

OCT 27 1980

OFFICE OF DOMESTIC POLICY
THE WHITE HOUSE

FROM THE OFFICE OF:

CAROL H. RASCO
ASSISTANT TO THE PRESIDENT
FOR DOMESTIC POLICY

TO: _____

DRAFT RESPONSE FOR CHR BY: _____

PLEASE REPLY (COPY TO CHR): _____

PLEASE ADVISE BY: _____

LET'S DISCUSS: _____

FOR YOUR INFORMATION: _____

REPLY USING FORM CODE: 1

FILE: *Disability Leadership*

RETURN ORIGINAL TO CHR: _____

REMARKS:

Copy for Carol Rasco

JUSTIN DART, JR.

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

OCT 27 RECD

Memo: 10/26/93

To: Mike Lux, Heather Booth, Bob Sevigny

From: Justin Dart & Allen S. Gray

Re: State Disability Constituency Health Care Reform Coordinators

Accompanying this memo is a list of 51 key disability community leaders, one from each state and the District of Columbia, who have agreed to act as disability constituency health care contacts for The National Health Care Campaign in their respective states. Each person is a proven, respected advocate for people with disabilities whose labor on previous legislation, such as the Americans with Disabilities Act, has led to victory.

We telephoned each individual personally to secure their assistance in promoting the President's leadership on health care. A follow-up letter was sent to each confirmed contact with information on their state's National Health Care Campaign coordinator, national contact (Bob Sevigny) and what the position entailed.

Each contact was advised they would be kept up-to-date on all aspects of the campaign through their state coordinator, as well as The National Health Care Campaign Headquarters in Washington, DC.

We will continue to fight to support the President's leadership for universal health care which includes people with disabilities. Please do not hesitate to contact us when we can be of particular assistance to The National Health Care Campaign.

HEALTH CARE FOR ALL AMERICANS NOW

Mr. Duane Frerich
Executive Director
Access Alaska, Inc.
3710 Woodland Dr., Suite 900
Anchorage, AK 99517
907/248-4777 (V/TDD)
NICKNAME: Duane
CONSTITUENCY: il

Mr. Larry Johnson
Assistant Director
Alabama Vocational Rehabilitation
2129 E. S. Blvd.
Montgomery, AL 36111
205/281-8780 (W)
205/281-1973 FAX
NICKNAME: Larry
CONSTITUENCY: vr

Ms. Nan Ellen East
Executive Director
Advocacy Services, Inc.
1100 North University, Suite 201
Little Rock, AR 72207
501/324-9215 (V/TDD)
501/324-9219 FAX
NICKNAME: Nan Ellen
CONSTITUENCY: p&a

Ms. Susan A. Webb
Executive Director
Arizona Bridge
to Independent Living
1229 East Washington Street
Phoenix, AZ 85034
602/256-2245 (V), 254-5639 TDD
602/254-6407 FAX
NICKNAME: Sue
CONSTITUENCY: il

Simi Litvak
World Institute on Disability
1720 Oregon St.
Berkeley, CA 94703
510/763-4100 (W)
510/465-3933 FAX
NICKNAME: Simi
CONSTITUENCY: int'l

Ms. Hedy Margolis
Chairperson
Colorado Coalition for Persons
with Disabilities
12100 W. Alameda Parkway
Lakewood, CO 80228
303/987-2490 (V), 987-5433 TDD
303/987-7678 FAX
NICKNAME: Hedy
CONSTITUENCY: gc

Dr. Thomas Connors
President
Connecticut Coalition of
Citizens with Disabilities
340 Twin Lakes Rd.
N. Branford, CT 06471
203/488-0391 (W)
NICKNAME: Dr. Connors
CONSTITUENCY: coali

Ms. Ruth Royal Hill
Administrator
Voc. Rehab. Services Administration
Dept. of Human Resources
605 G Street, N.W., Room 1111
Washington, DC 20001
202/727-3227 (W)
NICKNAME: Ruth
CONSTITUENCY: vr

Mr. Robert Piech
Director
DE Assistive Technology Initiative
A.I. DuPont Institute
P.O. Box 269 Circle
Wilmington, DE 19899
302/651-6830, 651-6791 dir.(W)
302/651-6793 FAX
NICKNAME: Bob
CONSTITUENCY: lead

