

WITHDRAWAL SHEET

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Date: 5/7/04

DOCUMENT NO. & TYPE	SUBJECT/TITLE	DATE	RESTRICTION
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1. Letter	To Donna Shalala from Barbara Waxman and Daniel Fiduccia, 2p (partial)	4/15/94	P6/B6
2. Letter	Draft of letter to Donna Shalala from Waxman and Fiduccia (above), 2p (partial)	11/1993	P6/B6

RESTRICTIONS

- P1** National security classified information [(a)(1) of the PRA].
- P2** Relating to 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].
- PRM** Personal records misfile defined in accordance with 44 USC 2201 (3).

- B1** National security classified information [(b) (1) of the FOIA].
- B2** Release could disclose internal personnel rules and practices of an agency [(b)(2) of the FOIA].
- B3** Release would violate a Federal statute [(b)(3) of the FOIA].
- B4** Release would disclose trade secrets or confidential commercial financial information [(b)(4) of the FOIA].
- B6** Release would constitute a clearly unwarranted invasion of personal privacy [(b)(6) of the FOIA].
- B7** Release would disclose information compiled for law enforcement purposes [(b)(7) of the FOIA].
- B8** Release would disclose information concerning the regulation of financial institutions [(b)(9) of the FOIA].
- B9** Release would disclose geological or geophysical information concerning wells [(b)(9) of the FOIA].

BOX II

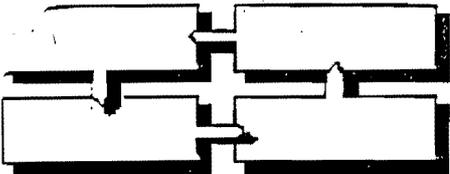
Marriage Penalty - Wax Man Case plus Kennedy Case
NICHD Funding
National and Community Service Act / Corps Follow Up
National Association on State Governors - Committees on PWD
National Information Infrastructure .. Aug. 4, 1994 Meeting
Other Disability Issues
PCEPD Presidential Message
P & A Directories
PCMR Appointments
Personnel Matters
Presidential Boards and Commissions
President's Committee on Employment of People with Disabilities
President's Committee on Employment of People with Disabilities -
ADA Ideas and Recommendations
Presidential Letters
Rasco Articles and Bios
Speech: Rehabilitation International
Rehabilitation Services, Teamwork 2000
RSA Commissioner Appointments
SSA Disability Backlog, Reengineering
School to Work
Self Advocacy Conference
Special Education
Special Education SAFE Meeting
Sandy Turnor
Technology Related Assistance for PWD Amendments of 1994
Technology Related Assistance for Individuals Amendments Act
Transitions (1 of 2)
Transitions (2 of 2)
Transitions meetings of 10/27/94
Transitions memo
TY's
Vocational Rehabilitation
Vocational Rehabilitation GAO Reports
Wall Street and Follow-up

ENCLOSURES FILED OVERSIZE ATTACHMENTS

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NARA 5906

MAY 5 REC'D



**Self-Advocacy Grassroots
Organizing Program**
CENTRAL NEW YORK REGION

MICHAEL J. KENNEDY, Regional Organizer
SALLY W. JOHNSTON, Field Assistant
200 Huntington Hall
Syracuse, NY 13244-2340
(315) 443-4336

May 2, 1994

Carol Rasco
Assistant to the President
Domestic Policy Council
1600 Pennsylvania Ave NW
Washington DC 20506

Dear Ms. Rasco,

First of all I want to say, that it was very nice hearing your closing remarks on the Health Care Reform. I really enjoyed your speech. I am glad to know that we finally have someone in the White House, who will listen to the needs of the disabled people.

I am also writing to ask you a personal favor, not only for me but for the other disabled people as well. I would like you to encourage the President to please, put in the Final Health Care Reform Plan, a clause that states: No Disabled Person will lose their Medicaid Benefits just because they get married.

You see with me I need total assistance. And seeing Medicaid is my only Health Insurance, I can not afford to have it taken away from me, especially based on the fact that I got married. My wife works, but her insurance that she receives through her work does not cover me. I work 2 part-time jobs, so I am ineligible for Health insurance through my work.

I feel you are taking away my Constitutional Rights by saying that we can keep our Medicaid Benefits if we are not married. This is why I would like you to encourage the President to put this clause into the Health Care Reform Plan immediately.

I am not asking for any other assistance, just that my Medicaid stay intact. It has been going on for a long time now, the Social Services Department penalizing a disabled person because he/she gets married. I get 49 hours of Aide Service 7 days a week. And with out Medicaid paying for my Aide Service, I do not exist.

C. Rasco
May 2, 1994
page 2

I would like to set up a meeting with you and the President in **person**. I would like to ask you and the President the following question, would you like someone to tell you, you can't be married and keep your full Medicaid Benefits? Even if it is your only primary Health Insurance?

Sincerely,

Michael J. Kennedy
Regional Organizer

cc: Beth Wallbridge

HB 3264 Stark
SB _____ Resel
"at this point"

Respond to:

P6/(b)(6)

April 15, 1994

Mr. Peter Edelman
Counselor to the Secretary
Department of Health and Human Services
Hubert H. Humphrey Building, Room #615F
200 Independence Avenue, S.W.
Washington, D.C. 20201

Dear Mr. Edelman:

As we understand that you are Secretary Shalala's counselor for disability issues, we are delivering our enclosed letter and its attached letters of support directly to you. We hope that by doing so, our concerns as a disabled couple will be presented more promptly to the Secretary than they would be through other channels.

The Social Security Administration's enforcement of the outlined discriminatory policies is a disgraceful tradition of imposing, without exception, far-reaching misery on people with disabilities and their loved ones.

Twice in the last two years, the Social Security Administration has stated there would be no cost to the government in ending some of these marriage penalties. Secretary Shalala herself has said she cannot defend them. Despite this, the Social Security Administration continues to engage in the purposeful discrimination which results in keeping people with disabilities alone, childless, and/or impoverished.

On behalf of all those Americans suffering at the hands of the Social Security Administration, we ask that you give this matter a high priority and spare it further review and comment. Each day these shameful policies remain in force is a violation of the constitutional, civil, and human rights of people with disabilities.

We hope that the Clinton Administration will provide unhesitating and unprecedented support of the complete independence, equality, and

Mr. Peter Edelman

- 2 -

April 15, 1994

integration of people with disabilities by granting the requests listed in our letter within 30 days.

Sincerely,


Barbara Faye Waxman


Daniel J. Fiduccia

BFW:DF/njc
Enclosure

c: Donna E. Shalala, Secretary
Department of Health and Human Services
John Monahan, Director, Intergovernmental Affairs
Department of Health and Human Services
Philip Lee, Office of the Assistant Secretary for Health
Department of Health and Human Services
Stan Herr, Kennedy Fellow
Domestic Policy Council
Bruce Reed, Deputy Assistant to the President for Domestic Policy
Shirley Chater, Commissioner
Social Security Administration
Susan Daniels, Associate Commissioner on Disability (pending White
House approval)
Social Security Administration
Paul Steven Miller, Deputy Director
U.S. Office of Consumer Affairs

THIS FORM MARKS THE FILE LOCATION OF ITEM NUMBER 1
LISTED IN THE WITHDRAWAL SHEET AT THE FRONT OF THIS FOLDER.

THE FOLLOWING PAGE HAS HAD MATERIAL REDACTED. CONSULT THE
WITHDRAWAL SHEET AT THE FRONT OF THIS FOLDER FOR FURTHER
INFORMATION.

lease; it is necessary to have two of them available at all times in the event one becomes inoperable. Barbara's condition also severely restricts her mobility. She requires a motorized wheelchair and a modified van to get around, as well as the assistance of a personal service assistant in her home. To fund the personal assistance services, Barbara receives the maximum available hours benefit under In-Home Support Services ("IHSS") - California's personal assistance service program under Title XX of the Social Security Act. It is no understatement to say that these benefits all are necessary to sustain Barbara's life, enable her to live in the community, and maintain an almost full-time job.

Although Daniel is not a recipient of any Social Security benefits, he also is disabled because he is an adult survivor of childhood cancer. Even though he has been cancer-free for 36 years, he has multiple lifetime medical conditions as the late effects of his cancer treatment. These conditions include spinal and respiratory diseases. In particular, Daniel's own limitations make it impossible for him to administer certain care that Barbara requires and that is currently provided by her personal assistant. Even so, because of spousal deeming, Daniel's small resources will make Barbara ineligible for SSI and associated benefits once we marry.

