

EXECUTIVE OFFICE OF THE PRESIDENT

26-Aug-1993 09:31am

TO: Stanley S. Herr

FROM: Carol H. Rasco
Economic and Domestic Policy

SUBJECT: RE: AAMR Meeting Invitation

You're just now hearing back from me as I left not long after the dessert party yesterday and didn't get back here until today.

The new time on Friday, June 3 sounds great for AAMR. I doubt I'll be able to accept the kind offer for reimbursement (there are so many picky rules about accepting that type thing) but I will definitely commit to the speaking engagement. I would not plan to go up until that morning more than likely but I am assuming there are all kind of early morning flights to Boston. I would plan to speak about thirty minutes, take q and a for whatever time you feel is reasonable for this group. I would suggest putting Joycelyn on the agenda for June 1 instead of giving them overload on the Administration in one day. As to Hamp, I would really like to keep that option in mind...it would be impossible for me to ask him to commit this far in advance since he will be going into a job placement this fall and we don't yet know the "rules" of his as yet unnamed employment site. If he were able to go I can incorporate him into my time or "eat into" my q and a time. I would definitely be able to accept assistance for his travel and that of an aide perhaps..so the bottom line on travel reimbursement would be that at most it would be two people, Hamp and an aide, but not a third (me).

Thanks so much for working this out, I am honored to be asked to speak before this group and will look forward to working with you in the spring on a dynamite speech!

EXECUTIVE OFFICE OF THE PRESIDENT

06-Jun-1994 10:05am

TO: Carol H. Rasco

FROM: Stanley S. Herr
Domestic Policy Council

SUBJECT: RE: survey for disability appointees

In reply to your note, you may wish to drop a note as well to the Boston program chair and new AAMR President since she was responsible for arranging your invitation, etc. She is also a great friend of what this Administration is seeking to do -- and of mine -- and will be a good ally over the coming year.

The address is Karen L. Middendorf
President, AAMR
IHDI-UAP
329 Mineral Industries Building
University of Kentucky
Lexington, KY 40506

p.s. She and David Braddock were both great in understanding the circumstances, and while regretting your absence, taking it in stride. They both sent their best wishes for your speedy recovery.

See you at noon!

Stan

~~FATV (202) 456~~ (savings \$ by express mail)

SUPPLEMENTAL MEMORANDUM TO CAROL H. RASCO

From: Stan Herr

Subject: Additional Talking Points for AAMR talk, June 3rd

Date: May 31, 1994

1. Secretary Riley is a late-addition to the program, making a plenary address in the Friday afternoon time slot. So you may wish to call attention to his appearance and the strong support he's given to inclusion in new laws such as Goals 2000, School to Work, etc.

2. The morning before you arrive David Braddock will have given the [AAMR] Presidential Address, "New Frontiers in Mental Retardation." I attach the draft he was kind enough to share because 1) it's a good overview of the state of the field in general and inclusion in particular, 2) it reinforces what he refers to as the ascendant role of family members and self-advocates in the mental retardation field, ^(pages) and 3) it lays out the wide disparities state-by-state in inclusion measures (see ^{pg 3 and} his appendices which notes AK near the top in education and bottom in ^{small-scale} residential and employment measures. Perhaps you may wish to make some reference to item 2) in your remarks.

3. Val Bradley, & J. Munroe (the self-advocate who referred to owning his "own door") have received and turned in their vetting papers, so their, on the way, with the other first-round POM.

New Frontiers In Mental Retardation

by David Braddock, Ph.D.

Presidential Address, 118th National Convention of the AAMR
Boston, Massachusetts
June 2, 1994

Draft
Carol - the
underlines
are mine
and lines
in margin to
indicate main
parts
Stan.

Introduction

It is an extraordinary honor to be introduced by Dr. Boggs at a convention in which Dr. Dybwad is participating as a distinguished speaker. For the opportunity to serve the association as president this past year, I express my gratitude to all of you. I also wish to acknowledge the contributions of the local arrangements committee, its chair, Mary Cerreto, and the 200 volunteers here in Boston helping to make this such an outstanding convention.

In honor of the location of this convention in the home city of former president John F. Kennedy, I have chosen to address the subject of "new frontiers" in the field of mental retardation. President Kennedy's acceptance speech for the 1960 democratic nomination was titled "The Opening of the New Frontier." He spoke of the new frontier as a set of challenges, and he told Americans that we stood on the edge of a new frontier, and it was full of opportunities and perils. I bring the same essential message today to AAMR, for I believe the field of mental retardation, like America in 1960, is at a turning point.

My remarks today will focus on three specific frontiers opening up dramatically before us: first, residential integration and community inclusion; second, employment integration; and third, educational inclusion. These three frontiers are accompanied by the attendant challenges of promoting the diffusion of these innovations across the states and supporting a vigorous and relevant research agenda. I will conclude my remarks with a few comments about AAMR's future in the mental retardation movement.

Howe's Legacy: Inclusion

The mental retardation movement is one of the great social movements of the 20th century. When I entered the field 26 years ago, community services were virtually non-existent in the United States. Fewer than 100 community residences had opened in this country prior to 1968 (Baker, Seltzer, & Seltzer, 1974). Self-advocacy, consumer choice, family support, inclusive education, and supported living were dreams. There was no legal right to education for children and youth with disabilities, no right to habilitation in the least restrictive setting, and no rights prohibiting discrimination against people with disabilities in employment, transportation and public accommodations. There was little funding for services. Per diems in institutions were below \$10 a day.

I quote now from a passage in a speech given a full century before I entered the field. The speech was given in 1866 by Samuel Gridley Howe—a prominent Boston physician and social reformer. Dr. Howe was the moving force in opening the first public mental retardation institution in the U.S. here in Boston in 1848. Yet, only 20 years after petitioning the Massachusetts legislature in 1846 to develop the first public residential institution, he recognized that community inclusion was preferable to segregating people with disabilities from community life. Dr. Howe stated with forcefulness and clarity in his 1866 speech that:

We should be cautious about establishing [institutions]... for any children and youth; but more especially we should avoid them for those who have natural infirmity; or any marked peculiarity of mental organization. . . Such persons spring up sporadically in the community, and they should be kept diffused among sound and normal persons. Separation, and not congregation, should be the law of their treatment. . . (Howe, 1866).

Howe's 1866 warning went unheeded. As America urbanized and industrialized over the next century, hundreds of thousands of persons with mental retardation were placed in large institutional settings. Even today--notwithstanding much rhetoric about new paradigms, choice, inclusion, and empowerment--one-half of all persons with mental retardation living in out-of-home placements in this country reside in congregate settings with 16 or more residents. Only about 30% of the 335,000 persons with mental retardation in out-of-home placements live in six bed or less residential environments (Braddock, Hemp, Bachelder, & Fujiura, in press). Howe's legacy of inclusion remains unfulfilled to this day. Let's explore this issue in greater detail.

