

# FOIA MARKER

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**Folder Title:**  
Health Care Statement to People with Disabilities 05/02/1994

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# Withdrawal/Redaction Sheet

## Clinton Library

| DOCUMENT NO.<br>AND TYPE | SUBJECT/TITLE                                                                                                                       | DATE       | RESTRICTION |
|--------------------------|-------------------------------------------------------------------------------------------------------------------------------------|------------|-------------|
| 001. fax                 | List of Disability Attendees for the 5/2/94 Meeting at the White House; RE: Personally Identifiable Information [partial] (4 pages) | 04/29/1994 | b(6)        |
| 002. fax                 | Mike Auberger to Debbie Fine; RE: Personally Identifiable Information [partial] (6 pages)                                           | 05/01/1994 | b(6)        |
| 003. list                | Political Appointees with Disabilities in the Clinton Administration; RE: Personally Identifiable Information [partial] (1 page)    | 00/00/0000 | b(6)        |
| 004. fax                 | Stories from Individuals with Disabilities; RE: Personal (6 pages)                                                                  | 04/29/1994 | b(6)        |
| 005. fax                 | Stories from Individuals with Disabilities; RE: Personal (2 pages)                                                                  | 05/01/1994 | b(6)        |

### COLLECTION:

Clinton Presidential Records  
Public Liaison  
William White Jr.  
OA/Box Number: 14205

### FOLDER TITLE:

Health Care Statement to People with Disabilities 05/02/1994

2007-0143-F  
db4557

### 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]

**THE WHITE HOUSE**

WASHINGTON

May 1, 1994

**HEALTH CARE STATEMENT TO PEOPLE WITH DISABILITIES**

DATE: Monday, May 2, 1994  
LOCATION: East Room  
TIME: 9:30 AM  
From: Alexis Herman  
Mike Lux  
Debbie Fine

**I. PURPOSE**

From a message perspective, this is an opportunity to emphasize guaranteed health benefits at work, which is part of the administration's two week focus. It is also a chance to emphasize insurance reform and long term care. Politically, the purpose of your statement to the disability community is to: (1) acknowledge and thank them for their support; (2) reassure them that they are important in this debate; (3) energize them for their Congressional visits while they are in Washington; and (4) mobilize them when they return to their communities.

**II. BACKGROUND**

Bridge to Freedom March and Rally

This event was scheduled for Monday because the disability community has organized a march and a rally entitled "Bridge to Freedom," on Monday to underscore the importance of health care reform and long term care, and to help mobilize the grass roots in support of these goals. They expect 1500-2000 people with disabilities, and family, friends and advocates of people with disabilities from all over the country. They are convening at the Arlington Cemetery and marching to the Lincoln Memorial for the rally. Following the rally, participants will go to Capitol Hill for meetings with their Congressional Representatives. All of the participants of the East Room event will join the march from the White House. Some will do regional satellite feeds into targeted media markets from the DNC following the rally.

You should be aware that the community invited you to participate in the rally. Instead of participating in the rally, we organized this event because of a precedent that was set last year not to attend marches on Washington, as you probably recall

with the civil rights and the gay rights marches. Attached is a letter from you that will be read at the rally by Tony Coehlo.

Following is background on the organizations sponsoring the march and rally on Monday, the members of which comprise the audience of the East Room event:

**American Disabled for Attendant Programs Today (ADAPT):**

ADAPT is a grassroots disability rights organization headquartered in Denver with approximately 5,000 members in thirty three states. Their members are typically severely disabled and often those who would be in nursing homes and other institutions if it weren't for ADAPT. Initially ADAPT's mission was transportation accessibility. With the passage of the Americans with Disabilities Act, they changed the focus to personal assistance services as the means to freeing people from nursing homes. Historically, ADAPT has used fairly radical and confrontational tactics to draw attention to the issues it is fighting for; this is the first time they have worked in cooperation with a Presidential administration. They have been testifying before Congress favorably about the Health Security Act (HSA) and have been generally active on its behalf. (Note that last year their leader, Reverend Wade Blank, and his son drowned. You sent a letter to be read at the memorial service.)

**National Council on Independent Living (NCIL):**

NCIL is the national membership association of 400 local not-for-profit corporations known as Independent Living Centers. On March 31st, NCIL organized a "Visit Your Member Day" and post card campaign. They recently organized a rally in Kansas at the state capital to pressure Slattery. In June when much of the legislative work moves to the House floor, many members of NCIL plan to come to Washington for several weeks to lobby Congress. Ira Magaziner addressed them on Thursday, April 28, on health care at their annual conference. NCIL's former Chairperson is Marca Bristo, who is your appointee as Chair of the National Council on Disabilities (confirmation pending.)

**Consortium of Citizens with Disabilities (CCD):**

CCD is a Washington based coalition of over 100 national consumer, advocacy, provider and professional organizations, which advocates on behalf of people of all ages with physical and mental disabilities and their families. CCD strongly supports the HSA and is actively working for its passage. The Ad Hoc Grassroots Committee of CCD, also called the Real Health Care for All Campaign, has been very active. They have produced 10,000 buttons and t-shirts and 100,000 stickers with the slogan "Real Health Care for All". They organized a major video teleconference in every state with 5,000 participants in November in order to educate the grassroots about the HSA, and to activate them. The teleconference was broadcast on America's Disability Channel. They have followed up the video teleconference with eleven teleconference phone calls to update state activists on the process legislatively. They have been turning out crowds for the town hall meetings. Every Friday approximately fifty of the activists meet for an update and lobby on the Hill.

### **Presentation of Signatures**

When Justin Dart introduces you, he will present a leather bound book with the following inscription on the cover: "Bridge to Freedom: Health Care; Lincoln Memorial May 2, 1994; The Representatives of 49 Million Americans with Disabilities Congratulate the President and Mrs. Bill Clinton on Their Courageous Leadership for Comprehensive Health Care and Personal Assistance Services."

### **Statistical Background**

According to the Bureau of Census there are 49 million people with disabilities. For many, their disability status -- compounded by the lack of available and affordable assistance -- renders them unable to get health insurance, and hurts their job prospects. Passage of a health care bill that achieves universal coverage with no pre-existing conditions and no life-time limits on care will help make what the Americans with Disabilities Act aims to achieve into reality. Currently, people with disabilities are either not hired because of the insurance 'risk' they pose, or they opt not to work because they fear losing the health benefits they now get through Medicaid. They typically pay more for their care, and have less access.

Following are some relevant statistics:

- Due to a variety of physical, mental and emotional conditions, an estimated 49 million noninstitutionalized Americans have a disability (20%). Of these persons, 24 million have a "severe" disability. (Bureau of Census 1/94)
- Disability rates are higher among those with low levels of education. Adults with a disability comprised a much larger share of persons without a high school diploma than of persons with higher levels of education. For example, 23 % of adults aged 25-64 who had not completed high school had a severe disability; for persons who were high school and college graduates, the respective figures were 9% and 3%. (Bureau of Census 1/94)
- Severe disabilities reduce employment chances. Those with disabilities constituted 13% of all employed persons; those with a severe disability comprised 3%. Although having a less than severe disability does not have a large effect on one's chance of being employed, having a severe disability does. Among person 2-64 years old, 81% without a disability and 76% with a disability that was not severe were employed. However, just 23% with a severe disability worked. Data show that persons with a disability -- particularly a severe one -- earn less than those without one. (Bureau of Census 1/94)
- While 15% of people with no disability are without coverage; 35 % of people with disabilities (including severe and non-severe) are without coverage. (Bureau of Census 1/94)

### Health Care Activity

The disability community has been very active in the health care reform debate, and in general has been supportive of the Health Security Act. Initially much of the community was more sympathetic to the single payer approach; after efforts by the leadership to educate the grassroots about the Health Security Act they are generally supportive of it. There has been substantial progress over the long term in the strength of their position and political sophistication in this debate. They state that HSA is the only plan that achieves real health care reform and that meets the needs of the disability community, while working privately with Congress to find better solutions to the shortcomings they identify. (The three most hot button concerns are listed below.) Collectively they have been working to educate and activate the grassroots. Members of the groups work with the DNC surrogate speakers bureau; they have been organizing regional hearings, teleconferences and building supportive crowds at town hall meetings.

### Issues to Highlight

The issues in the health care debate most important to the disability community are:

- universal coverage with no pre-existing conditions and no life-time limits;
- a defined comprehensive benefits package;
- home and community based long term care, with personal assistance services.

Two aspects of the Health Security Act that the disability community considers critical are:

- Through the new home and community-based program, a broad range of personal assistance services will be available to children and adults with severe disabilities. Personal assistance services has been the primary goal for the disability community because it is identified as the mechanism that allows people with disabilities to participate in society.
- Under the Health Security Act, employees with disabilities who require personal assistance with daily tasks will be eligible for new tax credits covering 0 percent of their personal care service costs - up to a maximum of \$15,000 each year.

Three issues of particular concern with the HSA are:

- Rehabilitation services for children with congenital defects are not fully covered, they are available only following an illness or an injury.
- Assistive hearing devices are not covered.
- Mental health benefits do not achieve parity until 2001.

This is your second event with the disability community since the meeting last July in honor of the third anniversary of the enactment of the Americans with Disabilities Act; the community is very excited about it.

### III. PARTICIPANTS

From the White House  
The President

In the Program

**Tony Coehlo:** As you know, you recently appointed him as the Chair of the President's Committee on the Employment of People with Disabilities. In addition to his political and business career, he is a well respected leader in the disability community. (As you know, he has epilepsy and his struggle with the disease was a major factor in influencing career.)

**Justin Dart:** He is the former Chair of the President's Committee on the Employment of People with Disabilities. As one of the key champions responsible for passage of the ADA, he is a well-respected national disability leader. He is a life-long Republican and friend and appointee of President Bush, but he is one of your strongest supporters on health care and has invested significant resources into the debate via existing coalitions and the DNC.

**Denise Figueroa:** She is President of National Council of Independent Living. She will present the book of signatures to you. **(No speaking role.)**

**Kate Miles:** Kate Miles is the mother of a child with multiple disabilities; her son Robby has severe epilepsy and mental retardation. She has used the devastating story of her family's struggle with today's health care system as a tireless advocate of long term care, appearing on long term care videos advocating for health care reform; she is very supportive of the HSA. Her family (husband Tom, daughter Kimberly and son Robby) will be seated in the front row. You shook Kate's and Robby's hands at the end of the ropeline (Robby was in the wheelchair lift) at the NCOA speech last Thursday. (Her story is attached.)

**Stephanie Thomas:** She is ADAPT's representative for presenting the book of signatures to you. She is one of the top leadership of ADAPT and works full time with the Texas chapter of ADAPT and the Texas Coalition for Citizens with Disabilities. **(No speaking role.)**

#### The Audience

The audience is comprised of approximately 125 activists in the disability community who are members of the sponsoring organizations of the Bridge to Freedom march and rally.

#### **IV. PRESS PLAN**

Open to the press.

#### **V. SEQUENCE OF EVENTS**

- You will proceed to the Green Room for hold.
- You will be announced into the East Room.
- You will join Tony Coehlo, Justin Dart and Kate Miles on stage.
- Tony Coehlo will make welcoming remarks and introduce Kate Miles.
- Kate Miles will deliver remarks and introduce Justin Dart.
- Justin will make remarks, announcing Stephanie Thomas and Denise Figueroa to the stage to present the book of signatures.
- Denise Figueroa and Stephanie Thomas will proceed to the stage from the front row.
- You will step down off stage to receive the book of signatures from Stephanie Thomas and Denise Figueroa.
- You will step back on to the stage, thank them for the book and deliver your statement.
- You will proceed off stage into the room to meet and greet the members of the audience.

#### **VI. REMARKS**

To be provided by speechwriters.