We are, and wish to continue to be, productive members of society. Daniel has been employed since 1979, albeit on a less-than-full-time basis since 1984 when he became mobility-impaired. On April 5, 1993, Barbara returned to work after nine years of living almost entirely on SSDI and SSI benefits. Her ability to return to work was and is dependent upon SSA's work incentive program for gainfully employed, severely disabled workers -- specifically, SSI §§ 1619(a) & (b), Plan to Achieve Self-Support ("PASS") and Impairment-Related Work Expense exclusions ("IRWE").

Regulatory Background

Under various regulations in 20 C.F.R Part 16, the regulatory regime governing medical, SSDI and SSI benefits substantially penalizes people with disabilities who choose to exercise their fundamental right to marry. For example, and without limitation, resource exclusions, income exclusions and various property exclusions (such as for transportation, household goods and personal effects) are all far lower for married couples than they are for two individuals who are both eligible for one or more SSA-administered benefit programs. This problem is exacerbated by the fact that the exclusion levels have

barely changed in decades -- a period during which the cost of medical care has skyrocketed.

Similarly, when SSI benefit payments are computed for couples, both members of which are eligible for benefits, all countable income is summed before it is compared to the SSI federal benefit rate, with the effect of substantially reducing the benefit from levels that would pertain if the people received benefits as two individuals. The spouse-to-spouse deeming provisions require that income or resources that either member of a couple have be deemed to be those of the disabled member to determine eligibility for SSI or the benefit payment amount. Moreover, marriage terminates altogether Medicare and SSDI benefits available to a disabled adult child who, absent marriage, is eligible for benefits under the account of an insured parent who is disabled, retired or deceased. Finally, personal assistance services are treated by SSA regulations as if they were a luxury. Benefits that enable disabled people to have attendants are reduced or terminated in the event a disabled person marries. SSA expects the spouse of the disabled beneficiary, especially if the spouse is "able and available," to provide personal assistance services to their disabled spouse. As discussed below, this expectation has serious implications including without limitation the effect of undermining the very bonds of intimacy and love that are fundamental to the marital relationship.

(The policy is even worse when applied to the beneficiary's children. If the beneficiary has a child, personal assistance services will only be extended to that child if he or she is also disabled. Not only is this policy clearly discriminatory, but it also sends a message to beneficiaries that they will be forced to care for their child on their own -- in effect, be penalized -- should they have a non-disabled child.

(SSA's failure to provide a few more hours of personal assistance services for child care has resulted in the loss of child custody for many beneficiaries. Instead of providing some additional hours of personal assistance services in the child's early years, the state spends far more money on parental-rights termination proceedings, foster home placement and adoption. Meanwhile, the unmistakable message to SSA beneficiaries from this regulatory scheme is that they need not presume ever to have a family life.)

These and other marriage penalties in the SSA regulatory scheme stem from decades-old policies and regulations first codified during the Nixon Administration in 1972. Among other infirmities, these regulations apparently stem either from

(a) a paternalistic or stereotypic assumption that a disabled person could and would only wish to marry an able-bodied person, and/or (b) the unlawful and outdated assumption that a disability is the disabled person's problem, not society's problem.

Beyond the discriminatory and outmoded assumptions that underlie them, these regulations have real world consequences that substantially impair disabled citizens' fundamental rights both to marry and procreate. In our case, for example, our marriage would apparently require immediate termination of Barbara's medical coverage. This would mean that to stay alive,

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The result is that committed and loving couples like ourselves are put to a Hobson's choice. We could marry, but then lose Barbara's benefits and face the very real prospect of serious medical risks, institutionalization and financial ruin that would inevitably result. Indeed, these medical risks in cases like Barbara's literally include death.

In lieu of openly and legally marrying, with the consequential diminution in benefits, couples like us can elect not to marry and simply live together, in violation of our personal desires and our constitutionally protected religious precepts, not to mention the SSI provisions regarding "holding out." Alternatively, we could have a religious (but not a civil) ceremony and live together, with the risk again of being viewed by SSA as "holding out" as a married couple.

We implore you to examine the offending regulations and take appropriate action to correct the situation. We wish to be able to marry and remain married. We note that when you met in Washington last May 9 with Americans Disabled for Attendant Programs Today ("ADAPT"), you were unable to defend these policies and specifically undertook to examine and appropriately correct them. The time to do so is now.

Argument

The Americans with Disabilities Act of 1990 and the Rehabilitation Act of 1973 clearly establish disabled persons as a protected class in this country. An important purpose of these statutes is to end the social isolation and practices that disadvantage disabled people in society. Nonetheless, despite these clear legislative mandates -- mandates that implicate constitutional protections under the Fifth and Fourteenth

Amendments -- SSA administers its programs in a manner calculated to keep disabled people either unmarried, childless and/or utterly impoverished. Without more, these facts render the regulations unlawful.

But there is more. The fact of SSA-administered benefits opens the beneficiary and his or her spouse or co-habitant to virtually unlimited and arbitrary invasions of their personal privacy. They must live in fear of being discovered by SSA claims representatives, who have an apparently limitless right to inquire into holding out issues past and present.

The reduction or termination of benefits upon marriage for personal assistance services relegates the spouse of a disabled person to the status of an unpaid volunteer attendant. This places an enormous burden on a couple that has at least one disabled partner; the non-beneficiary partner is excluded from most of society's privileges, forced to abandon his or her career and even his or her individual identity in favor of tending to his or her disabled partner. The problem is all the more serious in a situation like ours -- one apparently never contemplated by the regulations -- in which two disabled people elect to marry. We do not even have the option of having one of us care, 24 hours a day, 365 days a year, for the other. The insurmountable financial burden of employing personal assistance alone all but dooms the relationship from the start.

The benefit penalties for marriage, the assumptions in the SSA regulations that spouses will be able-bodied and the overarching policy statement inherent in the regulations to dissuade marriage and to encourage dissolution of marriages require disabled people to surrender their dignity as human beings and to eschew the fundamental right enjoyed by all other citizens to marry and have a family. The regulations put a rather perverse spin on the concept of "family values."

With the passage of the Americans with Disabilities Act and the 1992 amendments to the Rehabilitation Act, Congress has made independence, inclusion, productivity and equal opportunity the cornerstones of federal disability policy. However, SSA continues to adhere to policies and regulations that frustrate and undermine these goals.

The time has come for a thorough revision of the regulations in Part 16 to take account of the realities of health care costs and to eliminate the discrimination inherent in the regulations now. In particular, the marriage penalties are so fundamentally flawed and morally wrong that they must be eliminated permanently.

Honorable Donna E. Shalala
April 15, 1994

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We respectfully request that in the next 30 days you appoint a commission, a majority of which is comprised of people with disabilities, to (1) develop regulatory and, to the extent necessary, legislative changes to update the SSA regulatory scheme, in the process abolishing discriminatory and unfair marriage penalties, and (2) review the practices of SSA and the Health Care Financing Administration to ensure non-discrimination in these organizations' dealings with disabled people who marry. We suggest that the commission's charge include realistic, but short, temporal deadlines within which to make its recommendations, and that you implement those recommendations, with appropriate modifications, promptly to eliminate the unlawful features of the current regulatory scheme.

We ask also that you act immediately to (1) exercise your authority under §1614(f)(1) of the Social Security Act promptly to amend SSI rules so that spouse-to-spouse deeming ceases; (2) amend SSDI and Medicare rules so that disabled adult children who receive SSDI benefits and who marry are treated the same as workers insured under their own work record for purposes of eligibility for SSDI cash payments and Medicare; (3) ensure that national health care reform legislation proposed by President Clinton does not contain discriminatory and unduly burdensome marriage or relationship penalties; and (4) suspend all SSI investigations into couples holding out, and end the practice of denying benefits to persons holding out.

We are cognizant that the time frame we have suggested in this letter is a short one. We believe it is realistic, however. Since we became engaged, we have had to endure the daily agony of not knowing when or if we shall be married. This has caused great emotional distress, which aggravates our disabilities. Like many other disabled persons, we have no real choice for now but to accept the anguish and unfairness that SSA perpetrates each day through its discriminatory policies and practices, singling us out, as these policies and practices do, as different from other couples who are in love and wish to start a family.

Were this a new issue, we might be inclined to wait somewhat longer. But this is not a new issue. Your agency's own SSI Modernization Project recommended in 1992 that some of these policies be changed. Nothing happened after that. And as mentioned, in May 1993, you told ADAPT that you could not defend these policies. But again, nothing has changed. In recent weeks, you ordered an action plan for breast cancer services to be completed within six weeks. Thus, serious positive action can occur quickly with the appropriate commitment. We trust you will give our request a similar and appropriate high priority.