INSERT FIGURE 1

Residential Integration and Inclusion

A fundamental incongruity persists between modern rhetoric about community inclusion and how we pay for residential services and supports. The discovery of this incongruity is not new. Consider these remarks from the 1967 AAMR presidential address of Marguerite Hastings. I quote:

We verbalize that one of our goals for people with mental retardation is to have them accepted and become a part of the total community. Do we mean it? If we do, why are we continuing to ask for money for facilities and personnel that will

tend to separate and segregate them from that same community we want them to be a part of? (Hastings, 1967, p.6)

Ms. Hastings would be gratified to learn that, in 1992, federal & state governments committed over \$9 billion for intermediate care facility services for persons with mental retardation. This sum is many times larger than the total volume of funds budgeted for mental retardation services in 1967. Ms. Hastings would be shocked, however, to learn that three-fourths of the \$9 billion in ICF/MR funds allocated one-quarter of a century after her 1967 presidential address, paid for services provided in large congregate care settings.

Government's single largest program in mental retardation--the ICF/MR program--is primarily committed to segregation and congregate care. Marguerite Hastings was right in 1967. She saw things as they were and, like her contemporary Robert Kennedy, envisioned things as they might be. Long term care reform is overdue in this country. It's time for the federal government to bring public financial incentives into line with the integration, inclusion, and family support values of the Developmental Disabilities Act, the Individuals with Disabilities Education Act, and the Americans with Disabilities Act.

Variations in State Performance

Another important perspective on residential integration has to do with variations in state performance. In our federal system, states exhibit enormous differences in the extent to which health, education and social service innovations are adopted and supported over time. Although one-half of all persons with mental retardation resided in large congregate care settings in 1992, eight states (including Ms. Hasting's state of Maryland) provided services to more than 60% of consumers in family scale settings serving six or fewer persons (Appendix 1). Conversely, 10 states served fewer than 10% of their clients in such small settings. The lack of congruent federal financial incentives promoting community integration and inclusion values contributes to unacceptably extreme variations in the performance of state service delivery systems.

Vocational Integration

Employment integration patterns in the states, like residential integration, exhibit substantial variation as well (Appendix 2). In 1992, between 40-80% of the MR/DD agency-managed vocational clients served in Vermont, Arizona, Washington, New Mexico, Alaska, Colorado, and New Hampshire worked in integrated employment settings. Ten states, however, served fewer than 10% of vocational clients in integrated settings; and, the national average is just 18% (Figure 2). Innovation in vocational services is being pioneered first in a few states and localities while the preponderance of public resources and incentives encourages the utilization of segregated vocational settings.

INSERT FIGURE 2

Educational Inclusion

The new frontier in educational services for people with mental retardation is inclusive education, an educational approach in which students with disabilities participate in academic and extracurricular offerings to the maximum extent possible with their non-disabled peers. The variation in the extent to which school inclusion practices are being implemented in the states is just as dramatic as variations in residential integration. According to the U.S. Department of Education, 30% of the 535,600 students with mental retardation in the U.S. in 1990-91 were educated in regular classes (Appendix 3).

INSERT FIGURE 3

Ten states—led by the Commonwealth of Massachusetts—provided inclusive education to more than 50% of students with mental retardation; and ten states educated less than 15% in such settings. Unfortunately, several of the most populous states fall into the less progressive group of states including Illinois, Ohio, Florida, California, New York and New Jersey. Even though public law 94-142 was enacted into law nearly 20 years ago—requiring a free and appropriate public education for all children and youth with disabilities—progress on inclusion has been very slow. Enacting mandates, failing to fund them adequately, and then slacking off on enforcement provisions is a familiar Washington practice.

Promoting Innovation In the States

The tremendous diversity of state performance in residential, vocational and educational services for persons with mental retardation underscores the critical importance of national organizations in promoting the diffusion of innovation in our field. Organizations like the AAMR, the National Association of State Directors of Developmental Disabilities Services (NASDDDS), the Arc, and also the National Conference of State Legislatures, United Cerebral Palsy, TASH, and Self-Advocates Becoming Empowered are extremely important in the diffusion of best practices from state-to-state and locality-to-locality. The importance of multistate professional, parent, and now self-advocacy organizations, increases during periods of innovation and development in the field. This will certainly be the case in facilitating the expansion of supported living, personal assistance, family support, and self-advocacy agendas in the years ahead, and in promoting integrated employment and school inclusion.

Balancing Consumer, Family, and Professional Perspectives

During the course of the past two decades, an extremely important but often unrecognized transformation of public sector service delivery systems in the states has occurred. In the 1960s, over 90% of mental retardation residential and day services were provided directly by public sector organizations--primarily state government institutional programs. The percentage of the field's resources being managed by private sector organizations increased from 29% of all funds in 1977 to 62% in 1992 (Figure 4). By the year 2000, the percentage is likely to exceed 80%. States are increasingly playing roles as facilitators, regulators and funders of services and supports rather than as direct service providers. The private sector--both proprietary firms and non-profit organizations--is providing most direct mental retardation services today and it will continue to do so in the future at an increasing rate.

INSERT FIGURE 4

What are the implications of this growing concentration of resources in the private sector? In 1961, just before President John Kennedy took office, President Dwight Eisenhower gave a farewell address in which he expressed great alarm over the "conjunction of an immense military establishment and a large arms industry" (p. 121). Concerned that this powerful "military-industrial complex" might lead to unwarranted influence in the councils of government, he noted that the potential for an unprecedented and disastrous rise of misplaced power existed. In a representative democracy, Congress, and ultimately the people represent the vital countervailing influences that serve as self-correcting forces to prevent the abuses about which President Eisenhower warned.

In the mental retardation field, parents of persons with mental retardation and self-advocates are the ultimate countervailing forces to the abuse of professional power in the public or the private sector. It is an extremely healthy sign to observe that, at the close of this century, self-advocacy and parent-power are ascendant in the field. AAMR can play an important role in supporting this ascendancy by encouraging families, self-advocates, and direct support personnel to participate in the association. I intend to have the opportunity next year to vote for self-advocates to participate on the board of directors of this association. Many self-advocates today are salaried professionals in the field and possess extraordinary insights that need to be routinely considered in the affairs of the association at national, state, and regional levels.

I am not advocating that AAMR become a self-advocacy organization or a parents group for this is not our role. We are and must remain primarily an organization of professionals. However, we cannot discharge our responsibilities properly and continue to grow as professionals--as service providers, clinicians, administrators, teachers and

researchers--unless we both acknowledge and embrace our fundamental unity with the continuing human rights struggle of self-advocates and families.