Mr. Jim Parrish
Chairman
Florida Disability Caucus on
Disability Issues
16100 S.W. 74th Court
Miami, FL 33157
305/235-5274 (V/TDD)
305/254-2650 FAX
NICKNAME: Jim
CONSTITUENCY: ccdre

Ms. Nancy Molton
P6(b)(6)
NICKNAME: Nancy
CONSTITUENCY: blind

Ms. Carolyn Townsend
Acting Executive Director
Comm. on Persons w/Disabilities
500 Ala Moana Blvd.
5 Waterfront Plaza, Room 210
Honolulu, HI 96813
808/586-8121 (W)
808/586-8129 FAX
NICKNAME: Carolyn
CONSTITUENCY: gc

Mr. Denny Hoyt
Project Director
Alliance for Parent Leadership
100 Euclid St., Box 4158
Des Moines, IA 50333
515/280-1231 (W)
515/243-0172 FAX
NICKNAME: Denny
CONSTITUENCY: parfm

Mr. Kelly Buckland
Director
LINC
708 West Franklin Street
Boise, ID 83702
208/336-3335 (V/TDD)
NICKNAME: Kelly
CONSTITUENCY: il

Mr. Robert Kilbury
Executive Director
Coalition of Citizens with
Disabilities in Illinois
401 East Adams
Springfield, IL 62701
217/522-7016 (V/TDD)
217/522-7024 FAX
NICKNAME: Rob
CONSTITUENCY: coali

Ms. Nancy Griffin
Executive Director
Indianapolis Resource CIL
2511 East 46th Street, #V4
Indianapolis, IN 46205
317/541-0611 (V/TDD)
317/542-8090 FAX
NICKNAME: Nancy
CONSTITUENCY: trner

Ms. Gina McDonald
Executive Director
Kansas Association of Centers
for Independent Living
3258 South Topeka Blvd.
Topeka, KS 66611
913/267-7100 (W)
913/267-0201 FAX
NICKNAME: Gina
CONSTITUENCY: il

Ms. Kathy Williams
Director
Div. of Program Development
Office of Voc. Rehab.
Capital Plaza Tower - 9th Floor
Frankfort, KY 40601
502/564-3694 (W), 564-4440 TDD
NICKNAME: Kathy
CONSTITUENCY: lead

Ms. Yadi Mark
Advocacy Legislative Director
Paralyzed Veterans of America
3560 18th Street
Metairie, LA 70002
504/454-1178 (W)
504/455-7315 FAX
NICKNAME: Yadi
CONSTITUENCY: pva

Mr. John Winske
Executive Director
Massachusetts Coalition of
Citizens with Disabilities
80 Boylston St., Suite 950
Boston, MA 02116
617/482-1336 (V/TDD)
617/482-2248 FAX
NICKNAME: John
CONSTITUENCY: coali

Ms. Katy Beh Neas
Director of Legislation
AAUAP
8630 Fenton Street, Suite 410
Silver Spring, MD 20910
301/588-8252 (W)
301/588-2842 FAX
NICKNAME: Katy
CONSTITUENCY: CCDRE

Mr. Steven Tremblay
Executive Director
Alpha One
169 Ocean
South Portland, ME 04106
207/767-2189, 947-2352 (W)
207/799-8346 FAX
NICKNAME: Steve
CONSTITUENCY: il

Mr. Patrick Cannon
Executive Director
Commission on Handicapper Concerns
P.O. Box 30015
201 N. Washington Ave.
Lansing, MI 48909
517/373-8397, 373-0035 dir.(W)
517/335-6811 FAX
NICKNAME: Pat
CONSTITUENCY: gc

Mr. Tom Brick
Health Care Coordinator
State Council on Disability
Suite 145, Metro Sq. Bldg.
7th and Jackson Sts.
St. Paul, MN 55101
612/297-2920 (V/TDD)
612/296-5935 FAX
NICKNAME: Tom
CONSTITUENCY: gc

Mr. James Tuscher
Chairman
GCEPD
PARAGUAD
5100 Oakland Ave., Suite 100
St. Louis, MO 63110
314/534-5100 (W)
314/534-0055 FAX
NICKNAME: Jim
CONSTITUENCY: gc

