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Date: 3/27/04

DOCUMENT NO. & TYPE	SUBJECT/TITLE	DATE	RESTRICTION
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I. Letter	To Carol Rasco from Phoebe Snow re: daughter, 2p	1/20/94	P6/B6
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RESTRICTIONS

P1 National security classified information [(a)(1) of the PRA].
P2 Relating to appointment to Federal office [(a)(2) of the PRA].

P3 Release would violate a Federal statute [(a)(3) of the PRA].
P4 Release would disclose trade secrets or confidential commercial or financial information [(a)(4) of the PRA].

P5 Release would disclose confidential advice between the President and his advisors, or between such advisors [(a)(5) of the PRA].

P6 Release would constitute a clearly unwarranted invasion of personal privacy [(a)(6) of the PRA].

C. Closed in accordance with restrictions contained in donor's deed of gift.

B1 National security classified information [(b)(1) of the FOIA].

B2 Release could disclose internal personnel rules and practices of an agency [(b)(2) of the FOIA].

B3 Release would violate a Federal statute [(b)(3) of the FOIA].

B4 Release would disclose trade secrets or confidential commercial financial information [(b)(4) of the FOIA].

B6 Release would constitute a clearly unwarranted invasion of personal privacy [(b)(6) of the FOIA].

B7 Release would disclose information compiled for law enforcement purposes [(b)(7) of the FOIA].

B8 Release would disclose information concerning the regulation of financial institutions [(b)(9) of the FOIA].

B9 Release would disclose geological or geophysical information concerning wells [(b)(9) of the FOIA].

EXECUTIVE OFFICE OF THE PRESIDENT

12-Jan-1994 04:01pm

TO: Carol H. Rasco
FROM: Stanley S. Herr
Domestic Policy Council
CC: Christine M. Heenan
Rosalyn A. Miller
SUBJECT: RE: Wall Street Journal article

Chris and I now have the WSJ piece, had a preliminary exchange of ideas, and will meet on it tomorrow at 11am.

Can you please let me know if:

--you would like a draft for a letter to the editor or a full Op-Ed reply?

--you have any word limit you're operating under?

--you want the basic approach to recognize the validity of that mother's concerns, your own comparable experiences in Arkansas, and how our health care reform plan will simplify the now-fragmented delivery and reimbursement system that Ms. Jennings describes?

We're happy to take a crack at this and to teaming up.

Thanks for any feedback.

stan

MEMORANDUM TO CAROL H. RASCO

From: Stan

Jan. 13, 1994 noon

Chris and I conferred this morning and came up with these talking points for your interview on Friday. We feel that they could also serve as a framework for a written response to the Wall Street Journal. It seems to us that a relatively long letter to the editor might be the most appropriate vehicle for that response. Please let us know if we are on the right track and how we can be of further help to you.

TALKING POINTS FOR YOUR TELEVISION INTERVIEW:

1. Our Health Care plan recognizes the types of frustrations consumers like Ms. Jennings now experience in the delivery and reimbursement of health-related services.

2. Marianne Jennings is on the mark with her description of undue complexity, the duplication of caseworker reviews, lack of user friendly information approaches, etc. She and her family have faced first-hand the crazy-quilt, patchwork system that we have in America today, because we have no national

system.

3. As a mother in Arkansas of a son with multiple disabilities, I had my share of similar experiences (give some examples such as as the caseworker who saw Hamp as a baby crawling on your floor and still asked where was your disabled child; rejected application because in reciting 18 years of Hamp's medical history, one doctor's zipcode from years ago was omitted).

But the Medicaid program, with all its flaws, will continue to be the only resource for many people until we have a system of guaranteed private insurance.

4. Clinton Administration is also working to come up with new consolidated child services approaches in Indiana and West Virginia to demonstrate ways of unifying case management. Coordinated case reviews should eventually replace multiple visits by legions of caseworkers.

5. Administrative simplification in health care means reducing the hassles of determining and tracking coverage through a guaranteed comprehensive benefits package.

6. More standardization will mean fewer obscure turns and twists to getting benefits.

4. The President's plan seeks at every level of design of health care reform to end such horror stories as Ms. Jennings's, to put "patients over paperwork," to have report cards that give consumers meaningful information on which locally available health plans are more responsive and consumer friendly.

8. Parents of children with disabilities, like Ms. Jennings's child shouldn't need a lawyer's training and her abundant communication skills to be able to access services for their children.

9. We are committed to fashioning a system in which the race is not to the fittest or the most ardent battler of bureaucracies. Ms. Jennings eloquently describes some of the ills and unevenness of the status quo. I as a mother, and a policy maker, will also talk to Mrs. Clinton and know that we must and will do better to preserve the health and tap the potential of our children with disabilities than our fragmented health care system now allows.

10. Parents of disabled kids will have to mobilize to make health-care programs work properly. But as a recent article detailed ("The mothers of invention: How a mighty grass-roots movement of parents with disabled kids is changing the nation," US News & World Report, Jan. 10, 1994, at 38-42), mothers and fathers of children with disabilities are doing just that and bringing their expertise to bear on these complicated, but vital issues.

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FROM: Stanley S. Herr

SUBJ:

DATE:

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Carol: Here are some possible titles for your AAMR speech. It could also serve as your "stump speech" to any groups of this nature. The first one is my preferred suggestion. But I offer some variants.

On Putting People First: The White House Agenda for Mental Retardation

Reform and Renewal:

People First:

The Clinton Administration's Leadership for Choices and Inclusion

The content of this talk can feature health care reform, family leave act, national service act and its possible benefits for this field, special education, and all the rest of the good stuff we'll be working on this year.

AAMR's president is "thrilled" that you're coming!!

*****Regarding a meeting with Mrs. Shriver, I'm informed that she would expect to meet with us here at the White House.

As it turns out, Kennedy Foundation's executive director is meeting with Bill Galston next Teusday about a school program they're subsidizing. Mrs. Shriver may be joining them. I was queried whether they could just continue from there to meet with you. But based on what I know of your schedule, I suggested that Teusday, Wednesday or Thursday (Sept. 21, 22, or 23) late morning or mid-day would work best. I'll proceed on that assumption and work through Ros on scheduling this.

Have a good trip to Nebraska and a restful weekend.

MEMORANDUM TO CAROL H. RASCO

FROM: Stan Herr

SUBJ: NICHD Funding

DATE: December 9, 1993

The American Association of University Affiliated Programs for Persons with Developmental Disabilities (AAUAP) has prepared the attached summary urging increases in NICHD funding. They urge comparability with other NIH institutes after many years of significant underfunding, and point to research breakthroughs that could be accomplished in the disabilities field. You previously received their full submission, but at your suggestion (conveyed through me) they have compressed their points.

With the prevention of childhood diseases and disabilities and pediatric and maternal AIDS research being Administration priorities, there is a strong case to be made for added research funds to make the types of cost-savings outlined in this document. The type of research that we observed during our visit to the Kennedy-Krieger Institute could be expanded if we were able to approach the NICHD "professional judgment budget" of \$685 million (versus the FY 1994 budget of \$555 million for NICHD).

If I can assist you further on this matter, please advise.

MEMORANDUM TO CAROL H. RASCO

FROM: Stanley S. Herr

SUBJ: Budget Reflections

DATE: December 17, 1993.