Honorable Donna E. Shalala
April 15, 1994

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We and many of the organizations and individuals who support us stand ready to assist you in any way we can with this long-overdue reform effort. We look forward to your timely reply.

Very truly yours,


Barbara Faye Waxman


Daniel J. Fiduccia

P6(b)(6)

Enclosures

cc: Dr. Philip R. Lee,
Assistant Secretary for Heath (w/ enc.)
Michael L. Charlson, Esq.,
Heller, Ehrman, White & McAuliffe (w/enc.)

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(408) 245-2339

Anna G. Eshoo
14th District, California
Congress of the United States
House of Representatives
Washington, DC 20515-0514

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SPACE, AND TECHNOLOGY

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AND AVIATION
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ENVIRONMENT AND NATURAL RESOURCES
OCEANOGRAPHY AND THE OUTER
CONTINENTAL SHELF

NORTHERN CALIFORNIA
REGIONAL WHIP

March 18, 1994

The Honorable Donna Shalala, Secretary
Department of Health and Human Services
Hubert H. Humphrey Building, Room 615F
200 Independence Ave., S.W.
Washington, D.C. 20201

Dear Secretary Shalala:

My constituent, Mr. Daniel Fiduccia, has brought to my attention a problem which he feels denies certain disabled citizens of their fundamental rights to marry and to the equal protection of the laws.

The SSI financial penalties which follow a disabled person's marriage seem particularly unfair to those with disabilities similar to those of Mr. Fiduccia and in fact serve to preclude his marriage. I hope you can review these regulations and make modifications in the penalties so that they will no longer obstruct his ability to marry a beneficiary. This could make an enormous difference to Mr. Fiduccia and many others with disabilities.

Thank you very much for your attention to this matter. You may direct your reply and any questions to Anne Ream in my Palo Alto district office.

Sincerely,



Anna G. Eshoo
Member of Congress

AGE:ar

Center for Women Policy Studies

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Carolyn Warner
Sarah Weddington
Denie Weil
Janet Whitla
Judith Winston

March 29, 1994

Honorable Donna E. Shalala
Secretary
Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

Dear Donna:

I am writing to express my personal support -- and the support of the Center -- for Barbara Faye Waxman's challenge to the Social Security Administration's marriage penalty policies.

I have worked with Barbara for several years and have admired both her creativity and commitment to improving the world for women and men with disabilities. In fact, the Center honored her in 1993 with a Jessie Bernard Wise Women award, largely for her groundbreaking research and advocacy for women with disabilities.

Now, she is seeking our assistance to ensure that she and her fiance, Daniel Fiduccia, can marry without fear of losing essential Medicaid, Medicare, and personal assistance services benefits. These marriage penalties are inconsistent with the letter and spirit of the Americans With Disabilities Act and with our shared commitment to independent living for people with disabilities.

I know you will do all that you can to amend the pertinent regulations and help ensure Barbara and Daniel's happiness -- and Barbara's ability to continue her important work for disabled women's reproductive rights. In so doing, you also will benefit many other disabled couples who share Barbara and Daniel's problem but are too frightened at the possibility of losing benefits and medical care to go public.

Please let me know if I can provide any additional information or assistance. As always, I appreciate your willingness to consider these requests and will be pleased to consult with your staff at any time.

Sincerely,


Leslie R. Wolfe
President



ADAPT

FREE OUR PEOPLE

April 14, 1994

Honorable Donna Shalala
Secretary of Health and Human Services
Hubert H. Humphrey Building; Room # 615F
200 Independence Avenue, SW
Washington, DC 20201

Dear Secretary Shalala,

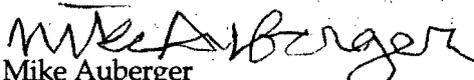
When you addressed ADAPT last May you spoke of creating a dialogue and partnership for change and that "special interests groups" would be working against that change, thus preventing full equality for citizens with disabilities incarcerated in nursing homes and other institutions. You also offered to "look into" the current marriage penalties that exist in Supplemental Security Income, Social Security Disability Insurance, Medicare, Medicaid and publicly funded personal attendant service programs. In fact, your own SSI Modernization Panel recommended these monstrous regulations be abolished.

Basically, if disabled adults openly marry - they are breaking the law! Several "choices" are forced upon us - "holding out," "annulment," "divorce," "living a life that is a lie," and/or "being forever alone." As you know, ADAPT abhors this kind of blatant bigotry against citizens with disabilities and fully expects you to look into this situation and rectify it immediately. Many ADAPT members throughout the nation are angry because the Clinton Administration continues to enforce penalties which make family life for people with disabilities a virtual impossibility. We will fight vigorously for ADAPT members, and all disabled citizens to fall in love, marry and have children, without risking their lives by putting their attendant services and/or medical benefits at risk.

If you truly believe and advocate for family values, and fiercely support disability issues as you say you do, and as President Clinton promised when he campaigned for office, then you will make good on your promise to ADAPT and the disability community, to do everything within your power to change this law now.

Any disability reform of your department which doesn't include abolition of the marriage penalties makes these other reforms trivial and hypocritical. I suspect that if your staff had to be separated from their spouses and families in order to maintain their existence and quality of life, these policies would be abolished overnight.

Sincerely,


Mike Auberger
Co-founder and National Organizer
ADAPT



WID
WORLD INSTITUTE ON DISABILITY

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OAKLAND
CA 94612-1500
USA

VOICE OR TDD
510 763 4100
FAX 510 763 4109

April 12, 1994

Honorable Donna E. Shalala
Secretary of Health and Human Services
Hubert H. Humphrey Building, Room 615F
200 Independence Ave., S.W.
Washington, DC 20101

Dear Madam Secretary:

I am a founder and the President of the World Institute on Disability. I have been one of the national Leaders in both the disability rights and independent living movements. For most of my adult life, I have been involved in the struggles of disabled individuals so that they could become full participants in community life. I am also the father of a child who is now 15 years old, so I speak from firsthand knowledge about marriage and parenting.

I am writing to you to urge that you take immediate and decisive action on an issue that currently is one of the most objectionable governmental policies ever enforced against disabled persons, namely, the economic penalties against marriage and intimate relationships in the Social Security disability benefit programs (Titles II and XVI).

As your own SSI Modernization Panel recommended, these provisions should be abolished at once and to do so would have negligible cost implications. As you know, Section 1614(f) (1) of the Social Security Act grants you the authority to abolish deeming at your pleasure. It is now time for you to take bold and decisive action to eliminate the injustices that these provisions are causing. In addition, I call upon you to undertake initiatives to see to it that "holding out" is also eliminated as an obstacle to intimate relationships.

Barbara Faye Waxman and Daniel Fiduccia are an excellent case in point. Barbara would literally risk her life if she marries because of the spouse-to-spouse deeming provision, and also risk her ability to live independently because of these antiquated concepts. Daniel is certainly in no condition to take care of her and foot all their medical bills. They both work and

MOVING TOWARD EQUALITY

live independently and wish to continue doing so, and these changes need to be made for them and all others who have been similarly penalized.

This administration is progressive, it endorsed many disability initiatives even before taking office, and it has been very supportive of the Americans with Disabilities Act and its goals. However, these Social Security policies clearly run counter to the goals and principles of the ADA. Further study and review are not necessary in this situation because the government is well aware of these penalties. What is needed now is for you to show bold leadership by granting the requests of Barbara and Daniel for themselves and for all other similarly situated adults.

Madam Secretary, you came to this office with a reputation for being an innovator and a staunch supporter of equal opportunity. We expect you will act quickly to end this deplorable situation.

I look forward to seeing you at our dinner honoring Phil Lee in San Francisco later this month.

Sincerely,

Ed Roberts

Ed Roberts
President

JUSTIN DART, JR.

907 6TH STREET, S.W., APT. 516C
WASHINGTON, D.C. 20024
202/488-7684, 484-1370TDD, 863-0010FAX

April 15, 1994

Honorable Donna E. Shalala
Secretary of Health and Human Services
Hubert H. Humphrey Building, Room 615F
200 Independence Ave., S.W.
Washington, D.C., 20201

Dear Secretary Shalala:

I am writing to join many others in supporting the requests of Barbara Faye Waxman and Daniel Fiduccia regarding the various marriage penalties of the Social Security Administration (SSA).

As Chairman of the President's Committee on Employment of People with Disabilities, I worked hard to see the Americans with Disabilities Act become law. That law guaranteed equal opportunity in employment and equal participation in society for millions of Americans with disabilities. For the first time in our nation's history, people with disabilities are protected from discrimination in hiring, and being disabled can not be grounds for termination.