THE WHITE HOUSE

WASHINGTON

April 29, 1994

Greetings to everyone gathered in our nation's capital to voice your support for providing health security to all Americans. I am delighted that so many of you have come together for this exciting event.

Now is the time to act on our awareness that disabilities are a natural part of the human experience. Having a disability does not diminish one's right to participate in any aspect of mainstream society. With the shared strengths of all those participating in this rally, you send a powerful message -- the key to improving the quality of life for millions of Americans with disabilities and their families is passing a comprehensive health care plan that meets the needs of each one of our citizens.

The active participation of groups like ADAPT, the National Council on Independent Living, and the Consortium of Citizens with Disabilities is essential in meeting this crucial goal. I commend you for working toward making health care reform a reality. Your knowledge and expertise are helping to advance the rights of and services for all Americans, especially those persons with disabilities, and I thank you for your leadership and dedication. Working together, we can build a health care system that moves our nation from exclusion to inclusion, from dependence to independence, and from paternalism to empowerment.

Hillary joins me in extending best wishes to all for a successful rally.

*Bill Clinton*

My name is Kate Miles, my husband Tom is a Sheet Metal Mechanic, and we have two children - Kimberly 11, and Robert 9, I'd like to share with you our story of the past seven years.

Seven years ago when Robert was 2½ years old, he started having epileptic seizures. At times over the years he has had in excess of two hundred multiple types of seizures per day. Robert has been on every anticonvulsant medicine on the market, all have been unsuccessful at controlling his seizures. Due to the effect of the seizures on the brain, Robert is mentally retarded and at times unable to walk or talk. He suffers from the most significant form of Epilepsy called Lennox-Gastaut syndrome.

At the time Robert first became ill, Tom was a first year apprentice with the Sheet Metal Workers Union. Our insurance coverage was 80% coverage with the 20% to be paid by the member. This coverage we were soon to discover is adequate if you are not suffering from a chronic illness. *\* check*

During the first three months of Rob's illness we were unable to keep him out of the hospital for more than two weeks at a time. During that period we accrued several tens of thousands of dollars worth of medical bills.

As we were a struggling young two income family making \$20,000 per year we applied for assistance, only to be denied - because we were, "just over the maximum income allowed." So we were turned over to some very unfriendly people at medical collections.

To make matters worse, after six months the insurance company stopped paying for an RN to come into the house to take care of Rob, so I was forced to quit working.

It was at that time it became impossible for us to pay our mortgage and foreclosure proceedings were started. Fortunately, we sold the house in time and took all the equity to pay off the medical bills.

We then had to find a place we could afford, now that we were a one income family - thus a move to the Eastern Shore. The move required Tom to spend four hours on the road each day going to and from work.

Robert's illness made him uninsurable because he now had a "preexisting condition," and we became all too aware of how important it was for Tom to keep his job. We knew if he lost his job or if his grades in the apprenticeship program were not passing, Robert would lose his insurance coverage.

After the move more admissions followed, and again the bills started mounting. It was at that time we were told to apply

for Children's Medical Services. Finally we were accepted for something. They agreed to pay the balance remaining on all bills - after the union had paid, on services pertaining only to Epilepsy. If it were not for this organization we would of been homeless.

Like many programs of this type, Children's Medical Services requires yearly renewal. In September of 1992 we moved to a new home, one that is wheelchair accessible. The next month our renewal came due and we were denied services based on our income being in excess of the \$22,000 per year maximum.

Tom could make ten times that amount and it would not be enough. The 80% the union has paid over the last seven years, has exceeded our total income for the same period. Children's Medical Services only pays on Epilepsy related services, they are not Robert's only problem.

Robert has chronic ear infections, upper respiratory infections, and pneumonia, all requiring several trips to the pediatrician's office per month. The wheelchair cost \$3,000 two years ago, and he has almost out grown it already. He requires physical and occupational therapy, weekly lab work, as well as his medicines that run approximately \$150 every ten days.

As if we don't have enough to worry about, we have recently been informed that Robert has used up \$160,000 of his \$250,000 of Major Medical in just seven years.

Due to the weak economy, last year Tom's company was forced to cut back to a four day work week, while at the same time the union eliminated many of the medical benefits and reduced the coverage to 50/50. Due to Robert's preexisting condition Tom is locked into his job, even if his employer cuts him back to a three day work week. The problems are never ending.

Two years ago while lifting Rob, I hurt my back. The injury has left me bedridden and unable to care for Robert many times since. It was one of these times I contacted the local agencies, to get some help taking care of Rob in our home. I was told that if he was on Medical Assistance they could send an aide, but because he was ineligible all they could offer was to institutionalize him. I informed them that I would not even consider putting Rob in an institution, and that he would not thrive without the love of his family nor would we. In an institution no one is going to get up during the night, while he is having his seizures, and let him know that it's "ok" and that mom loves him. No one in an institution could ever give him the love that the three of us give him at home. So that spring Kimberly who was then 8½, spent her spring break in the house taking care of her mother and brother, while Tom had to work two jobs to keep a roof over our heads.

This is why we so desperately need health care reform. What has happened to us and many other families like ours, is wrong - but we can stop this from happening to any more families by passing the president's health care reform bill. With the longterm care that is in the president's bill, institutionalizing Robert is something that we won't have to consider - even if it is phased in over the next six years, at least we will know that there is light at the end of the tunnel.

Lastly, I would like to thank President Clinton and Mrs. Clinton on behalf of our family for even taking on this enormous task. Up until now there has been no help or even recognition of this terrible burden on our family, we have fallen through the cracks too many times - thank you for fighting on our behalf.

## **The Health Security Act**

### **AMERICANS WITH DISABILITIES**

*Americans with disabilities are a large and diverse population. Of the estimated 35 to 43 million people with physical or mental impairments, a significant portion are of working age. For many, their disability status -- compounded by the lack of available and affordable assistance -- renders them unable to get health insurance, and hurts their job prospects. Meanwhile, families with insurance are reluctant to change jobs or move for fear of being denied health insurance coverage. Passage of this Act will cure this significant gap in the protections of the landmark Americans With Disabilities Act.*

*In a health insurance industry that competes by insuring only the healthiest people, Americans with disabilities are often discriminated against, dubbed "high risk" applicants because they may have higher health care costs. Those who are able to obtain insurance are often forced to pay the highest rates in the market, and are still faced with a lifetime limit on benefits and no guarantee of policy renewal. After that, they're on their own.*

#### **Guaranteed Comprehensive Benefits**

- Under health reform, all Americans -- including those with disabilities -- are guaranteed a comprehensive package of benefits at the community rate. Like all other Americans, persons with disabilities will be able to choose their doctor and health plan. Plans will not be allowed to discriminate based on pre-existing emotions.
- There will be no lifetime limit on care -- a change that will free many Americans with disabilities to go to work without fear of losing the health benefits they now get through Medicaid or change jobs without the fear of losing private coverage.
- Benefits will include not only acute-care services, but also certain rehabilitative services in both inpatient and outpatient settings.
- The guaranteed benefits package, protections from discrimination in health care, and new services will substantially improve access to health services for Americans with disabilities.

### **Community-Based Long-Term Care**

- A new community-based long-term care benefit will aid Americans of all ages with severe physical or mental disabilities, regardless of income. This benefit will serve up to 3.1 million individuals with disabilities.
- Children under the age of six with severe disabilities or chronic medical conditions who would otherwise require hospital or institutional care will be able to receive assistance in their homes and communities.
- Through the new home and community-based program, a broad range of personal assistance services will be available to children and adults with severe disabilities.
- States will have the flexibility to design their own approaches to community-based care. States may expand their programs beyond personal assistance to include a wide array of community services, such as: case management, homemaker and chore services, home modifications, respite services, assertive technology, adult day care, and rehabilitation services.
- For low-income persons with lesser levels of disability, states will be able to continue their home and community-based programs under Medicaid.

### **New Tax Credit**

- Under the Health Security Act, employees with disabilities who require personal assistance with daily tasks will be eligible for new tax credits covering 50 percent of their personal care service costs -- up to a maximum of \$15,000 each year.

### **Improved Medicaid Coverage**

- Residents of nursing homes and intermediate care facilities for the mentally retarded will be able to retain \$70 per month as a living allowance (compared to the \$30 per month ceiling at present).

- Single residents of such facilities may be able to retain up to \$12,000 in personal assets under eligibility determinations (compared to \$2,000 at present).

April 30, 1994

→ 7/11/94 6

**THE WHITE HOUSE**

WASHINGTON

May 1, 1994

**HEALTH CARE STATEMENT TO PEOPLE WITH DISABILITIES**

DATE: Monday, May 2, 1994  
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From: Alexis Herman  
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- home and community based long term care, with personal assistance services.

Two aspects of the Health Security Act that the disability community considers critical are:

- Through the new home and community-based program, a broad range of personal assistance services will be available to children and adults with severe disabilities. Personal assistance services has been the primary goal for the disability community because it is identified as the mechanism that allows people with disabilities to participate in society.
- Under the Health Security Act, employees with disabilities who require personal assistance with daily tasks will be eligible for new tax credits covering 0 percent of their personal care service costs - up to a maximum of \$15,000 each year.

Three issues of particular concern with the HSA are:

- Rehabilitation services for children with congenital defects are not fully covered, they are available only following an illness or an injury.
- Assistive hearing devices are not covered.
- Mental health benefits do not achieve parity until 2001.

This is your second event with the disability community since the meeting last July in honor of the third anniversary of the enactment of the Americans with Disabilities Act; the community is very excited about it.

### III. PARTICIPANTS

#### From the White House

The President

#### In the Program

**Tony Coehlo:** As you know, you recently appointed him as the Chair of the President's Committee on the Employment of People with Disabilities. In addition to his political and business career, he is a well respected leader in the disability community. (As you know, he has epilepsy and his struggle with the disease was a major factor in influencing career.)

**Justin Dart:** He is the former Chair of the President's Committee on the Employment of People with Disabilities. As one of the key champions responsible for passage of the ADA, he is a well-respected national disability leader. He is a life-long Republican and friend and appointee of President Bush, but he is one of your strongest supporters on health care and has invested significant resources into the debate via existing coalitions and the DNC.

**Denise Figueroa:** She is President of National Council of Independent Living. She will present the book of signatures to you. **(No speaking role.)**

**Kate Miles:** Kate Miles is the mother of a child with multiple disabilities; her son Robby has severe epilepsy and mental retardation. She has used the devastating story of her family's struggle with today's health care system as a tireless advocate of long term care, appearing on long term care videos advocating for health care reform; she is very supportive of the HSA. Her family (husband Tom, daughter Kimberly and son Robby) will be seated in the front row. You shook Kate's and Robby's hands at the end of the ropeline (Robby was in the wheelchair lift) at the NCOA speech last Thursday. (Her story is attached.)

**Stephanie Thomas:** She is ADAPT's representative for presenting the book of signatures to you. She is one of the top leadership of ADAPT and works full time with the Texas chapter of ADAPT and the Texas Coalition for Citizens with Disabilities. **(No speaking role.)**

#### The Audience

The audience is comprised of approximately 125 activists in the disability community who are members of the sponsoring organizations of the Bridge to Freedom march and rally.

#### **IV. PRESS PLAN**

Open to the press.

#### **V. SEQUENCE OF EVENTS**

- You will proceed to the Green Room for hold.
- You will be announced into the East Room.
- You will join Tony Coehlo, Justin Dart and Kate Miles on stage.
- Tony Coehlo will make welcoming remarks and introduce Kate Miles.
- Kate Miles will deliver remarks and introduce Justin Dart.
- Justin will make remarks, announcing Stephanie Thomas and Denise Figueroa to the stage to present the book of signatures.
- Denise Figueroa and Stephanie Thomas will proceed to the stage from the front row.
- You will step down off stage to receive the book of signatures from Stephanie Thomas and Denise Figueroa.
- You will step back on to the stage, thank them for the book and deliver your statement.
- You will proceed off stage into the room to meet and greet the members of the audience.