Research Frontiers

I turn now to the ~~third~~ important challenge of developing and supporting a vigorous research agenda. The mental retardation field has grown dramatically in the past 25 years. In terms of resource allocation, our field now approximates the size of the American truck manufacturing industry. We are a much more difficult "industry" to study than the trucking industry, however. Our research agenda embraces the molecule, the human organism interacting with the environment, and social, political and economic systems. These systems all have dynamic qualities that make scientific prediction difficult.

In mental retardation, the distinction between basic and applied research is not very useful. Our need for timely, recurring information about the structure, operation and trajectory of service delivery systems in thousands of states and communities across the country is ordinarily not recognized as "basic" research; but just like studies of genetic mechanisms in disease, it is fundamental to the knowledge base because the quality of so many people's lives depends on having timely information on the integrity of our systems of support. In particular, health care reform certainly presages a heightened need for research on reform's impact on consumers and families.

In the biomedical research arena, more than 50 gene therapy research trials are underway today. Most target various cancers; however, the technique has the potential to correct inherited disorders including cystic fibrosis, Duchenne muscular dystrophy, lysosomal storage diseases and numerous other genetic defects that lead to mental retardation. Professor W. French Anderson of the University of Southern California predicts that tens of thousands of people will benefit from gene therapy in the next several years, hundreds of thousands will benefit over the next decade and, after that, millions of persons. We need to be sure that a mental retardation research agenda remains prominent in the progress anticipated in gene therapy.

The goal of curing genetic disorders with gene therapy is extremely promising and we need to support increased federal appropriations for this activity. Gene therapy will not, however, correct most conditions that lead to mental retardation because most mental retardation is not genetic in origin. Professor Inder Verma (1990) of the Salk Institute reminds us that most human afflictions in the world today are environmentally induced, caused by microbial infections that spread because of poor sanitation, polluted drinking water, malnutrition, and other factors clearly outside the scope of genetic engineering. The application of current knowledge to address these causal factors is extremely important, especially in the developing world.

There are, unfortunately, many troubling parallels today between conditions in sections of many large urban centers in the United States and in developing nations. High infant mortality rates, lack of adequate prenatal care, prematurity, malnutrition, drug abuse

and violence, disintegration of families and poverty are common antecedents of mental retardation in the United States and in many parts of the world. We need to make a greater commitment to innovative research and demonstration efforts to address these problems in our own society and internationally.

Research is also urgently needed to address health promotion and disease prevention for consumers living in community settings, cultural factors and disability, transition from school to work, and families across the lifespan including young at-risk families and aging families. It is clear that, as the baby-boom generation ages, tens of thousands of middle-aged and older persons with mental retardation who are not now in any formal service system will require support. We know little about the service implications of this impending challenge.

AAMR has established an extremely important research tradition over its 118 year history. We publish some of the finest journals and books in the field and more than 1,000 of our members are associated with universities. In recent years, however, mutual understanding between researchers and other professionals has diminished, and this has been detrimental to both groups and to the consumers and families we serve. It's extremely important for social and biomedical scientists and education researchers to continue participating actively in AAMR--to remain in close touch with the myriad perspectives, ideologies, and approaches that comprise the broad intellectual life of the field. Many researchers who don't engage in this practice--especially social and educational scientists--risk a steady slide into irrelevancy.

Similarly, advocates and service providers in AAMR benefit from interacting with knowledgeable researchers because many researchers do have unique contributions to make by carefully identifying and examining complex problems and participating in finding solutions to them. Advocates and service providers should remember that less than one percent of the resources currently being allocated in the field today are associated with research, and the percentage is declining. Most major corporations commit between two and five percent of revenues to research and development activities. We need to enhance AAMR as a unique association in the field that is equally supportive of researchers, advocates, and service providers. We are stronger in diversity than in entrenched, ideologically rigid guilds.

Conclusion

Today, as in Samuel Gridley Howe's day, services for persons with mental retardation in the United States are being driven by ideological and economic factors. The dominant view is that people with mental retardation should be--in fact have a right to be--supported in families and in intimate, inclusive community settings emphasizing the use of natural supports. Institutions are closing. New Hampshire, Vermont, the District of Columbia, and Rhode Island operate "institution-free" service delivery systems and many states (mainly small ones) will soon follow suit. Still, the great variations in state patterns of service

delivery suggest that the transition to a completely institution-free society will unfold over many years extending well into the next century.

However, because so much of the service delivery system is already physically located in the community and operated by private sector organizations, it is misleading to speak of the "new frontier" in mental retardation as merely a transition from the institution to the community. The transition is rather from direct public sector operations to private sector management and the preferred context of these services is shifting from the large residential services model to the individualized supported living model. This new frontier was envisioned by Samuel Gridley Howe more than a century ago when he urged inclusion and cautioned that institutions were becoming asylums.

The new frontier in mental retardation was also articulated in 1962 by President Kennedy's Panel on Mental Retardation. The Panel asserted that it was:

Society's special responsibility to persons with extraordinary needs is 1) to permit and actually foster the development of their maximum capacity and thus bring them as close to the main stream of independence and "normalcy" as possible; and 2) to provide some accommodation or adjustment in our society for those disabilities which cannot be overcome (President's Panel, 1962, p. 13).

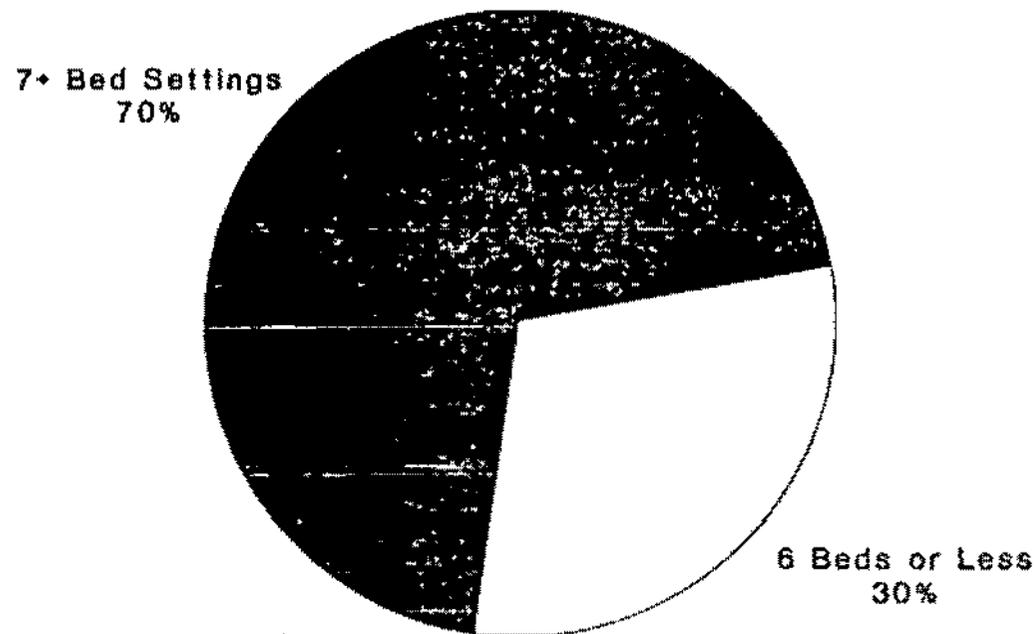
Samuel Gridley Howe, the Kennedy Panel, and Marguerite Hastings remind us that we must resist the temptation to believe that our generation is the first to discover immutable truths about the capacities of people with mental retardation.