In reply to your memo of yesterday eliciting any comments/reflections on the budget, I am enclosing OMB's summary tables on homeless assistance programs. The trends are certainly positive ones and reflect homelessness being HUD's number one priority and the higher profile the Administration has given this issue. But expectations in the homeless advocacy community are also high, and for the first time since this issue began to receive national prominence there is a glimmer of hope that the federal government will make a significant

inroad in this problem. At yesterday's Interagency Council for the Homeless meeting, affordable housing, prevention, mental health and substance abuse were labeled as the four top consensus areas for more action under the proposed federal plan to reduce/end homelessness. In light of those concerns and the possibilities for meeting realistic expectations for change, can we set aside more than 4,750 Section 8 vouchers for disabled homeless families? (see footnote 11 re Non-McKinney Act program). Supportive housing is also a key to keeping the disabled homeless off the streets and/or out of more expensive custodial institutions. I don't understand where we are in terms of increasing the stock of such supportive housing for FY 95. Perhaps you can seek clarification and enhancement in this key area of programming.

Re more NICHD funding, I previously sent you memos of November 15th and December 9th with supporting documentation on the case for coming closer to the professional judgment budget of \$685 million than the \$555 million FY 94 budget. Some of these research initiatives could prevent childhood disease and disabilities, including work to prevent mental retardation from lead-poisoning and other causes, and save health care and other federal budget costs. The documents you already have should provide sufficient briefing on these points.

Finally, although I have not yet been able to get specific information on the SSA disability determination staffing problem, (I have a call in to Lisa Fairhall of OMB x5880), I believe we still have a looming political and human problem with delays in processing the backlog in making decisions on disability applications. SSA's administrative budget requires some enhancement to implement Congressional mandates on beneficiary needs.

I hope these comments are of some assistance. If I can provide you with any further help, I will be happy to do so.

MEMORANDUM TO CAROL H. RASCO

FROM: Stanley S. Herr

SUBJ: ARC Communication on the November meeting with you

DATE: December 22, 1993

FYI, I attach The Arc Government Report of Nov. 29, 1993 which summarizes their staff's meeting with you. It is basically quite positive for the Administration. The one sentence on page 3 that I lined in the margin seems a bit overstated and I let Paul Marchand know that I did not recall that type of comment coming out of our meeting. His explanation is that President Clinton said something to that effect in his meeting with disability leaders last

summer, and there was nothing we said to rebut it at our meeting. He acknowledged that this shorthand might not be apparent to the average reader. Telling him that I personally thought of our meeting as a consultation not an argument, I pointed out that health care reform and other recent initiatives certainly indicate that despite a tough budget picture progressive change is not being stifled.

Our conversation was cordial, and I do not recommend any followup. He thanked me for the feedback.

MEMORANDUM TO CAROL H. RASCO

FROM: Stanley S. Herr

SUBJ: Growing Unified Disability Community Support for the President's Health-Care Reform

DATE: Dec. 28, 1993

I am pleased to enclose Justin Dart's Dec. 20th memorandum and CCD action alert that reflects a new sense of unity in the disability community to give forceful support to President Clinton's drive for universal rights to health care. Several of us have been working to get such a strong message out to keep universal coverage and long-term care as the focus and rallying point.

The "strengths" and "concerns" analysis that Alan Bergman has marshalled is

far more balanced than prior documents that we have previously seen coming from UCP. The concern on the outpatient rehabilitation benefit is also reasonably stated, and the First Lady's recent letters on revisiting that issue offer some hope of a principled equal access to physical therapy and related essential therapies to avoid regression and more costly treatment down the road. I am receiving information from several sources that such therapies are often in existing insurance plans now.

Let me close with best wishes to you, Mary-Margaret and Hamp for a happy and healthy New Year!

MEMORANDUM TO CAROL H. RASCO

FROM: Stanley S. Herr

SUBJ: Turner letter concerning Wright State University (WSU)

DATE: January 13, 1994

You asked me to look into the matter of the unsuccessful application of this University's request for renewal funding under the Student Support Services program. Based on two conversations with Richard Sonnergren (most recently yesterday) and the attached letters from his office to Jean Turner (your correspondent) and from Secretary Riley to Senator Metzenbaum, I've drafted the enclosed reply for your review. [Roz has the E-mailed version for typing convenience].

As background information for you, here is the status of this matter. Both of Ohio's senators and half of its House delegation have lined up in support of WSU's protest. Secretary Riley's letter notes that he has personally reviewed this matter and will only order a full outside reevaluation if his own experts in the Department find bias in the initial peer review process.

There were funds to approve only about 700 of the 1100 applications, and WSU's application fell a few places (and points) short of funding. If Sec. Riley should eventually fund WSU, he will reprogram some of the Department's funds this year.

In drafting your reply, I have taken a guarded approach since Sec. Riley is at least two steps from a possible refunding of WSU's disability student support program. Ms. Turner's letter includes her daughter's essay as a high school student that I felt was worth saluting and makes for inspiring reading and reveals a generation of students with disabilities that has high expectations for a full and mainstreamed life.

01-14-94 01:56p
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A .	3,224 06-21-93 09:43a	A .SNO	1,409 02-28-93 06:51p
AAMR .NEW	4,034 11-18-93 09:55a	ACROL .ME1	9,883 12-14-93 04:38p
ADA .	9,817 01-11-94 03:26p	ADA .1	4,364 12-13-93 05:12p
ADDRESS .	2,215 09-15-93 01:20p	AGENDA .	11,444 11-16-93 11:21a
AGENDA .N16	4,017 11-16-93 11:26a	AGH .	1,410 05-13-93 06:10p
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ARCSPEEC.	901 10-07-93 03:35p	ARRANGO .J11	842 01-11-94 03:35p
ARRANGO .LET	3,295 01-14-94 01:56p	ATLANTA .SP	21,286 11-02-93 03:40p
AWARD .SDM	1,633 12-13-93 12:38p	BENNETT .LET	1,979 01-10-94 03:32p
BG .	786 02-18-93 07:54p	BLAH2 .	3,439 05-05-93 07:50p
BLAY .	2,722 04-16-93 05:30p	BURGROWT.	4,518 02-09-93 02:50p
CARBON .PAP	61,234 07-25-93 02:53p	CARL .	3,372 06-22-93 07:12p
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MEMORANDUM TO CAROL H. RASCO

FROM: Stanley S. Herr
SUBJ: Vocational Rehabilitation
DATE: December 14, 1993

You asked me to find out the status of the Administration response to Senator Dole's request that we create a National Commission on Rehabilitation Services. On November 20th, the Minority Leader's office issued a press release reiterating his call for such a Commission to "examine serious failures in the nation's rehabilitation programs, including problems in the ... \$2 billion vocational rehabilitation program reported by the GAO in August." This Commission is authorized under the Rehabilitation Act Amendments of 1992, but there is some question as to whether the relevant appropriations committees would actually approve its funding.

Based on two telephone conversations with Howard Moses, Deputy Assistant Secretary, OSERS and conversations with Acting RSA commissioner Smith, Dave Ziskind, we will be receiving the actual response to Dole's proposal. I have, however, attached Secretary Riley's letter of Nov. 18th to chairman John Conyers (House Government Operations Comm.) which largely concurs with the recommendations contained in the GAO report, "Vocational Rehabilitation: evidence for Federal Program's effectiveness is Mixed." But the Department's position is that the GAO recommendation to institute the National commission on rehabilitation Services is not warranted because:

- the administration's incoming appointees should first be given a chance to evaluate the program;
- a new outside body is not needed when the National Council on disability could perform this type of review, along with existing authorities in OSERS, RSA, NIDRR, NIH, and the Access Board.
- the creation of a new body would only divert staff and resources from

existing vital program functions; and

- the Department will put in place its own "proactive strategy" to obtain the views of interested groups to improve employment outcomes prior to the next Rehabilitation Act reauthorization.