#### **VI. REMARKS**

To be provided by speechwriters.

THE WHITE HOUSE

WASHINGTON

April 29, 1994

Greetings to everyone gathered in our nation's capital to voice your support for providing health security to all Americans. I am delighted that so many of you have come together for this exciting event.

Now is the time to act on our awareness that disabilities are a natural part of the human experience. Having a disability does not diminish one's right to participate in any aspect of mainstream society. With the shared strengths of all those participating in this rally, you send a powerful message -- the key to improving the quality of life for millions of Americans with disabilities and their families is passing a comprehensive health care plan that meets the needs of each one of our citizens.

The active participation of groups like ADAPT, the National Council on Independent Living, and the Consortium of Citizens with Disabilities is essential in meeting this crucial goal. I commend you for working toward making health care reform a reality. Your knowledge and expertise are helping to advance the rights of and services for all Americans, especially those persons with disabilities, and I thank you for your leadership and dedication. Working together, we can build a health care system that moves our nation from exclusion to inclusion, from dependence to independence, and from paternalism to empowerment.

Hillary joins me in extending best wishes to all for a successful rally.

A handwritten signature in black ink, reading "Bill Clinton". The signature is written in a cursive, flowing style with a long horizontal stroke at the end.

My name is Kate Miles, my husband Tom is a Sheet Metal Mechanic, and we have two children - Kimberly 11, and Robert 9, I'd like to share with you our story of the past seven years.

Seven years ago when Robert was 2½ years old, he started having epileptic seizures. At times over the years he has had in excess of two hundred multiple types of seizures per day. Robert has been on every anticonvulsant medicine on the market, all have been unsuccessful at controlling his seizures. Due to the effect of the seizures on the brain, Robert is mentally retarded and at times unable to walk or talk. He suffers from the most significant form of Epilepsy called Lennox-Gastaut syndrome.

At the time Robert first became ill, Tom was a first year apprentice with the Sheet Metal Workers Union. Our insurance coverage was 80% coverage with the 20% to be paid by the member. This coverage we were soon to discover is adequate if you are not suffering from a chronic illness. *★ check*

During the first three months of Rob's illness we were unable to keep him out of the hospital for more than two weeks at a time. During that period we accrued several tens of thousands of dollars worth of medical bills.

As we were a struggling young two income family making \$20,000 per year we applied for assistance, only to be denied - because we were, "just over the maximum income allowed." So we were turned over to some very unfriendly people at medical collections.

To make matters worse, after six months the insurance company stopped paying for an RN to come into the house to take care of Rob, so I was forced to quit working.

It was at that time it became impossible for us to pay our mortgage and foreclosure proceedings were started. Fortunately, we sold the house in time and took all the equity to pay off the medical bills.

We then had to find a place we could afford, now that we were a one income family - thus a move to the Eastern Shore. The move required Tom to spend four hours on the road each day going to and from work.

Robert's illness made him uninsurable because he now had a "preexisting condition," and we became all too aware of how important it was for Tom to keep his job. We knew if he lost his job or if his grades in the apprenticeship program were not passing, Robert would lose his insurance coverage.

After the move more admissions followed, and again the bills started mounting. It was at that time we were told to apply

for Children's Medical Services. Finally we were accepted for something. They agreed to pay the balance remaining on all bills - after the union had paid, on services pertaining only to Epilepsy. If it were not for this organization we would of been homeless.

Like many programs of this type, Children's Medical Services requires yearly renewal. In September of 1992 we moved to a new home, one that is wheelchair accessible. The next month our renewal came due and we were denied services based on our income being in excess of the \$22,000 per year maximum.

Tom could make ten times that amount and it would not be enough. The 80% the union has paid over the last seven years, has exceeded our total income for the same period. Children's Medical Services only pays on Epilepsy related services, they are not Robert's only problem.

Robert has chronic ear infections, upper respiratory infections, and pneumonia, all requiring several trips to the pediatrician's office per month. The wheelchair cost \$3,000 two years ago, and he has almost out grown it already. He requires physical and occupational therapy, weekly lab work, as well as his medicines that run approximately \$150 every ten days.

As if we don't have enough to worry about, we have recently been informed that Robert has used up \$160,000 of his \$250,000 of Major Medical in just seven years.

Due to the weak economy, last year Tom's company was forced to cut back to a four day work week, while at the same time the union eliminated many of the medical benefits and reduced the coverage to 50/50. Due to Robert's preexisting condition Tom is locked into his job, even if his employer cuts him back to a three day work week. The problems are never ending.

Two years ago while lifting Rob, I hurt my back. The injury has left me bedridden and unable to care for Robert many times since. It was one of these times I contacted the local agencies, to get some help taking care of Rob in our home. I was told that if he was on Medical Assistance they could send an aide, but because he was ineligible all they could offer was to institutionalize him. I informed them that I would not even consider putting Rob in an institution, and that he would not thrive without the love of his family nor would we. In an institution no one is going to get up during the night, while he is having his seizures, and let him know that it's "ok" and that mom loves him. No one in an institution could ever give him the love that the three of us give him at home. So that spring Kimberly who was then 8½, spent her spring break in the house taking care of her mother and brother, while Tom had to work two jobs to keep a roof over our heads.



This is why we so desperately need health care reform. What has happened to us and many other families like ours, is wrong - but we can stop this from happening to any more families by passing the president's health care reform bill. With the longterm care that is in the president's bill, institutionalizing Robert is something that we won't have to consider - even if it is phased in over the next six years, at least we will know that there is light at the end of the tunnel.

Lastly, I would like to thank President Clinton and Mrs. Clinton on behalf of our family for even taking on this enormous task. Up until now there has been no help or even recognition of this terrible burden on our family, we have fallen through the cracks too many times - thank you for fighting on our behalf.

## **The Health Security Act**

### **AMERICANS WITH DISABILITIES**

*Americans with disabilities are a large and diverse population. Of the estimated 35 to 43 million people with physical or mental impairments, a significant portion are of working age. For many, their disability status -- compounded by the lack of available and affordable assistance -- renders them unable to get health insurance, and hurts their job prospects. Meanwhile, families with insurance are reluctant to change jobs or move for fear of being denied health insurance coverage. Passage of this Act will cure this significant gap in the protections of the landmark Americans With Disabilities Act.*

*In a health insurance industry that competes by insuring only the healthiest people, Americans with disabilities are often discriminated against, dubbed "high risk" applicants because they may have higher health care costs. Those who are able to obtain insurance are often forced to pay the highest rates in the market, and are still faced with a lifetime limit on benefits and no guarantee of policy renewal. After that, they're on their own.*

#### **Guaranteed Comprehensive Benefits**

- Under health reform, all Americans -- including those with disabilities -- are guaranteed a comprehensive package of benefits at the community rate. Like all other Americans, persons with disabilities will be able to choose their doctor and health plan. Plans will not be allowed to discriminate based on pre-existing emotions.
- There will be no lifetime limit on care -- a change that will free many Americans with disabilities to go to work without fear of losing the health benefits they now get through Medicaid or change jobs without the fear of losing private coverage.
- Benefits will include not only acute-care services, but also certain rehabilitative services in both inpatient and outpatient settings.
- The guaranteed benefits package, protections from discrimination in health care, and new services will substantially improve access to health services for Americans with disabilities.

### **Community-Based Long-Term Care**

- A new community-based long-term care benefit will aid Americans of all ages with severe physical or mental disabilities, regardless of income. This benefit will serve up to 3.1 million individuals with disabilities.
- Children under the age of six with severe disabilities or chronic medical conditions who would otherwise require hospital or institutional care will be able to receive assistance in their homes and communities.
- Through the new home and community-based program, a broad range of personal assistance services will be available to children and adults with severe disabilities.
- States will have the flexibility to design their own approaches to community-based care. States may expand their programs beyond personal assistance to include a wide array of community services, such as: case management, homemaker and chore services, home modifications, respite services, assertive technology, adult day care, and rehabilitation services.
- For low-income persons with lesser levels of disability, states will be able to continue their home and community-based programs under Medicaid.

### **New Tax Credit**

- Under the Health Security Act, employees with disabilities who require personal assistance with daily tasks will be eligible for new tax credits covering 50 percent of their personal care service costs -- up to a maximum of \$15,000 each year.

### **Improved Medicaid Coverage**

- Residents of nursing homes and intermediate care facilities for the mentally retarded will be able to retain \$70 per month as a living allowance (compared to the \$30 per month ceiling at present).

- Single residents of such facilities may be able to retain up to \$12,000 in personal assets under eligibility determinations (compared to \$2,000 at present).

April 30, 1994

# Withdrawal/Redaction Marker

## Clinton Library

| DOCUMENT NO.<br>AND TYPE | SUBJECT/TITLE                                                                                                                       | DATE       | RESTRICTION |
|--------------------------|-------------------------------------------------------------------------------------------------------------------------------------|------------|-------------|
| 001. fax                 | List of Disability Attendees for the 5/2/94 Meeting at the White House; RE: Personally Identifiable Information [partial] (4 pages) | 04/29/1994 | b(6)        |

### COLLECTION:

Clinton Presidential Records  
Public Liaison  
William White Jr.  
OA/Box Number: 14205

### FOLDER TITLE:

Health Care Statement to People with Disabilities 05/02/1994

2007-0143-F  
db4557

### 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]
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- b(9) Release would disclose geological or geophysical information concerning wells [(b)(9) of the FOIA]

CCD

~~XXXXXX~~

## LIST OF DISABILITY ATTENDEES FOR THE 5/2/94 MEETING AT THE WHITE HOUSE

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5/2/94 WHITE HOUSE LIST  
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# ADAPT

## FREE OUR PEOPLE

7 PAGES (INC. COVER SHEET)

TO: DEBBIE FINE

FR: MIKE AUBERGER

RE: WHITE HOUSE GUEST LIST FOR 5/2 MTG.

DT: MAY 1, 1994

VIA FAX (202) 456-6485

HERE'S THE FINAL INVITATION LIST OF 50

FROM ADAPT FOR THE 5/2 MEETING. PLS

CALL TO CONFIRM RECEIPT, AS JUSTIN HAS

OFFERED TO DRIVE OVER THE LIST IF WE

DON'T HEAR FROM YOU.

YOU CAN REACH ME AT:

(301) 937-4422 - HOTEL

(202) 215-4563 - CELLULAR PHONE

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| DOCUMENT NO.<br>AND TYPE | SUBJECT/TITLE                                                                             | DATE       | RESTRICTION |
|--------------------------|-------------------------------------------------------------------------------------------|------------|-------------|
| 002. fax                 | Mike Auberger to Debbie Fine; RE: Personally Identifiable Information [partial] (6 pages) | 05/01/1994 | b(6)        |

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b(9) Release would disclose geological or geophysical information concerning wells [(b)(9) of the FOIA]

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# Statistical Brief

## Americans With Disabilities

Due to a variety of physical, mental, and emotional conditions, an estimated 49 million noninstitutionalized Americans (about 1 in 5) have a disability. Of these persons, 24 million have a "severe" disability.

The first section of this Brief describes the disability status of persons aged 15 years and older; the last section details children's disabilities. The box on the back defines "severe" disabilities.

This Brief examines the number of persons with specific types of disabilities, their demographic characteristics, the impact of having a disability on employment status and health insurance coverage, and more. The data were collected in the Survey of Income and Program Participation (SIPP) between October 1991 and January 1992.

**Difficulty with a functional activity is the most common type of disability for adults.**

*Functional activities* include lifting and carrying a weight as heavy as 10 pounds, walking 3 city blocks, seeing the words and letters in ordinary newsprint, hearing what is said in normal conversation with another person, having one's speech understood, and climbing a flight of stairs.



