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P1 National Security Classified Information [(a)(1) of the PRA]
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U.S. Department of Health & Human Services

Office of the Assistant Secretary for Planning & Evaluation

Office of Disability, Aging, and Long-term Care Policy

Phone: 202-690-6443 FAX: 202-401-7733

FACSIMILE TRANSMISSION

To: Devorah R. Adler

Phone:

Fax: 202-456-5557

From: Hunter McKay

Date: Dec 14, 1998

Number of Pages:
(including cover)

Remarks:

Attached is the Concept Paper for Pathways. I looked back at the notes on the previous conference calls with HCFA and I don't think there has been any discussion of it yet.

Hunter

Tommy G. Thompson
Governor

Joe Leean
Secretary, DHFS

Linda Stewart
Secretary, DWD

State of Wisconsin

Department of Health and Family Services, P.O. Box 7850 Madison, WI.

Department of Workforce Development

Pathways to Independence

A Proposal to
Enhance the Wisconsin Workforce
Through More Reliable Health and Support Systems
For People with Disabilities

March 1998

Removing Policy Barriers to Employment on the Part of People with Severe Disabilities

I. Introduction

People with severe disabilities depend on the health and long term care system for their ability to live. Unfortunately, private health insurance is designed to avoid people with disabilities. Public health programs are characterized by formidable barriers and penalties which apply to people with disabilities who attempt to work. Examples of the problems such individuals face include:

Private health coverage is frequently unavailable. Where it is available, private insurance is generally unaffordable and inadequate for people with severe illness and disabilities. It is inadequate because it does not offer coverage for the type of long term supports which people with substantial disabilities require. Kennedy-Kassebaum (HIPAA) helps some, but does not offer much aid for people with significant disabilities because they generally lack prior group health coverage.

Public health insurance and long term care programs are tied primarily to income support programs such as SSI or SSDI. Acceptable termination of SSI/SSDI payments due to earned income leads to untenable loss of health and long term care coverage.

Fragmentation of public programs means that there is no single program which can "put all the pieces together." Each program (SSI, SSDI, Medicare, HUD) acts independently, often at cross purposes.

Working is Often Mathematically Impossible: The increased cost of taxes and basic work expenses (transportation, MA copayments, extra clothing or food), combined with uncoordinated reductions from SSI, SSDI, Medicaid, and other supports, can require over 200% of earnings. People with a disabilities subsisting on income below the poverty level tend not to have the money or assets necessary to support themselves during periods of "negative income."

Falling Off the Cliff: Federal SSDI payments end completely as soon as a person earns more than $500 in any random 9 months during any 5-year period. SSI and Medicaid have similar, though less abrupt, drop-off ledges. People who were not on either SSDI and SSI are left in never-never land and often must stop their work attempts in order to live.

Cost-Shifting to Medicaid and SSI: Falling off the federal SSDI cliff transfers costs abruptly to SSI and to Medicaid. State costs thereby increase.

Complexity and Fear: SSI and Medicaid contain many valuable protections for people who attempt and succeed at working, such as SSI's section 1619 provisions. However, the regulations are so complicated that few professionals understand them. The complexity creates uncertainty. The uncertainty creates fear among SSI recipients that they will lose vital health or long term care coverage. Such fear is itself a problem. Only the most courageous of persons with severe disabilities will risk their well-being by putting their life in the hands of complicated, uncertain safeguards.

A superior system would:

- ***Simplify the Security.*** Consolidate the current patchwork of independent health, long term care, and employment incentives into something which is coherent and which can easily be understood by anyone;

- ***Hold Harmless Each Person's Medicaid and Medicare Coverage.*** Ensure that people will continue to have affordable, adequate health and long term care coverage. Such a simple guarantee would replace the current and tentative message: "*perhaps* you will have coverage if you work;"

- ***Improve the Adequacy*** of health and LTC coverage available to support employment;

- ***Adopt a Comprehensive Approach*** which aligns all health, long term care, vocational rehabilitation, public assistance, and other vital employment programs in support of each person's vocational goals for paid employment;

- ***Ensure Cost-Effectiveness*** by means of an up-front risk agreement which guarantees to SSA that the current rate of SSI/SSDI savings due to return-to-work strategies are maintained.

II. The Federal Need for Comprehensive Demonstrations

Unfortunately, the rate at which SSI and SSDI recipients return to work is very low. Recent reports indicate that no more than 0.5% return to work each year (1.4% over 5 years), with about one-third of the "successes" later returning to SSI or SSDI.

Congress and Federal officials are keenly aware of the need to take action:

The General Accounting Office has issued a series of reports which explore some of the issues in detail and exhort us to act.

The Social Security Administration has promoted a number of demonstrations (e.g. Project Network) to test specific elements which might help in reforming the system.

Various Congressional representatives (e.g., Senator Jeffords, Representative Bunning) have introduced legislation which would improve certain aspects of the current system.

Each of the proposals introduced in Congress so far, and each of the federal demonstrations we have studied, offer the promise of some genuine improvements in the current system. Yet they all suffer from many of the same flaws.

Limitations of Most Current Proposals	
Piecemeal	No proposal offers a comprehensive approach which addresses all major barriers. No proposal requires all 5 major federal programs to work closely together (Medicare, Medicaid, SSI, SSDI, HUD).
Complex	Each proposal adds to the plethora of rules governing eligilbity and earnings. Instead, what we need is a very simple approach which consumers and their families can readily understand.
Unresearched	There is no data set which can answer the major questions about cost and effectiveness, so actuaries are left to their own reasonable assumptions.

III. Wisconsin Demonstration

We propose a powerful, researched, and comprehensive demonstration which would offer the data necessary to answer the above questions. By virtue of being a time-limited (5 year) program with a defined number of participants, concerns regarding possible undesirable effects can be minimized.

Target Groups: Up to 1800 cognitively intact individuals between the ages of 16 and 63 would be permitted in the service part of the program. The approximate number of people actively enrolling in the program would be:

- 600 - 800 persons with physical disabilities,
- 100 - 200 persons with HIV-AIDS and
- 200 - 600 persons with serious and persistent mental illness.
- 25 - 100 persons with a developmental disability

An additional number of volunteers would serve in a comparison or control group capacity.

Eligible people must be SSI or SSDI beneficiaries with long term disabilities in classifications under which SSA has indicated there is little likelihood that their conditions will improve. Quadriplegia, multiple sclerosis, muscular dystrophy, and advanced rheumatoid arthritis are examples. Somewhat different specifications may be required for persons with HIV-Aids, given the advent of new drugs.

Locations: About 5 – 15 Wisconsin counties would be included, one of which would be Dane county and another Milwaukee. Rural counties would be represented.

Enrollment: Enrollment would be voluntary. Disenrollment would also be voluntary, subject to any administrative delay time necessary to reinstate normal administrative procedures.

The 1% Solution - Usual Savings to SSA Guaranteed: The State and the SSI/SSDI volunteers who enroll in the project would guarantee that SSA would achieve savings in SSI/SSDI equal to the current rate of savings which results from beneficiaries returning to work (e.g. 0.5%/year, or 1% every three years). For example, volunteers would agree in advance that, in return for the benefits of project participation, their monthly payments would be reduced by 0.5%. Alternatively, the State would agree to cover the savings up-front in return for premium or income-sharing agreements with enrollees which become effective when participants secure employment. In effect, the volunteers and the State agree to take on some fiscal risk in return for certain hold harmless provisions and greater management discretion.

The above option has the added advantage of reducing administrative costs for both SSA and the State. There would no longer be a need for monthly income/asset reporting or verification, and the monthly check-writing by SSA would be streamlined.

Hold Harmless: In return for active participation and assumption of risk, enrollees would be held harmless against all SSI, SSDI, Medicaid, Medicare rules which would make them ineligible or reduce their benefits as result of earned income, including increases in net assets which result from earned income.

Enrollees would also be assured that the normal "clocks" for trial work periods, the Medicare extended period of eligibility, and related provisions would be suspended during the time they participate in the project. Thus, for example, a person who was employed for 48 months during the project would not have those 48 months counted as part of an extended period of eligibility when the project ended. Instead, the "clock" for each person's extended period of Medicare eligibility would start ticking again only when the project's five-year time period ends or the person disenrolls from the project. Similarly, time spent working during the five-year demonstration period would not count against the 9-month trial work period.