See page 6 of attached letter from Sec. Riley to Chair Conyers.

In private conversation with Mr. Moses, he augments the reasoning as follows:

- they are meeting with Sen. Dole's disability specialist, Alexander Vaschon this afternoon to explore their respective positions.
- without a permanent RSA commissioner they are hampered in making a full response;
- they are running all-out, but have not even been able to promulgate regulations based on the 1992 amendments yet, and don't expect to have final regs before September-October 1994;
- given the thorough review of the Rehabilitation Act entailed in the 1992 Amendments, they are unclear as to what more a National Commission would do to change the law;
- Vaschon may be looking for a broader review of the generic 140 plus job training programs and how persons with disabilities can make use of the full spectrum of job training and employment programs (OSERS would like to be involved in this type of broad review, but haven't been invited to do so yet);
- they have yet had detailed discussions with the National Council on Disability as to its willingness to undertake some type of quasi-outside study, and are awaiting Marco Bristo's appointment to the leadership of that Council.

The overall picture that emerges is not comforting. Moses and Smith confirm the truth of the Jack Duncan's claim that this year the Administration projects the lowest number of vocational rehabilitation placements for persons with disabilities in 48 years. Moses explains that this is in part due to the greater costs, and more insensive service needs of aiding more severely disabled rehabilitants.

Duncan (Council of State Administrators of Vocational Rehabilitation) has also stated that of 1.2 million people in VR programs only some 200,000 emerge in work settings, even defining such settings broadly as workshops or homemaking. Moses did not dispute this claim either.

If you need further information, I have requested:

- 1) the number of VR placements over the last five years;
- 2) any correspondence from the Department of Education to Senator Dole on this GAO report;
- 3) and additional fact sheets on problems and trends in vocational rehabilitation "slots."

I also have copies of the following GAO reports in case you would like a brief review on the long-standing problems we inherited in the field of vocational rehabilitation.

F.Y.I., OSERS is putting together their response to the wide-ranging cover-story critique of special education, published in U.S. News and World Report. They will send me a copy. Would you like a copy as well?

MEMORANDUM TO CAROL H. RASCO

FROM: Stan Herr

SUBJ: Replies to your queries on Vocational Rehabilitation and miscellaneous budgetary matters

DATE: December 16, 1993

1. Why are the regulations to the 1992 Amendments expected to be out until the Fall of 1994?

A. There is a lack of qualified staff to develop regulations of this magnitude. The regs are expected to be 300-400 pages long.

The lack of a permanent RSA Commissioner has hampered this process.

The process of seeking expanded field input will add 60-90 days delay, but this participation is expected to pay dividends.

Although they have issued proposed rules on the Client Assistance Program and Certain Centers for Independent Living portions of the Act (which he will send me), the rules on the basic state programs are still several months away from being published.

Howard Moses candidly also acknowledges that "we could do better."

2. "Do we know the hold up here" [on Marca Bristo's appointment]?

I am informed that her name has still not left the White House personnel office, but no problem is known. I have calls in to Paul Miller to confirm this point and to make sure we're doing everything we can to move this appointment forward.

3. On the current draft response of OSERS concerning the U.S. News & World Report investigation of special education, see enclosed document "A".

4. On the falling trends in the number of non-severely disabled persons rehabilitated while the number of severely disabled rehabilitant remains fairly constant, see page C-3 of document "B".

5. You also asked about our response to Senator Dole, and so enclosed is Secretary Riley's answer that more cost-effective methods exist to review the VR program than a National Commission on VR priced at \$ one million.

All these documents and views are provided by Mr. Moses, Deputy Assistant Secretary, OSERS.

6. In telephone conversation with Ed Burke, Acting Executive Director, National Council on Disability, he indicates statutory authority and interest in his agency in doing the type of study contemplated for a National Commission on Vocational Rehabilitation. However, his agency is small (only 9 FTES) and they would need additional resources to perform a significant review of the VR program.

7. I will see Burke tomorrow and also attend the first court case brought by the Department of Justice under title III of the ADA.

8. One other budgetary item to bring to your attention: Justice and probably the EOC could use additional FTES to provide more energetic enforcement of the Act. Right now the word on the street seems to be that the likelihood of enforcement action is so small that employers and public accommodations can afford "business as usual."

9. Ellie Acheson at Justice told me today that they hope to add four attorney positions on ADA enforcement, but it will be a while before they are filled. Four positions help, but the magnitude of the problem seems much larger to me.

10. I have placed calls per your assignments to me to Paul Miller and to the Kentucky parents.

Enclosures

inroad in this problem. At yesterday's Interagency Council for the Homeless meeting, affordable housing, prevention, mental health and substance abuse were labeled as the four top consensus areas for more action under the proposed federal plan to reduce/end homelessness. In light of those concerns and the possibilities for meeting realistic expectations for change, can we set aside more than 4,750 Section 8 vouchers for disabled homeless families? (see footnote 11 re Non-McKinney Act program). Supportive housing is also a key to keeping the disabled homeless off the streets and/or out of more expensive custodial institutions. I don't understand where we are in terms of increasing the stock of such supportive housing for FY 95. Perhaps you can seek clarification and enhancement in this key area of programming.

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If I can assist you further on this matter, please advise.

E X E C U T I V E O F F I C E O F T H E P R E S I D E N T

14-Jan-1994 01:20pm

TO: Stanley S. Herr

FROM: Carol H. Rasco
 Economic and Domestic Policy

SUBJECT: RE: Bergman's fax

Thanks for doinkg the meeting on the 26th! There are over 8-10 speaking engagements that pour in here daily....we need robots to send out. Some we can decline and be done, others we can decline and they find pressure points we can't avoid and thank goodness, there are a few, although a very few that we can decline and that is the end. Thanks so much.

MEMORANDUM TO CAROL H. RASCO

FROM: Stanley S. Herr

SUBJ: Phoebe Snow

DATE: Feb. 10, 1994

I've made two calls to Ms. Snow, got Dr. Roy Meyers (special education head at OSERS) to give her a New Jersey point of contact, and provided her with five names of New Jersey advocates with experience in resolving the types of education problems her multiply handicapped daughter is experiencing.

Ms. Snow is appreciative, would be delighted to sing again for the President, and may be calling me back with feedback on the outcome. In the process of aiding her, I've discovered that she grew up with one of my cousins, and that a law professor that I consulted went to the same Newark public schools. Small world stuff and in New Jersey no less!

So I think there is no need for a meeting here with Ms. Snow since she's basically received referrals from us that could be of some help in her personal advocacy. I'll make a copy of her letter in case she calls me back. Do you want to have someone call the DNC just to let them know that we attended to this?

*Yes - Thanks Stan - please call DNC
to give brief update,*

DEMOCRATIC ★ NATIONAL ★ COMMITTEE

FEB 1 - REC'D

David Wilhelm, Chairman

Memorandum

TO: Carol Rascoe
Assistant to the President
Domestic Policy Council

FR: Eric Sildon
Jay Dunn
Democratic National Committee

RE: Correspondence from Phoebe Snow

DT: January 27, 1994

Enclosed please find a letter addressed to you from Phoebe Snow. As you may know, Ms. Snow is a folk artist who was the principal performer at a Washington Reception for President Clinton in June 1993. This letter was passed on to us by Roy Furman, Finance Chair of the Democratic National Committee, who asked that we deliver it to you.

