS, etc.) are underutilized.
- There is a lack of adequate housing and transportation alternatives to support disabled individuals in their desire to return to work.
- There are insufficient education and training opportunities to support people in their return-to-work efforts.
- There are inadequate employment-based supports, including on site and off site accommodations and long term follow-along services.
- There is inadequate support for employers who want to hire individuals with disabilities, but who need technical assistance with accommodation issues and follow-along consultation.
- There is a general lack of information about what programs are currently available to support persons with disabilities in their employment goals.
- There is a lack of coordination between public programs that serve the disabled population and conflicting eligibility requirements that have served to create fragmentation and confusion among program consumers.

It needs to be emphasized that the premise of this report is that the problem of un- and underemployment is not lodged *within* individuals with disabilities. This is to say, un- and underemployment do not derive from an inherent weakness, "illness," or some other set of personal attribute(s) within a disabled individual, but rather they are problems that reside within the institutions of society, and therefore require a policy solution.

Solutions Proposed

A variety of governmental agencies and private organizations have been studying the problem of work disincentives for people with disabilities for a number of years. The proposed solutions converge into a number of key areas across these various studies that can serve to inform and illuminate the solutions available to state policy makers.

The following discussion summarizes these major research findings, policy analyses, and the solutions proposed.

A 1995 study of employment barriers faced by people with significant disabilities, commissioned by the Office of Disability, Aging, and Long-Term Care Policy within the Office of the Assistant Secretary for Planning and Evaluation, DHHS, describes the need for a new paradigm. With the passage of the ADA in 1990 which supports the full participation of people with disabilities in all aspects of society and its institutions, disability advocates have suggested the need for a major shift in how society thinks about disability.

> “The old paradigm viewed disability as a social problem and disabilities themselves as conditions to be cured. The new paradigm views people with disabilities as people with problems that can be solved if society provides sufficient support and access.” (Lewin Group, 1995: p. i)

In short, the solution proposed is that a major system re-design is called for, and that the new system be built on a foundation of physical, social and insurance supports that foster economic independence and self-sufficiency, and that access to these supports be maximized through program design.

A 1997 National Council on Disabilities (NCD) report, *Removing Barriers to Work: Action Proposals for the 105th Congress and Beyond*, summarized the solutions needed to correct existing work disincentives in the following way:

Proposals to Make Work Pay

- provide medical coverage for workers with disabilities
- replace the DI “income cliff” with gradual benefit reductions
- ensure that people do not lose their SSDI or SSI eligibility link because they work
- provide allowances (income disregards) for disability-related work expenses
- remove marriage penalties
- waive no fault overpayments
- raise resource limits

Proposals to Increase Consumer Choice and Access to Vocational Rehabilitation Services

- institute a “ticket” or voucher program
- provide access to investment funding (e.g., PASS)
- eliminate the scholarship penalty

Proposals to Increase Employer Incentives

- reimburse employers for disability expenses (e.g., tax credits)
- institute a tax credit for disability/diversity training

A 1997 Government Accounting Office Study, *Social Security: Disability Programs Lag in Promoting Return to Work*, proposes three strategies in the design of return-to-work programs:

1) Intervene as early as possible after an actual or potential disabling event.

2) Identify and provide necessary return-to-work assistance effectively by assessing individual potential and need for work-related supports; using case management techniques, where appropriate; offer transitional work opportunities; and ensure that medical care providers understand the work potential of disabled workers.

3) Structure cash and health benefits to encourage return-to-work by maintaining/assuring health benefits for disabled workers.

Each of these studies, and others as well, have made a substantial contribution to the legislative proposals introduced in the current Congressional session. Predictions of their passage range from mildly optimistic to pessimistic, but clearly the importance of the issue has been highlighted and it has received the national policy attention it deserves.

In many statehouses and executive departments around the country, including Alaska, state policy makers are seeking to craft policy reforms that are within their purview, and seeking waivers, where necessary, to push a work incentives policy agenda forward for the many individuals with significant disabilities who want to return to work.

A brief summary of two major federal work incentive bills under consideration follows.

HR 3433 *Ticket to Work and Self-Sufficiency Act of 1998* - this bill focuses on: 1) consumer choice including the provision to offer “tickets” which would allow disabled consumers to choose VR, employment, and other support services from an employment network; and 2) specific work incentives including the development of a cadre of work incentive specialists; demonstration projects to test the gradual reduction of DI benefits based on earnings similar to the SSI program; an extension of Medicare coverage for DI beneficiaries; and a disabled worker tax credit.

S. 1858 the *Work Incentive Improvement Act of 1998* - this bill would set in place a series of work incentive programs based on type and duration of disability. For example, SWOP (state work options program) would be targeted at non-working SSI and DI recipients between the ages of 16-65 who intend to return to work and need personal assistance services or prescription drug coverage. SWOP would provide authorization for an optional state Medicaid buy-in work incentive program. Once work ready, the OPTIONS program (Opportunity to Fully Integrate Through Occupations Program), also created by the bill, would become available. This bill attempts to solve the unique disincentives affecting different eligibility categories, for example, DI eligibles in their 5 month waiting period for benefits, long term disabled, and working persons with disabilities.

Need for More Information

In addition to policy reform solutions proposed, most studies have recommended further research because of the dearth of population-based empirical and qualitative evidence of the nature, magnitude, and structure of the problem of un- and underemployment among individuals with significant disabilities. A range of research topics have been proposed, many of which are relevant to the *Alaska Work Incentives Initiative.* The relevance of this issue is supported by the fact that we have scant state-level data available about the population and subpopulations of interest.

The lack of data greatly limits our ability to make accurate cost or policy projections of the impact of changing existing incentives and/or disincentives in the system from those that foster un- and underemployment among individuals with disabilities to those that promote gainful employment.

The 1995 study, *Barriers and Incentives to Improving Labor Force Participation for People with Significant Disabilities* commissioned by the Office of Disability, Aging, and Long-Term Care Policy within DHHS suggests that:

- disability research suffers from a lack of consistent definitions and detailed information about people's conditions and life circumstances;

- self-reported work limitation is an imprecise and incomplete measure of disability;

- the amount of knowledge that people with disabilities have about supports and work incentives should be taken into account when trying to understand the factors associated with labor force participation;

- research that simultaneously addresses many issues is more valuable than separate research projects on individual issues. "There is need to integrate, or at least coordinate, the many aspects of disability policy, but this is difficult to do when analysis is confined to addressing each aspect in isolation. *Research that jointly examines a wide variety of approaches to promoting employment (financial, incentives, rehabilitation, training, employer accommodations, assistive technologies, personal assistance services, etc.) and their relative cost-effectiveness should be encouraged."* (Lewin Group, 1995: p. 1-23)

In his 1997 paper, *Factors Affecting the Work Efforts of Disabled Worker Beneficiaries,* Hennessey argues the need for a better understanding of existing programs and their impact on work, he states, “[i]n order to assess the impact of changes in the VR program and other work incentive (WI) provisions in the DI program, we need to understand the effect of the present VR program and WI provisions.”

Finally, in the last section of the *Adult Public Assistance Program Status Report*, issued by the Division of Public Assistance in Alaska in 1997, the authors suggest that information presented in the report identified a number of areas where additional research was needed. Specifically, that research is needed:

- to better understand the demography of the APA population including where they come from, the age at which they enter the APA program, and what other services they receive;
- to complete a thorough review and evaluation of the APA program “to determine if changes should be made to the service delivery model” including identifying the most effective training and optimal partnerships for improving client services;
- to identify and eliminate existing barriers that prevent APA clients from working; and,
- to develop a more precise method for forecasting future program costs in both the APA and Medicaid programs.

Implications of Existing Knowledge for Alaska

A rapidly growing body of evidence is documenting the disincentives to work that are embodied in federal and state policies and programs that serve disabled individuals. Not only is consensus developing about the origins of the problem, but also the most promising solutions. The primary sources of data documenting the problem are either anecdotal or they derive from small studies of clients who have self-selected into the programs being studied.

The substantial missing piece in our current knowledge base is an estimate of the true nature and magnitude of the causes and consequences of the problem. And likewise, an estimate of the potential impact of changing existing public policy. In this context, impact has both a societal and an individual dimension. From a societal perspective, impact is very difficult to estimate without a well-defined denominator, that is, an ability to define and measure the population of interest. What we currently don’t know with any certainty, is the proportion of the severely disabled population that is not working because of the barriers to work they face in their environment.

At this time, we can only speculate about the population, and the fiscal and personal gains that might accrue from breaking down agreed upon policy barriers. Fortunately, a number of research and demonstrations projects soon to be funded by the Social Security Administration, will collect the needed data to fill this information void. In the interim, a growing number of states are moving forward will a range of incremental steps to tackle suspected policy barriers.