Income Barriers Eliminated: People with disabilities often rely on many different programs. Each program seeks to reduce its benefits when there is earned income. They make these reductions independently from one another, and mostly from gross income. The result is that total benefit reductions plus new taxes can easily exceed 100% of earnings. Instead, we propose that gross benefits remain unchanged at the "front end," in favor of later income-sharing based

on net income. SSA would not reduce payments when a person becomes employed. Neither the SSI deduction of $65 plus 1/2 of earnings, nor the SSDI reductions when earnings exceed $500/month, would apply. The substantial gainful activity (SGA) test would be irrelevant. Trial work periods would become irrelevant during the demonstration period.

Income-Sharing: The State may enter into income-sharing and risk-sharing agreements with participants to share in any **net** increases in income. The State would agree to re-invest proceeds from the income-sharing agreement back into the program. This arrangement creates a strong incentive for both participants and the State to find ways to increase employment, since the net benefits will be available to increase the support for employment.

Medicare and Medicaid: This project will require adjustments to permit continuation of the Medicare and Medicaid coverage each participant had at the time of enrollment, without regard to changes in employment, income, or assets created via earned income. We see two possibilities for this.

> ***(a) Continued SSI/SSDI Eligibility***: With continued categorical eligibility made possible by SSA's demonstration authority, the individual's Medicare/Medicaid coverage would presumably continue.
>
> ***(b) Medicare (s.222) and Medicaid (s.1115) Waivers***: Unfortunately, these waivers often take years in processing and negotiating. If HCFA is required to calculate cost–neutrality for Medicaid or Medicare separate from the total public cost, then we anticipate there will be some special hurdles to overcome. We do not know whether there will be savings for Medicaid if it is viewed in isolation – but we do believe there will be an overall public savings when SSI, SSDI, Medicaid, Medicare, food stamps, and HUD rental subsidies are all considered together.

Service Delivery Model: At each location we would implement a team-based, comprehensive package of supports which coordinates vocational planning and support; employer and employee coaching; financial planning; risk management; health and long term care; job search, job placement and on-going job support; transportation; training; and other necessary supports.

This service delivery model is based on our successful experiences with the Dane County Employment Initiative. This small-scale initiative is currently assisted by the Robert Wood Johnson Foundation and has 28 people with physical disabilities enrolled in a pilot feasibility test similar to the larger model we propose here. Enrollment is expected to be 105 during 1999. The current non-profit contractor, Employment Resources Inc., would operate the Dane County site under this proposal and would provide technical assistance to all other sites.

Potential for Expansion: We currently have an experienced contractor (Employment Resources, Inc.- "ERI") with a working service delivery model ready for expansion. In this Dane County site we also have the interagency agreements and contracts necessary to make a comprehensive model work. These involve the county Human Service Department (transportation, personal care, community-based long term care), the State Division of Vocational Rehabilitation

(vocational supports). , and the State Department of Health and Family Services (technical assistance, SSI and Medicaid safeguards, health and long term care, etc.). ERI has also entered into a copperative agreement with the Aids Service Network to begin applying the model to persons with HIV-AIDS.

For people with mental illness, we also have eleven Community Support Programs in various locations throughout Wisconsin which recently entered into agreements the Division of Vocational Rehabilitation to provide services similar to those being provided by ERI. Additional Community Support Programs have expressed strong interest.

Research Program: We would agree to an ambitious research agenda. Among other things, the research would address many of the fiscal questions which confound the national debates. We propose to include the following elements:

> ***Comprehensive Fiscal Analysis***: We would examine all public costs for each enrollee for one year before he or she entered the project and for the entire time of his/her project participation. This would permit a "before and after" comparison. Items to be inventoried are: all taxes paid, SSI, SSDI, Medicaid, Medicare, HUD Section 8 rental subsidies, food stamps, and related public benefits.
>
> ***Comparison and Experimental Research Designs***: In most sites we believe it will be feasible to maintain comparison groups for research purposes. And in one site (Milwaukee) we would consider an appropriate, carefully constructed experimental research design. In that county we expect the number of willing volunteers to exceed the number we could realistically serve in the model. Random assignment from the pool of eligible, interested persons may be a reasonable method of allocating scarce opportunities to participate. It is a rare opportunity to employ such a powerful research technique in the human service field; but it is one to which both public officials and persons with disabilities can agree in this case.
>
> Current wave of new participants in the Dane County Employment Initiatives Project were selected by the random assignment method which could be employed in Milwaukee county. We are pilot-testing many of the research instruments which will be needed in a large demonstration.
>
> The opportunity to implement a careful research design of a sizable demonstration will allow us to address key questions posed in Congressional debates. For example, would guaranteed continuance of health and long term care coverage through Medicare and Medicaid add to total public expenditures, or would so many additional people secure employment (and employer-provided health coverage) that there would be a dramatic public savings? In this relatively small-scale, controlled and researchable demonstration, we may find the answer.

IV. Benefits to the Federal and State Governments

We expect that the above one-time federal expenses would be offset over the long term by on-going savings, such as:

Reduced Administrative Costs: Fixed payments to SSI/SSDI beneficiaries under this demonstration will eliminate the need for monthly check-writing adjustments by SSA. Since income and asset levels would no longer affect monthly payments, a substantial administrative cost would be eliminated.

Increased Tax Revenues - Greater employment will yield increased tax receipts on the part of both state and federal governments.

Reduced Benefit Costs: Federal costs of the following programs would be reduced under this initiative, as (a) earnings increase and (b) a higher percentage of people engage in some form of paid employment. The following benefit programs reduce their payments as earnings increase:

Food Stamps
HUD Section 8 Rent Subsidies
Veterans Benefits

We propose that the payment amounts for SSI and SSDI remain fixed during the demonstration period. However, some premium or income-sharing with employed enrollees during the demonstration will help us pay for enrollee expenses. And improved employment rates achieved via the demonstration will pave the way for future federal savings in both SSI and SSDI after the demonstration period.

Reduced Health Care Expenses: To the extent that a higher percentage of beneficiaries secure employment with employers who offer health coverage, both Medicare and Medicaid expenses will be reduced even though Medicare and Medicaid coverage continue. Since Medicare and Medicaid are payers of last resort, only those expenses not covered by the private insurance will filter through.

To the extent that employment improves independence, self-confidence, discretionary income, and sense of well-being, then secondary illnesses, disabilities, or adverse behaviors may be reduced. We know, for example, that rates of alcohol and other drug abuse are very high among persons of working age who have a physical disability. There is reason to believe that paid employment will reduce the incidence and severity of such behaviors.

Enhanced Workforce: It is in the interests of the nation and the State of Wisconsin to have a workforce which is highly skilled and engaged in productive employment.

Prevention: There is some evidence to suggest that employment and other valued social roles help reduce secondary disabling conditions (e.g. depression, alcohol and other drug abuse), as well as contributing to improved self-esteem and citizenship.

VI Lead Agency Roles in Wisconsin

The Department of Health and Family Services and the Department of Workforce Development are collaborating closey in all aspects of this national demonstration.

The following chart outlines the lead roles each agency would play, based on their current responsibilities.

Proposed Lead Agency Roles and Responsibilities

Department of Health and Family Services	Department of Workforce Development
1. Health and Long Term Care Coverage: Provide management and training; issue RFP for demonstration sites; contract for local demonstration management; etc. Secure funding for management expenses, waiver development, research (e.g. from RWJ, HCFA, SSA, etc). *3. Match for Local Comprehensive Access and Assistance*: Secure most funds to match federal sources for the local comprehensive employment and case management assistance 3. *Federal Waivers*: Secure federal waivers and coordination of services (Medicare, Medicaid, SSI, SSDI, HUD, etc). *4. Local Health and Long Term Support*: Enlist and coordinate support from county social service and 51 boards for the on-going long term care people need and for the case management . *5. Research*: Develop and oversee research designs necessary for RWJ, HCFA, SSA. Contract for research functions where necessary. Secure funding for research.	*1. DVR Client Services*: Provide normal DVR client services (e.g. worksite accommodations, accessibility aids, training, adaptive aids) to project participants. Organize DVR District Office participation. *2. Secure Federal VR Funds:* Secure federal vocational rehabilitation funds (79% of cost) and provide some match (21% of cost) for the local intensive employment assistance.. Capture all available federal funds. Make the demonstration a top priority for (a) third-party funds if regular funding is not available, and (b) for reallocated dollars. Secure special grant funds if available from the federal Rehabilitation Services Administration. *3. Self-Employment*: provide training & technical assistance, start-up funds, and other supports for individuals wishing to engage in self-employment. *4. Financial Eligibility and Cost-Sharing*: Provide training and technical assistance to county economic support workers in any new eligibility protocols needed for the demonstration, revise DES policy manuals where necessary, ensure effective interface with CARES, etc.