In her letter, she describes the personal pain and difficulty she has endured with her daughter, Valerie, who was born with several mental and physical handicaps. You will notice in the text of her letter, Ms. Snow would greatly appreciate the opportunity to meet with you briefly to discuss alternative educational programs for children with severe mental and physical birth defects. In her letter, she shares her frustrations in and suggestions for current educational programs and facilities for children with disabilities.

I will call your office to learn if you think that a meeting with Ms. Snow is appropriate.



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

MEMORANDUM TO CAROL H. RASCO

FROM: Stanley S. Herr

SUBJ: Talking points and background for your keynote address to the Disability Leadership Forum, Community Leadership Development Program, co-sponsored by the National Easter Seal Society and University of Minnesota's Center for Citizenship and Democracy, September 23, 1994

DATE: September 22, 1994

Time and Place: Pat Romani will be giving you the information about your reception at the airport by Ms. Gordon and Ms. Brewster. You arrive in MN. at 3:54, and their events are as follows:

- 5 to 6 p.m. reception for Forum participants.
 - 6 pm Governor Carlson of Minnesota welcomes participants and dinner proceeds; other welcomes from Harry Boyte of U. of Minn. (his bio is attached as App. 1), and from Sandra ("Sandy") Gordon, Sr. V.P., Corporate communications for National Easter Seal Society (her bio is App. 2).
 - circa 6:45 to 7:00 p.m., Friday, September 23, 1994 (your post-dinner talk of 20-25 minutes begins).
- [This doesn't sound like gracious dinning, since supposedly their training session starts at 7 p.m.. Their coordinator tells me they will relax their timetable as necessary***]

The Marquette Hotel
710 Marquette Avenue
Minneapolis, MN.

Points of Contact:
Hotel Phone for Sara Brewster, Easter Seal Society's conference organizers: 612 333-4545
Hotel fax (612) 376-7419

Audience:
55 persons, of whom 27 are trainees who range in age from their 20s to mid-40s. About half the trainees are from Minnesota. According to the profile of participants (App. 3), most use wheelchairs, four are not disabled (e.g. Patricia Swartz is the mother of a 5-year old with cerebral palsy), and all are

currently involved in some level of civic organization. This is day one of a 3-day training session billed as the inaugural group on civic leadership skills and strategies. According to Ms. Brewster, this group is excited about becoming more intensely involved as volunteers and more effective in dealing with ADA and accessibility issues. Others in attendance are aides, members of pro bono advertising campaign, steering committee members.

Your dinner table companions will include Gov. Carlson (if he stays), Nan Skelton (whom I gather you know from NGA days, now a Humphrey Institute fellow), Harry Boyte, Dorothy Cotton (her bio is App. 4), Sandy Gordon, & Sara Brewster.

Session

You will be introduced by Sandy Gordon (FYI, see her description of the program, "About the Disability Leadership Forum," App. 5).

Talking Points: "Confessions of a Volunteer" (your talk is untitled, this is just a suggested theme).

- Recognition of Governor Arne Carlson as someone whose presence here confirms that he cares deeply about civic leadership and the heightened involvement of volunteers like you both in Minnesota and in your other home states of Colorado, Georgia, Indiana, New Jersey, Ohio, Oregon, and Texas.

- Congratulations to Sandy Gordon and Harry Boyte for this wonderful Community Development Leadership program.

- Also an honor to be on the program with Dorothy Cotton, an associate of the late Dr. Martin Luther King, Jr., and a woman whose life work has been the empowerment of new leadership and who has worked with White House staff on our themes government - citizen partnerships.

- [Addressing the Forum participants]: It is an especially deep pleasure to get to know each of you as volunteers and as leaders in your communities because I can identify with you.

- I was a full-time volunteer for many years and I have a few confessions to make that may connect up with your experiences.

- Lord knows, I didn't start out expecting to be the President's chief domestic policy adviser and in charge of the White House Domestic Policy Council.

- Carol: any pre-Hamp volunteer experiences that you want to share? [voluntary roles to set up contrast

- My life as a volunteer accelerated rapidly after the birth of my first child, Hamp who is now a young adult and increasingly involved in decisions for himself.

- But my encounters with bureaucracy and barriers, paperwork and pity, disability discrimination and disdain (pause) fundamentally changed the trajectory of my life.

- I became a parent who worked exclusively in the disability field as a volunteer until Hamp was seven.

- Along the way I discovered the joys and frustrations of being part of the disability rights movement, of making common

cause with other volunteers, working in coalitions, and becoming involved in the political process to make real changes in my son's life and the lives of other folks with disabilities.

- [Carol: the core of your remarks are your own stories of increasing activism as a volunteer see Williams letter to you, App. 5a;

the need to stay focused on goals and not get discouraged by slowness of change or setbacks along the way {Sara Brewster emphasized that point's relevance to this group};

stories that illustrate the point that members of the disability movement have to prepare themselves for the long-haul to see fundamental changes, not just to rally for spurts of civic involvement;

your transition from volunteer to political activist to running state government operations to policy adviser to the President.

- Your coming together raises the possibilities of Reinventing Citizenship in ways that reminds the public that people with disabilities are and must be "full participants in the shaping of our common life." (see App. 6, Reinventing Citizenship, p. 1).

- In thumbing through, your National Directory: 1993, Disability Leadership Forum: A Who's Who of people who make a difference, I was impressed with the breadth and range of your accomplishments. Of course, I checked out the Arkansas folks listed (Carol: see App. 7, pp. 3-4), but I was also impressed by reading about Massachusetts State Senator Frederick Berry, a State senator for 10 years, a civic leader with cerebral palsy who has worked in an array of volunteers involvements in both disability and non-disability contexts (Id. p. 46).

- I read of Bill Demby from Maryland, who lost both legs from the knee down in Vietnam, who is featured in some TV commercials playing basketball with artificial limbs. He is a counsellor in a local "disAbility Awareness Project." His motto: "To win you have to play the game. I win when I try.... I win when I walk into the field or court, ready to play." (Id. at 44).

- Well you don't have to be a war hero or shoot hoops to adopt that motto.

- I regularly meet with the Clinton Administration's appointees with disabilities, and each was selected for their abilities. They range from Assistant Secretaries to staff assistants, but they are each in the game and they are winners who are ready to play.

• On July 27th, they and 3300 other disability activists came to the White House to hear President Clinton celebrate the 4th anniversary of the ADA and honor their movement.

• President Clinton emphasized that the ADA is "about potential" and that it "stands for what is best in our heritage - - empowering americans to build better lives for themselves." and so pledged to see that the ADA is "fully implemented and aggressively enforced in our schools, our workplaces, in government and in public places for the benefit of all persons with disabilities."

• I too embrace that goal and am working to empower every adult, and every child through their families to develop to their fullest potential.

• I've recently set up a Federal disability accommodations working Group to help us as a Federal Government do a better job in accommodating our employees, our customers, and you our citizens.

• WE NEED YOU TO GUIDE US, AND TO WORK AT YOUR LOCAL LEVELS TO MAKE THE A.D.A., INCLUSION, AND GREATER INDEPENDENCE A REALITY FOR ALL OUR CITIZENS WITH DISABILITIES.

• We count on the spirit and deeds of volunteers like you to rebuild the American community -- your community.

• Last week, President Clinton swore in thousands of volunteers to Americorp, including volunteers with disabilities, in a powerful reminder that citizens with disabilities are givers of service, too.

• But that message comes as no surprise to you.

• You know, of course, that President Franklin Roosevelt's polio lead to increasingly severe disabilities during the course of his presidency. But the point I stress is that the general public at the time didn't realize it, and may not in 1944 have been as accepting of people with disabilities in visible leadership roles as I believe they are in 1994.