The body of this report discusses in detail a range of federal and state policies and programs serving individuals with significant disabilities. Further, the report specifies current Alaska caseloads by program, where these numbers are known.

What do we know about the prevalence of disability in Alaska? about access to needed supports? about current knowledge and use of work incentives?

We know ...

- that at any given time during this year some number close to, or in excess of, 11,000 Alaska residents will be receiving disability benefits (SSDI, SSI, APA, or some combination thereof);
- that the largest disability category among DI beneficiaries in Alaska, and most likely SSI recipients, is mental disorders;
- that the true number of Alaskans with mental, physical, and developmental disabilities is much larger than the numbers represented on the SSDI and SSI/APA rolls;
- that a very small percent (2-3%) of SSI recipients in Alaska are working;
- that there are large waiting lists for subsidized housing in Alaska, in Anchorage alone there is a 4-5 year wait for Section 8 housing;
- that there are long waiting lists for DDMH-funded vocational services for individuals with developmental and severe physical disabilities in Alaska, and that this source of funding is often inadequate to meet needs for those who do make it to the top of the list;
- that there is very little work incentive benefits counseling taking place in Alaska as evidenced by the extremely small numbers of SSI recipients taking advantage of 1619, PASS, and IRWE;
- that there are few prevocational services for individuals with serious mental illness in many, if not most, areas of the state;
- that of the approximate 300 individuals in Juneau with serious mental illness in 1997, only 36 applied for VR services in 1996;
- that, in all probability, the personal assistance program in Alaska has not been accessible to a large number of the population of individuals with severe physical disabilities because of strict eligibility criteria requiring a *medical* need and a physician's approval.

Professionals and advocates know many more limitations to the existing service system in Alaska as they pertain to persons with severe disabilities who could or want to be gainfully employed. It is easy and safe to hide behind the mantra of *unlimited need and finite resources*. This report was intended to explore this, among other issues. The authors have intentionally steered away from any kind of economic analysis at this time, primarily because the data do not currently exist to complete the task. Lack of good forecasting data is NOT an Alaska specific issue, the problem of inadequate client information systems exists in most states.

The recommendations that follow are intended to build in a forward direction from where Alaska is now to where Alaska wants to be ten years from now in terms of developing a comprehensive system of work incentives for Alaskans with severe disability. We recommend an incremental, realistic approach to system re-design -- one that is based on what is known about the problem at hand.

In the temporarily-abled world we talk about the need for infants to “crawl before walking.” This admonition is predicated on developmental theories which assert that a pre-determined sequence of developmental benchmarks is needed for mastering competencies across a whole range of cognitive and functional areas throughout life.

We believe this notion of developmental benchmarks provides a valuable framework for policymakers, advocates and consumers to engage in activities that will lead to appropriate, systemic, and lasting public policy change.

Recommendations for Immediate Next Steps and Future Steps

The recommendations that follow fall into two categories: 1) short term activities that will inform long term solutions (one year); and 2) longer term strategies targeted at policy reform and system re-design. The recommendations are not ordered in any preference or priority ranking.

SHORT-TERM ACTIVITIES

Information Gathering

1. During the 1998-99 state fiscal year, the Department of Health and Social Services should undertake a data integration project of all programs under its auspices that serve individuals with significant disabilities. Similar to the data integration project for children currently underway, this project would establish an integrated data file for client tracking, cost and utilization projections, and policy analysis purposes. [Fiscal Impact: low-moderate impact on agency budget depending on other departmental priorities]

Related activities should include:
(a) developing an agreed upon definition of *significant work disability* that includes individuals with physical, mental, and developmental disabilities;

(b) developing and implementing a minimum data set requirement for all clients served by all divisions within the department that serve the target population. These data would be required to be submitted on a quarterly basis. Included in the minimum data set should be client demographics (age, gender, education, marital status, living arrangements) and type (diagnostic category) and onset of disability (e.g., birth, sudden, or gradual); and finally,

(c) negotiating an interagency agreement with Department of Education and Social Security Administration to include VR clients and SSI and SSDI recipients in the merged data file for a one year period.

2. As the state Medicaid agency implements the Disabled Workers Buy-in program, it should design and implement an evaluation of the program including an assessment of outreach efforts, enrollment-disenrollment patterns, and enrollee characteristics, (including prior insurance history, disability category, standard demographic information, etc.) [Fiscal Impact: low-moderate].

3. The Governor, in cooperation with the Governor's Council on Disabilities and Special Education, should establish a high level "blue ribbon" task force to development a 5-year plan for an Alaska Work Incentive Inter-agency Integration Project.

The task force should include a decisionmaker from all divisions/programs in DHSS that serve individuals with significant disabilities (particularly those referenced in the body of this report) and a decisionmaker from the Department of Education (including VR, special education, and the Statewide Independent living Council), the Insurance Division, the Senior Services Division, and the Division of Economic Security (including the one-stop program).

Recommendations should include: options to create a *seamless system* of supports for individuals with severe disabilities who want to engage in gainful employment[1]; options to increase the availability of work incentives benefits counselors, including the advisability of seeking federal waivers from HCFA and SSA to increase return-to-work options. This task force should report their recommendations to the Governor by June 30, 1999. [Fiscal impact: low]

In our interviews with key stakeholders in Alaska we learned of many innovative programs for individuals with significant disabilities. At the same time, we heard of agencies and programs pursuing their program objectives in parallel paths, and most often not converging into a seamless system from a consumer perspective. In many cases, coordination takes place on an ad hoc or situation specific basis. Conflicting eligibility requirements for programs, and/or categorically-based funding streams with separate administrative structures, exacerbate the tendency to pursue narrow goals. The only way to assure that individuals are provided with the optimum supports early

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[1] In this context, the task force should also recommend a comprehensive definition of "gainful employment" that takes into consideration the unique characteristics and work barriers faced by individuals with physical, mental, and developmental disabilities.

after the onset of disability (for all individuals whose disability occurs suddenly or gradually over time), is to integrate the service system into a single entry model, where appropriate supports are available at the most opportune time of need. The potential efficiencies to be gained from service integration should support service expansion without the need to infuse large sums of new money into the system.

Expanding Access to Existing SSA Work Incentives

1. The Governor's Council on Disabilities and Special Education should coordinate and seek funding for a program to train work incentive benefits counselors to increase the number of disabled Alaskans who have access to existing SSA work incentive opportunities.

Further, we recommend that the target population for receiving benefits counseling be new beneficiaries of the state's APA program. [Fiscal Impact: moderate - depending on how widely diffused throughout the population centers of the state]

2. On pages 42-44 of the report we recommend that the Division of Public Assistance pursue clarification of current federal provisions regarding eligibility for Section 1619 for state-only APA recipients.

Health Care Coverage

1. The State of Alaska has taken the first step in expanding health care coverage to disabled workers, i.e., the Medicaid Buy-in. States have been given a great deal of latitude in designing these programs, including income disregards and asset limitations. We recommend that the Medicaid agency apply these provisions most liberally (for a model, we recommend looking at the proposal being developed by the State of Oregon). [Fiscal Impact: The true population of eligible individuals for this program is unknown at this time, therefore estimating a cost impact would be difficult. Oregon is "opening the gates" so to speak, with the intention of closing them a bit should the demand exceed expectations.]

LONG TERM STRATEGIES

Health and Long Term Care Assurances

The long term solution to health and long term care coverage should involve both the public and private sectors. Private industry should assume responsibility for providing health insurance to disabled workers in the same way it does for the temporarily-abled. A long term solution requires a public-private partnership where the state agrees to fund the increment above what would normally be provided to an employee (the difference between an experience-rated premium for a firm and the cost of insuring an individual with extraordinary needs). In this model, the state saves consider dollars because the individual is working, cash transfer payments are reduced or eliminated, and the costs of health care coverage are shared.

In terms of long term care coverage, the state should track the impact of the current PAS expansion to assure that all physically disabled individuals who need PAS to return-to-work have access to the program.

In both health and long term care coverage, individuals will need to maintain their link to SSI/APA in order to access Medicaid benefits. Until federal legislation is enacted that further uncouples Medicaid coverage from public assistance, the state may need to seek Medicaid waivers to assure this link.

System Re-Design

However configured, the system of long term supports needs to be made more seamless from a consumer perspective. When in doubt about program efficiency, states often will reorganize their bureaucracy. The recommendation here does not require re-organization at the department or agency level. It does require re-thinking how services are delivered at the client level. Co-locating support programs, for example, DDMH case workers and VR counselors is one example of approaches other states are taking. The model should take into consideration the unique cultural, geographic, and political characteristics of Alaska, and should be largely driven by the expressed preferences of its customers -- individuals with severe disabilities.