Tommy G. Thompson
Governor

Joe Leean
Secretary

State of Wisconsin
Department of Health and Family Services

OFFICE OF STRATEGIC FINANCE

1 West Wilson Street
P.O. Box 7850
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Removing Policy Barriers to Employment on the Part of People with Severe Disabilities

A Concept Paper

Wisconsin Department of Health and Family Services

Thomas E. Hamilton

Feb 1997 – Revised October 1997

The Need for a Simple Approach

People with disabilities who rely on public programs are affected by many rules. Those rules are complicated. Too complicated. Not even the professionals who administer them can fully understand how the many rules of one program interact with those of another. No rules are more complicated than those which determine eligibility for Medicaid, Medicare, SSI and SSDI.

Once the current complexity is penetrated an even more disheartening conclusion awaits: it is irrational for most people who rely on SSI or SSDI to attempt to work. The consequences are too dire. For people who depend on health care system for their very ability to live, the threat of losing such coverage due to earned income means that work can be life-threatening. The attached overview summarizes some of these problems and outlines a Wisconsin proposal for a dramatic demonstration.

In a Nutshell: "Pathways to Independence"

Currently less than 1% of SSI/SSDI beneficiaries leave those programs as a result of paid employment. To achieve superior results we propose a researched demonstration ("Pathways to Independence") which has the following features:

- ***A 1% Solution***: Wisconsin will agree to pay the Social Security Administration 1% of total SSI and SSDI checks received by demonstration enrollees over each three-year period, in return for considerable flexibility to "take off the handcuffs" and implement a demonstration with potential for dramatic results. This guarantees SSA at least the current success rate.

- ***Simple Guarantee:*** We would guarantee current beneficiaries that their Medicaid, Medicare, SSI, SSDI and HUD assistance will continue regardless of earnings (or assets derived from earnings), in return for later cost-sharing of ***net*** income.

- ***Simple Access to Comprehensive Help:*** We would offer enrollees consultation from a team which can provide coordinated access to all professionals and programs that may assist them in achieving their employment goals. The team would mobilize the supports needed by each individual. Greater flexibility in funding and coordination among all support programs would also reduce fragmentation.

Wisconsin Department of Health and Family Services

Pathways to Independence

Wisconsin Department of Workforce Development.

Enhancing the Workforce Through More Reliable Health and Support Systems for Persons with Disabilities

The Problem: The U.S. General Accounting Office has calculated that less than 1% of SSI or SSDI beneficiaries leave those programs each year as a result of paid employment. Of those who leave, about 1/3 return within 3 years.

More than 6.6 million Americans have a permanent disability and receive income support from the Social Security Trust Fund ("SSDI") or Supplemental Security Income ("SSI").

The federal government spent $36.6 billion dollars in the SSDI program in 1995, and $20.6 billion in SSI. Many states add their own funds to these federal SSI amounts to ensure an adequate financial safety net. Wisconsin adds approximately $127 million per year and has 121,000 SSI beneficiaries. Approximately 75,000 disabled workers receive SSDI in Wisconsin and an additional 30,000 worker-dependents receive SSDI.

Most people with disabilities want to work. Employers are increasingly interested in employing people with disabilities. Advances in technology offer employment hope even for those with the most severe disabilities. Removal of the following problems could significantly increase the employment of people with disabilities.

- *Health and Long Term Care*: SSI and SSDI beneficiaries inform us that loss of health and long term care coverage is the single most important barrier to paid employment (other than the person's disability itself). Earnings over $500/month can jeopardize such coverage. People with substantial disabilities depend on the services they receive from programs such as Medicaid and Medicare for their very ability to live. If employment jeopardizes their ability to live, they will rarely take the risk. And if the system is so complicated that uncertainty remains as to whether health or long term care coverage might be lost, then serious employment will still be viewed as life-threatening. The current complexity instills fear in consumers and leaves even professionals in bewilderment. *What is required is a very simple, clear-cut guarantee.*

- *Fragmentation:* People with substantial disabilities usually depend on many different public programs at the same time. Those programs, however, act independently. They often act at cross-purposes with one another. For example, HUD rent subsidies are reduced 30% for each dollar earned. SSI is reduced 50%. Food stamps are reduced by 25%. Due to this lack of coordination, the cost of working can often exceed 100% of income, especially when taxes and work expenses are added to the picture. *There is no one, and no authority, to coordinate all programs in support of an employment goal.*

- *Allied Supports*: People with disabilities are unusually reliant upon dependable support systems in order to work. Examples include: reliable transportation systems which match a job schedule; reliable personal attendant care for people in wheelchairs; adaptive aids, computers and mechanical devices which, if broken, can be repaired quickly; vocational training; worksite accommodations; timely medication management; mental health and motivational assistance. ***There exist no programs which can develop, access, and "pull all the pieces together." There is no program which can intercede quickly when there are breakdowns.***

Implications for Action: Since almost no beneficiaries leave SSI/SSDI, it will be of virtually no cost to the State and Federal governments to continue the Medicaid/Medicare coverage of current beneficiaries if they can secure paid employment. This would remove the impediment which people with severe disabilities fear most. It would also be of virtually no cost to continue the individual's SSI, SSDI, and HUD rental assistance, provided reasonable cost-sharing of the person's net income is arranged.

The potential financial benefits to the State and Federal Governments are substantial. Some people would secure work with employers who offer group health coverage, thereby reducing Medicaid and Medicare expenses. Earned income will also yield tax receipts while reducing expenses in SSI, food stamps, HUD rent subsidies, and veterans benefits.

Improved employment rates would also increase the independence of people with disabilities, reduce the health complications of disability, and strengthen our communities and workforce.

Current Proposals in Congress: Many members of Congress are interested in removing employment barriers. Many worthwhile proposals are being introduced. Our proposal does not replace such other efforts that seek nationwide improvements immediately. While we hope to have even greater prospects for long term success, we recognize that our approach merits serious evaluation and could not be implemented immediately everywhere. Instead, the Wisconsin demonstration offers a more intense approach which is at the same time much simpler. Instead of removing a few barriers and still leaving complexity and fragmentation in place, we seek to remove all major public policy barriers at once. We seek to align all major public programs in support of an employment goal. We seek a "breakthrough" approach.

A Wisconsin Demonstration: The Department of Health and Family Services and the Department of Workforce Development are working jointly to create a powerful initiative with potential for very positive results. We hope to enlist colleagues at the Federal level (especially HCFA and the Social Security Administration) to implement a demonstration with the following features:

- *Health/LTC Security*: Guarantee continued Medicaid and/or Medicare coverage to 1200-1800 current SSI and SSDI beneficiaries in 5-15 sites over a five-year period. If enrollees secure employment paying over $500/ month, they would be assured of continued coverage regardless of earnings (and regardless of assets which result from earnings.) People with physical disabilities, mental illness, or HIV-AIDS would be included. SSI, SSDI, and HUD rental assistance payments would continue at the level received before employment, but would be subject to cost-sharing with the program, with the State and with Federal authorities.

- *Simplified Access to Comprehensive Help*: Enrollees will be able to consult with a single team which can offer coordinated access to all professionals and programs which may assist them in achieving their employment goals. The team will mobilize the supports needed by each individual. Greater flexibility in funding and coordination among all support programs will reduce fragmentation.

- *Research:* A strong research design will document demonstration results for the three target groups. Analysis of comparison or control groups, together with comprehensive tracking of changes in public costs, will enable us to assess the potential impact of any larger-scale public policy changes.

- *The One Percent Solution*: At a minimum, Wisconsin would assure the Social Security Administration that SSI/SSDI federal costs would be reduced by 1.0% for project enrollees. This is the rate at which SSI/SSDI beneficiaries typically leave the program due to paid employment, as calculated by the U.S. General Accounting Office.