SB/94-1  
Issued January 1994

U.S. Department of Commerce  
Economics and Statistics Administration  
BUREAU OF THE CENSUS

Thirty-four million adults aged 15 and older had a functional disability — *difficulty* performing at least one of these tasks; for 15 million of them, the disability was severe — they were *unable* to perform one or more activities. The latter figure includes 1.6 million who *could not* see words or letters in ordinary newsprint and 900,000 who were *completely unable* to hear what was said in normal conversation.

**Fewer adults have trouble with ADL's and IADL's than with functional activities.**

*Activities of Daily Living (ADL's)* consist of getting in or out of a bed or a chair, bathing, getting around inside the home, dressing, using the toilet, and eating. About 8 million adults had difficulty with at least one of these tasks; 3.9 million of them required the assistance of another person, making the disability severe.

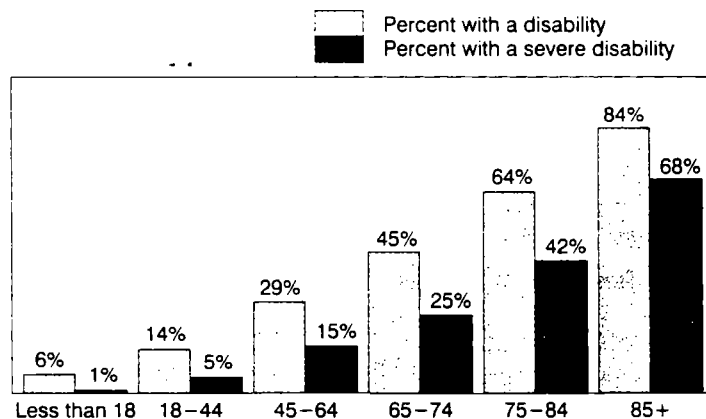
### Physical Conditions That Cause Disabilities

Conditions most frequently cited by persons 15 years old and over with a functional, ADL, or IADL limitation as a cause of the limitation(s): 1991-92

| Condition                                 | Number with condition (millions) |
|-------------------------------------------|----------------------------------|
| Arthritis or rheumatism .....             | 7.2                              |
| Back or spine problems .....              | 5.7                              |
| Heart trouble .....                       | 4.6                              |
| Lung or respiratory trouble .....         | 2.8                              |
| High blood pressure .....                 | 2.2                              |
| Stiffness or deformity of extremity ..... | 2.0                              |
| Diabetes .....                            | 1.6                              |
| Blindness or vision problems .....        | 1.5                              |

### With Increasing Age Comes A Greater Likelihood of Having a Disability

Percent of persons with a disability and percent with a severe disability, by age group: 1991-92



*Instrumental Activities of Daily Living (IADL's)* include going outside the home to shop or visit a doctor's office, doing light housework (such as washing dishes), preparing meals, keeping track of money and bills, and using the telephone. Twelve million adults had trouble with one or more of these activities; nine million needed assistance.

Not only were adults with functional, ADL, and IADL limitations considered to have a disability, but so too were those who —

- Used a wheelchair (1.5 million did so).
- Used a cane, crutches, or a walker for 6 months or longer (4 million).
- Had a mental or an emotional disability, such as Alzheimer's disease or mental retardation (6.9 million).
- Had a condition that limited the kind or amount of work they could do at a job (19.5 million aged 16 to 67).
- Had a condition that made it difficult to do housework (18.1 million aged 16 and over).

### **The elderly comprise a disproportionate share of persons with disabilities.**

As the graph on the front illustrates, the chances of having a disability increased with age; most persons aged 75 or older had a disability. In fact, those aged 65 or more comprised a far larger share of those with disabilities (34 percent) than of the total population (12 percent); they constituted an even greater percentage (43 percent) of persons with severe disabilities.

### **Disability rates are higher among those with low levels of education.**

Adults with a disability comprised a much larger share of persons without a high school diploma than of persons with higher levels of education. For example, 23 percent of adults aged 25 to 64 who had not completed high

## **What is a Severe Disability?**

Adults aged 15 and over were classified as having a severe disability if they used a wheelchair or had used another special aid for 6 months or longer, were *unable* to perform one or more functional activities or *needed assistance* with an ADL or IADL, were *prevented* from working at a job or doing housework, or had a selected condition including autism, cerebral palsy, Alzheimer's disease, senility or dementia, or mental retardation.

## **Disability and Health Insurance Coverage**

Health insurance coverage patterns for persons 15-64 years old, by disability status: 1991-92

|                      | No disability | Non-severe disability | Severe disability |
|----------------------|---------------|-----------------------|-------------------|
| Private insurance    | 80%           | 74%                   | 48%               |
| Government insurance | 5%            | 7%                    | 36%               |
| No coverage          | 15%           | 19%                   | 16%               |

school had a severe disability; for persons who were high school and college graduates, the respective figures were 9 percent and 3 percent.

### **Severe disabilities reduce employment chances.**

Those with disabilities constituted 13 percent of all employed persons; those with a severe disability comprised 3 percent. Although having a less-than-severe disability does not have a large effect on one's chance of being employed, having a severe disability does. Among persons 21-64 years old, 81 percent without a disability and 76 percent with a disability that was not severe were employed. However, just 23 percent with a severe disability worked. Data show that persons with a disability — particularly a severe one — earn less than those without one.

### **Disabilities affect 3 million children under age 15.**

Disability rates were 2 percent among children under 3 years old, 5 percent among those aged 3-5, and 6 percent among children aged 6 to 14.

The definition of disability was different for children than for adults. For those under age 6, a limitation in the usual kinds of activities

done by most children that age and the receipt of services or therapy for developmental needs were considered disabilities. Children 3-14 limited in their ability to walk, run, or use stairs were categorized as disabled, as were 6-to-14-year-olds whose ability to do regular school work was limited.

### **More information:**

*Americans With Disabilities: 1991-92.* Current Population Reports, Series P70-33. Contact Customer Services (301-763-4100) for ordering information.

### **Contacts:**

Persons with disabilities —  
John McNeil  
301-763-8300  
Statistical Briefs —  
Robert Bernstein  
301-763-1584

*This Brief is one of a series that presents information of current policy interest. It may include data from businesses, households, or other sources. All statistics are subject to sampling variability, as well as survey design flaws, respondent classification errors, and data processing mistakes. The Census Bureau has taken steps to minimize errors, and analytical statements have been tested and meet statistical standards. However, because of methodological differences, use caution when comparing these data with data from other sources.*

EXECUTIVE OFFICE OF THE PRESIDENT

29-Apr-1994 02:38pm

TO: Deborah L. Fine  
FROM: John O. Sutton  
Health Care Task Force

SUBJECT: RE: vans

Mobile Transport:

3 vans available that hold 2 people  
6 people total

\$50 1st person  
\$25 2nd person  
\$75 per van  
3 vans at \$75= \$225

Battle:

1 van that holds 5 people

\$125 total

They need a confirmation by 4 P.M. at the latest in order to hold the vans.

I'm bringing a memo to Andrea right now for the sign interpreter. That should be taken care of soon.

ROUGH DRAFT - REMARKS BY JUSTIN DART, 9:30AM, MONDAY, MAY 2, 1994, EAST ROOM MEETING WITH PRESIDENT AND DISABILITY COMMUNITY LEADERS. PLEASE ADVISE.

I HAVE NEVER BEEN SO PROUD TO BE AN AMERICAN AS I AM TODAY.

HERE WE ARE, THE REPRESENTATIVES OF OUR NATION'S POOREST, MOST ISOLATED AND OPPRESSED PEOPLE, DOING THE BUSINESS OF DEMOCRACY WITH THE PRESIDENT OF THE UNITED STATES. MR. JEFFERSON IS SMILING. MARTIN LUTHER KING AND WADE BLANK ARE SMILING.

FOR DECADES OUR EXCLUSIONARY, POVERTY-BASED HEALTH CARE SYSTEM HAS BEEN THE MAJOR BARRIER TO THE EQUALITY AND PROSPERITY OF PEOPLE WITH DISABILITIES.

BILL CLINTON HAS SAID, "AMERICA CAN DO BETTER, IF WE HAVE THE COURAGE TO CHANGE."

I HAVE NEVER BEEN IN A ROOM WITH SO MUCH COURAGE.

THE COURAGE OF THE MEMBERS OF ADAPT, NCIL AND CCD WHO HAVE MADE THE LONESOME SACRIFICES AND FOUGHT THE LONESOME BATTLES TO EMANCIPATE TENS OF MILLIONS OF PEOPLE WITH DISABILITIES FROM AN ETERNITY OF SLAVERY TO DEPENDENCY AND DISCRIMINATION.

AND THE COURAGE OF OUR PRESIDENT.

AT LONG LAST WE HAVE A PRESIDENT WITH THE COURAGE TO LAY HIS POLITICAL LIFE ON THE LINE FOR UNIVERSAL HEALTH CARE

THAT BEGINS TO MEET THE NEEDS OF PEOPLE WITH DISABILITIES.

THERE IS MASSIVE OPPOSITION - HISTORY'S MOST EXPENSIVE CAMPAIGN OF DECEPTION. BILL CLINTON HAS OUR SUPPORT, BUT WE'VE GOT TO DO MORE.

WE, AND THOUSANDS MORE, HAVE GOT TO DELIVER THE TRUTH TO EVERY CONGRESSIONAL OFFICE TODAY AND EVERYDAY UNTIL THE TRUTH PREVAILS.

MR. CONGRESSMAN, MS. CONGRESSWOMAN, HEALTH CARE IS A HUMAN RIGHT. 49 MILLION AMERICANS WITH DISABILITIES RESPECTFULLY DEMAND THAT YOU ACCEPT THE PRESIDENT'S CHALLENGE TO GUARANTEE COMPREHENSIVE, AFFORDABLE HEALTH CARE TO EVERY SINGLE AMERICAN, NOW.

UNIVERSAL COVERAGE NOW. LONG TERM CARE, INCLUDING A NATIONAL SYSTEM OF COMMUNITY-BASED ATTENDANT SERVICES, NOW. CONSUMER DRIVEN PSYCHIATRIC SERVICES, DURABLE MEDICAL EQUIPMENT, ASSISTIVE TECHNOLOGY AND PRESCRIPTION DRUGS, NOW.

MR. CONGRESSMAN, WE ARE WILLING TO DIE FOR OUR COUNTRY, BUT NOT FOR OUR INSURANCE COMPANIES.

NO MORE EXCUSES. NO MORE EXCLUSIONS. NO MORE PROFITEERING. NO MORE BAND-AID SOLUTIONS. REAL HEALTH CARE FOR ALL AMERICANS, NOW.

*move* MR. PRESIDENT, *I would like to invite* TWO AUTHENTIC AMERICAN PATRIOTS, STEPHANIE THOMAS AND DENISE FIGUEROA ~~ARE GOING TO PRESENT TO YOU~~



THIS LEATHER BOOK BEARING THE SIGNATURES OF ALL WHO WILL PARTICIPATE IN THE BRIDGE TO FREEDOM CELEBRATION AT THE LINCOLN MEMORIAL TODAY.

THE MESSAGE OF THIS BOOK IS THE MESSAGE OF OUR HEARTS.

MR. PRESIDENT, YOU HAVE INCLUDED US IN YOUR ADMINISTRATION AND YOUR DECISIONS. YOU ARE FULFILLING YOUR PLEDGES TO IMPLEMENT THE ADA. YOU ARE LEADING THE GOOD FIGHT FOR REAL HEALTH CARE.

WE KNOW WHAT YOU'RE UP AGAINST - THE VICIOUS POLITICAL AND PERSONAL ATTACKS. YOU PROVIDE A REAL PROFILE IN COURAGE.

WE RESPECT YOU, WE LOVE YOU, WE ARE WITH YOU NOW, NEXT YEAR, IN '96 - HOWEVER LONG IT TAKES TO FINISH THE JOB OF JUSTICE.