It is also critically important during this next decade of accelerating progress toward the inclusive society to recognize the difficult and important transitional role played by tens of thousands of current employees in large congregate care facilities. We must not forget that most of the 335,000 persons with mental retardation in out-of-home placements today currently live in such settings; and thousands of the employees in these settings (many of which are phasing down) are extremely committed to consumers and to community living objectives. Many of the most courageous staff in the field today work in large congregate care settings and they often struggle selflessly, with low pay, to promote greater independence and happiness for the consumers they serve.

My remarks today have stressed an important message for the future of AAMR: the association is stronger when we recognize and appreciate not only our cultural and geographic diversity; but also when we acknowledge and respect our diversity as service providers, clinicians, advocates, teachers, and researchers. AAMR must itself be an inclusive organization. Your participation in an inclusive association will make an important and lasting difference in your own professional life, and in the lives of people with mental retardation in our society. Thank you very much.

FIGURE 1

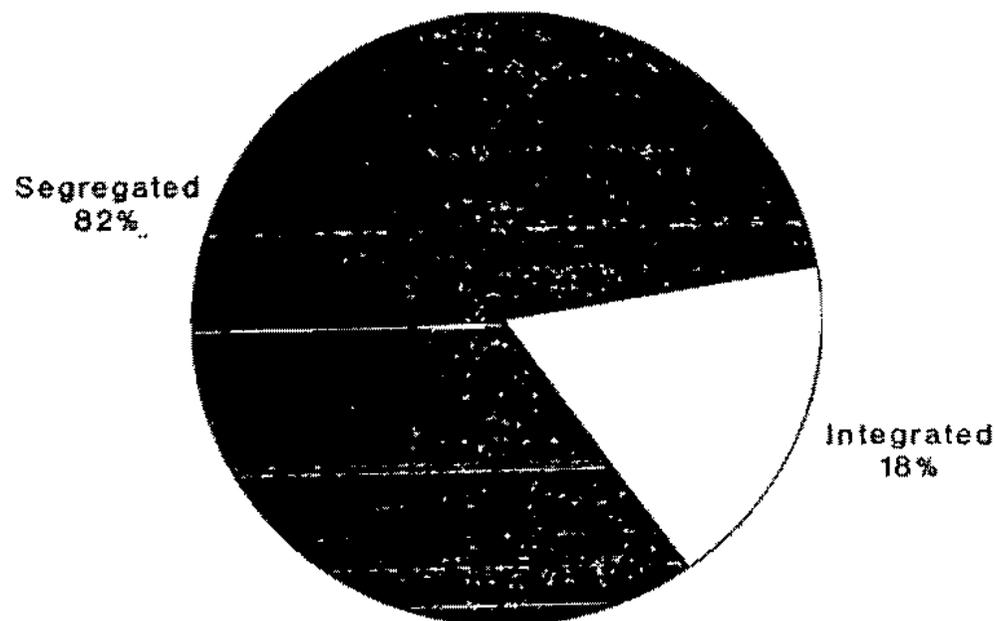
Percentage of Individuals Served by Size of Residential Setting



Total Persons Served: 335,615
1992

Source: Institute on Disability & Human Development, U of IL at Chicago, 1994

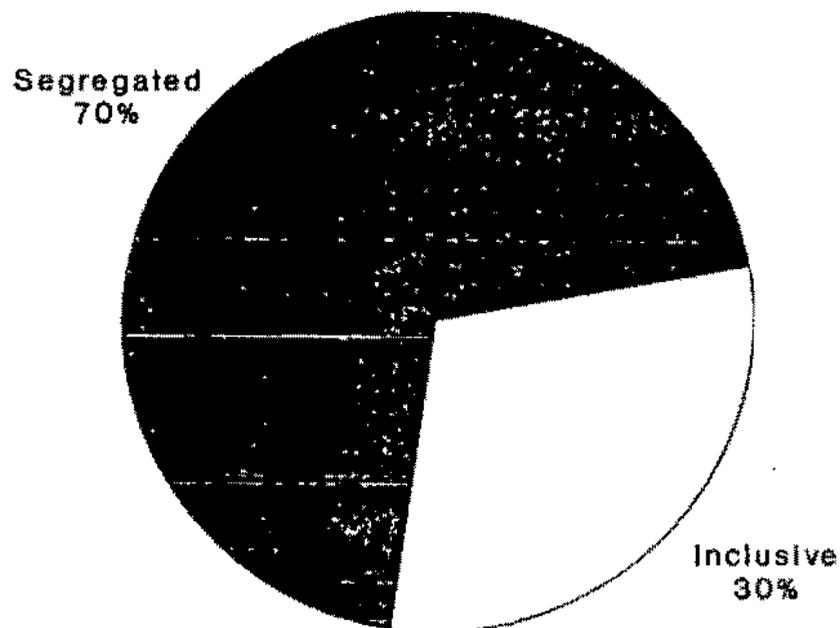
FIGURE 2
Vocational Integration:
Percentage of MR/DD Agency Managed
Clients Served In Integrated/Segregated Settings