• You know that now people with disabilities, and the family members of people with disabilities are ready to play a full, open, and winning role in the public life of their towns, states, and nation.

• I wish you every success on that public stage in whatever form of civic work you choose.

• And I hope that the journey of your voluntarism will be as satisfying and as much fun as it has been for me.

Thank you and let's get on with the exciting sessions that this weekend offers! [see App. 8 for conference purposes and agenda].



Please Post

**MAKE PLANS
NOW!**AMERICAN
SPEECH-LANGUAGE-
HEARING
ASSOCIATION**DON'T MISS IT!**

The American Speech-Language-Hearing Association (ASHA) invites all convention attendees to a miniseminar **addressing the next steps on disability policy with top White House official Carol Rasco and Tom Hehir, the Director of the Office of Special Education Programs (OSEP)**. Also participating will be **Barbara Wynn, Deputy Director, Bureau of Policy Development, Health Care Financing Administration (HCFA)**. The miniseminar will examine the effect of governmental policies on ASHA members and those they serve. For more information, please call Amie Amiot at (301) 897-5700, ext. 104.

WHO: *Carol Rasco*, Assistant to President Clinton for Domestic Policy
Tom Hehir, Director of the Office of Special Education Programs
Barbara Wynn, Deputy Director, Bureau of Policy Development,
Health Care Financing Administration

WHAT: Miniseminar: What Will They Do To You Next? - "Addressing the Next Steps on Disability Policy"

WHEN: Friday, November 18, 1994, from 12:00 p.m. to 1:30 p.m.

SEE YOU THERE!



AMERICAN
SPEECH-LANGUAGE-
HEARING
ASSOCIATION

GOVERNMENTAL AFFAIRS DEPARTMENT

FAX NUMBER (301) 897-7356

DATE: November 4 , 1994

SENT TO: Stan Herr

ATTENTION:

FAX NUMBER: 202 456 7028

SENT BY: Amie Amiot

CONFIRMATION REQUESTED YES NO

YOU WILL RECEIVE 1 PAGE(S) FOLLOWING THIS COVER PAGE.

IF YOU HAVE ANY QUESTIONS CONCERNING THIS TRANSMISSION PLEASE CONTACT Amie Amiot AT (301) 897-0104.

MESSAGE: New publicity piece for miniseminar. Thanks again for all your assistance.

Education 1/2 - IDEA
 Health 1/2 - Health Convention Party - coverse screening for members/
 Policy/Plan Change Title Benefits package
 Speech-Language
 Board - Universal
 proper person

MEMORANDUM TO CAROL H. RASCO

FROM: Stanley S. Herr

SUBJ: Talking points and background for ASHA Convention Speech

DATE: October 25, 1994

Time and Place: Friday, November 18, 1994 from noon to 1:30 p.m.
 New Orleans Convention Center, room 19.

Points of Contact:

Hotel Phone for Amie Amiot, Director of Federal education and regulatory Policy division, miniseminar coordinator: ~~7777~~

Hotel fax: Hilton: Reveranda Towers (504) 561-0500
 govt aid

Audience: motor - small group
 Developmental process - think + receive
 audience

American Speech-Language-Hearing association is the second largest membership organization in the special education field with 80,000 ~~200~~ members (after CEC).

14,000 aud
 Speech
 Language
 hearing -
 percent
 average

The Annual convention typically draws 11,000

Your miniseminar is scheduled in a room with a seating capacity of ~~100~~ 200

Sequence of events:

You will be introduced by Chairman of your Board, Lisa Brokey (CA).
 You will then give the lead-off talk of minutes.
 Tom Hehir, director of the Office of Special Education Programs (OSEP) will then discuss for minutes.
 Barbara Wynn, deputy director, Bureau of Policy Development, Health Care Financing Administration, will next cover for x minutes.

Sen John Breaux's participation

Melinda Harrison

No question

(410) 966-5674

Cambridge Room, Hilton

3:15
 2:30 Nov 18 (100)
 reception board

Atabrunch -
 Sunday
 Th - Fr

Hamp (25)
 (anyone - re next 2 years)
 entmowed

Hankin -
 2:30 parking
 has
 arranged
 very possible

20 years -
 Sr. Mandy
 insurance,
 payment
 health
 care
 5 years
 Medicare
 rates
 Sen. Finance
 Comm
 (410) 966-5674

(Hamp as last speaker)

not finalized yet
 President Florio at Spent-Item
 State Account of Florida
 experience w/ health care reform

draft on current status
MEMORANDUM TO CAROL H. RASCO

FROM: Stanley S. Herr

SUBJ: Talking points and background for ASHA Convention Speech

DATE: October 25, 1994

Time and Place: Friday, November 18, 1994 from noon to 1:30 p.m.
New Orleans Convention Center, room 19.

Points of Contact:

Hotel Phone for Amie Amiot, Director of Federal education and regulatory Policy division, and coordinator for your activities:

Hilton Riverside and Towers, (504)561-0500

Hotel fax:??

Audience:

American Speech-Language-Hearing association, I'm told, is the second largest membership organization in the special education field with some 80,000 members (CEC is the largest). Audiologists are 14,000; the rest of their members are speech and language therapists about equally divided in working in school or health care settings.

The Annual convention typically draws 11,000 participants.

Your miniseminar is scheduled in a room with a seating capacity of 200.

Sequence of events:

You will be introduced by the "chairman" of their board, Lisa Brekey, who is also president of their California state association.

You will then give the lead-off talk.

At my suggestion, Hamp would then follow and they are fine with that mother-son duo.

Tom Hehir, director of the Office of Special Education Programs (OSEP) will then discuss the IDEA Reauthorization for ___ minutes.

Barbara Wynn, deputy director, Bureau of Policy Development, Health Care Financing Administration, (a 20 year veteran in HCFA rate setting matters, who has also spent some time with the Senate Finance Committee staff, will next cover _____ for x minutes.

Melinda Harrison, President of their Florida Speech-Language-Hearing Association, would conclude with her experience in

working on state-level health care reform in that state.

Sen John Breaux's participation is still unconfirmed, but they say they remain hopeful that he will see yes (simply because its getting close to the event??). If he shows, presumably he would come after you and Hamp.

So that's the line up, and even if they wanted to, I doubt if there would be time for Q & A.

The (Ugh) Title:

Amie Amiot says we could get a change of title if we move quickly, and she'll get it printed in the "Convention Daily News."

It will still leave it in the "At Press Time" page of the program, but I think we can and should conduct this session under a more postive name.

Tom Hehir and I came up with:
"Next Steps in Disability Policy"

I'll do my best to negotiate that change or anything else you would prefer.

Expectatations:

They would like to hear as much as we can tell them about next steps in health care reform and IDEA Reauthorization.

I informed Ms. Amiot that on the former there may not be all that much to say at that point.

They understand that their would be a lot of personal and human interest aspects in your remarks. Miss America's accomplishments, and your encounter with her, would certainly be relevant and generally well-received.

PS. She says the association is a great supporter of the Administration, and strong endorser of our last health reform plan.

I'll talk to her re logistics
of Hamp's participation per your
E-mail.