The contractors will be working with the Governor's Council over the next year towards this end.

Enlisting Private Sector Employers

A major barrier to employment for individuals with significant disabilities is the lack of information and understanding by private sector employers about accommodations and the practical aspects of employing someone with a disability. A long term strategy will involve seeking creative ways to enjoin employers in the Alaska Employment Initiative. The federal Department of Labor has established a Disability program that is available to states for technical assistance in this area.

I. The Problem

The number of individuals receiving disability benefits from the Social Security Administration (SSA) has increased dramatically since the late 1980s. This trend is occurring throughout the country. Nationally, the number of Social Security Disability Insurance (SSDI) beneficiaries increased from 2.8 million in 1988 to almost 4.2 million in 1995. During the same time period, the number of Supplemental Security Income (SSI) recipients increased from 2.6 million to 4 million (with approximately 700,000 individuals under age 65 were receiving both SSDI and SSI).[i]

In a 1994 report issued by the Social Security Administration[ii], the following program growth trends were noted:

1. The number of beneficiaries with disabilities and program expenditures grew steadily over a ten year period and are expected to continue at an equal rate as baby boomers age (see Charts 1 & 2).
2. There is a significant increase in younger people coming onto the disability rolls. Between 1989 and 1993, the number of SSDI beneficiaries under the age of 30 increased 43%, and a 57% increase was projected through 1998 (see Chart 3).
3. The earlier individuals become beneficiaries, the longer they are likely to stay on the rolls (see Chart 4).
4. Less than one-half of 1 percent of beneficiaries with disabilities leave the SSDI rolls to go to work (see Chart 5).

In Alaska, equally dramatic increases in the Adult Public Assistance (APA) caseload (the state supplement to SSI), have been noted. Between 1990 - 1997, the APA caseload increased 49%, while the SSI-only (under age 65, excluding blind recipients) caseload increased by 7-8% annually.[iii] In large part, the difference in growth rates in Alaska between these two programs can be attributed to the higher income eligibility limits of the APA program, as other eligibility criteria for the two programs are the same.

According to a 1986 national survey, two-thirds of all working age people with disabilities who were not working at the time of the survey stated that they wanted to be employed.[iv] A variety of explanations for low employment rates have been put forth in the literature. For the most part, explanations found in the economic literature focus on the role of individual choice as individuals with disabilities maximize their economic position by choosing DI benefits, including the value of health insurance benefits through Medicare and Medicaid, over earned income.

Other research suggests that environmental characteristics such as the pace of work, workplace accommodations, co-worker and supervisor attitudes, and ability to take medical leave for disability-related reasons, are all important factors in the decision to work.[v] More recently, researchers in Wisconsin have asked individuals with significant physical disabilities the reasons they are not currently working, this consumer perspective is particularly illuminating. The majority of survey respondents between the ages of 16-64 years cited the disability itself (89%), fear of losing Medicare or Medicaid (54%), uncertainty about benefit loss (54%), and wouldn't be able to make up for lost benefits (56%) as the primary reasons for not working. The findings from this 1993 survey were validated in a 1997 survey of similar individuals participating in the Dane County Employment Initiative Project.[vi]

A 1997 US Government Accounting Office report[vii], summarizes the work disincentives in current SSA disability programs.

Table 1: Summary of Program Design and Implementation Weaknesses

Program weakness	**Description of program weakness**
Work capacity of DI and SSI beneficiaries may be understated.	Medical conditions alone are generally a poor predictor of work incapacity. While impairment has some influence over capacity to work, other factors -- vocational, psychological, economic, environmental, motivational -- are often considered to be more important determinants of work capacity.
Disability determination process may encourage work incapacity.	"All-or-nothing" decision gives incentive to promote inabilities and minimize abilities. Lengthy application process to prove one's disability can erode motivation and ability to return to work.
Benefit structure can provide disincentive to low-wage work.	The prospect of losing cash and health benefits themselves can reduce motivation to work and receptivity to VR and work incentives, especially when low-wage jobs are the likely outcome. People with disabilities may be more likely to have less time available for work, further influencing a decision to opt for benefits over work.

Work incentives are ineffective in motivating people to work.	Work incentives are complex, difficult to understand, and poorly implemented. Few beneficiaries are aware that work incentives exist. Work incentives do not overcome the prospect of a drop in income for those who accept low-wage employment.
VR plays limited role in disability programs.	Access to VR services through DDS referrals is limited: restrictive state VR policies limit categories of people referred by DDSs; the referral process is not monitored (reflecting its low priority and removing incentive to spend time on referrals); and success-based VR reimbursement system is ineffective in motivating VR agencies to accept beneficiaries as clients. Applicants and beneficiaries are generally uninformed about VR and are not encouraged to seek VR, affording little opportunity to opt for rehabilitation and employment. Studies have questioned the effectiveness of state VR agency services.

II. The Population Defined

According to the Social Security Administration, an individual is disabled if s/he has been medically certified as having a total and permanent disability and is unable to participate in substantial gainful activity (SGA) -- earnings in excess of $500/month. The full definition of disability is contained in Section 223(d) of the Social Security Act. For the purposes of the *Alaska Work Incentives Initiative*, three subpopulations of individuals with severe disabilities have been targeted: working age individuals with developmental, physical, and psychiatric disabilities who are eligible for Disability Insurance (DI), Supplemental Security Income (SSI) and/or Alaska Public Assistance (APA). The 1990 U.S. Census estimates that there were 26,667 Alaska residents between the ages of 16-64 with any type of work disability (7.8% of the population). Of these, 7,928 had a disability so significant they were unable to work (2.3% of the population).

LaPlante estimated the rate of work disability in the general population on a state-by-state basis. He developed a synthetic estimate using the Current Population Survey of the U.S. Census Bureau, the National Health Interview Survey, and the 1990 U.S. Census. He also compared the 1980 and 1990 Census data on rates of work disability (number of people with a work disability per 1000 population). It is of interest to note that Alaska was among the states with the lowest rates of work disability in 1980. Alaska actually had the lowest rate -- 54 per 1000 when the national average was 85.2 per 1000 people aged 16-64. By the time of the 1990 Census, Alaska had increased the most among all states in terms of increases in the rate of work disabilities, an increase of 22.8% -- from 54 per 1000 to 66.3 per 1000 population.[viii]

Developmental Disability -The Governor's Council on Disabilities and Special Education has estimated that approximately 10,940 Alaska residents have a developmental disability, a smaller proportion of whom are working age (approximately 7,000).[ix] According to Alaska statutes (AS 47.80.900(7), "a person with a developmental disability is a person who is experiencing a severe, chronic disability that (a) is attributable to a mental or physical impairment or combination of mental and physical impairments; (b) is manifested before the person attains age 22; (c) is likely to continue indefinitely; (d) results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency; and, (e) reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services that are lifelong or extended duration and are individually planned and coordinated."

Psychiatric Disability - The state estimates that approximately 25,200 residents of Alaska have a severe mental illness, and of these, approximately 6000 experience chronic mental illness. After much turmoil at the federal level, including retrenchment and law suits resulting in the restoration of benefits to persons with mental disabilities in 1984, the SSA defines mental impairments as those which are seriously enough to impact an individual's ability to perform SGA in a competitive work environment. Further, that whenever possible, psychiatrists and psychologists will be used to make DI and SSI medical determinations for individuals with mental impairments to avoid inappropriate determinations of eligibility.

For the purposes of the Alaska Work Incentive Initiative, severe and persistent mental illness includes the following diagnostic categories: schizophrenia, delusional (paranoid) disorder, mood disorders, anxiety disorders, somatoform disorders, organic mental disorders, personality disorders, dissociative disorders, and other psychotic or severe and persistent mental conditions manifested by behavioral changes and symptoms of comparable severity to those previously listed.

Physical Disabilities - The state estimates that there are approximately 15,000 individuals with a severe physical disability in Alaska. According to U.S. Census data, Alaska had 8,572 individuals with a mobility or self-care limitation in 1990.

In sum, these disability statistics are estimates of the prevalence of disability in the whole population and are therefore higher than the numbers of individuals on the disability rolls which are discussed in the following section.

III. Federal/State Disability-related Programs

The federal government has established a range of social insurance, cash transfer, and health and social service programs that benefit individuals with severe disabilities. These programs have evolved since 1935 with the passage of the Social Security Act, principally through amendments to the Act.

In some instances, for example SSDI, the program is fully funded and administered at the federal level. In others, program funding and administration is shared with the states, e.g., SSI. Additionally, private sector, largely employer-based disability programs exist for the benefit of workers.