Mr. Chester Helms
Director
Programs for Accessible Living
1012 South Kings Dr., Suite G2
Charlotte, NC 28283
704/375-3977 (V/TDD)
704/375-5907 FAX
NICKNAME: Chester
CONSTITUENCY: il

Mr. Larry Robinson
Co-Executive Director
Granite State Independent
Living Foundation
172 Pembroke Rd.
Concord, NH 03301-5767
603/228-9680 (W)
603/225-3304 FAX
NICKNAME: Larry
CONSTITUENCY: il

Ms. Donny Loux
Chief
Planning, Research and Program
Development, Rehab. Division
711 South Stewart Street
Carson City, NV 89710
702/687-4452, 800-992-0900 (W)
702/687-3292 FAX
NICKNAME: Donny
CONSTITUENCY: dd

Ms. Helen Kutz
Director
Client Assistance Program
Office of Handicapped Concerns
4300 North Lincoln, Suite 200
Oklahoma City, OK 73105
405/521-3756 (W)
405/424-1782 FAX
NICKNAME: Helen
CONSTITUENCY: p&a

Mr. James Healey
Rhode Island Arc
99 Bald Hill Road
Cranston, RI 02920
401/463-9191 (W)
NICKNAME: James
CONSTITUENCY: arc

Ms. Sharon Marie Hazard
ADA Project Coordinator
Coalition for Tennesseans
with Disabilities
P.O. Box 4688
Sevierville, TN 37864
615/428-6266 (W), 428-6264 TDD
615/428-6269 FAX
NICKNAME: Sharon
CONSTITUENCY: coali

Ms. Sandra Reen
Director
Virginia Board for the Rights
with Disabilities
P.O. Box 613
Richmond, VA 23205-0613
804/786-0016 (W)
804/786-1118 FAX
NICKNAME: Sandy
CONSTITUENCY: gc

Mr. Mark Smith
Executive Director
Coalition for Citizens with
Disabilities
2727 Old Canton Road, Suite 173
Jackson, MS 39216
601/362-9599 (W)
NICKNAME: Mark
CONSTITUENCY: coali

Mr. Darrell Farland
Executive Director
Governor's Comm. on Human Resources
State Capitol Annex, 3rd Floor
Bismarck, ND 58501
701/224-3950 (W)
701/224-3000 FAX
NICKNAME: Darrell
CONSTITUENCY: gc

Mr. Ethan Ellis
Director
New Jersey DD Council
32 West State Street, CN 700
Trenton, NJ 08625
609/292-3745 (W)
NICKNAME: Ethan
CONSTITUENCY: dd

Mr. Robert Mauro
Writer

NICKNAME: Robert
CONSTITUENCY: media

Mr. Eugene Organ
Executive Director
Oregon Commission for
the Handicapped
1257 Ferry St., S.E.
Salem, OR 97310
503/378-3142(V), 378-3599(TDD)
503/378-3599 FAX
NICKNAME: Eugene
CONSTITUENCY: gc

Ms. Betty Easler
Director
S.C. DD Council
Edgar Brown Building, Room 372
1205 Pendleton St., Rm. 372
Columbia, SC 29201
803/734-0465 (W)
803/734-0356 FAX
NICKNAME: Betty
CONSTITUENCY: dd

Ms. Belinda Carlton
Executive Director
Coalition of Texans with
Disabilities
316 W. 12th St., Suite 405
Austin, TX 78701
512/478-3366 (V/TDD)
512/478-3370 FAX
NICKNAME: Belinda
CONSTITUENCY: coali

Mr. David Sagi
Coordinator
ADA Implementaion Project
Vt. Dept. of Aging and Disabilities
103 S. Main St.
Waterbury, VT 05671-2303
802/241-3180 (V/TDD)
802/241-2979 FAX
NICKNAME: David
CONSTITUENCY: stada

Ms. Zana Smith
Project Director
Montana Independent Living
Project
38 South Last Chance
Helena, MT 59601
406/442-5755 (W)
406/442-1612 FAX
NICKNAME: Zana
CONSTITUENCY: il

Mr. Mike Schafer
Director
CIL League of Human Dignity, Inc.
1701 P Street
Lincoln, NE 68508
402/441-7871 (W)
402/441-7871 FAX
NICKNAME: Mike
CONSTITUENCY: il