Total Clients Served: 351,922
1992

Source: Institute on Disability & Human Development, U of IL at Chicago, 1994

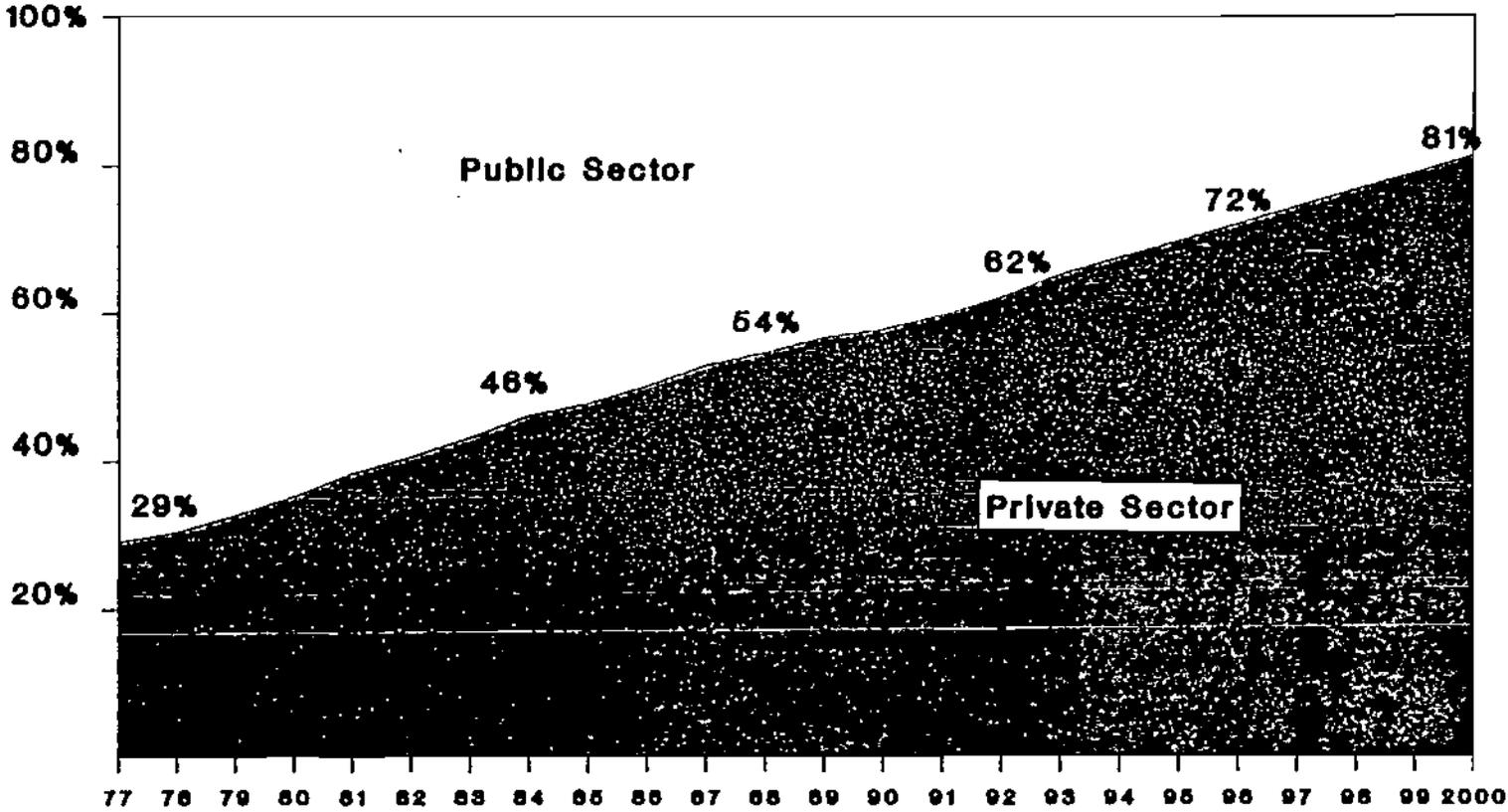
FIGURE 3
Educational Inclusion:
Percentage of Students With Mental
Retardation In Inclusive/Segregated Programs



Total Students: 535,600
1990/91

Source: Adapted From U.S. Department
of Education, 1993

FIGURE 4
The Growing Percentage of Privately Managed MR/DD Resources: 1977-2000



PROJECTED DATA 1993 - 2000

Source: Institute on Disability & Human Development, U of IL at Chicago, 1994

TABLE 1
Percent of Individuals Served by Size of
Residential Setting: Fiscal Year 1992¹

STATE	1-6 Bed Settings		7-15 Bed Settings		16+ Bed Settings		Total Served
	# Ind.	% of Total	# Ind.	% of Total	# Ind.	% of Total	
1 HAWAII	949	87.0%	6	0.5%	136	12.5%	1,091
2 ARIZONA	2,055	85.4%	0	0.0%	350	14.6%	2,405
3 VERMONT	552	71.5%	0	0.0%	220	28.5%	772
4 NEW HAMPSHIRE	907	71.2%	322	25.3%	45	3.5%	1,274
5 MICHIGAN	7,271	70.8%	404	3.9%	2,594	25.3%	10,269
6 MONTANA	982	70.4%	8	0.6%	404	29.0%	1,394
7 RHODE ISLAND	1,241	63.6%	444	22.6%	265	13.6%	1,950
8 MARYLAND	3,053	63.4%	0	0.0%	1,783	36.6%	4,876
9 NORTH DAKOTA	1,147	56.2%	469	23.0%	424	20.8%	2,040
10 COLORADO	2,163	54.7%	842	21.3%	949	24.0%	3,954
11 CONNECTICUT	3,335	54.0%	573	9.3%	2,265	36.7%	6,173
12 CALIFORNIA	16,286	48.1%	3,055	9.0%	14,537	42.9%	33,878
13 NEVADA	263	47.4%	0	0.0%	292	52.6%	555
14 PENNSYLVANIA	7,255	46.2%	1,423	9.1%	7,023	44.7%	15,701
15 MINNESOTA	4,595	45.8%	1,777	17.7%	3,666	36.5%	10,038
16 NORTH CAROLINA	2,899	44.5%	276	4.2%	3,342	51.3%	6,517
17 WASHINGTON	2,313	44.0%	908	17.3%	2,034	38.7%	5,255
18 DELAWARE	368	42.9%	66	7.7%	423	49.4%	857
19 ALASKA	291	41.3%	328	46.6%	86	12.1%	704
20 OREGON	1,249	40.2%	611	19.7%	1,248	40.2%	3,108
21 NEW JERSEY	3,954	37.8%	0	0.0%	6,504	62.2%	10,458
22 MASSACHUSETTS	3,775	37.0%	2,206	21.6%	4,214	41.3%	10,195
23 INDIANA	3,390	35.1%	1,474	15.3%	4,788	49.6%	9,652
24 WISCONSIN	4,155	33.4%	3,377	27.1%	4,921	39.5%	12,453
25 WEST VIRGINIA	445	32.1%	532	38.4%	410	29.6%	1,387
26 DIST OF COLUMBIA	324	30.7%	649	61.5%	82	7.8%	1,055
27 WYOMING	207	30.0%	180	26.1%	302	43.8%	689
28 LOUISIANA	2,146	29.1%	333	4.5%	4,907	66.4%	7,386
29 KENTUCKY	930	27.9%	148	4.4%	2,258	67.7%	3,336
30 GEORGIA	1,489	27.2%	7	0.1%	3,976	72.7%	5,472
31 UTAH	583	26.8%	350	16.7%	1,187	56.5%	2,100
32 OHIO	3,765	22.5%	3,112	18.6%	9,890	59.0%	16,767
33 NEBRASKA	716	22.2%	1,151	35.6%	1,363	42.2%	3,230
34 SOUTH CAROLINA	919	21.5%	1,109	25.9%	2,252	52.6%	4,280
35 FLORIDA	2,203	21.4%	3,782	36.7%	4,319	41.9%	10,304
36 IOWA	1,627	20.0%	1,875	23.1%	4,621	56.9%	8,123
37 MISSOURI	1,825	19.4%	2,085	22.2%	5,497	58.4%	9,407
38 SOUTH DAKOTA	297	19.4%	715	46.6%	522	34.0%	1,534
39 OKLAHOMA	857	15.0%	395	6.9%	4,475	78.1%	5,727
40 MAINE	205	13.0%	810	51.4%	561	35.6%	1,576
41 NEW YORK	3,304	10.6%	15,137	48.7%	12,670	40.7%	31,111
42 TEXAS	1,987	10.6%	3,855	20.5%	12,973	69.0%	18,815
43 ILLINOIS	1,780	9.1%	4,870	24.8%	13,002	66.2%	19,652
44 TENNESSEE	454	9.0%	1,593	31.7%	2,984	59.3%	5,031
45 ARKANSAS ²	341	8.1%	1,496	35.6%	2,370	56.3%	4,207
46 VIRGINIA	379	7.6%	906	18.2%	3,701	74.2%	4,986
47 MISSISSIPPI	220	7.1%	82	2.6%	2,806	90.3%	3,108
48 ALABAMA	178	4.5%	1,090	27.7%	2,663	67.7%	3,931
49 KANSAS	84	2.0%	2,409	58.7%	1,614	39.3%	4,107
50 IDAHO	12	1.1%	802	70.7%	320	28.2%	1,134
51 NEW MEXICO ²	0	0.0%	920	57.8%	671	42.2%	1,591
UNITED STATES	101,745	30.3%	65,962	20.5%	164,908	49.1%	335,615