I have been vigorously involved in health care reform efforts for two years. A new health care system must guarantee people with disabilities health care coverage, regardless of their job, financial, health or marital status. I am heartened that the President has made universal coverage a non-negotiable item.

Such a health care system would provide disabled persons with the medical care they need to survive and participate in society. They will not have to gamble on working and then losing their job and the health insurance benefits that go with it.

Besides health care reform, I believe the time has also come for serious welfare reform.

Specifically, the pernicious marriage penalties for Supplemental Security Income and Social Security Disability Insurance beneficiaries must be abolished. These penalties are based on outdated ideas. Except for SSA, no government agency, not even a branch of government, any longer subscribes to the humiliating and mean-spirited stereotypes that are manifested in these penalties.

Marriage penalties for disabled beneficiaries have led to divorces, annulments, illegitimate children and the termination of the parental rights of disabled adults. Such a system would be outrageous and inhumane when applied to any minority group, but these penalties are especially degrading and disgusting since people with disabilities have long been denied love, family and the benefits of being members of society.

HEALTH CARE FOR ALL AMERICANS NOW

Marriage penalties have even more damaging effects on people with disabilities. Because health care benefits and personal assistance services are conditioned on Social Security eligibility, disabled persons are confronted with the loss of their liberty and even their survival if they choose to marry. No other class of beneficiaries faces such consequences.

The time has come to end the policies and practices of the Social Security Administration which run counter to the purposes of the Americans with Disabilities Act and the Clinton Administration's health care reform efforts. Such policies are anachronistic and cruel reminders of the days when people with disabilities were condemned to a life of exclusion, dependence and charity.

I understand that all the requests which Barbara and Daniel ask of you are within your authority to grant immediately. I hope you will do so.

In closing, I remember that during this year's State of the Union address, President Clinton said it is wrong for the government to have welfare policies that break up families. I hope you will think of the thousands of disabled beneficiaries who would like to stay married or become married and start families when you consider these requests.

Sincerely,

A handwritten signature in cursive script that reads "Justin Dart" followed by a small flourish.

Justin Dart

DREDF

Disability Rights Education and Defense Fund, Inc.

Law, Public Policy, Training and Technical Assistance

April 13, 1994

Honorable Donna E. Shalala
Secretary of Health & Human Services
Hubert H. Humphrey Building, Room 615F
200 Independence Avenue, S.W.
Washington, D.C. 20201

Re: SSA Regulations Imposing Marriage Penalties on Benefit
Program Recipients with Disabilities

Dear Secretary Shalala:

On behalf of the Disability Rights Education and Defense Fund, Inc. (DREDF), I write with respect to the regulations governing the administration of various Social Security Administration ("SSA") benefit programs including Social Security Disability Insurance ("SSDI"), Supplemental Security Income ("SSI"), Medicare, Medicaid and publicly-funded personal assistance services programs.

DREDF is a national, non-profit law and policy organization dedicated to advancing the civil rights of individuals with disabilities through legislation, litigation, informal and formal advocacy, and education & training regarding disability rights issues. We are nationally recognized for our expertise in the interpretation of disability civil rights laws, including Title V of the Rehabilitation Act of 1973, and the Americans with Disabilities Act of 1990.

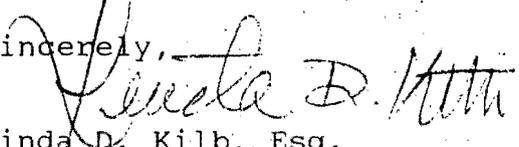
This letter is intended to support the position and arguments articulated by Daniel J. Fiduccia and Barbara Faye Waxman in their letter to you. DREDF shares the concern of Mr. Fiduccia and Ms. Waxman that various regulatory provisions implementing SSA benefit programs have the effect of penalizing individuals with disabilities who choose to marry. Spouse-to-spouse deeming and holding out provisions effectively require recipients with disabilities to choose between eligibility for life-sustaining benefits, and the right to marry. These penalties create discriminatory barriers and perpetuate discriminatory attitudes about people with disabilities, denying them the right to bring resources critical to independent living into a marriage relationship.

The Honorable Donna E. Shalala
RE: SSA Benefit Program Marriage Penalties
April 13, 1994
page 2

We urge you to reconsider the regulatory provisions implementing SSA benefit programs, to ensure that design of these programs does not impose discriminatory marriage penalties on eligible recipients with disabilities:

Thank you for your attention to this matter.

Sincerely,


Linda D. Kilb, Esq.
Managing Director

cc: Daniel J. Fiduccia
Barbara Faye Waxman

NCIL

National Council on Independent Living

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April 12, 1994

Honorable Donna E. Shalala
Secretary of Health and Human Services
Hubert H. Humphrey Bldg., Room 615 F
200 Independence Ave., S. W.
Washington, D.C. 20201

Dear Secretary Shalala:

The National Council on Independent Living (NCIL) is writing to you to request your intervention to rectify a severe problem in the regulations governing various benefit programs administered by the Social Security Administration which in effect penalizing beneficiaries who marry.

NCIL is the only grassroots, cross disability national organization run by and for people with disabilities. NCIL's membership, centers for independent living (CILs), are community based, consumer controlled non-profit organizations which provide independent living services to individuals with a variety of disabilities.

Through the passage of the Americans with Disabilities Act and the 1992 Amendments of the Rehabilitation Act, people with disabilities are beginning to move towards full integration in all aspects of American society. However, the freedom to chose to marry and have children, without the risk of impoverishment or institutionalization, continues to be denied to people with severe disabilities.

The current regulations in SSA mandates that individuals who currently receive SSDI or SSI benefits, and chose to marry, will lose their benefits and personal assistance services.

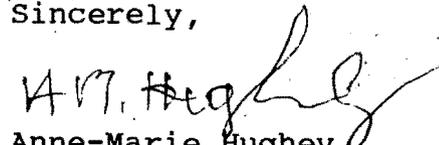
These regulations severely impact on a disabled individual's basic human rights. When two people who do not have disabilities, choose to marry, each individual has the right to receive income, maintain his or her own medical insurance and other personal needs. When a couple, where one or both partners have a disability, they may lose their social security income, medical benefits, and personal assistance services. If only one of the partners has a disability not only will they lose the above mentioned benefits, but they will also lose their individuality and equality. The nondisabled spouse will be placed in the role of sole provider and caretaker. This is a role for a parent of a child, not the spouse of an adult.

The reestablishment of family values and placing people first is a highly worthwhile goal of the Clinton Administration. However this goal can never be accomplished if regulations which penalize people for marrying and having children remain in the SSA regulations.

NCIL hopes that you will consider this request and assist us in the movement towards true independence and freedom for all people with disabilities.

Thank you.

Sincerely,


Anne-Marie Hughey,
Executive Director

cc: Denise Figueroa, President



UNITED
CEREBRAL
PALSY
ASSOCIATIONS

Advancing the independence of people with disabilities

April 4, 1994

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Honorable Donna E. Shalala
Secretary of Health and Human Services
Hubert H. Humphrey Building, Room 615F
200 Independence Ave, SW
Washington, DC 20201

Dear Secretary Shalala:

On behalf of United Cerebral Palsy Associations, Inc. (UCPA), I am pleased to write you to express support on the need for reform of current Social Security Administration policies which penalize persons with disabilities who choose to get married as defined in the letter setting forth the issues to you from Barbara Faye Waxman and Daniel J. Fiducia.

UCPA is a national organization of over 155 local and state affiliates who advocate for and/or provide service for persons with cerebral palsy and other severe and multiple disabilities and their families. UCPA is firmly committed to assuring quality services for persons with severe physical and multiple disabilities which reflect best practice, which recognize competence and choice, and which assure opportunities for increased independence, productivity and integration into the home, the school, the workforce and the community

Cerebral palsy is a term used to describe a group of chronic conditions affecting body movement and muscle coordination (not a disease or illness) that directly affects motor ability. There are more than 500,000 children and adults with cerebral palsy and similar disabilities in the United States. In addition, currently about 5,000 babies and infants are diagnosed with the condition each year and some 1,200 to 1,500 pre-school age children acquire cerebral palsy annually.

Many individuals with cerebral palsy are on the rolls of the Social Security Administration either as recipients of Supplemental Security Income in their own right or Social Security Disability Insurance as a dependent of a retired or deceased parent. As a result of the numerous changes in federal public policy culminating in the enactment of the Americans with Disabilities Act as well as rapid expansions in the applications of assistive technology for individuals with

Shalala
April 4, 1994
Page 2

severe disabilities, opportunities abound for people with cerebral palsy and other severe disabilities to pursue the American dream including the opportunity to marry and have children.