MR. PRESIDENT, WE THE PEOPLE MAY LOSE A FEW BATTLES, BUT OUR COMMUNITY HAS JUST BEGUN TO FIGHT. WITH YOUR CONTINUING LEADERSHIP FOR THE PRINCIPLES OF UNIVERSAL HEALTH CARE, PERSONAL ASSISTANCE SERVICES AND SIMPLE JUSTICE, WE WILL FREE OUR PEOPLE. WE SHALL OVERCOME.

66235

May 1, 1994

MEMORANDUM FOR SARA RYAN

FROM: Debbie Fine

SUBJECT: Acknowledgments, Reserved Seating, Numbers for 5/2 Disability Event

1. The following are individuals to be acknowledged by the President at the beginning of his remarks:

Mike Auberger, ADAPT

Bob Kafka, ADAPT

Denise Figueroa, President, National Council on Independent Living

Paul Marchand, Chair of CCD and Director of Govt Relations at the ARC

Marca Bristo, President's Designate for Chair of National Council on Disabilities (Senate voting within a week or so)

Reverend Wade Blank: NOTE he was the leader of ADAPT until he drowned last year with his son. The President sent a letter to be read at his memorial service, but it would be good for him to acknowledge him as a leader in the community.

With the exception of Wade Blank, all of the above will be present.

2. The following should have spaces reserved in the front row:

Tom Miles

Kimberly Miles

Bobby Miles (wheelchair user)

Stephanie Thomas (wheelchair user, book presenter)

Denise Figueroa (wheelchair user, book presenter)

Carol Rasco

Alexis Herman

3. The following will meet with you and me in the Green Room at 9:00 AM (Do you want the book presenters to be there too):

Tony Coehlo

Justin Dart

Kate Miles

Stephanie Thomas???

Denise Figueroa???



4. There are 60 people in wheelchairs attending (including Justin Dart who will be on stage.) There is one person who I was unable to find out about.

As I have counted, there are a total of 137 people attending (including those on stage and Alexis Herman and Carol Rasco ) and not including Mike or me or other staff.

5. The sign language interpreter is coming to OEOB at 8:30AM. Her name is Sambia Shivers Barclay.

# Withdrawal/Redaction Marker

## Clinton Library

| DOCUMENT NO.<br>AND TYPE | SUBJECT/TITLE                                                                                                                       | DATE       | RESTRICTION |
|--------------------------|-------------------------------------------------------------------------------------------------------------------------------------|------------|-------------|
| 003. list                | Political Appointees with Disabilities in the Clinton Administration;<br>RE: Personally Identifiable Information [partial] (1 page) | 00/00/0000 | b(6)        |

### COLLECTION:

Clinton Presidential Records  
Public Liaison  
William White Jr.  
OA/Box Number: 14205

### FOLDER TITLE:

Health Care Statement to People with Disabilities 05/02/1994

2007-0143-F  
db4557

### 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]  
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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]  
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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]

⑤ Judy From Dublin  
66235

Political Appointees with Disabilities in the Clinton Administration

3w  
wC Cynthia Spires  
Special Assistant, Office of the Secretary  
Department of Housing and Urban Development

(b)(6)

(410) 715-1984

Howard Moses  
Deputy Assistant Secretary  
Office of Special Education and Rehabilitation Services  
Department of Education  
(202) 232-2183

SS#

waiting  
for info

Elizabeth Savage  
Civil Rights Division  
Department of Justice

(b)(6)

(202) 667-1567

wC Michael Winter  
Special Assistant, Office of the Secretary  
Department of Transportation

(b)(6)

(703) 528-5034

Judy Heumann and Bob Williams will both be out of town.

Paul Miller (White House Access)  
Commissioner-designee, Equal Employment Opportunity Commission

Michela Aliota (White House Access) -- Out of Town???  
Office of the Vice President  
(202) 362-6202

→ Bob Serigny  
Carol Rasco  
Katie Miles  
Lobby Miles  
Tom Miles  
Kion Miles

[003]

wC Robert Serigny

(b)(6)

## MEMORANDUM

TO: Debbie Fine/Mike Lux  
FROM: Bob Seigny  
RE: Proposed Media Market List  
DATE: April 21, 1994

Enclosed are suggestions for spokespeople for a May 2 event with the disability community.

New York: Barbara (Bobbi) Linn, Director, Bronx Center for Independent Living, 3525 Decatur Ave, Bronx, NY 10467, (W) (212 or 718) 515-2800

Gil Yildiz, Director, Brooklyn, Center for Independent Living, (718) 998-3000

Anna Fay, Institute for Rehabilitation Medicine, (914) 961-6032

Frank Bow, Professor, Hofstra University, 23 Cooper Beech Lane, Lawrence, NY 11516 (Deaf Relay: 800 855-1155) (H) (516) 374-5847; (W) (516) 463-6600

Philadelphia: Bob Michaels, Director, Philadelphia Center for Independent Living (Liberty Enterprises), 1 Winding Way, Suite 108, Philadelphia, PA 19131, (215) 581-0666

Kathleen Kleinman, TRIPIL, 120 East Hallam, Washington, PA 15301 (W) (412) 223-5115

Topeka: Gina McDonald, Executive Director, Kansas Association of Centers for Independent Living, 3258 South Topeka Blvd., Topeka, Kansas, 66611, (W) (913) 267-7100

Minneapolis: Jay Johnson, Executive Director, Options - Interstate Resource Center for Independent Living, 318 Third St. NW, East Grand Forks, MN 56721 (W) (800) 726-3692 or (218) 773-6100

Austin: Belinda Carlton, Executive Director, Coalition of Texans with Disabilities, 316 W. 12th Street, Suite 405, Austin, TX 78701

Bob Kafka, Co-Director, ADAPT of Texas, 1339 Lamar Square, Drive #8, Austin, Texas, 78704, (W) (512) 442-0252; (H) (512) 482-8543

Stephanie Thomas, ADAPT of Texas, 1339 Lamar Square, Drive #8, Austin, Texas, 78704, (W) (512) 442-0252

Salt Lake: Helen Roth, Executive Director, Options for Independence, 1095 North Main, Logan, Utah 84321, (W) (801) 752-7655

Houston: Lex Frieden, Senior VP The Institute for Rehabilitation Research (Baylor Medical

School), 1333 Moursund, Houston, TX 77030, (W) (713) 797-5283; (H) (713) 666-9482

Peg Nosek, Phd., Independent Living Utilization Project, 2323 South Shepard, Suite 1000 Houston TX 77019, (W) (713) 520-0232; (H) (713) 661-4678

Albuquerque: Ann Thomas, Asst. to President, University of New Mexico, (W) (505) 277-5251 or (505) 345-5000

Detroit: Art Humphrey, Great Lakes Rehab. Corporation CIL, 4 East Alexanderine, Suite 104, Detroit, MI 48201, (W) (313) 822-3371

San Diego: Bill Stothers, Editor, Main Stream Magazine, 2973 Beech Street, San Diego, CA 92102, (W) (619) 234-3138

Cleveland: David Williams, Disability Resources, 899 North Cleveland Street, Box 428, Elyria, Ohio, (W) (880) 333-6900 (H) (614) 612-8585

St Louis: Max Starkloff, Executive Director, Paraquad Inc. (CIL), 4475 Castleman, St. Louis, MO 63110, (W) (314) 534-5100; (H) (314) 531-1591

James Tuscher, Program Director, Paraquad Inc., 4475 Castleman, St. Louis, MO 63110, (W) (314) 534-5100

San

Francisco: Gerald Baptiste, Associate Director, Berkley CIL, 2539 Telegraph Ave. Berkeley, CA 94704 (W) (510) 841-4776

Ed Roberts, President, World Institute on Disability, 510 16th Street, Oakland, CA 94612, (W) (510) 763-4100; (H) (510) 655-5946

Los Angeles: Stanley Greenberg, Executive Director, Westside Center for Independent Living, 12901 Venice Blvd., Los Angeles, CA 90066, (W) (310) 390-3611

June Kailes, Disability Policy Consultant, 6201 Ocean Front Walk, Suite 2, Playa Del Rey, CA 90293-7556, (W) (310) 821-7080 or (310) 821-8393

Albany: Denise Figueroa, President, National Council on Independent Living, Troy RCIL, Troy Atrium, 4th and Broadway, Troy, NY 12047, (W) (518) 274-0701

Indianapolis: Nancy Griffin, Executive Director, Indianapolis Resource CIL, 2511 East 46 Street, #V4, Indianapolis, Indiana 46205, (W) (317) 541-0611

Raleigh-  
Durham:

Edward T. Smith, Chairman, Governor's Advocacy Council for Persons with Disabilities, 6501 Woodshire Place, Raleigh, NC 27612-2343, (W) (919) 733-0431; (H) (919) 846-6332

**PARTICIPANTS IN WHITE HOUSE STAKEOUT**  
**MONDAY, MAY 2, 1994**  
**10:15 A.M.**

STEPHANIE THOMAS: Will present President Clinton with book of signatures on behalf of all march and rally participants; member of ADAPT.

DENISE FIGUEROA: Will also present President Clinton with book of signatures on behalf of all march and rally participants; member of NCIL.

SHARON ATKINSON: Originally from Memphis, she moved to Colorado where she now lives with her mother.

RICK JAMES: Moved out of his parents' home in Montana to Colorado; now living in Utah.

KEN HEARD: Lives in Phoenix, Arizona with his wife; has struggled in a state that until recently did not provide adequate Medicaid coverage.

~~ADAPT~~ PHYLLIS BURKHEAD: Has moved in and out of state institutions and nursing homes for several years; her services are due to be cut soon.

- Charlie Carr

- Jay Johnson

Steven Hook

June Kailas

Katherine Kleemann ADAPT

Sandra Weber

Becky Ogels

John Gladstone

ADAPT

# Withdrawal/Redaction Marker

## Clinton Library

| DOCUMENT NO.<br>AND TYPE | SUBJECT/TITLE                                                      | DATE       | RESTRICTION |
|--------------------------|--------------------------------------------------------------------|------------|-------------|
| 004. fax                 | Stories from Individuals with Disabilities; RE: Personal (6 pages) | 04/29/1994 | b(6)        |

### COLLECTION:

Clinton Presidential Records  
Public Liaison  
William White Jr.  
OA/Box Number: 14205

### FOLDER TITLE:

Health Care Statement to People with Disabilities 05/02/1994

2007-0143-F  
db4557

### RESTRICTION CODES

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

- P1 National Security Classified Information [(a)(1) of the PRA]
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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)]

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John Gladstones  
2300 Race  
Philly - 19013

---

NH - yes 14 yrs  
no services at time

---

over protected family  
[why here] - to get national  
care for people w/ disabilities  
- The Way The ~~Good~~ God Good  
Intended us to be - to use our  
mind and to make our own  
decision.

Have seen people / and friends  
commit suicide - inhuman no one  
cares  
Punishment is to stay in bed  
- takes dignity & self respect

---

On fight as long as it takes

# Withdrawal/Redaction Marker

## Clinton Library

| DOCUMENT NO.<br>AND TYPE | SUBJECT/TITLE                                                      | DATE       | RESTRICTION |
|--------------------------|--------------------------------------------------------------------|------------|-------------|
| 005. fax                 | Stories from Individuals with Disabilities; RE: Personal (2 pages) | 05/01/1994 | b(6)        |

### **COLLECTION:**

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**Schedule Proposal****4/25/94**

|                                            |                                 |                                  |
|--------------------------------------------|---------------------------------|----------------------------------|
| <input checked="" type="checkbox"/> ACCEPT | <input type="checkbox"/> REGRET | <input type="checkbox"/> PENDING |
|--------------------------------------------|---------------------------------|----------------------------------|

**TO:** Ricki Seidman  
Assistant Secretary to the President and Director  
of Scheduling and Advance

**FROM:** Mike Lux

**REQUEST:** Remarks to the disabilities community at the Lincoln Memorial rally for health care reform.

**PURPOSE:** To thank the disabilities community for its support on health care, to reenforce the constituency's importance to the administration and to energize the rally's participants for their Hill visits while they are in town.