¹Source: Institute on Disability and Human Development, University of Illinois at Chicago, 1994. "Total Individuals Served" include persons in nursing facilities. States ranked by % in 6 or less settings.

²Data are estimated.

TABLE 2
States Ranked by % of Workers with Mental Retardation
in Supported/Competitive Employment¹

Number Served in 1992:

STATE	Segregated Work Programs	Segregated Day Training	Supported/ Competitive Employment	Total Segregated Programs & Integrated Employment	Percentage in Integrated Employment
1 VERMONT	15	52	487	554	86.35%
2 ARIZONA	NA	1,353	1,600	2,953	54.18%
3 WASHINGTON	1,473	890	2,506	4,869	51.47%
4 NEW MEXICO	437	11	468	916	51.09%
5 ALASKA	159	52	195	406	48.03%
6 COLORADO	NA	NA	1,880	4,277	43.96%
7 NEW HAMPSHIRE	598	385	586	1,569	37.35%
8 OREGON	3,046	0	1,617	4,663	34.68%
9 VIRGINIA	2,828	700	1,842	5,370	34.30%
10 MINNESOTA	3,904	4,686	4,455	13,048	34.17%
11 CONNECTICUT	2,114	2,416	2,320	6,850	33.87%
12 PENNSYLVANIA	7,969	4,279	5,718	17,966	31.83%
13 MARYLAND	NA	4,160	1,767	5,927	29.81%
14 UTAH	859	32	376	1,267	29.68%
15 SOUTH DAKOTA	835	127	339	1,301	26.06%
16 MICHIGAN	2,650	5,960	3,000	11,630	25.80%
17 FLORIDA	NA	8,793	2,964	11,757	25.21%
18 KENTUCKY	NA	NA	572	2,562	22.15%
19 MISSISSIPPI	1,618	NA	451	2,069	21.80%
20 OHIO	16,400	5,976	6,228	28,604	21.77%
21 DELAWARE	NA	NA	144	719	20.03%
22 NEBRASKA	1,720	50	397	2,167	18.32%
23 OKLAHOMA	1,779	0	392	2,171	18.06%
24 NORTH DAKOTA	584	514	236	1,334	17.69%
25 NORTH CAROLINA	4,644	0	950	5,594	16.98%
26 LOUISIANA	1,620	1,287	578	3,485	16.59%
27 SOUTH CAROLINA	3,970	1,523	1,092	6,585	16.58%
28 IOWA	5,456	NA	1,052	6,508	16.16%
29 MASSACHUSETTS	5,400	1,500	1,325	8,225	16.11%
30 HAWAII	NA	NA	126	825	15.27%
31 KANSAS	2,508	3,249	1,034	6,791	15.23%
32 MONTANA	1,022	287	233	1,542	15.11%
33 WISCONSIN	6,832	11,076	3,091	20,999	14.72%
34 MAINE	NA	2,300	389	2,689	14.47%
35 NEW JERSEY	4,645	1,029	896	6,570	13.64%
36 WEST VIRGINIA	1,318	1,126	385	2,831	13.60%
37 WYOMING	372	181	87	640	13.59%
38 RHODE ISLAND	NA	1,558	241	1,799	13.40%
39 NEW YORK	14,848	22,201	4,917	41,966	11.72%
40 TENNESSEE	NA	3,219	425	3,644	11.66%
41 GEORGIA	NA	NA	986	8,514	11.58%
42 INDIANA	7,726	2,035	381	10,642	8.28%
43 IDAHO	388	4,601	450	5,439	8.27%
44 MISSOURI	NA	1,763	131	1,894	6.92%
45 ALABAMA	525	2,544	228	3,297	6.92%
46 ILLINOIS	6,657	13,355	1,370	21,382	6.41%
47 NEVADA	545	56	35	636	5.50%
48 DIST. OF COL.	200	879	49	1,128	4.34%
49 TEXAS	8,814	7,771	650	17,235	3.77%
50 ARKANSAS	1,468	4,044	182	5,694	3.20%
51 CALIFORNIA ²	NA	20,389	0	20,389	0.00%
UNITED STATES	127,946	148,441	62,326	351,922	17.71%

¹ Sources: Institute on Disability and Human Development (IADHD), U of Ill at Chicago, 1994;

Boston Children's Hospital (1993) (1990 data for AK, KY, & VA).

² California's Supported Employment workers served by state vocational rehabilitation agency.