Requirements for an Effective Demonstration: Substantial initial investment of funds to ensure success (about $8400 per person above existing VR service levels, plus management and research costs) would be required for the most intensive approach needed by people with substantial disabilities. People with lower levels of disability may be able to benefit with less intensive approaches. We anticipate reallocating funds from existing programs to provide most of the necessary resources, and seeking private foundation grants.

Federal waivers in SSI, SSDI, Medicaid, and Medicare will also be required. Since the process of securing federal waivers often takes many years, we will seek the assistance of Congress to direct the Health Care Finance Administration to grant timely waivers which enable the breakthrough approach we desire.

Building on a Foundation: With assistance from the Robert Wood Johnson Foundation, key elements of this proposed demonstration have already been pre-tested in Wisconsin. Collaborative efforts involving the Dept. of Health and Family Services, Division of Vocational Rehabilitation, Wisconsin counties, and private agencies suggest many ways to reduce fragmentation. Local pilot tests have confirmed the value of team-based comprehensive approaches for both persons with physical disabilities and people with mental illness. And research associated with these efforts indicates a strong potential for benefits to the individual and for public financial savings.

Governor Tommy Thompson has committed his Administration to securing both the funds and federal waivers necessary for this approach. In his 1998 "State of the State" address he urged a speedy solution:

"We are wasting too much talent by allowing legitimate fears over health care to keep people with disabilities out of the workforce. Give them their freedom by protecting their health."

State of *Wisconsin*
Department of Health and Family Services
Department of Workforce Development

DEPARTMENT OF HEALTH & HUMAN SERVICES
Health Care Financing Administration

Center for Medicaid and State Operations
7500 Security Boulevard
Baltimore, MD 21244-1850

JUL 29 1998

Dear State Medicaid Director:

In the Americans with Disabilities Act (ADA), Congress provided that "the Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals." 42 U.S.C. § 12101(a)(8). Title II of the ADA further provides that "no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs or activities of a public entity, or be the subject of discrimination by any such entity." 42 U.S.C. § 12132. Department of Justice regulations implementing this provision require that "a public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities." 28 C.F.R. § 35.130(d).

We have summarized below three Medicaid cases related to the ADA to make you aware of recent trends involving Medicaid and the ADA.

In L.C. & E.W. v. Olmstead, patients in a State psychiatric hospital in Georgia challenged their placement in an institutional setting rather than in a community-based treatment program. The United States Court of Appeals for the Eleventh Circuit held that placement in an institutional setting appeared to violate the ADA because it constituted a segregated setting, and remanded the case for a determination of whether community placements could be made without fundamentally altering the State's programs. The court emphasized that a community placement could be required as a "reasonable accommodation" to the needs of disabled individuals, and that denial of community placements could not be justified simply by the State's fiscal concerns. However, the court recognized that the ADA does not necessarily require a State to serve everyone in the community but that decisions regarding services and where they are to be provided must be made based on whether community-based placement is appropriate for a particular individual in addition to whether such placement would fundamentally alter the program.

In Helen L. v. DiDario, a Medicaid nursing home resident who was paralyzed from the waist down sought services from a State-funded attendant care program which would allow her to receive services in her own home where she could reside with her children. The United States Court of Appeals for the Third Circuit held that the State's failure to provide services in the "most integrated setting appropriate" to this individual who was paralyzed from the waist down violated the ADA, and found that provision of attendant care would not fundamentally alter any State program because it was already within the scope of an existing State program. The Supreme Court declined to hear an appeal in this matter, thus, the Court of Appeals decision is final.

most integrated setting

HCFA does not want to define
most integrated & fundamental
alteration.

determination made by treatment
team — we can't define.

DOJ amicus is early in
process.
develop position during Jan.

21 states signed on to
cert petition in Olmstead.

HHS → MC proj. course
DOJ file before 2/98? NO

workgroup w/ advocates & states
2/98 est.

State specific def's of —
most integ

In Easley v. Snider, a lawsuit, filed by representatives of persons with disabilities deemed to be incapable of controlling their own legal and financial affairs, challenged a requirement that beneficiaries of their State's attendant care program must be mentally alert. The Third Circuit found that, because the essential nature of the program was to foster independence for individuals limited only by physical disabilities, inclusion of individuals incapable of controlling their own legal and financial affairs in the program would constitute a fundamental alteration of the program and was not required by the ADA. This is a final decision.

While these decisions are only binding in the affected circuits, the Attorney General has indicated that under the ADA States have an obligation to provide services to people with disabilities in the most integrated setting appropriate to their needs. Reasonable steps should be taken if the treating professional determines that an individual living in a facility could live in the community with the right mix of support services to enable them to do so. The Department of Justice recently reiterated that ADA's "most integrated setting" standard applies to States, including State Medicaid programs.

States were required to do a self-evaluation to ensure that their policies, practices and procedures promote, rather than hinder integration. This self-evaluation should have included consideration of the ADA's integration requirement. To the extent that any State Medicaid program has not fully completed its self-evaluation process, it should do so now, in conjunction with the disability community and its representatives to ensure that policies, practices and procedures meet the requirements of the ADA. We recognize that ADA issues are being clarified through administrative and judicial interpretations on a continual basis. We will provide you with additional guidance concerning ADA compliance as it becomes available.

I urge you also, in recognition of the anniversary of the ADA, to strive to meet its objectives by continuing to develop home and community-based service options for persons with disabilities to live in integrated settings.

If you have any questions concerning this letter or require technical assistance, please contact Mary Jean Ducken at (410) 786-3294.

Sincerely,

Sally K. Richardson
Director

cc: All HCFA Regional Administrators

All HCFA Associate Regional Administrators
for Medicaid and State Operations

MA } lawsuits + 2 others
TX

States would agree that communications to date these are not unacceptable to States?

① Reality
Helen L. nothing new.
Self eval process

② Perception

only req'y States don't have to fundamentally alter their prg ——— what does that mean ——— there's no answer

amicus in Olmstead (DOJ)

Cost not issue for one, might be issue for ~~cost~~ class action suit

CT – fine. moved before letter released to get Δ.

how does it apply to Medicare.

ADAPT
CAMPAIGN for REAL CHOICE

ADAPT demands that Secretary of Health and Human Services Donna Shalala do the following:

1) **Meet with 15 ADAPT representatives by January 31, 1999 to develop a transition plan that will result in each State assuring "most integrated setting."**

2) **Include sufficient funding in the President's 2000 budget for implementation of "most integrated setting" at the state level.**

3) **Propose to Congress an initiative that would increase the federal matching rate for home and community services.**

4) **Direct Nancy Ann Min DeParle, Administrator of the Health Care Financing Administration (HCFA) to implement "most integrated setting" at the state level.**

5) **Proprose legislation that would eliminate nursing home beds when they become vacant.**

6) **Propose legislation that would take the "cap" off all nursing home/ICF-MR waivers.**

7) **Contract with ADAPT for technical assistance and training on "the most integrated setting".**

8) **Review and implement the recommendations of the University of California at San Francisco in a report funded by HCFA concerning the institutional bias of the long term service and support system.**

9) "Real" Date Certain

DEPA TMENT OF HEALTH & HU AN S RVICES

Office of the Secretary

Washington, D.C. 20201

To ADAPT:

11/3/98

The Secretary of HHS and top Administrative officials agree to meet with 15 Adapt representatives by January 3, 1999 to develop a transition plan that will result in each and every state complying with the most integrated setting requirements of the ADA The meeting agenda will include the Secretary 's assurance that she will work with ADAPT so that the FY 2000 Budget includes sufficient funds to carry out the aforementioned objective.

Sincerely,

John J. Callahan
Assistant Secretary of
Management and Budget

1045

AGENDA

Secretary's Meeting with ADAPT

Attendees: Secretary Shalala, Sally Richardson, Bob Williams, Dave Garrison, 3 ADAPT Members

Length of Meeting: One hour

I. Welcome and Introductions (Secretary Shalala) (5 minutes)

- Goals for the meeting:
  - Secretary Shalala will outline her disability policy goals
  - Sally Richardson and Bob Williams will give an update on the Home and Community Based Services Work Group
  - Secretary Shalala will listen to the concerns of the ADAPT members and discuss potential actions that HHS might take to further common goals.