**BACKGROUND:** There will be approximately 1,000-2,000 activists from the disabilities community in Washington for a march from Arlington Cemetery to the Lincoln Memorial. The march and event at the Memorial were organized to emphasize the importance of health care reform and long term care to people with disabilities, and to help mobilize the grass roots in support of these goals. Following the event at the Memorial participants will go to the hill for meetings with their Congressional Representatives.

ADAPT, National Council on Independent Living, and National Rehabilitation Association are the sponsoring organizations. They are the national grassroots disability organizations that are the most active in the health care reform debate.

**PREVIOUS PARTICIPATION:** The President met with leaders from the disabilities community in honor of the 3rd anniversary of enactment of the Americans with Disabilities Act last July.

**DATE AND TIME:** Monday May 2; 1:00PM until 2:00PM.

**DURATION:** 15-20 minutes

**LOCATION:** Lincoln Memorial.

**PARTICIPANTS:** The President; Justin Dart, former Chair of the President's Committee on Employment of People with Disabilities; Representative Major Owens; Senator Kennedy; Tony Coehlo, Chair of the President's Committee on the Employment of People with Disabilities (tentative).

**REMARKS REQUIRED:** Speech to be provided by speechwriters.

**MEDIA COVERAGE:** Open to the press.

MEMORANDUM

TO: Alexis Herman, OPL  
FROM: Bob Sevigny, DNC  
RE: Events for the Disability Community  
DATE: March 29, 1994

You asked for additional information on the two events for the disability community scheduled for May 2 that we previously discussed. Those events are: (1) a march over the Memorial Bridge to the Lincoln Memorial with a series of speeches planned at the Memorial; and (2) a proposed national disability teleconference on health care with the President or First Lady. Details on these events and relevant background information are set forth below:

1. Lincoln Memorial Event

**General Outline:** This event is designed to emphasize the importance of health care reform and long term care to people with disabilities and to help mobilize the grass roots in support of these goals. The President or First Lady would be asked to make a ten to fifteen minute speech on the impact/benefit of health care reform and long term care on people with disabilities. If we thought it would be useful, an opportunity to take select questions from the audience or meet with representatives from the grassroots of the community could be easily arranged.

**Timing/Schedule:** As currently planned, the march will begin at Arlington Cemetery and proceed across the Memorial Bridge at approximately 11:30 A.M. It is scheduled to arrive at the Lincoln Memorial at 12:40 P.M. Once the group arrives at the Lincoln Memorial there will be a series of speeches from approximately 1:00 P.M. until 2:00 P.M. The event organizers have provided a tentative schedule for the event (see attachment A) but have stated that they would make whatever adjustments are necessary to conform to the President's or the First Lady's schedule.

**Sponsors/Participants:** March is sponsored principally by three major groups:

- American Disabled for Attendant Programs Today (ADAPT), a national grassroots disability organization that will come to Washington to demonstrate in favor of health care reform and long term care. ADAPT was in Washington last summer for a march for attendant care services and met with HHS Secretary Schalala.
- National Council on Independent Living (NCIL), perhaps the preeminent national grass roots organization of and by people with disabilities with Independent Living Centers serving people with disabilities in virtually every major metropolitan area in the nation;
- National Rehabilitation Association (NRA), a national organization of persons working in rehabilitation and employment services for persons with disabilities.
- In addition, most national disabilities organizations have national offices and local chapters or affiliates that will be participating in support of this event. If the President were to agree to speak at the Lincoln Memorial the organizers of this event would seek additional sponsors from major disability organizations and other groupings including the Long Term Care Campaign, AARP, and the Health Care Reform Project.

Other Invited Guests: Event organizers have invited Senator Edward Kennedy, Senator Tom Harkin, Representative Major Owens, Representative Pat Schroeder, and Justin Dart to address the audience.

Crowd Size: As currently envisioned, without the President or First Lady, the march is expected to attract approximately 2,300 people. If the President or First Lady were to appear and sufficient advance notice of that fact was given (three to four weeks) crowd size could be substantially increased with cooperation from key organizations in the community. In addition, Justin Dart has offered to commit up to \$10,000 to rent busses to bring people in from nearby communities. Other groups could also be expected to commit resources to bring people in to hear the President.

Media Coverage: March organizers have an excellent track record in attracting media coverage in Washington and have hired media person to work this event. Prime Time Live from ABC and HBO Cable have already committed to cover this event. They have also been very successful in the past in obtaining coverage on CNN. Event organizers have already contacted all local and national media and they will arrange for radio, TV and print media interviews in advance of the main group of arriving in Washington. They will work with invited speakers media people to maximize media coverage. In addition, event planners intend to videotape the entire event and distribute the video tape throughout the community in support of health care reform. Clearly, news that the President or First Lady would address this group would tremendously increase media coverage of the event.

\*Positive Considerations: This will almost certainly be one of if not the largest disability event ever held even without the participation of the President or the First Lady. With their participation the event would clearly break all records for this community and would be an excellent vehicle for reaching via free media people with disabilities all across the nation. The audience will be composed of leaders and grassroots activists from the disability community from virtually every state and significant disability organization in the country including many people who would never otherwise have the opportunity to see or hear the President or the First Lady. Opportunities for media coverage will be very good. Event participants will spend the remainder of their time in Washington demonstrating in favor of health reform or lobbying members of Congress in support of health reform and long term care.

\*Concerns: Even with a very large crowd by disability community standards (5,000 to 10,000 people) the crowd at the Lincoln Memorial may look small to TV cameras that may cover the event thus diminishing its potential impact. Weather is another imponderable for such a large outdoor event although the event is scheduled to occur rain or shine. Finally, with a crowd this size, it is certainly possible that there may be some people opposed to actions by the President. This is particularly the case if it is perceived that the President has consented or acquiesced to the elimination of long term care from the health care plan. Event organizers have, however, given their word that there will be no negative incidents. With this in mind, the organizers have already told Act Up that they will not be permitted to participate in either the march or the Lincoln Memorial event.

## 2. National Town Meeting for People with Disabilities

This event was apparently conceived of as either an alternative to or a supplement to the march and Lincoln Memorial event to attract the President or First Lady. The idea is again that it is critically important for the President or the First Lady to address the interests or concerns of people with disabilities to enable us to mobilize the grassroots of the community in support of the community. While few specific details on this proposal have been set, it appears that preliminary discussions were held between Pat Wright and Senator Kennedy's office and with Senator Harkin's staff. No commitments seem to have been made but there was apparently interest in the proposal. In addition, Justin Dart has reserved a large committee room in the Hart Senate Office Building on May 2 that was used for hearings on the American's with Disabilities Act.

The concept is that the audience would be composed of a representative group of people with disabilities (leaders and grassroots) from all over the country that had come to Washington for the Lincoln Memorial event or other disability events occurring around that time. The audience size could number several hundred in the room that has been reserved.

The format would probably be to have the President or First Lady give a brief introduction and overview of the health care and long term care and then allow questions and interaction from the studio audience and from persons at satellite down and up link locations across the country. If Senators Kennedy and Harkin were to participate in this event, they would presumably be given the opportunity to make brief opening statements and also respond to questions. Length of the event would probably be either an hour or an hour and a half.

Down link sites could be set up across the country to permit the principals to interact with a large national audience. Additionally, if the President or First Lady were to agree to appear, discussions would begin with C-Span and other TV networks to arrange for the broadest possible national airing of this event. Finally, the entire event would be videotaped for distribution in the disability community.

**\*Positive Considerations:** The event would have the possibility of reaching a very wide national audience in the disability community. The audience and the questions could be carefully screened so there would be very little likelihood of an embarrassing situation. The room could easily be packed with people so there would be no concerns that the event would look small relative to other events conducted for other constituency groups. Also, there would be no concerns about weather impairing the event. This event would allow the President or the First Lady to directly address and energize the "grassroots" and leadership of the disability community on this critically important issue. This would be an unprecedented event that would clearly indicate the President's interest in this community and that he shares their concerns on this and other important issues.

**\*Concerns:** Clearly, the consensus of the disability community is that it is vital to have an event with the President or the First Lady on the subject of health care regardless of where the

ultimate location is or what forum is chosen. However, holding this town meeting event on the same day as the Lincoln Memorial event could be viewed as undercutting a large grass roots event and slighting some of those who traveled to Washington, at great cost and difficulty, to participate. If the decision is made to choose the televised national town meeting format over the Lincoln Memorial event, one solution to this problem could be to simply hold it on another date either shortly before or after the march or in the morning of the day on the day of the since timing would not be as critical for a teleconference.



# **A D A P T**

## **FREE OUR PEOPLE**

### **March Participants:**

The march participants will be comprised of four different groups;

1. American Disabled for Attendant Programs Today, (ADAPT) members who have come from twenty-eight states to advocate for health care issues related to disability such as personal assistance services.

ADAPT is a grassroots disability rights organization headquartered in Denver with approximately five thousand members in thirty-three states.

ADAPT anticipates having five hundred members attending the march.

2. National Council for Independent Living, (NCIL) members will be holding their annual convention in Bethesda, Maryland.

NCIL is an organization of four hundred Independent Living Center directors and staff who provide services and advocacy directors.

NCIL will have approximately eight hundred members attend the march.

3. The National Rehabilitation Association, (NRA) will be holding their annual convention in Washington D.C..

NRA has over five thousand members who are employed in rehabilitation and employment services for people with disability.

NRA will have approximately five hundred members attend the march.





# **A D A P T**

## ***FREE OUR PEOPLE***

4. The Local Disability Community at large are individuals with disabilities who live within one hundred and fifty miles of Washington D.C.. As was the case with the ADA March the local community turned out in large numbers.

The Local Disability Community will have approximately five hundred people attend the march.

It is clear that the Bridge to Freedom March will be the largest disability event ever.



STATE OF TEXAS  
OFFICE OF THE GOVERNOR  
AUSTIN, TEXAS 78711

ANN W. RICHARDS  
GOVERNOR

March 24, 1994

The Honorable William Jefferson Clinton  
The President  
The White House  
1600 Pennsylvania Avenue  
Washington, D. C. 20500

Dear Mr. President:

I am writing in support of the provisions for home and community-based care, including attendant services, in your health reform bill.

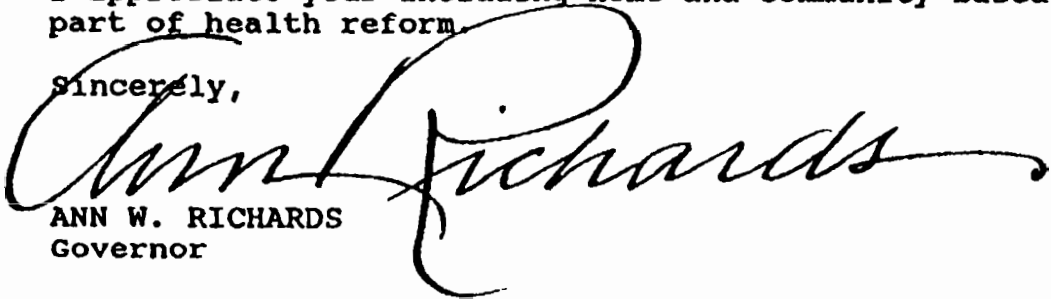
As you know, today's federal programs and health insurance policies have an institutional bias so people too often are forced into a hospital or nursing home to get the services they need. Living in an institution is usually more costly, and most people would choose to live in their own home rather than enter a hospital or nursing facility. They should have that choice.