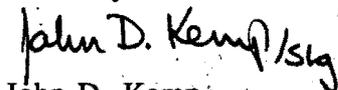
Unfortunately, many policies of the Department of Health and Human Services which were crafted prior to the Americans with Disabilities Act, de facto, although not intended to, prevent many people with disabilities from marriage or if they choose to marry, penalize them through reduction of income, benefits and support. These contradictory policies are fully described in the letter to you from Ms. Waxman and Mr. Fiducia.

United Cerebral Palsy Associations urges you to respond to the requests in the Waxman/Fiducia letter and to begin the process by appointing a commission, a majority of which is comprised of people with disabilities, to (1) develop regulatory and, to the extent necessary, legislative changes to update the SSA regulatory scheme, in the process abolishing discriminatory and unfair marriage penalties, and (2) review the practices of SSA and the Health Care Financing Administration to ensure non-discrimination in these organizations' dealings with disabled people who marry.

UCPA is prepared to assist you in any way possible to rectify these anti marriage and family policies, including suggestions of persons with cerebral palsy to be considered for your appointment to the requested commission.

Thank you for your immediate attention to this urgent matter impacting the lives of thousands of men and women with disabilities throughout the Nation. Please do not hesitate to contact me or Allan I. Bergman, Director of State-Federal Relations at (202) 842-1266 for additional information on this issue.

Sincerely,



John D. Kemp
Executive Director

cc: Allan I. Bergman
Michael Morris

SOCIETY FOR DISABILITY STUDIES

Gallaudet College Dept. of Sociology, 800 Florida Ave., NE, Washington, DC 20002

April 12, 1994

Honorable Donna E. Shalala
Secretary of Health and Human Services
Hubert H. Humphrey Building, Room 615F
200 Independence Ave., S.W.
Washington, DC 20101

Dear Secretary Shalala:

The Society for Disability Studies (SDS) is a nonprofit scientific and educational organization established to promote interdisciplinary research on humanistic and social scientific aspects of disability and chronic illness. The Society works to create forums for the exchange of information relevant to the experiences of individuals with disabilities and to promote the full participation of persons with disabilities in society.

We are concerned that the efforts of people with disabilities to enjoy a full life are being frustrated by the Social Security disability benefit programs under Titles II and XVI. The policies referred to are the economic penalties against marriage and intimate relationships enforced against people with disabilities. The Society urges you to take immediate action to remedy this highly objectionable policy.

Your own SSI Modernization Panel recommended that these provisions should be abolished at once and to do so would have negligible cost implications. Section 1614(f) (1) of the Social Security Act grants you the authority to abolish deeming. Clearly you could take action to eliminate the injustices these provisions are causing now. We ask that you also see to it that "holding out" is eliminated as an obstacle to intimate relationships.

We applaud the efforts of Barbara Faye Waxman and Daniel Fiduccia in bringing this issue to our attention. Barbara would literally risk her life if she marries because of the spouse-to-spouse deeming provision, and would also risk her ability to live independently because of these antiquated concepts. Daniel is not able to take care of her and underwrite all their medical bills. They both currently work and live independently. Yet, marriage under the current regulations makes continued independence impossible. Changes need to be made for them and all others who have been similarly penalized.

This administration is progressive, it endorsed many disability initiatives even before taking office, and it has been very supportive of the Americans with Disabilities Act and its goals. However, these Social Security policies clearly run counter to the goals and principles of the ADA. Further study and review are not necessary in this situation because the government is well aware of these penalties. What is needed now is for you to show bold leadership by granting the requests of Barbara and Daniel for themselves and for all other similarly situated adults.

Madam Secretary, you came to this office with a reputation for being an innovator and a staunch supporter of equal opportunity. We expect you will act quickly to end this deplorable situation.

Sincerely,

A handwritten signature in cursive script that reads "Sharon Barnhartt". The signature is written in dark ink and is positioned above the typed name.

Sharon Barnhartt, Ph.D.
President
Society for Disability Studies



NATIONAL MULTIPLE SCLEROSIS SOCIETY

733 THIRD AVENUE, NEW YORK, N.Y. 10017-3288 (212) 986-3240 FAX (212) 986-7981

April 12, 1994

The Honorable Donna E. Shalala
Secretary of Health and Human Services
Hubert H. Humphrey Building, Room 615F
200 Independence Avenue, S.W.
Washington, DC 20201

Dear Secretary Shalala:

I write to support the efforts of the disability community to urge your immediate action to update SSA regulations and practices which discriminate against people with disabilities who choose to marry.

Current regulations impose a "marriage penalty," or financial penalty, reducing an individual's benefits, and access to benefits, upon marrying. Additionally, regulations are such that they provide strong disincentives to rearing a family.

The National Multiple Sclerosis Society represents a third of a million people with MS, many who become disabled and are entitled to SSDI, and sometimes SSI, benefits. At least two-thirds of our clients are women, and most are of working age with work experience - usually diagnosed between the ages of 20 and 40.

It is our belief that SSA regulations need to reflect current views of disability by supporting measures to enhance participation in all aspects of life enjoyed by those without disabilities. In this case it means, continuing benefits to provide work incentives after marriage, and expanding benefits to allow for child-rearing and development of families.

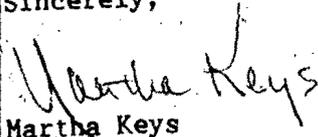
At the very least, benefits should be continued at the same rate as they would if couples were not married, rather than reduce benefits assuming "two can live as cheaply as one." Current practices at SSA have led to hiding relationships, cohabitation against religious choices and additional penalties from SSA if found to be "holding out."

Once again, the National Multiple Sclerosis Society urges you to take immediate action to eliminate current marriage penalties setting a reasonable, but short, timeline for developing appropriate modifications with strong input from people with disabilities. Additionally, we urge you to suspend investigations into couples holding out during this time, and amend SSDI and Medicare rules so that disabled adult children who receive SSDI benefits and who marry are treated the same as workers insured under their own work record.

- contd. -

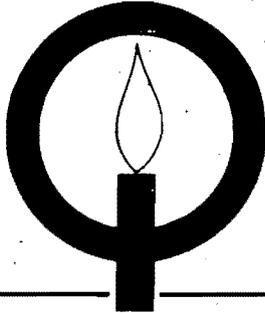
We would be pleased to work with you in developing the appropriate guidelines and look forward to hearing from you regarding your timeline for reviewing current regulations.

Sincerely,



Martha Keys
Vice President
Public Affairs

MK:ea



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Honorable Donna E. Shalala
Secretary of Health and Human Services
Hubert H. Humphrey Building
Room 615F
200 Independence Avenue, S.W.
Washington, D.C. 20201

Dear Madam Secretary:

On behalf of our 40,000 members who are children with cancer, survivors of childhood cancer and their families, I am writing to bring your attention to a serious deficiency in the regulations governing various benefit programs administered by the Social Security Administration (SSA) and ask for your assistance in correcting these deficiencies.

The deficiency I am referring to is the automatic financial penalty reducing or altogether terminating benefits available under the Social Security Disability Insurance (SSDI), Supplemental Security Income (SSI), Medicare, Medicaid and publicly funded personal assistance services programs placed upon disabled citizens if they choose to marry. This penalty, in essence, has the effect of denying disabled citizens their rights to marry and procreate and to equal protection under the laws.

This concern is a priority for our organization and members, like Daniel Fiduccia, as it has the potential to directly effect every child who has ever, or will ever, be treated for childhood cancer. With the medical advancements that have taken place over the years, survival is a reality as 70% of all children diagnosed with cancer are surviving and it is estimated that by the year 2000, one out of every 900 Americans between the ages of 14 and 36 will be a survivor of childhood cancer.

Honorable Donna E. Shalala
March 28, 1994
Page 2

However, the aggressive nature of the therapies which have brought about this remarkable success, are not without long term, permanent side effects. In several cases, it is necessary for survivors, who are disabled by their treatment, to receive financial assistance so they may be productive members of society and enjoy their rights as guaranteed under the Constitution.

Moreover, most survivors of childhood cancer who are receiving social security benefits are doing so not so much for the financial assistance, but rather so they can get health care coverage and receive regular and necessary check-ups and exams. In essence, our government penalizes survivors of childhood cancer twice; first, it legitimizes the denial of health insurance for them and then, if they qualify for health care through social security, they can never be married for fear of losing access to the health care they desperately need.