II Background on HHS HCBS Efforts (Sally Richardson and Bob Williams) (15 minutes)

- UCSF study and HHS followup activities
- Policies and activities related to "most integrated setting"
- Date certain activities for FY 1998 and 1999
- Cash and Counseling update
- Employment of people with disabilities

III Opportunity for ADAPT to present issues and concerns to Secretary (40 minutes)

(57840)

Civil Rights Division

Disability Rights Section
P.O. Box 66738
Washington, DC 20035-6738

JUL - 6 1998

LETTER TO ADAPT REGARDING SELF_EVALUATION

Mr. Michael Auberger
ADAPT
Post Office Box 9598
Denver, Colorado 80209

Mr. Bob Kafka
ADAPT of Texas
1339 Lamar Square Drive
Suite 101
Austin, Texas 78704

Dear Mr. Auberger and Mr. Kafka:

Thank you for your letter seeking clarification of the Americans with Disabilities Act's (ADA) self-evaluation requirements as they relate to the "integration mandate" of title II.

The ADA requires every public entity to conduct a self-evaluation of its "current services, policies, and practices, and the effects thereof, that do not meet the requirements of [the title II regulations] . . . ." 28 C.F.R. 35.105(a). One of the fundamental requirements of the title II regulations is that public entities "administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities." 28 C.F.R. 35.130(d).

This integration requirement applies to all State activities, including the provision of nursing home, institutional, and community-based services to people with disabilities. L.C. v. Olmstead, No. 97-8358 (11th Cir. April 8, 1998); Helen L. v. DiDario, 46 F.3d 325 (3d Cir. 1995). Therefore, a State must review, as part of its self-evaluation, its policies and practices regarding the provision of nursing home, institutional, and community-based services to ensure that individuals with disabilities receive services in the most integrated setting appropriate to their needs.

If a State has failed to address the ADA's integration requirement in its self-evaluation, then its self-evaluation is incomplete. In these circumstances it would be appropriate for State officials to address the integration issue. As provided in the Department's implementing regulation at 28 C.F.R. 35.105(b), interested persons, including individuals with disabilities or organizations representing individuals with disabilities, must be given an opportunity to participate in the self-evaluation process.

Sincerely,

John L. Wodatch
Chief
Disability Rights Section

Comments
Janet Reno, Attorney General of the United States
National Council On Independent Living
Awards Luncheon
May 15, 1998
Washington, D.C.

"... We believe that states have an obligation to provide services to people with disabilities in the most integrated setting appropriate to their needs. And we have used the law to fight for this. Many individuals with disabilities are being placed in nursing homes or other institutional settings even when they don't really need to be there."

"... But some states don't understand what I've been talking about and they refuse to make reasonable modifications in their policies that would allow this to happen. They deny people with disabilities from receiving community based services under already existing state programs.

That is why we have argued that the ADA's integration mandate should be applied in these situations.

We say reasonable steps should be taken to provide services in the community where that is the appropriate setting for the individual. I am happy to report that the only two courts of appeal to address this issue have agreed with our reading of the law." ...

Janet Reno, United States Attorney General made the above statement at the National Council On Independent Living's Annual Meeting. Janet Reno's statement is in direct response to ADAPT's efforts to require states to make their programs accessible under the Americans With Disabilities Act (ADA). State Programs like Medicaid would be required to insure that they were delivered in the most integrated setting.

<u>NEWS FLASH....NEWS FLASH....NEWS FLASH....NEWS FLASH....</u>

Date Line: Metropolis

Superman (Christopher Reeves) has just endorsed MiCASA.

Project Name: Work Incentive, Counseling and Assistance Program for SSI Recipients

Initial Year Funds Approved: $341,481

Target Population: SSI recipients in Mental Health Centers and those working with VR

Abstract: This project, run by Division of Vocational Rehabilitation (VR), in cooperation with Division of Mental Health (MH), will provide SSI recipients in MH Centers and those working with VR with improved access to vocational services and employment outcomes, and improved benefits counseling on the impact that work will have on their benefits. The project will document the impact of these improved benefits, and compare the costs of providing these benefits with the savings that Federal and State governments will realize if these individuals go to work in much larger numbers than previously. It includes consumers as benefit counselors and evidence of good intra-agency collaboration.

Sites: Statewide

Wisconsin -- Lead Agency: Department of Health and Family Services

Project Name: **Pathways to Independence**

Initial Year Funds Awarded: $946,525

Target Population: Individuals with physical disabilities, mental illness, developmental disabilities and AIDS/HIV

Abstract: This project is the product of 5 years of study and pre-testing. It will provide 1800 SSI/SSDI beneficiaries in four target groups with comprehensive help in securing and maintaining gainful employment in 15 to 20 sites. It will make better use of existing work incentives, and add new assurances of health and long term care coverage regardless of earnings. It will reduce fragmentation and assure participants are better off as a result of employment. The two lead agencies, The Department of Health and Family Services and the Department of Workforce Development will solicit proposals from local public or private organizations to serve as the Pathways access points, establish local networks and provide services. The services will include health and employment consultation to "pull all the pieces together" by involving vocational rehabilitation counselors, representatives from housing and transportation, prospective employers, mental health professionals and case managers for long term care services. The local organizations will also give advice about use of work incentives (1619, Impairment Related Work Expenses, PASS, etc.), help develop employment goals, assess skills, recruit employers and match employees to jobs. The project reflects significant outreach, coordination of services, counseling, follow-on support. Wisconsin will pursue a Medicaid buy-in under section 1733 of the Balanced Budget Act and combine several data bases to house all data in a single data base. If SSDI waiver authority is restored, they will seek a waiver to freeze trial work period for the 5 year duration of the project and elimination of the SSDI payment "cliff".

Sites: Fifteen sites to be determined by competition after award.

[Go Back To Results]

Mingle MC/MCare #
Want to do capitation rates

Bill Clarke HCFA

Hunter McKay ASPE (6906443)

(319 8140)

DHFS

HOME
NEWS & INITIATIVES
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Long Term Care

The Capital Times

MADISON, WISCONSIN Wednesday, June 17, 1998

Wisconsin's economy is booming, unemployment is at record lows, and employers are scrambling to find workers. Yet thousands of Wisconsin citizens who can work and who want to work remain on the labor sidelines.

These citizens are people with disabilities. In 1995, only 7.5 percent of people with severe disabilities in the United States were employed.

Many people with disabilities want to work. And many can work, thanks to advances in health care and technology that have made it possible for individuals with even very severe disabilities to hold a steady job. Advances such as voice-activated computers, new psychotropic medications and motorized wheelchairs mean that people with disabilities are able to compete in the job market.

The tragedy is that thousands of people with disabilities who don't work are unable to reap the rewards of a healthy economy such as purchasing a new car or buying their first home.

So why don't more people with disabilities go to work? The current disability benefit system actually creates barriers to attaining a working income and accumulating assets. There are two major problems. First is the fear of losing health and long-term care coverage, including Medicaid, Medicare and attendant services. Whether they work or not, many people with disabilities need these programs to survive.

Second, the complex and fragmented disability system lacks common income eligibility standards. Even a modest level of work, while acceptable for one program, might mean the loss of eligibility for another program. And that could set off a chain reaction that results in the loss of all or nearly all supports.

We can address these problems. Gov. Thompson has proposed a new initiative called Pathways to Independence. A joint effort by the Department of Health and Family Services and the Department of Workforce Development, Pathways to Independence is a research and demonstration project that will build on existing services and address the issues of health and long-term care coverage and system complexity.

During a five-year test period at multiple sites, the project would serve about 1,200 to 1,800 Wisconsin residents with physical disabilities, mental illness, HIV/AIDS and develop-mental disabilities. Proposed services include benefit counseling to help individuals navigate the current system, and intensive vocational services to help them set and meet their employment goals.

The proposal faces a big challenge: to implement the necessary program changes to make Pathways to Independence a reality, the state needs federal permission in the form of waivers. These federal waivers would allow us to secure the health and long-term care coverage and the cash benefits for project participants who are already receiving these benefits.

Obtaining federal approval can be a tedious, time-consuming process. But Gov. Thompson and both departments strongly believe the project is well worth the effort.

Pathways to Independence creates a "win-win" opportunity for Wisconsin. The taxpayers win because, upon entering the work force, people with disabilities become wage earners who will contribute Social Security taxes and income taxes. Wisconsin's employers also win because they will be able to tap the full potential of Wisconsin's work force.