In Texas, we are implementing a Medicaid waiver to allow people to receive community-based services rather than being forced into nursing facilities. But to make community-based services available to everyone, we need for them to be covered under the national health reform bill.

Representatives of the national ADAPT organization have requested a meeting with you in May. Members of the Texas chapter of ADAPT are committed and effective supporters of community services, and I believe they can have an impact on national health reform. I hope you can meet with their representatives.

I appreciate your including home and community-based care as a part of health reform.

Sincerely,

  
ANN W. RICHARDS  
Governor



# ADAPT

## FREE OUR PEOPLE

### MEDIA:

ADAPT over the past ten years has a long and successful history with the Washington print and visual media. ADAPT has built a local and national credibility with the media.

ADAPT is already in contact with the D.C. media in preparation for our arrival in May. Primetime from ABC and HBO Cable have both committed to follow the events surrounding ADAPT's presence in Washington. All the local and national media have been contacted once. We are now arranging for radio, TV, and Newspaper interviews prior to the main body of ADAPT arriving.

ADAPT will have one person assigned to media relations. Our media specialist has been dealing with the D.C. and national media for more than five years.

ADAPT's media specialist will begin daily contacting the D.C. media approximately two weeks prior to our arrival. At that time we will begin to publicize the May 2, 1994 March.

ADAPT will work with our invited speakers media liaison to insure the maximum media saturation.

### PARTICIPANTS

ADAPT has invited Senator Kennedy, Representative Owens, Justin Dart and Representative Shroeder to speak to the disability community attending the march and events at the Lincoln Memorial on May 2, 1994.

At this time not all of our speakers have confirmed their appearance. If the President or the First Lady accept their invitation we will adjust the schedule to accommodate theirs. ADAPT will make any accommodations necessary to our program to permit the President or First Lady to address the crowd.

All speakers will be addressing Health Care Reform and its effects on people with disabilities.



# ADAPT

## FREE OUR PEOPLE

A BRIDGE TO FREEDOM

HEALTH CARE

MAY 2, 1994

PROPOSED AGENDA

*2:30 depart  
Hall visits*

*Mike Arbinger  
303 733 9324*

11:30 A.M. - March leaves Arlington Cemetery

12:40 P.M. - March arrives Lincoln Memorial via Memorial Bridge

12:50 P.M. - Music performed by Johnny Creshendo

*English disabled  
musician  
guitar  
folk songs*

12:55 P.M. - M.C. Bob Kafka welcomes crowd

*ADAPT —  
512-442-0252*

Introduces Justin Dart

01:00 P.M. - Justin Dart speaks

01:10 P.M. - Bob Kafka introduces Rep. Major Owens

01:10 P.M. - Rep. Owens speaks

*Chair of Senate  
Subcommittee on  
Select &  
+ Civil Rights*

01:20 P.M. - Bob Kafka introduces Stefanie Thomas

01:20 P.M. - Stefanie Thomas speaks

01:30 P.M. - Bob Kafka introduces Senator Ted Kennedy

01:30 P.M. - Senator Kennedy speaks

01:40 P.M. - Bob Kafka introduces Johnny Creshendo



# **A D A P T**

## ***FREE OUR PEOPLE***

A BRIDGE TO FREEDOM

HEALTH CARE

MAY 2, 1994

PROPOSED AGENDA

- 01:40 P.M. - Johnny Creshendo performs
- 01:45 P.M. - Bob Kafka introduces President Clinton
- 01:45 P.M. - President Clinton addresses crowd
- 01:55 P.M. - Bob Kafka thanks the President and  
Introduces Michael Auberger
- 01:55 P.M. - Michael Auberger speaks
- 02:05 P.M. - Bob Kafka closes ceremonies
- 02:05 P.M. - Johnny Creshendo performs
- 02:05 P.M. - Crowd begins to disperse
- 02:10 P.M. - Cleaning crew begins
- 02:25 P.M. - Required cleaning ends

# DEMOCRATIC NATIONAL COMMITTEE

## CONSTITUENCY DEPARTMENT

PH 202-863-8000

FAX 202-863-8140

### FAX COVER SHEET

TO: DEBBIE FINE

FROM: ROBERT SEVIGNY -- DIRECTOR, DISABILITY OUTREACH

DATE: 4/15 TIME: 12:35 AM PM EST

FAX: 456-7362 # OF PAGES (incl. cover): 2

SUBJECT: MAY 2 EVENT

IF YOU HAVE TROUBLE WITH THIS TRANSMISSION,

PLEASE CALL BOB AT 202-863-8098.

COMMENTS: FYI - JUSTIN DART  
+ CCD GRASS ROOTS TASK FORCE  
ARE MAILING OUT THOUSANDS  
OF THESE. NOTE THE SPONSORS.  
- MISSED YOU AT BREAKFAST -

THIS MESSAGE IS INTENDED ONLY FOR THE USE OF THE INDIVIDUAL OR ENTITY TO WHICH IT IS ADDRESSED. THIS MESSAGE MAY CONTAIN INFORMATION THAT IS PRIVILEGED, CONFIDENTIAL AND EXEMPT FROM DISCLOSURE UNDER APPLICABLE LAW. IF THE READER OF THIS MESSAGE IS NOT THE INTENDED RECIPIENT, OR THE EMPLOYEE OR AGENT RESPONSIBLE FOR DELIVERING THE MESSAGE TO THE INTENDED RECIPIENT, YOU ARE HEREBY NOTIFIED THAT ANY DISSEMINATION, DISTRIBUTION, OR COPYING OF THIS COMMUNICATION IS STRICTLY PROHIBITED. IF YOU HAVE RECEIVED THIS COMMUNICATION IN ERROR, PLEASE NOTIFY US IMMEDIATELY BY TELEPHONE AND RETURN THE ORIGINAL MESSAGE TO US AT THE ABOVE ADDRESS VIA THE U.S. POSTAL SERVICE. THANK YOU.

# **BRIDGE TO FREEDOM: HEALTH CARE**

## **AMERICA NEEDS YOU**

### **ON MAY 2**

**Monday, May 2, 1994, Washington, D.C. Gather at the Arlington Cemetery Metro at 10:30 am. March across the Memorial Bridge to the Lincoln Memorial. Rally at 12:30 pm. On to the Congress Metro and back buses.**

Reasoned consultation and political compromise have not been enough. We are in grave danger of losing the war for universal health care that includes people with disabilities. America needs your personal presence on May 2nd to send a loud and clear message to the Congress and the nation.

**FIFTY YEARS OF EMERGENCY ROOMS, HUNGRY HOMES, OF POVERTY, PAIN AND PREMATURE DEATH. NOW! NO MORE EXCUSAS. NO MORE EXCUSES. NO MORE BAND-AIDS. COMPREHENSIVE, AFFORDABLE CARE FOR ALL AMERICANS, NOW! UNIVERSAL COVERAGE, NO LONG TERM CARE, INCLUDING A NATIONAL SYSTEM OF HOME-BASED ATTENDANT SERVICES, NOW! LONG TERM DRUGS, HOME SERVICES, DISABLED MEDICAL EQUIPMENT ASSISTANCE, AND MORE! YES! AND PRESCRIPTION DRUGS, NOW!**

A list of those present will be published. President and Mrs. Clinton and we have pledged for all history the patriotic stand a stand for health care when it counted. We look forward to being with you, your families and all who love justice on May 2.

Mike Aubrey, Alan Berman, Nancy Brown, Marca Bristo, Judi Chamberlin, Justin Dart, Yoshiko Kamekura, Denise Figueroa, Bob Gries, Ed Kafka, Paul Marchand, Gina McDermott, Mary B. Miller, Denise Moore, Raul Patta, Bill Schmidt, Hardy Stone, Pat Wright, Tony Wright, George Zuckerman.

\* Bridge to Freedom was initiated by ADAPT, and is supported by the National Council of Independent Living, the Consortium for Citizens with Disabilities and many other groups. For further information call Karen Tamley at 303-733-9324, Allen Gray at 703-823-8116.

## **NO MORE BAND-AIDS. REAL HEALTH CARE FOR ALL!**

MEMORANDUM

TO: Debbie Fine/Mike Lux  
FROM: Bob Sevigny  
RE: Proposed Upcoming Disability Events  
DATE: March 7, 1994

Debbie: Idea 1 is definitely out. We should do an event request for the May 2nd event for POTUS, and push hard for it. I also think getting HRC to do one of the "smaller events" coming up is worth doing, so we should try for that as well!

You asked me to produce suggestions for upcoming events/activities with the disability community. I am still talking to Paul Marchand and other disability leaders to develop a final suggestion list, but I thought a preliminary memo would be useful to you.

As we have often discussed, there needs to be a significant and high profile event or events involving the President or the First Lady focusing on health care and the broader concerns of the disability community. Candidly, there needs to be more than one event if we are serious about this effort. It is clear that the community needs direct reassurance that their needs and concerns are understood and shared. We are well past the point when this can be done by a cabinet member or other White House official. As Paul Marchand has pointed out, the disability community is well aware of the level of attention devoted to the elderly and other significant constituencies by the President and the First Lady -- they want, and deserve, the same quality of attention and will insist on it if we want their steadfast support as we get deeper in the health care fight.

The following targets of opportunity present themselves:

**1. Televised national town meeting with the disability community with either the President or the First Lady addressing issues of concern to the community -- principally or exclusively health care.** The format I envision would have the President or First Lady give a brief introduction and overview of the health care and/or other issues and then allow questions and interaction from the studio audience and from persons at satellite down and up link locations across the country. The President's Committee on Employment of People with Disabilities<sup>1</sup> and the National Council on Disability may be willing to sponsor this town meeting -- it falls within their mission to educate the community on vital issues and they had already planned events on the health care issue.

Such an event would allow the President or the First Lady to directly address and energize the "grassroots" and leadership of the disability community on this critically important issue. This would be an unprecedented event that would clearly indicate the President's interest in this community and that he shares their concerns on this and other important issues. **This event, should it occur, would electrify the disability community and generate political benefits for years to come on a multitude of issues.**

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<sup>1</sup> The President's Committee previously sponsored a national teleconference on health care that had nearly 5,000 participants. The teleconference was videotaped and broadcast on America's Disability Channel.



There are several particularly attractive elements to this idea. First, the major organizations representing the community are cash poor but frequently have access to extensive resources including TV studios and satellite down/uplink facilities and several have expressed interest in such an idea. Both the President's Committee and the National Council have statutory authority to accept in-kind contributions and cash contributions. Thus they could accept contributions of facilities and other resources by other organizations that would definitely like to see such an event occur. Second, these organizations, although supporting us on the health care issue, are generally barred from "political" activity. Conducting this event under the aegis of the President's Committee and the National Council would completely avoid the political restriction. Finally, the President would not be subject to Hatch Act restrictions in terms of the political content of his remarks so he would be free to say essentially anything on the politics of health care or other issues.<sup>2</sup>

If we go with this project, we should seriously consider utilizing Gallaudet University as the Washington site for the event. They have extensive facilities and, based on previous discussions I had with them, I think would be more than willing to cooperate. Gallaudet is a national symbol of education and accomplishment for the deaf and people with disabilities. Moreover, there are **26 million** deaf and hard of hearing people in this country that are generally ignored and left out politics by both parties -- this would be an extraordinary gesture to those people. Finally, the President technically is in charge of this Federal institution -- but no President has visited Gallaudet since Lyndon Johnson.

*Added to calendar*

**2. Large civil rights march to Lincoln Memorial event by national disability groups scheduled for May 2nd.** This will be an exceptional event for the disability community principally sponsored by NCIL (National Council on Independent Living) and ADAPT (a national "direct action" disability group famous for demonstrating for the rights of the severely disabled.) Joining NCIL and ADAPT for the march and Lincoln Memorial event will be CCD and virtually every significant disability group in the nation. NCIL and ADAPT are probably the principal grass roots organizations for people with disabilities and they are joining forces to work in favor of the principals of health reform advanced by the President. They will be lobbying members of Congress and ADAPT has "promised" direct action events, including civil disobedience, targeted at opponents of health care reform and long term care (hopefully, they will not include "us" on their hit list.) There will be a very good opportunity for a significant speech by the President on health care and other disability related issues (commitment to ADA enforcement) and the event would offer excellent visuals and other media opportunities.