EXECUTIVE OFFICE OF THE PRESIDENT

25-Oct-1994 12:46pm

TO: Stanley S. Herr
FROM: Carol H. Rasco
Economic and Domestic Policy
CC: Jeremy D. Benami
Rosalyn A. Miller
SUBJECT: RE: Silverstein and New Orleans talk

Handing
Carve U!
12,000

1. a. Did Bobby have ideas about what a stacked or non-stacked Childhood SSI Commission would look like? I am very eager for input on this issue as I think the potential ramifications are big, big, big....and could be very negative at the drop of a hat if we aren't careful. I'm just not sure I know all the pitfalls we ought to try to avoid in even the appointment process.

I know you all said originally he wanted to meet with me on this topic? Do you think your meeting took care of that or is there some base touching or more I should do with him on this?

b. IDEA: Does he have more specifics to offer? I am very eager again to do this right.

2. a. Tom Hehir and IDEA: you mentioned they are ready to bounce more ideas off us....does this mean we are ready for me to attend another meeting or what?

b. New Orleans: I HATE that title and was quite frankly (but not to be shared outside us) pretty insulted. I think it is worth a conversatoin between you and AMy if you agree. Also, my original invitation said nothing about a seminar format or even a panel but invited me to speak. They then followed up inviting Hamp to accompany me and speak and we are well underway with all those logistics of travel, the aide to go with him, our rooms, etc. BUT with this new piece about a seminar and the other panelists, that is why I asked Jeremy to have you start finding out format, content expectations, etc. Also, I had planned to have Hamp close out the mother/son duo but need to know if these folks had other plans.

on
my
available

The only logistical piece I can think of to settle is that I will need a clip on mike for Hamp if possible and would like to have him do a little practice session at some point if the room will be available for that. ROz has all our travel schedules,

etc. and other logistical info that has been determined if you need to see it (I already have the tickets in hand for example).

Thanks.

draft on current status
MEMORANDUM TO CAROL H. RASCO

FROM: Stanley S. Herr

SUBJ: Talking points and background for ASHA Convention Speech

DATE: October 25, 1994

Convention Daily
9,000
letters
Time and Place: Friday, November 18, 1994 from noon to 1:30 p.m.
New Orleans Convention Center, room 19.

Points of Contact:

Hotel Phone for Amie Amiot, Director of Federal education and regulatory Policy division, and coordinator for your activities:
Hilton Riverside and Towers, (504)561-0500
Hotel fax:??

Audience:

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At my suggestion, Hamp would then follow and they are fine with that mother-son duo.

Tom Hehir, director of the Office of Special Education Programs (OSEP) will then discuss the IDEA Reauthorization for ²⁰ ~~30~~ minutes.

Barbara Wynn, deputy director, Bureau of Policy Development, Health Care Financing Administration, (a 20 year veteran in HCFA rate setting matters, who has also spent some time with the Senate Finance Committee staff, will next cover ²⁰ ~~30~~ for x minutes.

Melinda Harrison, President of their Florida Speech-Language-Hearing Association, would conclude with her experience in

2:30

INCLUSION --- LRE

1. 22 YEARS AGO IN THIS VERY CITY A GROUP OF PARENTS LIKE YOU, AND A HANDFUL OF LAWYERS LIKE ME WON AN HISTORIC VICTORY FOR THE RIGHTS OF ALL CHILDREN WITH DISABILITIES TO ATTEND A FREE AND APPROPRAITE PUBLICALLY SUPPORTED EDUCATION.

2. ONE OF THE REMARKABLE FEATURES OF THAT LANDMARK CASE MILLS V BD OPF EDUCATION THE OBLIGATION TO OFFER DUE PROCESS SO THAT PARENTS ARE EMPOWERED TO HELP DEFINE AND ENFORCE A MANDATE OF FAPE AND LRE.

3. THREE YEARS LATER, CONGRESS CODIFIED THOSE RIGHTS IN LAW AND UNDER IDEA IT IS NOW THE LAW OF THE LAND THAT TO THE MAXIMUM EXTENT APPROPRIATE, CHILDREN W/ DISABILITIES ARE EDUCATED W CHILDREN WHO ARE NON DISABLED.

4. REGULATIONS GO ON TO SAY THAT 'SPECIAL CLASSES, SEPARATE SCHOOLING OR OTRHER REMOVAL OF CHILDREN WITH DISABILITIES FROM TEH REG ED ENVIRONMENT OCCURS ONLY WHEN THE NATURE OR SEVERITY OF THE DISABILITY IS SUCH THAT ED IN REG CLASSES W/ THE USE OF SUPPLEMENTARY AIDS AND SERVICES CANNOT BE ACHIEVED SATISFACTORILY.'

5. NOW THE GENIUS OF THIS LAW, AND WHY IT IS ABOUT TO HAVE ITS 20TH ANNIVERSARY NEXT YEAR IS THE CHOICES THAT IT PERMITS -- THIS IS NOT A ONE SIZE FITS ALL APPROACH, BUT ONE WHICH REQUIRES A CONTINUUM OF ALTERNATIVE PLACEMENTS, A HIGHLY INDIVIDUALIZED PLACEMENT PROCESS, AND ONE THAT REQUIRES ANNUAL RVIEW, AN IEP-BAXSED PLACEMENT WHER PARENTS PARTICIPATE IN DESIGNING THE IEP, PLACEMENT "AS CLOSE AS POSSIBLE TO TEH CHILD'S HOME." AND PALCEMENT IN A SCHOOL W NON-DISABLED PEERAS 'UNLESS THE IEP REQUIRES SOME OTHER ARRANGEM, ENMT.'

6. PRESIDENT CLINTON AND HIS ADMINISTRATION DEEPLY BELIEVE IN TEH PRECEPTS OF INCLUSION AND THE PRINCIPLE OF LRE.

TIME AFTER TIME THE PRTESIDENT HAS REITERATED HIS NOW FAMOUS STATEMENT OF NATIONAL DISABILITY POLICY -- THAT IT BE BASED ON INCLUSION, NOT EXCLUSION; INDEPENDENEC, NOT DEPENDENEC; AND EMPOWERMENT, NOT PATERNALISM.'

7. ON JULY 27TH, INVITED 3300 LEADERS OF DISABILITY RIGHTS MOVEMENT TO HELP CELEBRATE THE 4TH ANNIVERSARY OF ADA. LARGEST GATHERING NOTED THE ADA AS ONE OUR 'LAWS OF INCLUSION' AND PLEDGED TO AGGRESSIVELY ENFORCE IT IN OUR SCHOOLS AND WORKPLACES, IN OUR NATIONAL GOVERNMENTS AND LOCAL COUNCILS.

8. WHEN TEH PRESIDENT AND THE FIRST LADY ASK US A PEOPLE TTO "FINALLY OVERCOME THE REMAINING HANDICAPS OF PREJUDICE AND

STEREOTYPE". THEY DO SS FROM A BASIS OF FIRST-HAND KNOWLEDGE.

9. LAST YEAR YOUR TELECONFERENCE CELEBRATED RACHEL HOLLAND'S VICTORY IN THE FEDERAL COURTS OUT IN CALIFORNIA TO ASSURE HER RT TO ATTEND REGULAR CLASSES AS A STUDENT W/DD.

10. THIS YEAR I'D LIKE TO HIGHLIGHT THE RECENT SUCCESS OF THE SAMOZA FAMILY OF NYC IN WINNING INCLUSION FOR THEIR TWIN 10-YEAR OLD DAUGHTERS ANASTASIA AND ALBA -- WHO HAVE SEVERE CEREBRAL PALSY.