It is shameful that an individual who has overcome one of the most deadly diseases known, or any American citizen, must "sneak around" behind the back of SSA "investigators", potentially violate their own personal and religious preferences as protected under the Constitution, and then face potential medical risks, institutionalization and financial ruin if they choose to marry or are deemed by the SSA to be "holding out."

The Candlelighters Childhood Cancer Foundation and its 40,000 members join together with other disability, feminist, human rights and religious organizations, as well as members of Congress, in calling upon you to 1) suspend all SSI investigations into couples holding out, and end the practice of denying benefits to persons holding out; 2) exercise your authority under SS1614(f) (1) of the Social Security Act promptly to amend SSI rules so that spouse-to-spouse deeming ceases; 3) amend SSDI and Medicare rules so that disabled adult children who receive SSDI benefits and who marry are treated the same as workers insured under their own work record for purposes of eligibility for SSDI cash payments and Medicare; and 4) ensure that national health care reform legislation proposed by President Clinton does not contain discriminatory and unduly burdensome marriage or relationship penalties.

I thank you for your serious consideration of our requests and your prompt attention to this matter.

Sincerely,



James R. Kitterman
Executive Director

福 福 福 福 福 福 福 福

Gazette International Networking Institute (G.I.N.I.)

5100 Oakland Avenue, #206 • Saint Louis, Missouri 63110-1406 USA • 314/534-0475

March 25, 1994

Honorable Donna E. Shalala
Secretary of Health and Human Services
Hubert H. Humphrey Building, Room 615F
200 Independence Avenue, S.W.
Washington, D.C. 20201

Dear Madam Secretary:

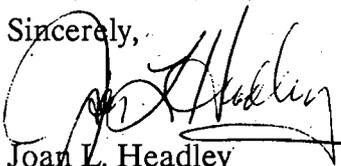
Gazette International Networking Institute (G.I.N.I.) has been advocating for people with disabilities since the late 1950's. It is not a coincidence that our advocacy work began after the development of the polio vaccines. Funds dried up and many were sent home from the wards with rocking beds and iron lungs. These individuals, many using mechanical ventilation, became experts at integrating into the community and actively changed policies which excluded them from society.

The current Social Security practices which go into effect when individuals marry are exclusionary and in need of reform. G.I.N.I., on behalf of the many individuals it represents, wholeheartedly agrees with the statements of Barbara Faye Waxman and Daniel J. Fiduccia and their description of the problems the current policies cause.

Particularly troubling is the stereotypical and paternalistic message regarding people with disabilities as to when and whom they marry and whether they have children. Equally troubling is the reluctance of Social Security to pay for personal assistance services maintaining the integrity of the family unit while paying for expensive institutionalization which separates families.

G.I.N.I. joins Barbara and Daniel in respectfully requesting that you act immediately to rectify the situation.

Sincerely,



Joan L. Headley
Executive Director



April 13, 1994

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Honorable Donna E. Shalala
Secretary of Health and Human Services
Hubert H. Humphrey Building, Room 615F
200 Independence Avenue, SW
Washington, DC 20201

Dear Madam Secretary:

The National Coalition for Cancer Survivorship is writing to support the efforts by Barbara Faye Waxman and Daniel J. Fiduccia to eliminate the Social Security Administration's marriage penalty policies towards persons with disabilities. The National Coalition for Cancer Survivorship is the largest grassroots network of individuals, organizations and institutions advocating on behalf of people with all types of cancer. NCCS's primary mission is to maximize the potential for cancer survivors and their loved ones to live the best quality of life possible following a diagnosis of cancer.

The more than eight million cancer survivors in the United States are covered by the Americans with Disabilities Act as individuals with a current or past disability and as individuals who are regarded as having a disability. The benefit programs administered by the Social Security Administration impose significant, and sometimes life-threatening financial penalties when a disabled person marries. These regulations conflict with statutory protections for persons with disabilities and with their fundamental right to marry.

Accordingly, we ask that you act immediately to (1) suspend all SSI investigations into couples "holding out"; (2) exercise your authority under §1614(f)(1) of the Social Security Act promptly to amend SSI rules so that spouse-to-spouse deeming ceases; (3) amend SSDI and Medicare rules so that disabled adult children who receive SSDI benefits and who marry are treated the same as workers insured under their own work record for purposes of eligibility for SSDI cash payments and Medicare; and (4) ensure that national health care reform legislation proposed by President Clinton does not contain discriminatory and unduly burdensome marriage or relationship penalties.

We strongly urge your consideration of these essential and equitable reforms.

Sincerely,

Ellen L. Stovall
Executive Director

cc: Barbara Faye Waxman & Daniel J. Fiduccia

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- Executive Committee

**NATIONAL CATHOLIC OFFICE
FOR PERSONS WITH DISABILITIES**
P.O. Box 29113 • Washington, DC 20017
202-529-2933 (v/TT)
202-529-4678 (FAX)

April 13, 1994



TO WHOM IT MAY CONCERN:

There are few telephone calls as distressing as those this office receives from Catholics who wish to be married in the Church but who fear they will jeopardize those services which are essential for survival. The possibility that medical or other benefits linked to eligibility for Social Security may be terminated following marriage prevents people with disabilities, as well as those who are elderly, from moving forward with plans for this important sacramental confirmation of their love.

I am aware that upon occasion there has been modification of the regulations which govern continued eligibility for essential services. Years ago, while directing a program of University Year in Action (a citizen volunteer initiative funded by the federal agency, ACTION) I found it difficult to recruit disabled students because of their fear that re-evaluation on the basis of "Substantial Gainful Activity" would jeopardize their health coverage. Through Senator Alan Cranston's good offices, we were able to alter the language and remove the threat.

While aware of the interconnectedness of various aspects of the Social Security Administration regulations, I would like to add our voice to those which are being raised requesting that those words which currently endanger those who are contemplating marriage be altered or eliminated. There seems little social benefit in discouraging people from taking this step toward formalizing their relationship.

Do not hesitate to call me if there are additional details of our concern which you would wish us to address.

Very truly yours,

Mary Jane Owen, M.S.W.





April 4, 1994

Honorable Donna E. Shalala
Secretary of Health and Human Services
Hubert H. Humphrey Building, Room 615F
200 Independence Avenue, S.W.
Washington, D.C. 20201

Dear Secretary Shalala,

We write to offer our encouragement and support to amend deleterious policies in the regulations governing various benefit programs administered by the Social Security Administration. The regulations under 20 C.F.R. Part 16 governing medical, SSDI, and SSI benefits act to punish people with disabilities who choose to marry by stripping them of necessary benefits.

These policies enforce inequities when they provide married couples less assistance than two single individuals even though a person with disabilities when married requires no less financial assistance than a single person with disabilities. Further, these policies continue to render disabled people isolated and disadvantaged by not allowing them to exercise choices which they should otherwise be able to do.

We urge you to review the practices of SSA and make appropriate and necessary changes to update the SSA regulatory scheme so as to abolish discriminatory and unfair marriage penalties.

Thank you for your consideration on this matter, and we look for to future improvements.

Sincerely,

Abby Abinanti
Legal Director

National Office

870 Market Street
Suite 570
San Francisco
CA 94102

Telephone: 415 392 6257

Fax: 415 392 8442

Public Policy Project

452 Broadway
Suite 500A
New York
NY 10013

Telephone: 212 343 9589

Fax: 212 343 9687

California Women's Law Center

6024 Wilshire Blvd., Los Angeles, California 90036
Phone: 213/935-4101 Fax: 213/935-0497

March 21, 1994

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Honorable Donna E. Shalala
Secretary of Health and Human Services
Hubert H. Humphrey Building, Room 615F
200 Independence Avenue, S.W.
Washington, D.C. 20201

Dear Madam Secretary,

We are writing to join others in urging you to take vital and immediate action to redress the defects in the regulations governing a number of benefit programs administered by the Social Security Administration (SSA) which effectively preclude people with disabilities from marrying.

A number of regulatory requirements and mandates offer people with disabilities a particularly tragic Hobson's choice: to forgo marriage and family or to lose benefits which are vital to their very existence. No one should be forced to confront such a choice. It is time to make it possible for people with disabilities to enjoy the same rights to privacy, marriage and family that we all take for granted.

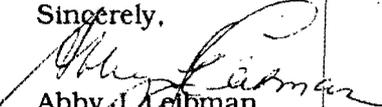
The underlying assumptions which gave rise to these regulatory requirements are outdated, rely on offensive stereotypes and in our opinion are clearly unlawful.