1. Social Security Disability Insurance (SSDI) - This social insurance program is a part of Old Age Security Disability Insurance (OASDI) program largely financed through the FICA tax collected from most active workers and their employers (see Attachment 1 - *Estimated Number of Persons with Taxable Earnings in Alaska*). SSDI provides monthly benefits to disabled insured workers (and their dependents and survivors) who are deemed to be medically disabled and unable to work at or above Substantial Gainful Activity (SGA) which is fixed at $500 month. Monthly benefit levels are based on a worker's average lifetime earnings. Once totally disabled, workers must wait five months before their DI benefits begin. If a DI beneficiary returns to work, and then is forced to leave the job because of the disability within five years of initial disability determination, there is not a new waiting period to resume benefits. In 1996, there were 5,740 SSDI disabled beneficiaries in Alaska who received an average monthly payment of $693 [x] (see Attachment 2 - *Number of Alaska OASDI beneficiaries and amount of benefits*).

There are notable differences in DI diagnostic categories between Alaska residents and national averages. For mental disorders, nervous system and sense organ disease, and injuries -- Alaska residents have a notably higher proportion of cases than the national average, whereas the proportion is lower for infectious and parasitic (includes HIV/AIDS), circulatory and musculoskeletal system disease (see Table 2).

Table 2
Percentage Distribution of SSDI Recipients by Diagnostic Group, Alaska versus US, 1996

	Infectious and parasitic	Neoplasms	Endocrine nutrition-al and metabolic	Mental disorders (other than retardation)	Mental retardation	Disease of nervous system and sense organs	Disease of circulatory system	Disease of respiratory system
Alaska	1.4	3.3	4.1	32.8	5.7	11.2	7.6	3.1
US	2.1	3.0	4.7	26.9	5.4	9.6	12.3	3.6

The SSDI program has a number of work incentives that have been added over the years to encourage beneficiaries to work. (a) *IRWE* (impairment-related work expenses), an income disregard individually approved by local SSA field office staff; (b) a *TWP* (trial work period), which gives DI recipients an opportunity to test their ability to go back to work during which time their earnings will not affect their benefits or count as SGA. Individuals are allowed up to nine months of trial work in any five year period. Once a worker's income exceeds SGA following the *TWP*, benefits continue for three more months and then are totally discontinued; (c) *EWE* (extended period of eligibility) which allows a person to return to DI benefits after the trial work period if at any time during the next 36 months they fail to engage in SGA; and finally, (d) *Medicare continuation* which maintains Medicare coverage for former DI beneficiaries for at least 39 months after a successful trial work period. After this period, the former DI beneficiary can continue to purchase Medicare coverage at the full premium cost.

In spite of these various work incentives, as noted earlier, less than one percent of DI beneficiaries return to gainful employment. This group of disabled workers faces the most formidable obstacles to employment because the consequences of work under the current system are most intractable.

2. Supplemental Security Income (SSI) - this means-tested (asset and income limitations) cash transfer program was enacted in 1974 through amendments to

SSA for aged, blind and disabled individuals with incomes below the federal poverty level. Unlike the DI program, there is no waiting period before an eligible individual starts receiving cash benefits (see Attachment 3 for the *legislative history of SSI benefit rates*).

The federal benefit level is adjusted each January to account for increases in the CPI and benefits decrease as countable income increases. To calculate the SSI payment level, the FBR (federal benefit rate) and any state supplement (for example, in Alaska the APA program) are added together and then any countable income is subtracted. In 1996, there were 6,119 disabled and blind individuals receiving federally administered SSI payments in Alaska (4,646 of whom were between the ages of 18-64). This number represents federal SSI recipients only and does not include APA beneficiaries.[xi]

Federal SSI payments in Alaska during 1996 totaled $2.5 million with an average payment to SSI disabled recipients of $365/month. In addition, 4,726 individuals received $1.08 million in state-only APA payments.

A draft report issued by the Alaska Division of Public Assistance (DPA) in 1997 estimated the adult (ages 19-64) SSI caseload for December of 1996 at 3,737 individuals, of whom: 34% (1,692) were physically disabled; 39% (1,946) mentally disabled; 2% (99) blind; and 25% (1,227) were aged. The APA caseload in 1997 was 11,487, of whom approximately 60% were also receiving SSI payments. The APA caseload has grown rapidly during the 1990s, with the number of disabled recipients doubling between 1990 and 1997, whereas the number of aged beneficiaries grew by 24 percent. A snapshot of the combined SSI/APA caseload in 1995 reveals: 6,626 recipients receiving both SSI and APA; 366 SSI only; and 4,774 APA only for a total caseload of 11, 766. Another way to look at the disability caseload is by labor market region. Table 3 illustrates the number and percentage of SSI/APA clients by labor market region and compares this population to SSDI recipients.

Tables 3
Residency of APA/SSI and SSDI Recipients by Alaska Labor Market Region, 1996

Labor Market Region	# of SSI/APA recipients (n=11,400)	% of total SSI/APA recipients	# of SSDI beneficiaries (n=5,622)	% of total SSDI beneficiaries
Anchorage/Matanuska-Susitna region	5,315	47%	3,110	55%
Gulf Coast region (Kenai, Kodiak, Valdez, Cordova)	1,088	9%	665	12%
Interior region (Fairbanks, Yukon-Koyukuk)	1,623	14%	805	14%
Northern region (Nome, Barrow, Kotzebue)	655	6%	200	4%
SE region (Juneau, Ketchikan, Sitka, ...)	1,214	11%	600	11%
SW region (Bethel, Dillingham, Aleutians, ...)	1,318	11%	145	3%

Source: DPA Report. 1997 and SSA Statistics, December, 1996

As with the SSDI program, the SSI program has a number of work incentive features; in actuality, the SSI work incentives are more generous and comprehensive than those associated with SSDI, and subsequently yield higher rates of return to work.

(a) *Impairment-Related Work Expenses (IRWE)* are expenses that can reduce earnings below the SGA level. Allowable expenses include those that enable a person to work, the costs of an item or service necessary to work, allowable costs not paid for from another source (e.g., Medicaid), expenses that are "reasonable", and expenses that were incurred in a month when the individual was working.

(b) *EIE* (earned income exclusion) allows a significant amount of earned income to be excluded when figuring the SSI payment level, for example, the first $65 of earnings in a month plus one-half of the remainder.

(c) Student EIE allows a person under the age of 22 who is regularly attending school to exclude up to $400 of earned income per month, with a maximum annual exclusion of $1,620.

(d) *PASS* (plan for achieving self sufficiency) allows an SSI recipient to set aside income and/or resources for a specified period of time (up to 4 years) for a specific work goal. SSA must evaluate and approve all PASS plans but the plans can be developed by a range of professionals as well as the individual SSI recipient.

(e) *Property Essential to Self Support* allows an individual to exclude certain resources that are essential to self-support in calculating personal asset limitations (up to $6,000 in value).

(f) *1619 (a)* allows SSI recipients to receive cash payments even when they earn income that exceeds SGA. An individual must be eligible for an SSI payment for at least one month before s/he begins working at SGA and must meet all other eligibility rules; and *1619(b)* which allows working SSI recipients under age 65 to maintain their Medicaid coverage (the eligibility qualifications are the same as 1619(a)) and includes the requirement that an individual needs Medicaid coverage to work. Each eligible individual has a personal threshold, determined by SSA, which is based on the combined value of earnings, prior Medicaid utilization, and any publicly-funded attendant care.

In Alaska (as of March 1998), of the 6,464 disabled SSI recipients, 491 (2.8%) were working (this number includes 1619 participants). More specifically, 56 recipients were working under the 1619(a) provisions, and an additionally 94 were working under 1619(b). Alaska ranks 25th in the country for number of SSI disabled recipients between the ages of 18-64 who are 1619 participants -- a total of 2.69 percent. Of Alaska's fifty-six 1619(a) participants, the average March (1998) earnings were $794/month (slightly higher than the national average of $775); alternatively, the average monthly earnings for the ninety-four 1619(b) participants were $941 (the national average being $918). In March, 1998, only three of Alaska's SSI recipients were on record as having benefited from a PASS plan, six of them used IRWEs, and two used Blind Work Expenses (BWEs).[xii] A comprehensive, up-to-date discussion of SSI work incentives is appended in Attachment 4. This document provides a national overview, with Alaska-specific data on who is currently using SSI work incentives.

Finally, it should be noted that when a client enters the public benefits system through the APA door, a broad range of other state programs are made available to them. A 38-page form is filled out which is then used to determined eligibility for other programs including: general relief, subsidized housing, SSA disability determination, interim assistance, transportation, Medicaid, adult foster care, food stamps, vocational rehabilitation, and guardianship services.