Also, individuals with disabilities will be given the freedom to seek and hold a job in a way that has not been available before. They will be able to share in the emotional rewards and self esteem of having a job - and this, perhaps, makes the human spirit the biggest winner of all.

Joe Leean is secretary of the Department of Health and Family Services. Linda Stewart is secretary of the Department of Workforce Development.

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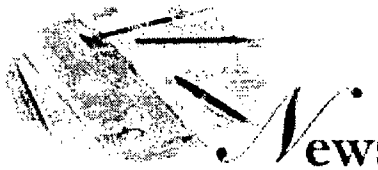
Send Your Comments to: webmaster



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9/18/98, Governor's Pathways to Independence Gets Big Federal Grant

CONTACT:
David Blaska (608) 266-6925

FOR IMMEDIATE RELEASE

(MADISON, September 18, 1998) -- Gov. Tommy G. Thompson today announced that Wisconsin has received a $946,525 federal grant to help fund the state's Pathways to Independence initiative, a program designed to remove barriers to employment for people with disabilities.

Wisconsin was one of nine states that received grants totaling $4.4 million. Wisconsin's grant is the single largest.

"In the past, fear of losing their insurance coverage has prevented people with disabilities from seeking jobs. Pathways to Independence will let them keep their Medicaid or Medicare coverage while they work," Gov. Thompson said. "It only makes common sense to help the disabled secure health coverage so they can pursue their own careers and help build our economy."

Gov. Thompson has instructed the Department of Health and Family Services and the Department of Workforce Development to work together to gain the necessary federal waivers and funding. In late October, the two Departments will issue a joint request for proposals from local organizations to begin piloting Pathways. Beginning in January, up to 1800 working age people with disabilities can be enrolled over the course of the next five years.

Gov. Thompson noted that although implementing this ambitious initiative is a challenge, he hopes to be able to announce even greater progress in helping people with disabilities reach their full employment potential within the next several months.

The grant was awarded from the federal Social Security Administration.

-30-

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Send Your Comments to: webmaster

nothing to OMB

Pathways

no offical wairer application sent to HCFA.

handled out of CMSO.

concept paper floating around since 998 "SSDI to people who would lose eligibility for Mcare part A b/c they've been working too long.

Mcare expansion of eligibility

confusion as to whether there is any wairer authority to do this.

Mcaid 1115 SSI people to keep MC when they go back to work.

this would use savings from the SSA program.

I don't need a wairer 4733 I

expand beyond to the min

1902(r)(2)

Withdrawal/Redaction Marker
Clinton Library

DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
001. email	Jonathan Young to Christopher Jennings et al. re: Agenda for 11:00 AM Meeting (partial) (1 page)	10/29/1998	P6/b(6)

COLLECTION:
Clinton Presidential Records
Domestic Policy Council
Devorah Adler
OA/Box Number: 20463

FOLDER TITLE:
Disability [Folder 2]

2012-0463-S
rc741

RESTRICTION CODES

Presidential Records Act - [44 U.S.C. 2204(a)]

P1 National Security Classified Information [(a)(1) of the PRA]
P2 Relating to the appointment to Federal office [(a)(2) of the PRA]
P3 Release would violate a Federal statute [(a)(3) of the PRA]
P4 Release would disclose trade secrets or confidential commercial or financial information [(a)(4) of the PRA]
P5 Release would disclose confidential advice between the President and his advisors, or between such advisors [a)(5) of the PRA]
P6 Release would constitute a clearly unwarranted invasion of personal privacy [(a)(6) of the PRA]

C. Closed in accordance with restrictions contained in donor's deed of gift.
PRM. Personal record misfile defined in accordance with 44 U.S.C. 2201(3).
RR. Document will be reviewed upon request.

Freedom of Information Act - [5 U.S.C. 552(b)]

b(1) National security classified information [(b)(1) of the FOIA]
b(2) Release would disclose internal personnel rules and practices of an agency [(b)(2) of the FOIA]
b(3) Release would violate a Federal statute [(b)(3) of the FOIA]
b(4) Release would disclose trade secrets or confidential or financial information [(b)(4) of the FOIA]
b(6) Release would constitute a clearly unwarranted invasion of personal privacy [(b)(6) of the FOIA]
b(7) Release would disclose information compiled for law enforcement purposes [(b)(7) of the FOIA]
b(8) Release would disclose information concerning the regulation of financial institutions [(b)(8) of the FOIA]
b(9) Release would disclose geological or geophysical information concerning wells [(b)(9) of the FOIA]

Jonathan M. Young
10/29/98 09:39:07 AM

Record Type: Record

To: See the distribution list at the bottom of this message

cc: Teresa M. Jones/OPD/EOP, Gina C. Mooers/OMB/EOP, Chantell S. Long/OPD/EOP, Sandra Yamin/OMB/EOP

Subject: Agenda for 11:00 AM Meeting in OEOB 472

I'm looking forward to our meeting. Based on last Friday's meetings and the September conference calls, here's how I suggest we proceed. I have a 10:00 AM security briefing. Page me or call my mobile at P6/(b)(6) if you need me for anything.
[001]

- **Welcome & Introductions** (I'd be happy to introduce each of you and the dis. reps, perhaps you can introduce any supporting staff with you.)

- **Review of how the process works** (As far as I understand, this is one of the first times the disability community has had a chance, like other constituencies, to be involved in the front end of the budget process. I think it would be worthwhile for OMB to tell them how this process works best and how it can be most mutually beneficial. Dis reps tell me they would like to talk some generally about how disability can be integrated.)

- **Brief Review of Victories and Losses for FY1999** (From community perspective, winning on preventing IDEA amendments, getting dollars for civil rights enforcement, and fighting a good fight on Jeffords-Kennedy are key.)

- **Administration Priorities for FY 2000** (As we discussed Friday, it would appear best for us to begin with how the Presidential priorities are beginning to fall into place, not necessarily in terms of budget details, but the overall themes.)

- **How Disability Fits** (As we discussed Friday, it would appear best for us to offer ways in which we think disability fits into next year's budget, rather than leave us exposed to the dis. reps. saying disability isn't part of the President's agenda. Some suggestions: enforcing IDEA, accessibility in school modernization process, continuing with Jeffords-Kennedy and any other work incentives, access to specialists for patients bill of rights, exploring ways to move away from the default toward institutions in favor of community-based options, civil rights enforcement, assistive technology, saving Social Security.)

- **How Disability Community Can Support Administration** (It may be worthwhile to give the community a couple of suggestions about where we'd like to seem them helping out the President's agenda, even where there's not a specific disability angle, e.g. education, patients bill of rights, saving social security. Or maybe you want them to bring that up?)

- **Invite Disability Reps Feedback** (After we've spelled out the above, perhaps we could invite the dis reps for feedback on the extent to which we're on the right track, and then give them a chance to talk about any additional interests.)

- **Follow-up** (The dis reps understand than one hour does not allow for extensive specificity.

Maybe we'd like to invite them to join future topic-specific meetings. Also, I face a sizable level of criticism for bringing only 7 people into the room for the community [some people and orgs will certainly be left out]. Maybe later we could invite a bigger group to a briefing when the budget is in the final stages of design. Community reps told me they decided not to put anything in writing at this point but would be glad to do so if you thought it would be helpful as a follow-up.)

As far as I understand, the disability representatives are thinking in terms of six broad topics:

- Kids (education, health, etc.
- Work (Jeffords-Kennedy, etc.)
- Community (health, housing, attendant care, etc.)
- Rights (enforcement)
- Social Security (saving it, reform of disincentives)
- Infrastructure (accessibility, assistive technology, etc.)

Message Sent To:

Christopher C. Jennings/OPD/EOP
Barbara Chow/OMB/EOP
Michael Cohen/OPD/EOP
Lisa M. Brown/OVP @ OVP
Jeanne Lambrew/OPD/EOP
Daniel N. Mendelson/OMB/EOP

DEPARTMENT OF THE TREASURY
OFFICE OF TAX POLICY

1500 PENNSYLVANIA AVENUE, N.W.
WASHINGTON, DC 20220

NUMBER OF PAGES: 5 DATE: 11/6/98

TO: Jeanne Lombrew | 456-5557 | _____
Name | FAX number | Confirmation No.