11. MARY SAMOZA CREDITED THE PRESIDENT FOR THE SUCCESS OF HER ADVOCACY EFFORTS.

12. I REALLY WANT TO SHARE THE GIRLS' OWN LETTERS

13. WHAT COULD BE MORE ELOQUENT THAN THAT ON WHAT INCLUSION AND
1RE

14. MISS AMERICA HEATHER WHITESTONE

15. WELCOMED TO WH BY DP, POTUS AND FITS LADY

FOR WHAT SHE SAYS ABOUT INCLUSION, AND SUPPORT

16. DELIGHTED RE ALBA, ANASTASIA, AND HEATHER'S STORIES SHOW FOR HOW YOU AND WE ARE SUCCEEDING IN GIVING EQUAL ED. AND AND A CHANCE TO THRIVE AND SUCCEED IN THE MAINSTREAM OF AM LIFE



MOTHER AND SON — Carol Rasco nuzzles son Hamp, 19, at their home in Little Rock recently. Rasco, the White House domestic policy adviser, says Hamp and daughter Mary-Margaret have helped her form the core of her domestic policy views.

Motherhood mo

Clinton adviser wants to h

BY JASON DePARLE
New York Times News Service

At first glance, it seems a simple portrait of privileged Southern living — a sparkling backyard pool, a family gathered in a comfortable den, a 4-foot-wide television that flickers with camcorder images of a relative's sprawling new home.

Only one thing suggests that Carol Rasco has seen more than suburban comfort. That is a figure, strapped in a wheelchair. It is her son, Hampton (he is called Hamp).

He is probably the only mentally retarded 19-year-old to have taught a presidential confidante. Rasco, the White House domestic policy adviser, says nothing has taught her more about the need for a responsive government than the challenge of raising a son who was born with brain damage.

"My children so much form the core of what my view of domestic policy is about," said Rasco, who also has a healthy 12-year-old daughter, Mary-Margaret.

Rasco can tell excruciating stories of getting the runaround from government agencies, and she often does. Her long and lonely road as a mother has shaped one of her policy goals, which she says is to "help all parents be the best they can be."

Some women in power might view their domestic lives as inappropriate topics for inquiry; profiles of the president's men, after all, do not usually focus on their roles as fathers. But Rasco

invites such inquiries, questions about her policies into a conversation about motherhood.

She did that recently at a group of company chief executives. She scrapped her prepared remarks on global competitiveness to extemporize reasons why their future force, today's children, are strong advocates.

She remembers thinking, "dear, do I risk this?" But she says that other speakers' cover abstract statistics, and the executives how her experiences had led her to see the need for child advocacy. She put out a strong advocate, and her son would not have gotten the job he needed," she says.

As a former elementary school teacher in a White House thick with Rhodes scholars, Rasco occupies an odd presidential niche. She has nothing of the traditional reputations enjoyed by her two counterparts, Robert Rubin, the economic policy adviser, or W. Anthony Lewis, the national security adviser.

She is happy to describe herself as an implementer of policies rather than their architect, and she seems to have taken a back seat on major issues like the budget and health care reform. Her colleagues

This Article Laminated
Especially For You

Compliments

The First National Bank
Of DeWitt

hospital visits, outpatient rehabilitation, home health care, adapted durable medical equipment (including orthotic and prosthetic devices and training in the use of those items), mental health services, and many other essential services.

Furthermore, congressional committees are expected to clarify that rehabilitation services will be available to those who need them as a result of illness, injury or congenital disabilities. Such services will also be offered to maintain functioning and prevent deterioration.

• It provides a major expansion of long-term care coverage by adding home and community-based services for people with severe disabilities, regardless of age or income. With a projected three million people with disabilities and their families benefitting from this new program, this coverage allows people with disabilities to live in their own homes -- with their families where appropriate -- and to enjoy fuller and more satisfying lives.

for our
conversations
these
2 sentences
must be
deleted
for now

Article for Exceptional Parent, 5-11-94
For further information and liaison,
contact Stan Herr at (202) 456-5570.

EMPOWERING PEOPLE WITH DISABILITIES AND THEIR FAMILIES

By Carol H. Rasco

I come to you to express my deep commitment, and that of the Administration, to the empowerment of people with disabilities.*

Those of you who work in this field -- whether as volunteers professionals, or family members -- boost our determination and our capacity to resolve the tremendous challenges that remain before us. Your dedication and compassion inspires us to embrace the responsibility of meeting them.

As a parent who worked exclusively in this field as volunteer until my son was seven and who now works as a policymaker, I want to tell you about some of the ideas and individuals that inspire me in my daily work. Although I will focus here on health care reform, our reform agenda also extends from education reform to welfare reform, and from safer streets to safer transitions to adulthood for all our youth.

The White House Domestic Policy Council coordinates the efforts of the Administration, the Cabinet secretaries, and the other federal agencies involved with the development of every aspect of our nation's domestic policy. As a director of the Council's day-to-day work, I bring a strong determination that all children shall be empowered to develop to their fullest potential. To meet this crucial goal, our children need each of us to believe in them and we as parents need the opportunities to nurture their growth.

As President Clinton has recently stated, "Having a disability does not diminish one's right to participate in all aspects of mainstream society." On the Domestic Policy Council we take that right very seriously. Working together in public-private partnerships, we are responding to the President's call to "craft policies of inclusion, independence, and empowerment that will inspire positive changes in this country and in nations around the world."

Health care reform is an indispensable part of that mission. The President's health care plan is a dramatic advance for people with disabilities and their families. Here's why:

- It guarantees universal coverage for all Americans, and the peace of mind of having health care that is always there.

- It outlaws the current insurance practices of excluding people with pre-existing health or disability conditions, or of jacking up your rates if you get sick or become disabled.

- It forbids insurance companies from picking only the lowest-risk individuals and families, and rejecting others.

- It builds on today's private insurance system, which is primarily employer-based, while making insurance more affordable for the self-employed and subsidized for the unemployed. As a result, no one will be uninsured, even if they or members of their family experience a disability, injury, or sickness.

- It offers a nationally uniform and comprehensive benefit package -- in contrast to some of the other legislative proposals -- that includes a range of preventive services, doctor and

- It adds significant civil rights protections for the enjoyment of health care benefits, consumer involvement in the design of the new home and community-based services for individuals with disabilities, and health care "report cards" so that families can assess which health plan best fits their needs and reward that plan with their membership.

[On May 2nd, I was delighted to be with the President as he hosted 125 leaders of the disability community in a tremendously enthusiastic rally for health care reform. As the President emphasized: "This is a battle that you may be able to lead for the rest of America.... And so I ask you: Be an agent of change, an agent of empowerment. Never forget that you are carrying on your shoulders not only your cause, but ours as well. You can break through to those members of Congress. You can do it." From the White House, these leaders were joined by about a thousand others who marched across the Memorial Bridge to rally at the Lincoln Memorial, then to lobby on Capital Hill].

Now

is the time to guarantee health security for ourselves, for our children, and for the generations to come. Without secure health coverage, too many of us are not free to change jobs or to move to a different location or to venture from disability rolls to payrolls. Without that security, employers may be reluctant to hire a person with a disability or a person with a family member who is disabled.

These basic principles unite us. But it is our common love for our families that propels us to act.

Early in my son's life, a physical therapist who had dedicated her long career to helping young children with disabilities shared with me the words of essayist and poet Joseph Addison, "Everyone must have something to do, someone to love, something to hope for."