TABLE 3
States Ranked by % of Students Aged 6-21 with Mental Retardation
in Regular Classes and Resource Rooms in 1990/91¹

STATE	Total Students with MR	# in Regular Class	# in Resource Rooms	Total in Regular Education	% in Regular Classes & Resource Rooms
1 MASSACHUSETTS	28,291	17,200	4,370	21,570	76.24%
2 MINNESOTA	9,693	268	7,076	7,344	75.77%
3 VERMONT	1,462	964	135	1,099	75.17%
4 WYOMING	625	241	228	469	75.04%
5 TEXAS	23,570	1,160	14,913	16,073	68.19%
6 SOUTH DAKOTA	1,466	28	915	943	64.32%
7 IOWA	10,363	31	6,421	6,452	62.26%
8 KENTUCKY	17,987	1,693	9,157	10,850	60.32%
9 ARKANSAS	10,204	1,098	4,533	5,631	55.18%
10 IDAHO	2,727	494	957	1,451	53.21%
11 NEBRASKA	4,154	653	1,350	2,003	48.22%
12 NORTH CAROLINA	20,054	1,834	7,383	9,217	45.96%
13 MONTANA	1,065	219	256	475	44.60%
14 WASHINGTON	7,655	1,211	2,162	3,373	44.06%
15 OKLAHOMA	11,184	892	3,892	4,784	42.78%
16 MAINE	2,027	160	693	853	42.08%
17 NEW HAMPSHIRE	882	195	131	326	36.96%
18 ALASKA	436	25	136	161	36.93%
19 SOUTH CAROLINA	13,928	481	4,662	5,143	36.93%
20 GEORGIA	22,724	1,745	6,242	7,987	35.15%
21 TENNESSEE	12,553	733	3,629	4,362	34.75%
22 OREGON	3,525	337	779	1,116	31.66%
23 DELAWARE	1,380	73	363	436	31.59%
24 ALABAMA	25,254	2,032	5,682	7,714	30.55%
25 NORTH DAKOTA	1,346	140	271	411	30.53%
26 WISCONSIN	4,483	155	1,186	1,341	29.91%
27 NEW MEXICO	1,914	31	507	538	28.11%
28 WEST VIRGINIA	7,768	47	2,073	2,120	27.29%
29 COLORADO	2,927	59	689	748	25.56%
30 MISSISSIPPI	6,191	236	1,274	1,510	24.39%
31 VIRGINIA	12,584	310	2,678	2,988	23.74%
32 KANSAS	5,300	241	995	1,236	23.32%
33 NEVADA	1,190	4	264	268	22.52%
34 UTAH	3,265	227	504	731	22.39%
35 HAWAII	1,329	31	257	288	21.67%
36 PENNSYLVANIA	32,660	967	6,021	6,988	21.40%
37 CONNECTICUT	3,574	98	589	687	19.22%
38 MICHIGAN	18,427	624	2,811	3,435	18.64%
39 MISSOURI	17,539	904	2,344	3,248	18.52%
40 ARIZONA	5,082	27	778	805	15.84%
41 OHIO	41,933	917	5,250	6,167	14.71%
42 MARYLAND	5,295	191	416	607	11.46%
43 INDIANA	19,245	102	1,928	2,030	10.55%
44 DIST. OF COL.	922	9	80	89	9.65%
45 LOUISIANA	10,715	168	662	830	7.75%
46 FLORIDA	24,759	376	1,197	1,573	6.35%
47 CALIFORNIA	24,801	695	476	1,171	4.72%
48 NEW YORK	19,678	86	840	926	4.71%
49 RHODE ISLAND	1,043	21	26	47	4.51%
50 ILLINOIS	23,077	116	644	760	3.29%
51 NEW JERSEY	5,344	32	104	136	2.54%
UNITED STATES	535,600	40,581	120,929	161,510	30.15%

¹Source: Adapted from U.S. Department of Education. (1993). *Fifteenth annual report to Congress on the implementation of IDEA*.
 By: Institute on Disability and Human Development, University of Illinois at Chicago, 1994

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

The White House Domestic Policy Council coordinates the efforts of the Administration, Cabinet secretaries and other federal agencies involved with the development of every aspect of our nation's domestic policy. As 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 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.

* This article is a revised and expanded version of remarks delivered by Ms. Rasco to the Arc Governmental Affairs Seminar, held in Washington, DC, on March 21, 1994. Nonprofit and disability organizations may freely make copies of this article for their members' information.

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.



Carol Rasco and son Hamp celebrate his 20th birthday. (Photo: Charles Archambault/Archambault Photography)

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

Furthermore, under Senator Edward Kennedy's proposal—now in congressional committee markup—outpatient rehabilitation services would be available to those who need them to restore capacity or minimize limitations as a result of illness, injury, "disorder or other health condition." And to maintain functioning or to prevent or minimize deterioration, rehabilitation services would be provided through a four-step process—initial evaluation and periodic oversight by a qualified rehabilitation health professional; design of a maintenance or prevention program; instructions for the patient, family members or support personnel to carry out the program; and patient reevaluations.

- 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 dis-

300 copies
50 photocopies
more to obtain
if needed --
Klem 6-2-94

abilities and their families benefiting 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.

- 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 determine the health plan that best fits their needs and reward that plan with their membership.

The disability rights movement can play a critical role in this drive for universal coverage. 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, on 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, move to a different location or 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 has a disability.

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 my son, 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. In this process, we have myriad 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, 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 persons with disabilities have to hope for? And what do we who love them have to hope for? Linda Charlton, the 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... 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."

Broken
type

(H)

(H)

These are dreams and feelings to which any parent can relate. Many of them were fulfilled for me when my son was asked last year by the members of his high school graduating class to give one of the commencement addresses. I will never forget that moment, nor will I 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 for 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, to be whole and part of whole communities, people deserve something to do, someone to love and something to hope for.

The leaders of the disability community are campaigning to achieve these goals and objectives. I sincerely want to thank all those leaders, including Paul Marchand and the rest of Aze'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 choice, comprehensive benefits and freedom from unfair and exclusionary insurance practices.*

I believe that a new day has dawned for America's citizens with disabilities and for all our people. We won't always succeed and we won't always be able to do everything that we want. But with your energy and resolve, we can have health security now. And I can promise you this: we will never relent in our effort to give every person a chance to develop—fully. Because, at the end of Bill Clinton's second term, at the start of the third millennium, I want to be able to say to Hamp Rasco and Mary-Margaret Rasco and to all of America, with a clear conscience and full heart—"We did our best." And for all our children's sakes, I want each of us to be able to look at one another and say—"We did our best."