FROM: Bill Strang | 622-1317
Name | Phone Number

Sender's FAX number: 202/622-1772 **Location: Room 4206**

Comments/Special Instructions: _____

November 6, 1998

To: Jeanne Lambrew

From: Bill Strang

cc: Sonia Conly, Andrew Bershadker, Joel Platt, Janet Holtzblatt, Steve Arkin, Lily Khang, Phil Ellis

Re: Reconciliation of alternative definitions and numbers of the physically/mentally challenged

Regarding your question concerning the reconciliation between my number of 10 million employees with the much smaller number of employees with at least one ADL, see the attached pages. The first page reconciles alternative definitions. The table on the second page reconciles some of the numbers. The third page shows the definition of "handicapped individual" in Sec. 190(b)(3) of the tax code, which I read (the terminology is not identical, but it is close) as being the set of those with "functional limitations" and/or at least one ADL. This is clearly at least as large as the set of those with functional limitations alone. From the table on page 2, in 1994, about 8 percent of the about 125 million employed (or about 10 million) had a functional limitation. In short, the 190(b)(3) definition is much broader that those with ADLs.

We await further guidance on an appropriate definition for the proposed tax credit. Specifically, even if 2+ ADLs gets us about the right number of individuals, it may not be the most deserving group of that number. For example, a paraplegic who needs to be driven to work might be far more productive than a blind person (who has a functional limitation but no ADLs) working on a computer. The alternative definitions on the first page may help better identify the best-targeted group.

I will be out of the office next week, so call Sonia or Andrew Bershadker (622-4981), who is taking over for me on this issue, if you have further questions.

SIPP DISABILITY SCALE

Current Population Reports

Household Economic Studies

Americans With Disabilities: 1994-95

By John M. McNeil

CENSUS BUREAU

P70-61
August 1997

Introduction

The passage of the 1990 Americans With Disabilities Act (ADA) brought with it an increased awareness of the need to monitor the situation of people with disabilities. Perhaps the most important current source of periodic data on the number and characteristics of people with disabilities is the Survey of Income and Program Participation (SIPP). The extensive information collected in SIPP makes it possible to relate disability status to a range of other variables including income, employment, health insurance coverage, and the receipt of program benefits.

The estimates in this report are based on data collected in the SIPP during the period October 1994 - January 1995. Data from the 1993 panel were combined with data from the 1992 panel to maximize the size of the sample. The universe for this study excludes people living in institutions. This report updates an earlier report, Americans With Disabilities: 1991-92 , Series P70-33.

Highlights

- At the end of 1994, 20.6 (+/- 0.3) percent of the population, about 54 (+/- 0.7) million people, had some level of disability; 9.9 (+/-0.2) percent or 26 (+/- 0.5) million people had a severe disability.
- Among the 237 million people 6 years old and over, 1.8 (+/- 0.2) million used a wheelchair. An additional 5.2 (+/- 0.3) million used a cane, crutches, or a walker and had used such an aid for 6 months or longer.
- Among people age 6 and over, 8.8 (+/- 0.3) million had difficulty seeing, and 10.1 (+/- 0.4) million had difficulty hearing. The number unable to see was 1.6 (+/- 0.1) million, and 1.0 (+/- 0.1) million were unable to hear.
- The number of people age 6 and over who needed the assistance of another person with one or more activities of daily living (ADL) (see the box below for a list of ADLs) was 4.1 (+/- 0.2) million. Of the 4.1 million needing assistance, 2.2 (+/- 0.2) million were 65 years old or older.
- Among people age 15 years old and over, 15.3 (+/-0.4) million were unable to perform one or more functional activities, and 9.0 (+/-0.3) million needed the assistance of another person with one or more instrumental activities of daily living (IADL) (see the box on page 1 for a list of IADLs). Of the 9.0 million people needing assistance

Definition of Disability Including Functional Limitations, ADLs, and IADLs

People 15 years old and over were identified as having a disability if they met any of the following criteria:

- Used a wheechair or were a long-term user of a cane, crutches, or a walker
- Had difficulty performing one or more functional activities (seeing, hearing, speaking, lifting/carrying, using stairs, or walking)
- Had difficulty with one or more activities of daily living (the ADLs included getting around inside the home, getting in or out of bed or a chair, bathing, dressing, eating, and toileting)
- Had difficulty with one or more instrumental activities of daily living (the IADLs included going outside the home, keeping track of money and bills, preparing meals, doing light housework, taking prescription medicines in the right amount at the right time, and using the telephone)
- Had one or more specified conditions (a learning disability, mental retardation or another developmental disability, Alzheimer s disease, or some other type of mental or emotional condition)
- Were limited in their ability to do housework
- Were 16 to 67 years old and limited in their ability to work at a job or business
- Were receiving federal benefits based on an inability to work

People age 15 and over were identified as having a severe disability if they were unable to perform one or more functional activities; needed personal assistance with an ADL or IADL; used a wheelchair; were a long-term user of a cane, crutches, or a walker; had a developmental disability or Alzheimer s disease; were unable to do housework; were receiving federal disability benefits; or were 16 to 67 years old and unable to work at a job or business.

20 to 24 s old	82	77.4	17.1	5.4	53.5	34.9	11.6
25 to 54 years old	1,929	82.0	13.2	4.8	42.4	28.6	28.9
55 to 64 years old	276	60.7	12.6	26.7	41.5	14.8	43.7
65 years old and over	71	(2)	(2)	(2)	(2)	(2)	(2)
Females	1,813	68.2	11.8	20.0	45.5	20.2	34.4
20 to 24 years old	67	63.9	18.9	17.2	52.3	23.9	23.8
25 to 54 years old	1,468	73.9	10.6	15.6	44.0	21.0	35.1
55 to 64 years old	211	40.8	21.9	37.3	50.1	15.5	34.4
65 years old and over	67	(2)	(2)	(2)	(2)	(2)	(2)
White	3,632	74.1	12.0	13.9	43.0	24.7	32.4
Black	420	67.4	17.1	15.5	51.8	20.0	28.2
Hispanic origin [3]	383	66.5	22.8	10.7	49.5	37.0	13.4

[1] Includes other races, not shown separately. [2] Data not shown where base is less than 75,000. [3] Persons of Hispanic origin may be of any race.

Source: U.S. Bureau of Labor Statistics, *News*, USDL 96-446.

No. 643. Percent Distribution of Employed Persons by Disability Status: 1991 to 1994

[Data from the Survey of Income and Program Participation]

DISABILITY STATUS	1991	1993	1994	DISABILITY STATUS	1991	1993	1994
All employed persons (1,000)	119,432	122,614	125,591	Lifting and carrying	2.3	2.6	2.5
Total of employed persons	100.0	100.0	100.0	Climbing stairs	2.3	2.6	2.8
With no disability	86.6	86.2	86.2	Walking 3 city blocks	2.4	2.6	2.7
With a disability	13.4	13.8	13.8	With an ADL [1] limitation	0.8	1.0	0.9
Severe	2.8	3.2	3.4	With an IADL [2] limitation	1.1	1.3	1.4
Not severe	10.6	10.6	10.4	Needs personal assistance and an ADL or IADL	0.7	0.9	0.9
With a functional limitation	8.4	8.9	7.9				
Severe	1.7	2.0	2.1	Uses a wheelchair	0.1	0.1	0.1
With difficulty:				Does not use a wheelchair,			
Seeing words and letters	2.0	2.2	1.6	but uses a cane, crutches,			
Hearing normal conversation	3.2	3.5	2.7	or a walker	0.4	0.5	0.4

[1] ADL's are activities of daily living and include getting around inside the home, getting in or out of a bed or chair, taking a bath or shower, dressing, eating, and using the toilet. [2] IADL's are instrumental activities of daily living and include going outside the home, keeping track of money and bills, preparing meals, doing light housework, and using the telephone.