We respectfully request that you suspend SSI investigations into couples "holding out;" cease denying benefits to couples "holding out;" amend the SSI rules to eliminate spouse to spouse deeming; amend SSDI and Medicare rules so that disabled adult children who receive SSDI benefits and who marry are treated the same as workers insured under their own work record for purposes of eligibility for SSDI case payments and Medicare; and ensure that national health care reform does not contain discriminatory penalties regarding marriage.

We would also like to request that you establish a commission to review, revise or develop new regulatory and statutory mandates which will remove unfair and discriminatory marriage penalties.

Secretary Shalala, you have the opportunity to redress a terrible injustice in the law and its application. We urge you to use your authority to make it possible for people with disabilities to enjoy the same rights to family that so many of us take for granted.

Sincerely,


Abby J. Leibman
Executive Director



CALIFORNIA SOCIETY OF PHYSICAL MEDICINE AND REHABILITATION

April 8, 1994

Honorable Donna E. Shalala
Secretary of Health and Human Services
Hubert H. Humphrey Building, Room 615 F
200 Independence Avenue, S.W.
Washington, D.C. 20201

Dear Madam Secretary:

I am writing in support of efforts to revise the Social Security Administration's marriage and work penalty policies as they relate to persons with disabilities.

I am the President of the California Society of Physical Medicine and Rehabilitation, the organization for approximately 400 California physicians who specialize in the rehabilitation of persons with disabilities. I am a polio survivor and the mother of a multiply handicapped child. In 1988, I was honored to receive the United States Physician of the Year Award from the President's Committee on Employment of Persons with Disabilities.

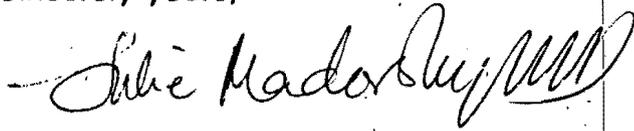
In my medical practice, and in my activities in the California State Independent Living Advisory Council, I have seen repeatedly how federal programs can act as a disincentive to persons with disabilities in their pursuit of health, productivity, and self esteem.

- Often, I have empathized with patients who were medically, emotionally, and educationally prepared to go to work, but declined to do so because they faced the very real consequence of permanently losing Medicare benefits.
- On several occasions, I have attended secret "relationship commitment ceremonies" of persons with disabilities who could not openly marry or declare their love for each other due to fear of losing both medical coverage and attendant services.
- I have seen marriages disintegrate because an able-bodied spouse was forced to perform services which are routinely provided to unmarried individuals with disabilities by a paid personal care assistant under Title XX of the Social Security Act. A dramatic example of such services is what in medical terms is called "bowel training" - digital rectal stimulation, manual extraction of stool, and the clean-up and disposal of involuntary bowel movements. It is an understatement to say that the potential for marital intimacy is devastated when a spouse is forced to handle his or her beloved's incontinent stools.
- I have also witnessed the legal dissolution of marriages involving one or two persons with a disability, where the couple could not survive without the additional medical, financial, and/or personal care services which they received as unmarried individuals.

Honorable Donna E. Shalala - Cont'd.
April 8, 1994
Page Two

It seems to me that our nation would be well served by a speedy review and revision of our Social Security programs as they relate to disincentives to marriage and employment of persons with disabilities. Such revisions, I believe, would be not only ethical and humane, but cost-effective to society as well.

Sincerely yours,



JULIE G. MADORSKY, M.D.
President

JGM:nc

cc: Robert P. Christopher, M.D., President
American Academy of Physical Medicine & Rehabilitation
122 South Michigan Avenue, Suite 1300
Chicago, Illinois 60603-6107

Robert H. Meier, III, M.D., President
American Congress of Rehabilitation Medicine
5700 Old Orchard, First Floor
Skokie, Illinois 60077-1057



Westside Center for Independent Living, Inc.

April 13, 1994

Honorable Donna E. Shalala
Secretary of Health and Human Services
Hubert H. Humphrey Building, Room 615F
200 Independence Avenue, S.W.
Washington, DC 20201

Dear Secretary Shalala:

This letter is being written in support of a request from Barbara Faye Waxman and Daniel J. Fiduccia. They have brought several issues to your attention concerning disincentives in the Social Security system making it virtually impossible for people with disabilities to marry and raise a family.

The Westside Center for Independent Living is committed to the creation of a world which people are valued equally regardless of differences of any kind. Such a world would encourage people with disabilities to marry and have families in the same manner as do people who are not disabled. Clearly, present laws and regulations militate against that situation. We urge you to address this issue at the earliest possible time.

Thank you for your immediate attention to this matter.

Sincerely,

A handwritten signature in cursive script that reads 'Stanley Greenberg'.

Stanley Greenberg, Ph.D.
Executive Director

Main Office

12901 Venice Boulevard
Los Angeles, California 90066
(310) 390-3611/Voice • (310) 398-9204/TDD
(310) 390-4906 Fax
(310) 539-1811 South Bay

Linkages Project

12901 Venice Boulevard
Los Angeles, California 90066
(310) 390-3611/Voice • (310) 398-9204/TDD
(310) 390-4906 Fax

Computer Training Project

12655 W. Washington Blvd., Suite 101
Los Angeles, California 90066
(310) 390-3406/Voice & TDD
(310) 670-4413 Fax

QUEEN OF APOSTLES CHURCH

4911 Moorpark Avenue
San Jose, California 95129-2199

Phone (408) 253-7560
Fax (408) 253-9530

April 5, 1994

Honorable Donna E. Shalala
Secretary of Health and Human Services
Hubert H. Humphrey Building, Room 615-F
200 Independence Avenue, S.W.
Washington, D.C. 20201

Dear Madam Secretary,

I wish to express my wholehearted support of Daniel Fiduccia and Barbara Faye Waxman. I have read their letter to you, and I ask that you grant their requests.

The policies they have described in their letter are simply deplorable. They indicate a belief that people with disabilities are not as entitled to marriage and family as other people.

I have already talked to Daniel, who is a member of my parish, and Barbara about their marriage ceremony. However, since they have no idea when they will be allowed to be married, they cannot even schedule their participation in the marriage classes that are necessary for them to be married in the Catholic Church.

They have been engaged since last summer, and desperately want to be married. I hope you will attend immediately to their requests.

Sincerely,



Rev. James Mifsud, S.M.
Pastor

Laura Remson Mitchell

P6/(b)(6)

April 13, 1994

The Honorable Donna E. Shalala
Secretary of Health and Human Services
Hubert H. Humphrey Building, Room 615 F
200 Independence Ave., S.W.
Washington, D.C. 20201

Dear Madam Secretary:

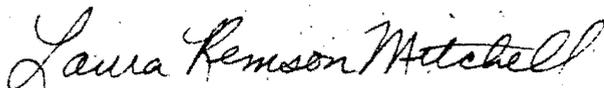
I am writing to you in support of efforts by Barbara Faye Waxman and Daniel Fiduccia to change the way Social Security benefit programs for people with disabilities are administered so that beneficiaries of these programs will not be penalized for marrying and/or for working.

I am a public policy analyst, consultant and free-lance writer specializing in disability and health-care issues. I also have a disability myself (I have multiple sclerosis), although I am not on any Social Security programs. Both in my professional work (with the National Multiple Sclerosis Society, among others) and in my volunteer activities (as an MS peer counselor, as chair of the health committees for two statewide disability organizations in California, and as coordinator of the Southern California Disability Campaign for Health-Care Reform) I have become very aware of the financial penalties imposed on people with disabilities who are on Social Security programs when they try to live independently and exercise their civil rights.

The situation facing Barbara and Daniel is a good example: Barbara and Daniel want to marry. Both have serious medical conditions, and Barbara needs the services she receives through her eligibility for certain Social Security programs in order to survive. Yet when they marry, the change in eligibility rules affecting married SSI, SSDI and Medicare beneficiaries would result in her loss of critical health and personal assistance benefits.

In the era of the Americans with Disabilities Act, at a time when people with disabilities are trying harder than ever to live independent, productive lives (including working and paying taxes), it is outrageous that unrealistic Social Security regulations should force couples like Barbara and Daniel to choose between marriage and survival. I urge you to take prompt action to correct these problems, as outlined in the letter that Barbara and Daniel sent you on this subject. I understand that some of these steps also have been recommended by the SSI Modernization Project.

Sincerely,



Laura Remson Mitchell



**UNITED
CEREBRAL
PALSY
ASSOCIATIONS**

Advancing the independence of people with disabilities

*Why commission?
\$00 much release?
more facts?*

called 12-23-93

MEMORANDUM

LEONARD H. GOLDENSON
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DEPUTY
EXECUTIVE DIRECTOR

TO: Selected Advocates
FROM: Allan I. Bergman *Allan*
RE: Barbara Waxman's ADA discrimination case
DATE: December 8, 1993

Barbara Waxman and her fiance are serious about the attached draft letter to Donna Shalala and moving forward with it. Please review the following document and if you have any constructive criticism that could help strengthen their position, please call me in the next few days at 202-842-1266.