Carol H. Rasco is the Assistant to the President for Domestic Policy. In this capacity, she is President Clinton's chief domestic policy adviser, coordinating the staff of the White House Domestic Policy Council. She is the mother of Mary-Margaret Rasco and Hamp Rasco.

THE WHITE HOUSE
OFFICE OF DOMESTIC POLICY

CAROL H. RASCO
Assistant to the President for Domestic Policy

To: Stan

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: _____

Reply using form code: _____

File: _____

Send copy to (original to CHR): _____

Schedule ? : Accept Pending Regret

Designee to attend: _____

Remarks This preliminary program
is a duplicate - thought you
want to see it along with most
recent letter from AMR
Key

MAR 28 REC'D

AMERICAN ASSOCIATION ON MENTAL RETARDATION

AAMR

March 24, 1994

Ms. Carol H. Rasco
The Assistant to the President for
Domestic Policy
The White House
Washington, DC 20050

Dear Ms. Rasco:

On behalf of the American Association on Mental Retardation we would like to thank you for agreeing to participate in our 118th Annual Meeting in Boston, MA, May 31 - June 4, 1994. We are especially pleased to have you as a Plenary Speaker on Friday, June 3, 1994 from 10:30 to 12:00 noon, along with Professor Martha Field from Harvard Law School.

No A+A confirmed

Enclosed you will find a copy of our Preliminary Program which covers the highlights of our meeting. If the final program is ready before the meeting we will send you a copy prior to your departure.

We hope you will be joining us for other activities at the meeting. Please take a moment to fill out the Registration Form in the enclosed Preliminary Program. Your registration and any other activities you choose will be complimentary.

Confirmed non requested

We also need to know if you will require any audio/visual equipment for your presentation. Please give us this information by April 11, 1994.

Once again, thank you so much for taking time from your busy schedule to be with us in Boston. If you have any questions or there is anything you need please don't hesitate to call Paula A. Hirt or Stephen H. Stidinger at 202/387-1968.

Sincerely,

M. Doreen Croser
Executive Director

444 NORTH CAPITOL STREET NW SUITE 846 WASHINGTON DC 20001-1570

PHONE: 202.387.1968 FAX: 202.387.2103

June 1 -
June 2 - (1:15)
June 3 -

From Wyatt to
The White House;

Personal Propertues on
Disability Policy

by Stanley S. Herz
Kenneth Patrick Folbr
Director Policy with
White House

(55/-)
60 (65-)
110

MD
Inhouse Ed.
Quality/Amount
Promotion -

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

26-Aug-1993 02:48pm

TO: Carol H. Rasco

FROM: Stanley S. Herr
Domestic Policy Council

SUBJECT: RE: AAMR Meeting Invitation

Good afternoon, Carol--

A few items for your interest:

1. I spoke with Karen Middendorf, President-Elect of AAMR who is in charge of planning the Boston program, to confirm the June 3rd speech date. Karen will be sending a formal invitation/cum confirmation for your files. She is delighted to have you on the program!
2. She is seeking my suggestions for a person to be the speaker who follows your opening 30 minute talk and 15 minute question and answer session. Karen ventured the name Bob Williams, our new appointee at the Administration for Developmental Disabilities. I suggested that he was terrific and quite eloquent, but wondered if this would be a variant of the overload concern you raised. She is therefore rethinking her plenary speaker choice, with Bob as a possibility should Dr. Elder decline the invitation for June 1st. Do you have any feelings on this question of the follow-up speaker? I could always come up with a senior academic in the Boston area with a pro-inclusion orientation.
3. In the event, Hamp does participate with you, AAMR would be willing to make travel reimbursement for Hamp and his aide. It is fine to leave it for a last-minute "surprise" appearance as far as AAMR is concerned. This keeps your options (and his) open.
4. By the way, you were correct that an early flight could get you into Boston that same day. E.g, 7:10 am from National on Delta #4300 arriving Boston at 9a.m For more \$, and a full-size, faster plane, there's a 6:50 am departure arriving at 8:12 a.m. in Boston. Several flights would permit same day return e.g., on Delta at 6:15 or 8:40 if you wanted an evening departure.
5. By November 1st, AAMR would need your speech title, photo and brief bio for the printed program. I'll calendar this when that date is closer.

I'm very happy this worked out.

6. Friendly reminder -- could you please drop the thank you notes you mentioned sending regarding my volunteering with you and the White House to:

Mrs. Eunice Kennedy Shriver

The Joseph P. Kennedy, Jr. Foundation
1350 New York Avenue, N.W., Suite 500
Washington, DC 20005-4709

Dean Donald G. Gifford
University of Maryland School of Law
500 W. Baltimore Street
Baltimore, MD 21201

I know they'll appreciate the gesture.

7. Publications you wanted. I'm sending over the American Bar Ass'n Report on the Unmet Legal Needs of Children and Their Families. Titled "America's Children at Risk: A National Agenda for Legal Action." It seems an excellent overview of many issues of concern to the Clinton Administration. See, e.g., on inclusive education and the startling statistic that only 32.5% of children with disabilities receive any education in a regular class. p. 29 tabbed.

I'm getting you a complimentary copy of the "Implementing the Americans with Disabilities Act" book. Should arrive in a few days.

Over and out.

Stan

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

06-Oct-1993 11:32am

TO: Carol H. Rasco
TO: Rosalyn M. Kelly

FROM: Stanley S. Herr
Domestic Policy Council

SUBJECT: AAMR Speech

Per our conversation, I've submitted as your keynote address title, PUTTING PEOPLE FIRST: SOME PERSONAL & WHITE HOUSE PRIORITIES. the AAMR president liked it; hope you do too.

They requested your bio and, as we already discussed, the publicity photo. If you're not careful, I'll submit a candid of you with my kids or you and the President!!!

You'll be in excellent company on that program; the followup speaker is Martha Field (a Harvard Law professor, mother of a daughter with brain damage, and friend of mine). The audience is in for a special experience with the two of you.

Thanks for the good meeting today. Can Ros send me the details on your visit to Kennedy-Krieger in Baltimore. And I'll pull together a few talking points as we discussed.

Dr. Jocelyn Elder (circled) Sept 7th
Permitting Agency Surgeon

Covey - Keynote Address wed, June 1st
Position/Structure 1:15 - 2:30

2 other plenary & debriefing lecture //
Gunnar Rybward

Hubie Brown (Dean, S.W. School)
Henri Noonan

Friday, June 3rd

10:30 - 12:00

Permits
Kids →

Chances + Issues
New Donations

Expenses (No Problem)

Time

Anne / Report (Habit brought)

Bob Williams →

Finals to attend
night before address

Dinner

- morning way -

PPI

- Picture / Bio →
- Title - no. wt