Source: U.S. Census Bureau, Internet site <http://www.census.gov/hhes/www/disable/dissipp.html> (Accessed 18 June 1997)

No. 644. Persons Not in the Labor Force: 1996

[**In thousands. Annual average of monthly figures.** For the civilian noninstitutional population 16 years old and over. Based on the Current Population Survey; see text, section 1, and Appendix III]

STATUS AND REASON	Total	AGE			SEX	
		16 to 24 years old	25 to 54 years old	55 years old and over	Male	Female
Total not in the labor force	**66,647**	**11,160**	**16,720**	**36,768**	**24,119**	**42,528**
Do not want a job now [1]	61,197	9,110	16,205	35,882	21,929	39,267
Want a job now	5,451	2,050	2,514	886	2,190	3,261
In the previous year—						
Did not search for a job	3,161	1,100	1,407	654	1,185	1,976
Did search for a job [2]	2,290	950	1,108	232	1,005	1,285
Not available for work now	732	365	328	40	277	455
Available for work now, not looking for work	1,558	585	780	192	728	830
Reason for not currently looking:						

ıe allocation of interest to
end of para. (e)(1) . . . Sec.
onstruction period interest
terest and taxes" in para.
l) Real property construc-
Construction period interest
, effective for tax. yrs. be-
which commences after

follows:
l interest and taxes.
section or in section 266
e of an individual, no de-

r accrued in a taxable year beginning in—

ential real property r than low income housing)	Low-income housing	The percentage of such amount allowable for each amortization year shall be the following percentage of such amount see subsection (f)
1978	1982	25
1979	1983	20
1980	1984	16⅔
1981	1985	14⅓
1982	1986	12½
1983	1987	11⅓
after 1983	after 1987	10"

duction shall be allowed for real property construction period interest and taxes. For purposes of this section, an electing small business corporation (as defined in section 1371(b)), a personal holding company (as defined in section 542), and a foreign personal holding company (as defined in section 552) shall be treated as an individual."

In '81, P.L. 97-34, Sec. 262(a), amended the table in subsec. (b) . . . Sec. 262(b), amended subsec. (d), effective for tax. yrs. begin. after 12/31/81.

Prior to amendment, the table in subsec. (b) read as follows:

:ollows:
l.
:al property acquired, con-
ot, and cannot reasonably
ness or in an activity con-

d Sec. 201(c)(1), P.L. 94-
s:
property, if the construc-
y of the first taxable year

an electing small business
ın 1371(b)), or a personal
section 542)," following
c. (a) and added the last
cluded in the amendment
below.
'ode Sec. 189. Sec. 201(c)

shall apply—
property, if the construc-
75,
ıperty (other than low-in-
ıing after December 31,

ʒ, to taxable years begin-

:rms 'nonresidential real
r than low-income hous-
ruction period' have the
9 of the Internal Revenue
of this section)."

cle owned or leased by the taxpayer for use in connection with his trade or business more accessible to, and usable by, handicapped and elderly individuals.

(2) Qualified architectural and transportation barrier removal expense. The term "qualified architectural and transportation barrier removal expense" means, with respect to any such facility or public transportation vehicle, an architectural or transportation barrier removal expense with respect to which the taxpayer establishes, to the satisfaction of the Secretary, that the resulting removal of any such barrier meets the standards promulgated by the Secretary with the concurrence of the Architectural and Transportation Barriers Compliance Board and set forth in regulations prescribed by the Secretary.

(3) Handicapped individual. The term "handicapped individual" means any individual who has a physical or mental disability (including, but not limited to, blindness or deafness) which for such individual constitutes or results in a functional limitation to employment, or who has any physical or mental impairment (including, but not limited to, a sight or hearing impairment) which substantially limits one or more major life activities of such individual.

(c) Limitation.

The deduction allowed by subsection (a) for any taxable year shall not exceed $15,000 .

In '90, P.L. 101-508, Sec. 11611(c), substituted "$15,000" for "$35,000" in subsec. (c), effective for tax. yrs. begin. after 11/5/90. —P.L. 101-508, Sec. 11801(a)(14), repealed subsec. (d), effective 11/5/90 except as provided in Sec. 11821(b) of this Act, reproduced in note following Code Sec. 184.

Prior to repeal, subsec. (d) read as follows:

"(d) Application of section.

ɔve architectural and
: handicapped and eld-

:ect to treat qualified ar-

DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of the Secretary

Washington, D.C. 20201

To ADAPT:

11/3/98

The Secretary of HHS and top Administrative officials agree to meet with 15 Adapt representatives by January 3, 1999 to develop a transition plan that will result in each and every state complying with the most integrated setting requirements of the ADA The meeting agenda will include the Secretary 's assurance that she will work with ADAPT so that the FY 2000 Budget includes sufficient funds to carry out the aforementioned objective.

Sincerely,

John J. Callahan
Assistant Secretary of
Management and Budget

DEPARTMENT OF HEALTH & HUMAN SERVICES
Health Care Financing Administration

Center for Medicaid and State Operations
7500 Security Boulevard
Baltimore, MD 21244-1850

JUL 2 9 1998

Dear State Medicaid Director:

Dear State Medicaid Director:

In the Americans with Disabilities Act (ADA), Congress provided that "the Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals." 42 U.S.C. § 12101(a)(8). Title II of the ADA further provides that "no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs or activities of a public entity, or be the subject of discrimination by any such entity." 42 U.S.C. § 12132. Department of Justice regulations implementing this provision require that "a public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities." 28 C.F.R. § 35.130(d).

We have summarized below three Medicaid cases related to the ADA to make you aware of recent trends involving Medicaid and the ADA.

In L.C. & E.W. v. Olmstead, patients in a State psychiatric hospital in Georgia challenged their placement in an institutional setting rather than in a community-based treatment program. The United States Court of Appeals for the Eleventh Circuit held that placement in an institutional setting appeared to violate the ADA because it constituted a segregated setting, and remanded the case for a determination of whether community placements could be made without fundamentally altering the State's programs. The court emphasized that a community placement could be required as a "reasonable accommodation" to the needs of disabled individuals, and that denial of community placements could not be justified simply by the State's fiscal concerns. However, the court recognized that the ADA does not necessarily require a State to serve everyone in the community but that decisions regarding services and where they are to be provided must be made based on whether community-based placement is appropriate for a particular individual in addition to whether such placement would fundamentally alter the program.

In Helen L. v. DiDario, a Medicaid nursing home resident who was paralyzed from the waist down sought services from a State-funded attendant care program which would allow her to receive services in her own home where she could reside with her children.

The United States Court of Appeals for the Third Circuit held that the State's failure to provide services in the "most integrated setting appropriate" to this individual who was paralyzed from the waist down violated the ADA, and found that provision of attendant care would not fundamentally alter any State program because it was already within the scope of an existing State program. The Supreme Court declined to hear an appeal in this matter; thus, the Court of Appeals decision is final.

10/29

DISABILITY MTG.

UNITED CP Ass
Easter Seals
Nat Parent Network

Justice For All

just background & importance of inclusion.

① SS reform
disability lawyer for SS reform
② PB BOR?
③ long term care
way to avoid institutionalization.
this should be elevated
④ early intervention & ed
⑤ civil rights enforcement & protection
⑥ Infrastructure
personnel prep.
spec ed. training, etc.

wants indication of

this is a presidential priority.

① THANKS for fighting IDEA rider
Undo DC App rider limiting att fees for Inc. fam. (2)

② CHILD CARE INIT.
~~didn't really feel like it~~ app version for kids w disabilities

③ IDEA
couldn't go back to comm. w/ no new $ in part B of idea.

Early Int. Under IDEA
wants increases
commensurate w/ Head
Start.

PTI Line didn't get
increase

GAO study on IDEA?
family support legislation

Children's SSI
reinstatement

Barbra partisan explanation
taking civil rights
protections away from Underst.
limited prop

All kids in Literacy
prog including Dis.

need for structural improvements in $ early intervention Centers.

Need methodology for cost estimates for JK → build into this budget work related barriers and costs.

need to prove that we can move people off the rolls. CTRs: avoid temptation to ~~waiver~~ add more to our JK.

Title I increase less than COLA

baseline funding for centers.

insufficient support for rehab.

out of nursing homes
no housing
no supp. svcs.

Boston HUD → Ronkonkoma
650 people LI 400
complex → sfd 12/78

get rid of institutional bias under Medicaid

Long Term Care
MI Casa Bill
offsets fam mem
working, etc.

GAO studies, MetLife → cost sharing.

HCFA Backing Away from guidance → Medicare Helen Ellen.

disability comm wants to get on discuss Medicare Commission agenda.

anti-dumping notice

States need TA to implement most integrated setting policy

Need public forum to discuss transition

ADA
504
Civil Rights → ? DOJ EEOC
Fair Housing

Reg Reform Act → review of maj. Regs → review disability rights reg before next admin.

disability solutions
school construction

Task force on employment
Exec order in State of Orion.