The link to Medicaid is strong and direct. Of the 6,626 PA/SSI recipients in Alaska in 1995, all were eligible and users of Medicaid, "Medicaid payments comprise[d] over 60% of the total dollar amount of benefits received by this population."[xiii] The average Medicaid cost per recipient was $8,590. The APA/SSI population represented 20% of the total Medicaid budget in 1995 with major spending categories that included: 27% for long term care; 19% for in-patient hospitalizations; 13% for mental health services; 11% for pharmacy; and 11% for physician services.[xiv]

3. Food Stamp Program - According to the U.S. Department of Agriculture, Food and Consumer Service, "Annual Historical Review of FNS Program," 46,000 Alaska residents participated in the federal food stamp program in 1996 (almost double the number who participated in 1990) for a total cost of $54 million. Of this number, 2,119 (approximately 19%) were APA clients with an average monthly allotment of $74 (representing a dollar value of $156, 621). This amount is for food stamps only and excludes costs to the federal government for administering the program. Food stamps are used by a sizable number of disabled persons on SSI/APA to supplement the purchasing power of their cash assistance, in spite of the fact that they represent a relatively small percentage of the total user population. In the Wisconsin employment barriers survey, and subsequent feasibility study, consumers reported little fear of the impact of losing food stamps in terms of their reasons for not returning to work. Therefore, it is unknown, but unlikely, that fear of loss of food stamps is a significant work disincentive to low income disabled individuals.

4. Medicare (Title XVIll of the SSA) - Medicare is a federal entitlement to all U.S. citizens who contribute to the Social Security Trust Fund, through FICA taxes, for a specified number of quarters during their working career. The vast majority of Medicare beneficiaries are individuals over the age 65 years. Medicare benefits are provided through two separate programs -- Part A (hospital insurance) and Part B (supplemental medical insurance, generally covering out-patient services and some home health care). Both programs involve some cost-sharing (see Attachment 5 - *Medicare cost sharing and premium amounts, 1966-97*).

Because Medicare is part of the OASDI provisions of the Social Security Act, its eligibility is programatically linked to SSDI status. It is important to note that Medicare, unlike Medicaid, has very limited long term care provisions beyond a 100 day per year limit in a skilled nursing facility. Also, Medicare does not have a prescription drug benefit which is a major shortcoming of coverage for individuals with on-going prescription drug needs, e.g., those with chronic mental illness. Finally, it is important to note that the co-payments and deductibles associated with Medicare are formidable, particularly for persons with certain significant disabilities or chronic disease.

5. Medicaid *(Title XIX of the SSA)* **-** Medicaid is an entitlement program that is available to "dependent" low income citizens based on individual and/or family assets and income. The program was initially established to pay for the health care needs of individuals unable to work -- primarily dependent children in female-headed households, and elderly, blind, and disabled citizens. Historically, eligibility for Medicaid has been tied to eligibility for cash assistance programs such as the Aid to Families with Dependent Children

(AFDC) program and the Supplemental Security Income (SSI) program. Since 1989, the federal government has gradually expanded the eligible population in an attempt to cover those low income individuals most at risk of having no health insurance coverage -- primarily low income pregnant women and children otherwise not eligible for assistance because of excess assets or income.

Since passage of the federal legislation that created AFDC, Medicaid, and SSI (1935, 1965, and 1972 respectively), federal and state policy environments have changed substantially. No longer does single parenthood signal economic dependency, as evidenced by recent federal legislation eliminated welfare “as we know it.” In its place, the Temporary Assistance to Needy Families (TANF) program was implemented in 1997 which provides time limited assistance to single parents of dependent children.

Likewise, the presence of a severe disability does not necessarily imply that disabled individuals should remain economically dependent on the state, particularly the provisions that require individuals to be below the poverty level with very limited assets in order to qualify for health care coverage. Advances in assistive technology, breakthrough pharmaceuticals, and the Americans with Disabilities Act, have greatly expanded the set of options available to individuals with severe disabilities in terms of their ability to achieve employment and yet antiquated public policies prevent this gain from being realized.

Alaska Medical Assistance Program - [Authorizing statutes and administrative codes (AS 47.07.010-080; AS 47.25.120; and 7 AAC 43 & 47)]. As noted earlier, Medicaid is a grant-in-aid program that is jointly funded by the federal and state governments and administered, including setting the state's need standard and eligibility thresholds, at the state level. The federal government establishes minimum program standards among the 50 states and, in Alaska, pays approximately 50 percent of program costs for the general population (includes both benefits and administration), and 100 percent of the costs for Alaska Natives and American Indians.

For the State of Alaska to depart from the federal rules and regulations, it requires special authorization -- usually through a state plan amendment or a federally-approved waiver.

HCBC Waiver - Alaska currently has one waiver program for adults with physical disabilities that provides home and community-based attendant care and homemaker services to approximately 80 individuals a year in lieu of nursing home or other institutional placement. To be eligible, individuals may have incomes up to 300% of the nursing home income eligibility criteria. The average APD waiver client costs are $38-40,000 year[xv] This population is projected to grow, particularly in light of the recent legislative changes noted below.

Personal Care Assistance (PCA) Program - The state MA program has a personal care attendant (PCA) benefit as part of its state plan benefit package. Until the 1998 legislative session, eligibility for this benefit required a physician's referral, thus limiting access to individuals whose personal assistance needs were not of a strictly medical nature. Proposed rule changes issued 6/10/98 would amend 7 AAC 43.750 of the Alaska Administrative Code to clarify that "personal care services are provided to persons with *health-related needs"* [emphasis added] and that determination of services is to be provided based on an assessment of those needs made in accordance with other referenced sections in 7 AAC 43". Further, the amendments delete the requirement that services must be prescribed by a physician to be reimbursable. This rule change has been projected to double the general fund MA obligation from $98.6 million in 1998 to $198 million in subsequent years.

The PCA program in Alaska is primarily agency-based (e.g., home health agencies), with a much smaller independent contractor program. Under the independent contractor model, consumers are responsible for hiring and supervising their PCA. This model is more often the choice of younger, working age adults.

Most referrals to the PCA program come from hospital or nursing home discharge planners. A uniform PCA assessment tool is used to assess level of need and is often done by care coordinators from various community-based agencies who are certified as direct MA providers.

Medicaid Buy-in for Persons with Severe Disabilities - Legislation passed in the 1998 session of the Alaska Legislature, making Alaska the first state in the country to pass such legislation, requires the state Medicaid agency to amend the state plan to implement a Medicaid buy-in program for individuals with severe disabilities up to 250% of the federal poverty level. States have been given significant latitude in how they define income and assets in implementing this provision. The buy-in will be based on a sliding fee scale yet to be developed.

Research suggests that the primary work disincentive in Medicaid results from its categorical link to means-tested cash assistance programs -- both SSI and the former AFDC program. As long as Medicaid eligibility is programatically linked to public assistance, people are incentivized to protect their health care coverage by surpressing the earned income that would make them ineligible for Medicaid. Compounding this problem is the reality that most, if not all, SSI disabled individuals have been, or would be, underwritten out of private health care coverage because of their pre-existing medical conditions. The MA buy-in program will provide a significant remedy to this policy dilemma but it will not ameliorate it entirely, particularly for the DI population.

6. Rehabilitation Act of 1973 *(as amended)* - Federally administered by the Rehabilitation Services Administration (RSA), basic vocational rehabilitation services are state administered through federal grants from RSA. These federal funds are allocated on a formula basis and require a state match. The combined federal-state funding is intended to operate state vocational rehabilitation (VR) programs that will assist individuals with disabilities prepare for, and engage in gainful employment. Through several amendments to the federal act, VR services have become increasingly targeted at the most severely disabled. Of the more than one million individuals served nationally through VR programs in 1996, two-thirds had a severe disability.

RSA also makes money available to states and other public and private agencies to expand or improve upon basic rehabilitation services. For persons with severe disabilities, RSA has a *Special Projects and Demonstrations* program. This program provides grants up to 36 months to test new approaches for providing services. Recent priority areas for funding include: transition services for youth with disabilities; projects to increase client choice; projects to increase the use of rehabilitation technologies; projects targeted at individuals with persistent mental illness; and services for persons living with HIV/AIDS.

In Alaska, the Division of Vocational Rehabilitation is located in the state Department of Education. Alaska's VR program consists of: basic vocational rehabilitation services; the *Business Enterprise Program*; *Assistive Technologies of Alaska* Program; and the Americans with Disabilities Act (ADA) Compliance Office. Additionally, DVR houses the Disability Determination Office (DDS) for the federal Social Security Administration. Innovative initiatives sponsored by Alaska DVR include: the *Interagency Vocational Employment Network* (IVEN) in Fairbanks; the Dream-based Education Alliance, *Life Skills Academy*, which is currently being operated from the Alternative Career Education Program (ACE); *Employment First* in Anchorage targeted at individuals with persistent mental illness; and the *Alaska Transition Initiative,* a five-year federally grant funded program to develop a statewide transition system for students -- each model program is sponsored, in part, with VR funds. Additionally, DVR works closely with the Native Corporation-operated VR programs.