Unfortunately, May 2nd is very late in the legislative calendar for health care and, unless there are substantial delays, too late to mobilize the grass roots of the community. However, the

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<sup>2</sup> Statutory anti-lobbying restrictions would, however, apply so the President could not expressly urge people to go out and call their Senator or Representative. The only way around the lobbying restriction would be for the DNC, the NHCC, or the Health Care Reform Project pick up the tab for the whole project.

event is sure to receive extensive media coverage and would be a superb opportunity for the President, First Lady, or Vice President to recognize the importance of this constituency and express solidarity with their concerns. Again the benefit from this event would be tremendous within the community and would help us on many different issues.

I think this is an important event which should be done, but it should be done in conjunction with another, and earlier, health care event.

**3. Variety of disability groups coming to Washington for national conferences over the next two months, any of which would be delighted to have the President, First Lady, or Vice President address them or appear at an event.** There will be a number of individual disabilities groups having Washington events in the next two months. Unfortunately, these are smaller events, generally focused on the needs of one particular segment of the disability community, and not necessarily optimum media vehicles for the appearance of a principal. (One exception to this would be the NCIL fundraising event scheduled for late April -- they have already requested the First Lady or the Vice President.) We are still trying to get a final schedule of these events from CCD.

**4. Create an event at which the President or the First Lady can meet with leaders and/or grass roots representatives from the disability community, discuss their concerns, respond to selected questions, and urge them to support health care reform.** Such an event should receive the widest possible coverage and, if possible, should be video taped for broad distribution in the community. It would be difficult to devise an event that would have the necessary visibility and impact to mobilize the constituency nation wide.

# DEMOCRATIC NATIONAL COMMITTEE

## CONSTITUENCY DEPARTMENT

PH 202-863-8000

FAX 202-863-8140

### FAX COVER SHEET

TO: DEBBIE FINE

FROM: ROBERT SEVIGNY -- DIRECTOR, DISABILITY OUTREACH

DATE: 3/8/94 TIME: 12:52 AM/PM-EST

FAX: 456-2362 # OF PAGES (incl. cover): 4

SUBJECT: DISABILITY PLAN

IF YOU HAVE TROUBLE WITH THIS TRANSMISSION,

PLEASE CALL BOB AT 202-863-8098.

COMMENTS: \_\_\_\_\_

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## MEMORANDUM

TO: Debbie Fine/Mike Lux  
FROM: Bob Sevigny  
RE: Proposed Upcoming Disability Events  
DATE: March 7, 1994

You asked me to produce suggestions for upcoming events/activities with the disability community. I am still talking to Paul Marchand and other disability leaders to develop a final suggestion list, but I thought a preliminary memo would be useful to you.

As we have often discussed, there needs to be a significant and high profile event or events involving the President or the First Lady focusing on health care and the broader concerns of the disability community. Candidly, there needs to be more than one event if we are serious about this effort. It is clear that the community needs direct reassurance that their needs and concerns are understood and shared. We are well past the point when this can be done by a cabinet member or other White House official. As Paul Marchand has pointed out, the disability community is well aware of the level of attention be devoted to the elderly and other significant constituencies by the President and the First Lady -- they want, and deserve, the same quality of attention and will insist on it if we want their steadfast support as we get deeper in the health care fight.

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---

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There are several particularly attractive elements to this idea. First, the major organizations representing the community are cash poor but frequently have access to extensive resources including TV studios and satellite down/uplink facilities and several have expressed interest in such an idea. Both the President's Committee and the National Council have statutory authority to accept in-kind contributions and cash contributions. Thus they could accept contributions of facilities and other resources by other organizations that would definitely like to see such an event occur. Second, these organizations, although supporting us on the health care issue, are generally barred from "political" activity. Conducting this event under the aegis of the President's Committee and the National Council would completely avoid the political restriction. Finally, the President would not be subject to Hatch Act restrictions in terms of the political content of his remarks so he would be free to say essentially anything on the politics of health care or other issues.<sup>2</sup>

If we go with this project, we should seriously consider utilizing Gallaudet University as the Washington site for the event. They have extensive facilities and, based on previous discussions I had with them, I think would be more than willing to cooperate. Gallaudet is a national symbol of education and accomplishment for the deaf and people with disabilities. Moreover, there are 26 million deaf and hard of hearing people in this country that are generally ignored and left out politics by both parties -- this would be an extraordinary gesture to those people. Finally, the President technically is in charge of this Federal institution -- but no President has visited Gallaudet since Lyndon Johnson.

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4/17/94



**UNITED STATES**  
**OFFICE OF CONSUMER AFFAIRS**  
1620 L ST. NW Suite 700, Washington, D.C. 20036

**TO:** DEBBIE FINE / MIKE LUX

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**FROM:** PAUL MILLER

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**MESSAGE:** FYI for discussion

1 pgs attch.



## HEALTH CARE REFORM

- Disabled Surrogates on Health Care -- Who Are They?
- NCIL/ADAPT Week in Washington -- April 27th thru May 3rd
  - May 2nd Town Hall Meeting on Capitol Hill with Hillary Clinton  
Co-Sponsored with Senators Kennedy and Harkin  
Held in 216 Hart Senate Hearing Room (where ADA hearings began)
  - April 28th NCIL Gala Dinner
- National Council on Disability Town Hall Meetings [8:30 a.m. - 3:30 p.m.]
  - March 30 -- San Diego, California
  - April 5 -- Austin, Texas
  - April 6 -- Topeka, KS
  - April 9 -- New York, NY
  - April 11 -- Philadelphia, PA
- Second Bay Area Health Care Rally -- East Bay
  - In Planning Stage
- PSM Scheduled Travel and Possible Insertion of Health Care Events
  - Des Moines -- April 12, 1994
  - Los Angeles -- April 18-20, 1994
  - Denver -- May 12-13, 1994
  - Seattle -- May 16-17, 1994
  - Atlanta -- May 18-20, 1994
- Town Hall Meetings In Selected Congressional Districts -- Any Scheduled???
- Other Disability Related Conferences/Lobby Days Presently Scheduled
  - Health Care Reform Summit -- Hyatt, Washington, D.C.  
April 5, 1994, 8:00 a.m.-5:00 p.m.
  - ARC Governmental Affairs Seminar, J.W. Marriott, Washington, D.C.  
March 20, 1994 7:00-8:30 p.m.  
March 21, 1994 9:00-10:30 a.m., Plenary Session
- Production and Distribution of Open Captioned Video Tape Geared Towards Persons with Disabilities on Health Care
  - Distribute to Individual Independent Living Centers (Possibly at the NCIL Meeting in Washington, D.C. April 29-May 3)



## Bob Sevigny Media List

4/21/94

Mr. Patrick Cannon  
Executive Director  
Commission on Handicapper Concerns  
P.O. Box 30015  
201 N. Washington Ave.  
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517/335-6811 FAX  
NICKNAME: Pat  
CONSTITUENCY: gc HC: cy

Dr. Stanley Greenberg  
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Ms. Laura Mitchell  
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818/882-6462 (W)  
818/709-8390 FAX  
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Mr. Daniel Robert  
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Disabled in Action  
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212/366-0432, 229-7777 (H)  
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304/558-0941 FAX  
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215/568-3519 FAX  
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Ms. Belinda Carlton  
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Ms. Anne Weeks  
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Ms. Cassie James  
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|                                          |                         |                |
|------------------------------------------|-------------------------|----------------|
| Post-It™ brand fax transmittal memo 7671 |                         | # of pages > 1 |
| To <b>Bob Sevigny</b>                    | From <b>Justin Dart</b> |                |
| Co.                                      | Co.                     |                |
| Dept. <b>DNC</b>                         | Phone #                 |                |
| Fax # <b>863-8140</b>                    | Fax #                   |                |

Please fill out this form to help us ensure that everyone involv

Debbie Fine  
66485

EVENT "MESSAGE" FORM

EVENT:

Disabilities Meeting

DATE OF EVENT:

Monday, May 2

RESPONSIBLE FOR COMPLETING THIS FORM: David Dwyer or:

Mike Lux

RETURN COMPLETED FORM TO EVENT COORDINATOR

DEADLINE:

INITIALED BY SCHEDULING DIR:

SS /  
Stephen Eric Street

DESIRED "HEADLINE": President's <sup>health care</sup> ~~health care~~ <sup>proposed by</sup> disability activists

MESSAGE THAT THE PRESIDENT WILL CONVEY: Health care reform solves problems for people with disabilities by  
(1) guaranteeing benefits at work (2) eliminating pre-existing conditions and lifetime limits and (3) providing home based  
long term care

DESIRED VISUAL FOR EVENT:

Disability leaders giving the President a plaque thanking him for  
his leadership on health care

DESIRED AUDIENCE AT SITE:

Disability rights activists from around the country

CONCISE ANSWER TO THE QUESTION, "WHY ARE WE DOING THIS EVENT?":

To energize people with disabilities to fight  
for the health, and to remind people what health care reform does for people with  
disabilities, pre-existing conditions

**Schedule Proposal****4/25/94**

|                         | <input checked="" type="checkbox"/> ACCEPT                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                | <input type="checkbox"/> REGRET | <input type="checkbox"/> PENDING |
|-------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------|----------------------------------|
| TO:                     | Ricki Seidman<br>Assistant Secretary to the President and Director<br>of Scheduling and Advance                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |                                 |                                  |
| FROM:                   | Mike Lux                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |                                 |                                  |
| REQUEST:                | Remarks to the disabilities community at the Lincoln<br>Memorial rally for health care reform.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |                                 |                                  |
| PURPOSE:                | To thank the disabilities community for its support on<br>health care, to reenforce the constituency's importance to<br>the administration and to energize the rally's participants<br>for their Hill visits while they are in town.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |                                 |                                  |
| BACKGROUND:             | <p>There will be approximately 1,000-2,000 activists from<br/>the disabilities community in Washington for a march<br/>from Arlington Cemetery to the Lincoln Memorial. The<br/>march and event at the Memorial were organized to<br/>emphasize the importance of health care reform and long<br/>term care to people with disabilities, and to help mobilize<br/>the grass roots in support of these goals. Following the<br/>event at the Memorial participants will go to the hill for<br/>meetings with their Congressional Representatives.</p> <p>ADAPT, National Council on Independent Living, and<br/>National Rehabilitation Association are the sponsoring<br/>organizations. They are the national grassroots disability<br/>organizations that are the most active in the health care<br/>reform debate.</p> |                                 |                                  |
| PREVIOUS PARTICIPATION: | The President met with leaders from the disabilities<br>community in honor of the 3rd anniversary of enactment<br>of the Americans with Disabilities Act last July.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |                                 |                                  |
| DATE AND TIME:          | Monday May 2; 1:00PM until 2:00PM.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |                                 |                                  |
| DURATION:               | 15-20 minutes                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |                                 |                                  |
| LOCATION:               | Lincoln Memorial.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |                                 |                                  |
| PARTICIPANTS:           | The President; Justin Dart, former Chair of the President's<br>Committee on Employment of People with Disabilities;<br>Representative Major Owens; Senator Kennedy; Tony<br>Coehlo, Chair of the President's Committee on the<br>Employment of People with Disabilities (tentative).                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |                                 |                                  |
| REMARKS REQUIRED:       | Speech to be provided by speechwriters.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |                                 |                                  |
| MEDIA COVERAGE:         | Open to the press.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |                                 |                                  |