Ms. Julie Ballinger
Acting Director
Independence Resource Ctr.
2520 Virginia, N.E., Suite 200
Albuquerque, NM 87110
505/271-1565 (W)
NICKNAME: Julie
CONSTITUENCY: il

Mr. Ken Campbell
Executive Director
Ohio D.D. Council
8 E. Long Street, 6th Floor
Columbus, OH 43215
614/466-5205 (W)
614/466-0298 FAX
NICKNAME: Ken
CONSTITUENCY: dd

Ms. Kathleen Kleinmann
President
Penn. Council on Independent Living
69 East Beau Street
Washington, PA 15301
412/223-5115 (W)
412/223-5119 FAX
NICKNAME: Kathleen
CONSTITUENCY: il

Ms. Rae Unzicker
Coordinator
National Assoc. of Psychiatric
Survivors
Box 618
Sioux Falls, SD 57101
605/334-4067 (W)
605/334-2298 FAX
NICKNAME: Rae
CONSTITUENCY: PSYCH

Ms. Sherry Repscher
Executive Director
GCEPD
120 North 200 West
P.O. Box 45500
Salt Lake City, UT 84145-0500
801/538-4210 (W), 538-4192 TDD
801/538-4279 FAX
NICKNAME: Sherry
CONSTITUENCY: gc

Mr. Larry Watkinson
Owner
Munchies and Moren, Co., Ltd.
P.O. Box 2075
Olympia, WA 98507
206/754-0900 (W)
206/754-0924 FAX
NICKNAME: Larry
CONSTITUENCY: ?

Ms. Jayn Wittømyer
Executive Director
Wisconsin Council on
Developmental Disabilities
One West Wilson St., P.O. Box 7851
Madison, WI 53707-7851
608/266-7826 (W), 266-6660 TDD
NICKNAME: Jayn
CONSTITUENCY: dd

Ms. Anne Weeks
Executive Director
Huntington Center
for Independent Living
914 1/2 Fifth Avenue
Huntington, WV 25701
304/525-3324, 800-243-4245 (W)
NICKNAME: Anne
CONSTITUENCY: il

Mr. Darlo Koldenhoven
Program Consultant
Independent Living
1104 Hershler Bldg
Cheyenne, WY 82002
307/777-6841 (W)
NICKNAME: Darlo
CONSTITUENCY: il

THE WHITE HOUSE
WASHINGTON

TO: Judy Feder
Mary Harahan
Sara Rosenbaum

FROM: Carol H. Rasco *CR*

SUBJ: Update on disability issues

DATE: February 3, 1994

file

I feel the need to sit down, if even for thirty minutes, for an update on disability issues as they relate to the Health Security Act. While I have several meetings in coming weeks where this issue might arise, I know for certain when I am on the floor of the Arkansas General Assembly next Thursday, I will be asked questions on this topic.

I am asking Rosalyn Miller of my staff to contact each of you by the close of business tomorrow to try to find a time Monday, Tuesday or Wednesday that we might sit and visit. If you feel there are others who should sit with us, please do not hesitate to share that with Rosalyn.

Thank you.

cc: Stan Herr

	Mon	Tues	Wed
Sara	X	open	open
Judy (meghan)		10:00-11:00 3:00-5:00	10:00-11:00(?) 2:00-4:00(?) 4:00-5:00
Mary (Brenda)			2:00-→

Sent 9/8/93
logged 9/8/93
pr

Stan

Please review
this - then let's
talk

CSK:sw

Contact:

P6(b)(6)

SEP 3 REC'D

Repr. Tim Slattery

August 30, 1999

P6(b)(6)

TO: Carol Kasper

Re: U.S. Senate Bill 1284

Passed U.S. Senate by Voice Vote

To be voted on by House of Reps. on ~~or~~
~~about~~ 9/17/99.

Kansas Rep. on the House Committee

of Energy and Commerce is from

Stattery. Help us to stop this

bill which would destroy state

or individual rights concerning

the DD's. Returning all DD's to

families would be disastrous.

Help! Help!

Respectfully,

Alice D. Hixson

parent and DD advocate

Alice D. Hixson

P6(b)(6)

P6(b)(6)

For your information ..

I am a parent of an institutionalized son in
Parsons State Hosp. + Ins. Co. Everyday I thank God
and the U.S. and Kansas for providing a safe place
for him. So do MANY others!