The mission of the Alaska DVR is "to enhance opportunities for self-reliance, independence, employment and productivity of persons with disabilities by providing, in partnership with persons with disabilities a variety of individualized services which assist in overcoming barriers to employment, independence and community integration; by advocating for development of services and programs to address the needs of persons with disabilities."

According to the 1996 annual report (covering the period July 1, 1995 to June 30, 1996):

- approximately 13,000 Alaskans received SSDI and SSI payments totaling $84 million;
- 5,343 disability determinations were processed by DDS;
- 4,349 Alaska residents received DVR services;
- 494 were successfully rehabilitated with the assistance of DVR (22% of whom were ethnic minorities); and,
- 95% of successfully rehabilitated clients entered competitive employment or self-employment.

7. Technology Assistance Act - the 1988 federal Technology Related Assistance Act established a policy framework for assistive technology (AT) but not a stable or centralized source of funding. The Act defines assistive technology as "any item, piece of equipment, or product system, whether obtained commercially off the shelf, modified or customized, that is used to increase, maintain, or improve functional capacities of individuals with disabilities." At this time, the most prevalent source of funding for assistive technology is private -- largely out-of-pocket expenditures made by individuals with disabilities or their families. The federal role in AT funding has been largely through amendments to the tax codes which encourage, and in some instances mandate, coverage by third parties (employers, insurers and workers compensation programs). The

National Council on Disability (1993) has summarized the various programs and legislative actions that provide funding for AT.

Public Programs

- Medicare
- Medicaid
- SSDI
- SSI
- Vocational Rehabilitation programs
- Veterans Administration
- Workers Compensation Programs
- Individuals with Disabilities Education Act (IDEA)

U.S. Tax Code Provisions

- Medical Care Expense deduction
- Business deduction
- Employee Business deduction
- ADA Credit for small business
- Credit for architectural and transportation barrier removal
- Targeted jobs tax credit
- Charitable contributions deductions

Federal Legislation

- Americans with Disabilities Act
- Technology Related Assistance Act
- Decoder Circuitry Act
- Telecommunications Accessibility Enhancement Act of 1988

In Alaska, the lead agency for assistive technology development and dissemination is the Division of Vocational Rehabilitation. Assistive Technologies of Alaska (ATA) was created through a federal National Institute on Disability and Rehabilitation Research (NIDRR) grant in 1990. The mission of ATA is “to ensure all Alaskans have the assistive technology and related services needed to live, work, and participate in their community.”

The four major stated activities of ATA are: 1) to help people with disabilities find the AT they need and to identify funding sources to pay for needed AT; 2) to provide training on issues related to AT; 3) to create awareness of AT among the user population and others; and 4) to advocate for systems change, including making AT more available and accessible. The advocacy function is provided in cooperation with the Disability Law Center.

8. Housing - The Alaska Housing Finance Corporation (AHFC) is the state's lead agency for housing policy and program development. AHFC manages the HUD Section 8 program as well as the Public Housing Program. Subsidized and public housing in Alaska are at virtually 100 percent occupancy rates, with waiting lists in some communities that extend out 4-5 years. Particularly for individuals with psychiatric disabilities, there is a critical need for low cost housing and emergency shelters. In Anchorage, the area wait list for Section 8 housing in January, 1998 included 3023 individuals.

The Section 8 rental subsidy program provides certificates and/or vouchers to eligible families to rent housing in the private market. Eligibility is based on two basic criteria: 1) applicants must qualify as a family, generally including 2 or more individuals although single person "families" are allowable if the individual is over age 65, handicapped, disabled, or displaced; and 2) gross family income must fall below one of two income limits -- *low* and *very low* (Alaska income limits for 1998 are appended in Attachment 6). The rental subsidies are based on regional fair market rents that are established on an annual basis by HUD and issued in the federal register (see Attachment 7 for 1998 Alaska FMRs).

In addition to the overall shortage of subsidized housing slots (vouchers), once qualified and holding a voucher, individuals are vulnerable to losing their subsidy as earned income increases. This is a major work disincentive that is recognized nationally among states involved in work incentive initiatives. There are several promising programs operated by HUD that offer hopeful alternatives to low income individuals in terms of assuring housing, including home ownership as work effort and earned income increases. The *Family Self-Sufficiency Program* is a HUD-sponsored program to promote the coordination of public housing and Section 8 rent subsidies with other public and private resources to help families achieve self-sufficiency and economic independence. The potential of this program for individuals with disabilities who venture into gainful employment is that it caps rent increases for individuals who experience increasing earned income. The difference in what would be paid versus what is paid in rent is put in an escrow savings account for the individual's use after participation in the subsidy program ends.

A similar program, *Economic Development and Supportive Services* grants, authorized under the Omnibus Consolidated Rescissions and Appropriations Act of 1996, provide HUD grants to public housing authorities (PHAs) to form partnerships with nonprofit agencies to: provide economic development opportunities and supportive services to disabled residents of public housing to live independently and achieve economic self-sufficiency.

Section 5(h) of the 1937 Housing Act provides for a flexible home ownership program wherein PHAs may sell public housing units to residents.

More recently, HUD funded a Moving to Work demonstration project involving 24 PHAs around the country. Although this initiative is targeted at TANF families, it serves as an interesting model that could be replicated among individuals with severe disabilities who want to return to work. The demonstration allows HUD to suspend many of its rules for project participants, thus creating the flexibility that may be necessary to make work profitable for severely disabled individuals.

IV. Alaska-specific Employment Barriers for Individuals with Severe Disabilities

People with disabilities living in the State of Alaska face the same barriers to employment as those faced by residents of the "lower 48." These barriers stem from disability policy found largely in the Social Security Act of 1935 and its various amendments, and the administrative rules and regulations that accompany the legislation. Even though amendments to the Act provide for various work incentives intended to safeguard cash and health benefits while a beneficiary attempts return to work, these provisions are: 1) largely unknown to beneficiaries; 2) fraught with complexities that only someone with intimate knowledge of the rules (*Program Operating Manual System*) can decipher; and 3) subject to change depending upon prevailing political forces. As a result, numerous studies, including a recent study conducted by the U.S. General Accounting Office, indicate that these work incentive provisions play a very small role in return to work for the limited number of SS recipients who succeed in doing so.

Inequities between the Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) programs relative to work incentives are a major issue. For example, an individual who is receiving federal SSI benefits can go to work and earn a fair amount of money before SSI cash benefits cease altogether because of the *earned income exclusion* work incentive (Section 1619(a) of the Social Security Act. Likewise, under Section 1619(b), s/he can also earn a substantial amount of money before losing Medicaid coverage.

To illustrate this point ~ in 1998, an SSI recipient can earn a gross monthly wage of up to $1,073 before losing the entire SSI cash payment, if s/he does not receive any additional unearned income. Medicaid eligibility would continue until the individual exceeded the state threshold for SSI, which is $32,643 in 1998 in Alaska. As mentioned earlier, other generous deductions are allowed for different categories of SSI recipients, e.g. the *student earned income exclusion* which is in addition to the earned income exclusion, *impairment-related work expenses*, or *blind work expenses*, each of which further lowers the countable income used by the SSA to determine eligibility for cash payments. The work incentive called *Plan for Achieving Self Support*, or PASS, allows a recipient to set aside some or all of his/her countable earned or unearned income to pay for items or services needed to achieve a specific vocational goal. This provision can also be used to lower the countable income of an SSDI beneficiary, thus allowing that individual to qualify for federal SSI eligibility. If employment is secured within the time a PASS is in effect, the SSDI individual can then access the 1619(b) work incentive program (Medicaid continuation).

Ironically, SSDI-only beneficiaries do not have as many options available to them as do SSI recipients. This is ironic because SSI recipients do not have a sufficient work history to qualify for disability insurance benefits, while DI beneficiaries are entitled to these cash benefits precisely because they have an employment history and paid into the Social Security Trust Fund. In one sense, some people with severe disabilities are "rewarded" for not having prior work experience before applying for benefits while others are penalized.

The greatest disincentive created by the current public benefit system is what has become known as the "DI Cliff," this occurs when an SSDI beneficiary goes back to work, is employed for more than nine months, and consistently earns in excess of $500/month. This individual is considered to be engaged in “substantially gainful activity” by SSA and cash benefits are terminated following a three-month grace period, even though medically and functionally the disability remains.