I am constantly reminded of those words not only for Hamp, but for all the people with whom I've worked. In our quest to empower people, we must strive to fulfill these ends at each stage in life. WE HAVE QUESTIONS TO ASK AND ACTIONS TO TAKE

What do persons with disabilities have to do? For a young child, is a preschool program or other early intervention available? For a school-age child, is school relevant, safe, and effective? Are our schools and transitional programs teaching both how to make a living and how to live? And, for adults, is there a job or day activity or voluntary service that satisfies and excites? As President Clinton said in Memphis last November, "I do not believe we can repair the basic fabric of society until people who are willing to work have work. Work organizes life. It gives structure and discipline to life. It gives meaning and self-esteem to people who are parents. It gives a role model to children...."

We cannot, I submit to you, repair the American community and restore the American family until we provide the structure, the value, the discipline, and the reward that work gives." Those powerful thoughts are particularly apt, for our citizens with disabilities who, too often, experience high rates of unemployment and underemployment.

What do they have to hope for? And what do we who love them have to hope for? Linda Charlton, mother of a two-year-old daughter with Down syndrome, recently described her goals for her Katie before a superb and productive meeting of the President's Committee on Mental Retardation.

"First, we want her to feel loved...to give her a sense of high self-esteem so that she can experience life with confidence. She is a very social child, and while I think she has the capacity to make many friends, I wonder how other children will accept her. We envision her attending public schools, at least for the most part, and one day we hope to see her graduate from high school. There's even a part of us that hopes she'll continue her education after that...but we'll have to wait and see, and we'll also have to see what it is that Katie wants to do. I wonder if she'll ever get married...if she doesn't, I hope at least she has a companion to enjoy life with. And if we could, we'd like to see her remain as happy as she is today...Our Katie -- who loves people, music, dogs, rain, sunshine, swings, cookies, apricots, baths, and the color red.

These are dreams and feelings to which any parent can relate. Many of them were fulfilled for me when my son Hamp was asked last year by the members of his graduating class to give one of the commencement addresses at his high school. I will never forget that moment, nor will Hamp. Here was the young man whom we were once told would not survive, or if he passed the hurdle of his first days would have to be institutionalized. But

Hamp defied those predictions, living at home and attending school with his non-disabled peers. This is the speech that he wrote, on his own, politely declining his mother's offer of help. Hamp said that this was his speech to give.

"Hello, my name is Hamp Rasco. I am pleased to share with you what attending Hall High has meant to me.

I enjoyed the pep assemblies and the band. I enjoyed talking with friends in the cafeteria, and going out into the community with my CBI class.

After graduation I plan to find a job in the community where my social skills can be put to use. This is important to me because I want to make new friends with all kinds of people.

I would like to encourage other students with special needs to never give up, work hard to do a good job and be proud and happy about what you do at school.

I want to thank Dr. Anderson and the Vice Principals for their support of my program. I want to tell Ms. Chapman and Mr. Smith how much I appreciate all the work they have done on my behalf and all students with special needs. And I also thank Ms. Yates. And, finally, I especially want to thank my parents for believing in me and always encouraging me to be all that I can be. I really hate to leave all my friends at Hall, but I must move on.

Thank you. Good evening."

Like Hamp, we must all move on. Great challenges lie ahead, indeed. And as you well know, they are not limited to health care reform. From the White House to your house, we must work together. We need to reassure the countless young people like Hamp across this country that they will always have health

insurance, that they can have jobs, and that they are an essential part of life in our communities. For, surely, people deserve something to do, someone to love, and something to hope for to be whole and part of whole communities.

The leaders of the disability community are campaigning to achieve these goals and objectives. I want sincerely to thank all those leaders, including Paul Marchand and the rest of Arc's Government Relations staff, for their hard work in fighting to bring health security to every American. In addition, I commend the 100 sister organizations united in the Consortium for Citizens with Disabilities for their steadfast support. Now, we must intensify those efforts. We must each tell our personal stories so that members of Congress have before them the human faces of health care reform. We need each of you to help seize this moment of opportunity to guarantee private insurance for all our citizens, coverage that offers you choice, comprehensive benefits, and freedom from unfair and exclusionary insurance practices.

THE WHITE HOUSE
OFFICE OF DOMESTIC POLICY

CAROL H. RASCO
Assistant to the President for Domestic Policy

AUG - 8 RECD

To: Stan

Jeremy

Draft response for POTUS
and forward to CHR by: _____

Draft response for CHR by: _____

Please reply directly to the writer
(copy to CHR) by: _____

Please advise by: _____

Let's discuss: _____

For your information: for you to follow

Reply using form code: _____

File: _____

Send copy to (original to CHR): _____

Schedule ? Accept Pending Regret

Designee to attend: _____

Remarks: _____

NATIONAL COUNCIL ON DISABILITY



Facsimile Transmission

Date: 8/8/94

To: CAROL RASCO

From: MARCA BRISTO

Message: PER OUR CONVERSATION I'M FORWARDING YOU A COPY OF THIS LETTER TO SECRETARY PEÑA.

Number of pages including cover sheet: 4

Please call us at (202) 272-2004 if any page is unclear.



NATIONAL COUNCIL ON DISABILITY

An independent federal agency working with the President and the Congress to increase the inclusion, independence, and empowerment of all Americans with disabilities.

August 8, 1994

The Honorable Federico F. Peña
Secretary of Transportation
400 Seventh Street, S.W.
Washington, DC 20590

Dear Secretary Peña:

It has recently come to our attention that the Department of Transportation is currently in the process of issuing *Proposed Rules* regarding the accessibility of Over-the-Road Buses (OTRBs) for persons with disabilities. As President Clinton's most senior advisory body on disability policy and legislation --including a mandate to advise the President and Congress on the implementation of the Americans with Disabilities Act (ADA)-- the National Council on Disability would urge you to utilize the findings and recommendations of the independent study on this matter conducted by the Congressional Office of Technology Assessment as the basis for your upcoming *Notice of Proposed Rulemaking*. As you are, no doubt, aware, this issue generated considerable controversy during the debate over the passage of the ADA. In deference to the transportation industry, the Administration, the Congress, the National Council on Disability, and 43 million Americans with disabilities agreed to put aside their differences and go forward for the common good, leaving this issue in the capable trust of the Office of Technology Assessment for an independent evaluation. It is, therefore, in the interest of fairness and justice that the National Council on Disability urges you to go forward with the findings and recommendations contained in the Office of Technology Assessment's report.

We are aware of the fact that you have recently met with representatives of the disability community and are appreciative of your willingness to consider a variety of viewpoints on this issue. Indeed, the tremendous energy and leadership you have demonstrated in your work at the Department of Transportation to date gives us confidence that you will address this important issue with vigor. Please be assured that we are ready to provide you with any assistance we might be able to provide in bringing this matter to an appropriate conclusion.

Members of the transportation industry have generally attempted to present this issue as if they were attempting to make a decision regarding a charitable contribution. However, this is --and always has been-- a civil rights issue. No other industry has been granted the concessions that the transportation industry has enjoyed over the past four years, and it is the case that if further extensive delays in implementation are granted or

The Honorable Federico F. Peña
August 8, 1994
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significantly inadequate compliance guidelines are adopted (as some have proposed), an entire generation of people with disabilities might go without the civil rights protections mandated in the ADA. Justice deferred is justice denied. We urge you to not let good faith on our part be rewarded with recalcitrance and backlash on the part of the industry.

Once again, let me reiterate our confidence in your willingness to work toward a just resolution to this issue. I would be very pleased to meet with you and discuss this matter in person. Please let me know of any ways in which we might support you in ensuring justice for millions of Americans with disabilities.

Sincerely,


Marca Bristo
Chairperson

bcc: ✓ Carol H. Rasco

Assistant to the President for Domestic Policy

Michela Alioto

Deputy Assistant for Domestic Policy, Office of the Vice President