1522 K STREET, NW
SUITE 1112
WASHINGTON, DC 20005-1202
800.USA.5UCP
VOICE/TT 202.842.1266
FAX 202.842.3519

NOV 16 '93 21:16 HEDJEM 25TH FLR

P.2

DRAFT

_____, 1993

Honorable Donna Shalala
Secretary of Health and Human Services
Robert H. Humphrey Building, Room 6157
200 Independence Avenue, S.W.
Washington, D.C. 20201

Dear Madam Secretary:

We write to bring to your attention, and to solicit your intervention to correct, serious defects in the regulations governing various benefit programs administered by the Social Security Administration ("SSA") -- defects that have the effect of denying disabled citizens their fundamental constitutional rights to marry and procreate and to equal protection of the laws. We refer to financial penalties that apply automatically in the event of marriage to reduce substantially, if not altogether, benefits available under the Social Security Disability Insurance ("SSDI"), Supplemental Security Income ("SSI"), Medi-Care and Medi-Cal ("Medicaid") programs. For the reasons set forth below, these marriage penalties are irrational,

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THIS FORM MARKS THE FILE LOCATION OF ITEM NUMBER 2
LISTED IN THE WITHDRAWAL SHEET AT THE FRONT OF THIS FOLDER.

THE FOLLOWING PAGE HAS HAD MATERIAL REDACTED. CONSULT THE
WITHDRAWAL SHEET AT THE FRONT OF THIS FOLDER FOR FURTHER
INFORMATION.

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Honorable Donna Shalala
_____, 1993

Page 3

available hours benefit under In-Home Support Services -- California's personal assistance service program. It is no understatement to say that these benefits all are necessary to sustain Barbara's life.

Although Daniel is not a current recipient of any Social Security benefits, he also suffers from several serious medical disorders that date back to his childhood. As a child, Daniel survived a battle with [name of disease]. He has been cancer-free for [number] years. Nonetheless, as a result of the radiation and other treatments that he underwent to cure the cancer, Daniel has [describe residual effects]. In particular, Daniel's own limitations make it impossible for him to administer certain care that Barbara requires and that is currently provided by her personal assistant.

We are, and wish to continue to be, productive members of society. Daniel has been employed, albeit on a less-than-full-time basis, since he graduated from college [15] years ago. On April 5, 1993, Barbara returned to work after nine years of living almost entirely on SSDI and SSI benefits. Her ability to return to work was and is dependent upon SSA's work incentive program for gainfully employed, severely disabled workers --

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Honorable Donna Shalala
_____, 1993

Page 4

specifically, SSI §§ 1619(a) & (b), Plan to Achieve Self-Support ("PASS") and Impairment-Related Work Expenses ("IRWE").

Regulatory Background

Under various regulations in 20 C.F.R Part 16, the regulatory regime governing medical, SSDI and SSI benefits substantially penalizes people with disabilities who choose to marry. For example, and without limitation, recourse exclusions, income exclusions, and various property exclusions (such as for transportation, household goods and personal effects) are all far lower for married couples than they are for two individuals who are both eligible for one or more SSA-administered benefit programs. This problem is exacerbated by the fact that these exclusions have barely changed in decades -- a period during which the cost of medical care has skyrocketed.

Similarly, when SSI benefit payments are computed for couples, both members of which are eligible for benefits, all countable income is summed before it is compared to the SSI federal benefit rate, with the effect of substantially reducing the benefit from levels that would pertain if the people received benefits as two individuals. The "deeming" provisions require that income or resources that either member of a couple have be

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Honorable Donna Shalala
_____, 1993

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marriage would apparently require immediate termination of Barbara's medical coverage and PASS benefits. This would mean that to stay alive, Barbara's entire salary would have to be

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The result is that loving couples like ourselves are put to a Hobson's choice. We could marry, lose our benefits and face the possibility of institutionalization, serious medical risks and financial ruin that would inevitably result. Indeed, these medical risks in cases like Barbara's are literally death.

In lieu of openly and legally marrying, couples like us can elect not to marry and simply live together, in violation of our personal desires and religious precepts. Alternatively, we could have a religious ceremony and live together, and risk being viewed by SSA as "holding out" as a married couple. We might also legally marry but attempt to hide the fact from SSA, in clear violation of the law.

Many disabled people around the country have elected these latter alternatives; but for obvious reasons, none is satisfactory. We instead implore you to examine the offending

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Honorable Donna Shalala
_____, 1993

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regulations and take appropriate action to correct the situation. We note that when you met in Washington last May 9 with Americans Disabled for Attendant Programs Today ("ADAPT"), you were unable to defend these policies and specifically undertook to examine and appropriately correct them. The time to do so is now.

ARGUMENT

The Americans with Disabilities Act of 1990 and the Rehabilitation Act of 1973 clearly establish disabled persons as a protected class in this country. An important purpose of these statutes is to end the social isolation and practices that disadvantage disabled people in society. Nonetheless, despite these clear legislative mandates -- mandates that implicate constitutional protections under the Fifth and Fourteenth Amendments -- SSA administers its programs in a manner calculated to keep disabled people either unmarried, childless and/or utterly impoverished. Without more, these facts render the regulations unlawful.

But there is more. The fact of SSA-administered benefits opens the beneficiary and his or her spouse or co-habitant to virtually unlimited invasions of their personal privacy. If a beneficiary elects, perhaps for bona fide reasons

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Honorable Donna Shalala
_____, 1993

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require disabled people to surrender their dignity as human beings and to eschew the fundamental right enjoyed by all other citizens to marry and have a family. The regulations put a rather perverse spin on the concept of "family values."

The time has come for a thorough revision to the regulations in Part 16 to take account of the realities of health care costs and to eliminate the discrimination inherent in the regulations now. In particular, the marriage penalties are so fundamentally flawed and morally wrong that they must be eliminated permanently.

We respectfully request that in the next 30 days you appoint a commission, a majority of which is comprised of people with disabilities, to (1) develop regulatory and, to the extent necessary, legislative changes to update the SSA regulatory scheme, in the process eliminating marriage penalties, and (2) review the practices of SSA and the Health Care Financing Administration to ensure non-discrimination in these organizations' dealings with disabled people who marry. We suggest that the commission's charge include realistic, but short, temporal deadlines within which to make its recommendations, and that you implement those recommendations,

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EXECUTIVE OFFICE OF THE PRESIDE
EXECUTIVE OFFICE OF THE PRESIDE

17-May-1994 04:28pm

TO: Carol H. Rasco

FROM: Stanley S. Herr
Domestic Policy Council

SUBJECT: draft reply to M. Kennedy -- who attended PCMR eve
SUBJECT:

nt

Carol -- I drafted this letter after a second conversation with Peter Edelman. The 34d and 4th paragraph closely tracks his suggestions to me. He confirmed that someone in ASPE/HHS is doing a review for the Secretary for the "fresh look" rather than simply sending it to SSA. Peter said you could send him copies of this correspondence to FAX 690-7595 as they review this issue. FYI, they have had this very issue raised by a California woman named Barbara Waxman who has garnered support letters from at least a dozen mainline disability organizations and leaders such as Justin Dart. Peter has also met with Ms. Waxman. For your convenience, I E-mail this draft and copy with yellow folder follows. Stan

May , 1994

Michael J. Kennedy
Regional Organizer
Self-Advocacy Grassroots Organizing Program
200 Huntington Hall
Syracuse, NY 13244-2340

Dear Mr. Kennedy:

Thank you for your recent letter and your kind remarks about my speech.

I appreciate hearing your concerns on the issue of marriage and the receipt of certain Medicaid benefits, and can sympathize with those concerns.

This issue has been raised for many years. It is now, however, receiving a fresh look by this Administration but I would caution that the process of deciding on even a minor change takes considerable time.

I would encourage you to support strongly the Health Security Act

because the President's plan already offers universal coverage and would make long-term care available without regard to income. It thus would remedy the very concern you raised.

I will pass on your letter to those in the Administration who are reviewing this entire matter.

With best wishes to you and your wife.

Sincerely,

Carol H. Rasco
Assistant to the President
for Domestic Policy

FAX -

JDAMA
Recruit Dept
Foreign
Debski
312)
469-2512

call Pauline
addr
report place
515 N. State St.
Chicago Illinois