It should be noted that the first nine months of employment for DI beneficiaries is considered a *trial work period* and no amount of income will affect cash benefits. While this is intended to be a work incentive, studies have demonstrated that most DI beneficiaries do not continue working beyond this trial work period. It has been suggested that fear of loss of the Medicare coverage received by virtue of DI status is a major work disincentive, since the majority of DI return-to-work individuals do not work to the degree that they are eligible for employer-sponsored health insurance. In reality, when cash benefits stop because of substantial gainful activity, Medicare coverage continues for three years, as does the ability to reinstatement cash benefits if an individual’s income falls below $500 per month.

For SSDI recipients, *impairment-related work expenses* approved by the SSA can be deducted from a beneficiary’s gross monthly wage when evaluating substantial gainful activity. But unlike SSI, there is no earned income exclusion or gradual reduction in cash benefits, no plan for achieving self support (PASS) unless SSI eligibility has been established, and no on-going Medicare coverage as income continues within a specified income threshold.

In addition to the federal SSI and SSDI programs, Alaska residents who are deemed to be blind or disabled by SSA are also eligible for a state supplement called Alaska Public Assistance (APA). With this relatively generous supplement to SSI comes a different set of work disincentives that will be reviewed in the following section.

ALASKA PUBLIC ASSISTANCE (APA)

The APA cash payment is the state supplement to the federal SSI program. The Alaska Division of Public Assistance (DPA) administers the APA benefit, which is managed locally in DPA Regional offices located around the state.

Eligibility for APA - A finding of blindness or disability by the Social Security Administration triggers the authorization for APA and Medicaid benefits, provided an individual meets all eligibility requirements. Alaska uses the federal definitions of blindness and disability, so any changes in federal policy will affect APA eligibility. If a federal determination of disability has not already been established, an APA applicant who claims eligibility due to disability must apply for SSI within 30 days of applying for APA. Individuals must also re-apply for SSI if an APA-only recipient and their income decreases, thus making SSI eligibility more likely.

Unlike SSI, in which the eligibility and payment standard for household income are the same, the APA program has different need standards for eligibility and calculation of payment levels. To determine eligibility for APA, a state eligibility technician first determines if a disabled individual's income meets the state's “maximum need standard.” This is the amount of allowable, countable earned or unearned income, which is dependent upon living arrangement and marital status. For example, the 1998 maximum need standard for a single individual living alone is $917. Countable income is determined after certain income exclusions, which not coincidentally, are identical to those used in determining the federal SSI payment. Allowable income includes SSI, SSDI, earned income (after exclusions), the countable income of a spouse, and other unearned income as determined by the state.

If an individual's countable income is below the maximum need standard, s/he is deemed eligible for APA benefits. Next, the eligibility technician will calculate the payment amount by applying the "maximum payment standard." This is the highest amount of APA possible, depending on living arrangement and marital status. For example, the 1998 maximum payment standard for a single individual living alone is $856. This amount combines the federal SSI benefit rate plus the maximum APA payment of $362.

To calculate the APA payment amounts, eligibility technicians subtract countable income from the maximum payment amount. At one time, the maximum need standard and the maximum payment amount were the same. However, the state chose not to automatically increase the APA benefit each year by a cost-of-living-adjustment. As a result, the maximum payment amount is capped at $856 while the need standard continues to rise each year. Therefore some individuals are able to meet the need standard but not the payment standard. In these cases, the state pays the individual one dollar of APA benefit in order to assure continued Medicaid coverage.

Individuals may be eligible for APA benefits even if they are not eligible for SSI as long as they meet the APA need standard and are within the asset limits (which are the same as for SSI). In other words, an applicant may be eligible for APA benefits if they are receiving SSDI benefits that are above the SSI maximum payment amount plus the $20 general exclusion. In 1998 that amount is $504 ($494 federal benefit rate + $20).

If an individual loses SSA or SSI benefits for reasons other than income or assets (e.g. earned income over SGA), the state may do a state-only disability determination and continue APA eligibility using the Disability Determination Service of the Division of Vocational Rehabilitation. This is an incentive for DI-only beneficiaries in Alaska, but includes a risk that will be elaborated upon in the section of this report entitled "Incentives and Disincentives created by the Adult Public Assistance Program." It should be noted that eligibility for APA means automatic eligibility for Medicaid, even if the person is not SSI eligible.

Interim Assistance (IA) - is provided to individuals whose application for APA and Medicaid is pending a decision on their eligibility for SSI benefits. IA does not automatically mean eligibility for Medicaid benefits. To receive IA benefits, an individual must apply for APA and an eligibility technician determines whether or not to place them in the IA program. The eligibility technician must do a full eligibility determination for APA before approving IA. A temporary disability or blindness determination is necessary - the individual must provide evidence from a medical provider that blindness or disability exists.

IA is only available to people who have applied for SSI benefits, which they must do in 30 days or the IA will be terminated and the APA application denied. This includes people who have been determined eligible for SSA disability benefits but are in the 5-month waiting period for cash benefits.

APA accepts the final SSA determination of blindness or disability and may use this as a basis for denial of APA and Medicaid, or do a state-only disability determination for APA. In order to receive IA, the applicant must sign a form authorizing the SSA to send the initial SSI payment(s) to APA for reimbursement for IA benefits provided. IA will continue through an SSI denial appeal process.

Other Income - In addition to SSA benefits, APA/SSI recipients in Alaska may be eligible to receive other unearned income that affects their benefits in different ways. One such income source is the Alaska Longevity Bonus Payments, or ALB, which is in the process of being phased out but still may affect some disabled elderly residents. The ALB is a payment of up to $250 per month to elderly Alaska residents who have been residents for at least one year and are at least 65 years of age. State law requires that SSI benefits lost due to ALB be replaced through the ALB Hold Harmless program (ALB-HH) which is totally state-funded. The ALB-HH and APA are combined to make one payment. ALB-HH also replaces any Medicaid benefits lost, however, Medicaid does not count ALB payment as long as it does not cause a person's total income to exceed 300% of the SSI standard which, in 1998, is $1,482. ALB will also cover SSI overpayments.

Similar provisions apply to payments received through the Permanent Fund Dividend (PFD). This is a payment made to every Alaska resident once a year. In 1998, the PFD amount is $1,300. The PFD is considered income for SSI purposes and results in an overpayment of SSI for the month in which it is received. The state, however, pays the overpayment. SSI recipients receive a confusing letter from the SSA that says they received an overpayment but with no payment due.

For some individuals, receipt of this lump sum payment causes them to have excess resources; that is, the SSI/APA program limits a single individual from having more than $2,000 in liquid or non-liquid assets. The state gives an individual four months in which to “spend down” to this asset limitation. In the meantime, the state pays the SSI overpayment during the four month period. Most individuals do not have the problem of excess resources, as they have outstanding bills or can pre-pay rent or utility expenses.

Spousal income is counted when determining eligibility for APA. With current “welfare to work” policies in force for the former AFDC population, welfare benefits are now time-limited and require recipients to work off benefits within a specific period of time. In this scenario, work may produce enough income to make a disabled spouse ineligible for APA/Medicaid, but not provide enough disposable income to live on nor provide health coverage for the individual and/or family.

Incentives and Disincentives to Work Created by the APA Program

SSA regularly reviews continued eligibility for SSA and SSI benefits based on income and assets. If eligibility ends but the disability continues, the state may ask the Disability Determination Service to do a state-only determination of disability or blindness to continue the APA benefit. For example, an SSDI beneficiary who returns to work above SGA ($500+/month) will eventually lose DI cash benefits due to the substantial gainful activity rule. As long as this individual is not considered by the SSA to be “medically recovered,” the state may continue to provide APA benefits if the individual stays below the maximum need standard and asset limit. This will result in continued Medicaid coverage, an incentive for individuals who need Medicaid in order to live independently in the community. Because earned income is counted differently than unearned income when calculating eligibility and APA payment, an SSDI beneficiary may potentially have significant earnings and still qualify for APA and Medicaid.

This is an incentive to work for APA recipients whose disability is permanent (e.g. spinal cord injury or mental handicap). If an individual is receiving SSDI and goes to work with earnings over SGA, s/he will eventually lose eligibility for SSDI benefits. The APA can do a state-only disability determination and, as long as the individual meets the maximum need standard, can continue to receive APA benefits and Medicaid. In APA, earned income is counted differently from unearned income -- only the first $65 and one-half the remainder is considered “countable income”. The individual must still meet the appropriate maximum need standard. Therefore, an individual who is determined eligible through the state-only disability determination can earn up to $1,919 per month in 1998 before losing Medicaid eligibility due to earned income, as long as they have no unearned income and they remain below the asset limit.

The earned income could be even higher if the individual has *impairment related work expenses* (IRWE) that would be excluded from income in determining eligibility or calculating payment level. The APA manual lists items that may qualify for this exclusion, but it is not an all-inclusive list. The DPA is responsible for approving IRWE for individuals who are not eligible for SSA benefits (APA-only).

When individuals are in their trial work period, both earned and unearned income are considered in determining eligibility for APA, therefore, there is a real danger of losing eligibility if the earned income becomes too high. Keeping in mind that the maximum need standard of $917 in 1998, and the maximum payment standard of $856, the following example demonstrates the point.

> A beneficiary receiving $600 of SSDI would have countable income of $580 and would therefore be eligible for $276 in APA. If the same beneficiary goes to work and earns $600 per month, has no *impairment related work expenses*, and has not previously used any of her trial work months, her new countable income would be $847.50 which is below the maximum payment standard. The new APA payment would be $8.50 and Medicaid eligibility would continue.
>
> If her income were $800, during the trial work period her countable income would be $947.50, which is above the need standard. She would no longer be eligible for APA and would lose Medicaid as well. However, if she had already used her nine months trial work period, once her SSDI benefit stopped her countable income would be $357.50, which is well below the need standard as well as the payment standard. She would receive an APA payment and Medicaid eligibility.

Alaska should consider a policy whereby some or all of either the earned or unearned income is disregarded during the trial work period, allowing the individual to continue eligibility.

Another largely unknown work incentive contained within the APA manual is an exclusion to earned income called amount to fulfill a PLAN FOR ACHIEVING SELF SUPPORT (PASS). It is described as any earned or unearned income of a blind or disabled recipient that the recipient needs to fulfill a plan for achieving self-support. This PASS can be approved by either the Social Security Administration or the state Division of Vocational Rehabilitation. An individual who is not eligible for SSA benefits or who cannot "spend down" sufficiently through a PASS to qualify for SSI, may have income excluded and be eligible for APA as long as s/he meets the other eligibility criteria.

The Division of Public Assistance should review this section of the manual and determine if they intended that non-SSI eligible individuals are eligible to exclude income in a PASS. If so, potential beneficiaries of this provision should be informed of it.

In addition to continuing the APA and Medicaid benefit if the state-only disability determination confirms continued eligibility status, the APA will pay both the Part A and Part B Medicare premiums for an individual. SSDI beneficiaries who lose their health benefit due to earnings in excess of SGA, can "buy-in" to Medicare at a premium of $411 per month, the same as that for retired persons. The APA would pay this premium for individuals who lose the SSDI cash benefit because of work but maintain their disability status through the state-only determination process. Most people are not aware of these options and, as a result, they either don't go to work or they deliberately keep their earned income below $500 per month.

The state should make an effort to inform Medicare recipients of this existing option.

Persons eligible for APA-only and not SSI (due to excess income) will lose APA and, most significantly, Medicaid if they go to work and their countable income exceeds the need standard. Unlike someone receiving SSI, who has continued access to Medicaid with an income up to $32,000 using the 1619(b) work incentive, an individual who receives only the APA benefit cannot continue Medicaid eligibility. There is no 1619(b) work incentive program for individuals receiving APA-only. However, there is a federal mandate for states who provide an SSI supplement to continue Medicaid eligibility for individuals who receive only the state supplement but lose the supplement due to earned income under Section 1905(q) of the Social Security Act. The Alaska Division of Public Assistance believes this provision only applies to states that have, or at one time had, their state supplement federally administered. If the DPA were using only the language in Section 1619(b), it would support this interpretation because 1619(b) is a FEDERAL work incentive that is available only to individuals eligible for benefits under 1611 or a FEDERALLY ADMINISTERED state supplement.

The language in S.1902, S.1905, and S.1616 of the Act supports a different interpretation. Section 1902(10)(A)(II) establishes that a State plan for Medical Assistance must " provide for making medical assistance available ...to all individuals with respect to whom supplemental security income benefits are being paid under Title XVI.... Or who are qualified severely impaired individuals (as defined in section 1905(q).

Section 1905(q) states that "[T]he term “qualified severely impaired individual” means an individual under age 65 who for the month preceding the first month to which this subsection applies to such individual received a payment of supplemental security income benefits under section 1611(b) on the basis of blindness or disability, a supplementary payment under section 1616... or a supplementary payment under section 1616(c)(3) and was eligible for medical assistance under the State plan approved under this title..."

Section 1616(c)(3) states that "[A]ny state...making supplementary payments described in subsection (a) shall have the option of making such payments to individuals who receive benefits under this title under the provisions of section 1619 or who would be eligible to receive such benefits but for their income".

Section 1616(a) defines the state supplement as “[A]ny cash payments which are made by a State (or political subdivision thereof) on a regular basis to individuals who are receiving benefits under this title or who would but for their income be eligible to receive benefits under this title... and the Commissioner of Social Security and such State MAY ENTER (emphasis added) into an agreement which satisfies subsection (b)" (which describes how the SSA will make supplement payments for the State).

It could be concluded that Alaska is mandated to provide Medical Assistance to APA recipients who lose their cash benefit because of earned income. The author of the 1619 language, Mr. Allen Jensen, advised looking at the Title XIX language rather than the Title XVI language.

The Division of Public Assistance is advised to carefully review the language contained in the above mentioned sections of the Act.

Communication Gaps

While one would surmise that an individual receiving SSI and APA is in a good position to return to work by successfully utilizing the available work incentives, problems occur -- many of which are a result of inadequate communication between the SSA and DPA. For instance, advocates for people with disabilities indicate that when individuals lose their SSI cash benefit due to earned income, the DPA will receive a termination print-out from SSA listing these people, but not the reason or their current status. Therefore, individuals who should be eligible to continue Medicaid eligibility under 1619(b) status may be cut off from both APA and Medicaid inappropriately.

According to state staff, DPA now receives a list of 1619(b) status recipients from the SSA. It is also possible for APA workers to do a computer inquiry for status information on a recipient, but it takes 3-4 days to get a response. Finally, if an APA worker calls the SSA office, s/he is able to get the correct status from the claims representative. These actions require willingness on the part of APA staff to take a proactive approach, which is often constrained by workload issues. Due to large caseloads, APA workers do not have the extra time needed to deal with problems that result from inadequate information and inefficient communication systems.

Even when front-line staff are willing to do whatever is necessary to bridge the communication gap, with a state the size of Alaska, and the dispersion of the population into remote areas, most APA and SSA staff function in a vacuum unless there are planned face-to-face meetings. The state has plans to hire a statewide "APA coordinator" in the next fiscal year. This position will offer the opportunity to create a liaison between the community, the SSA, the VR agency, and DPA.

A major work disincentive in Alaska is the added complexity that APA rules bring to the existing confusion inherent in SSA programs. The problems are not insurmountable provided all federal, state, and agency stakeholders continue to talk to each other, learn about each other systems, and jointly brainstorm around solutions.

The state should convene regular stakeholder meetings to clarify policies and practices within and between individual agencies and bureaucracies, and to seek consensus on needed recommendations for reform of existing policies and administrative practices that prevent individuals with severe disabilities from pursuing gainful employment.

ENDNOTES

[i] Social Security Administration. (1994). Developing a World-Class Employment Strategy for People with Disabilities, September.

[ii] Social Security Administration. (1994). Developing a World-Class Employment Strategy for People with Disabilities, September.

[iv] Lou Harris Poll, 1986.

[v] For a thorough review of the literature on work incentives, see Lewin-VHI, Inc. *An Exploratory Study of Barriers and Incentives to Improving Labor Force Participation Among Persons with Significant Disabilities,* 1995.

[vi] Bartfeld and Hanes. (1993) *Employment Experience of Working Age Adults,* and Hanes (1997), *Baseline Survey, Dane County Employment Initiative.*

[vii] U.S. Government Accounting Office. (1997) Social Security: Disability Programs Lag in Promoting Return to Work, GAO/HEHS-97-46.

[viii] LaPlante, M. *State Estimates of Disability in American,* National Institute for Disability and Rehabilitation Research, U.S. Department of Education, 199X.

[ix] Gollay. *Summary Report on the Implications of Modifying the Definition of a Developmental Disability, U.S.* Department of Health & Welfare, 1981 in *Developmental Disabilities Plan for the State of Alaska: Fiscal Years 1998-2000.* This method of estimation assumes that 1.8% of all Americans have a developmental disability.

[x] U.S. Social Security Administration, *State Statistics*, Office of Research, Evaluation and Statistics, December, 1996.

[xi] U.S. Social Security Administration, *State Statistics - Alaska*, Office of Research, Evaluation and Statistics, December, 1996.

[xii] Social Security Administration. Quarterly Report on SSI Disabled Workers and Work Incentive Provisions, March, 1998.

[xiii] DPA. Adult Public Assistance Program Status Report. October, 1997, p. 18

[xiv] DPA. Adult Public Assistance Program Status Report. October, 1997.

[xv] Personal interview with Kay Burrows, Director of Senior Services Division