I taught at John Brown University some years ago
and received my MS from U. of Ark. Fayetteville. I first met
at Farmington Rural HS. - find memories.

VOICE OF THE RETARDED

5005 Newport Drive
Suite 108
Rolling Meadows, IL 60008

(708) 253 - 6020 - Phone

(708) 253 - 6054 - FAX/Phc

August 26, 1993

The Honorable Jack Fields
2228 Rayburn
House Office Building
Washington DC 20515

COPY

Dear Representative Fields,

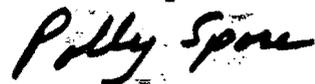
As a national non-profit organization representing the families of mentally retarded persons in 47 states, VOR is writing to express deep concern about the U.S. Senate Bill 1284, sponsored primarily by members of the Senate Committee on Labor and Human Resources, and, we are told, drafted with the Consortium for Citizens with Disabilities. It would, in our opinion, invade the administrative sovereignty of states by giving certain federally-funded agencies a "first-among-equals" status for policy formulation. These agencies in the Consortium today do not really represent persons with retardation: rather, they represent the preferences of many individuals who have conflicts of interest regarding the agency activities.

We are advised that this bill was heard by a 2-member Developmental Disabilities panel, as one of six reauthorization bills, on April 19, 1993. It then passed the Senate by a voice vote on August 5, 1993, and is now to be considered by the House Committee on Energy and Commerce.

Our specific objections are detailed in the attached pages.

If we can be of assistance in providing further analysis or data, please let us know. We would like to telephone you next week for further discussion.

Sincerely,



Polly Spare
President

P6/(b)(6)

An Association of Individuals and Parent Groups working for Persons with Mental Retardation

Non-Profit • Tax Exempt • Voluntary

ANALYSIS

DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS ACT AMENDMENTS OF 1993

PURPOSE

"...To expand or modify certain provisions relating to programs for individuals with developmental disabilities, Federal assistance for priority area activities for individuals with developmental disabilities, protection and advocacy of individual rights, university affiliated programs and projects of national significance..."

ADDITIONAL PURPOSE

"...To reunite families with members who have been placed out of the home..."

POLICY

It would be U.S. policy that all programs, projects and activities receiving financial assistance under this Act be carried out consistent with principles that "individuals with developmental disabilities are capable of achieving independence, productivity and inclusion in the community."

CONCERNS OF CONSUMER FAMILIES

- (1) The notion that all individuals are capable of independence and inclusion is grossly unrealistic. The following is a June 1993 quote from Elizabeth Boggs, of The ARC: "I fear that we are going to go through a period of euphoria where we destroy all of the infrastructure we have built up over the years. We will try to replace it with a faith that the community will take up the slack..."
- (2) In any family with a severely or profoundly mentally retarded member, returning that person to the home means a life sentence of 24-hour care for an adult with a mental age of an infant or young child (bathing, diapering, laundry, cooking, hand feeding, transporting to medical care, in-home therapists (where available) and social workers) 365 days per year for the rest of that disabled person's life or the end of the family, whichever comes first. Government would not dare impose this sentence upon a criminal.
- (3) Choice option of residential care as a Health Care Financing Agency requirement would be eliminated. This removes all consumer choice in an essential service arena.

**VOR IS DEDICATED
TO THE
FOLLOWING PRINCIPALS**

- to create an awareness of VOR, our concerns and goals;
- to be the foremost national organization to promote the general welfare of all persons with mental retardation;
- to assure quality care, essential services and to improve the quality of life for all.
- to educate and disseminate information to the general public, families, lawmakers, state and federal officials.
- to act as a resource for parents, families, guardians and all persons who are mentally retarded.
- to review and monitor legislation that would impact on developmentally disabled persons and their families.
- to promote freedom of choice; a spectrum of treatment/rehabilitation services, and residential services to meet the special needs of special citizens.
- to promote research into the causes, prevention and treatment of mental retardation.
- to seek caring persons to support our efforts on behalf of those who cannot speak for themselves.

SEP 3 REC'D

*Our friend
on national
level -*

VOICE OF THE RETARDED

*and maybe
the only such
organization*

VOR

FOUNDED 1983

5005 NEWPORT DRIVE
SUITE 108
ROLLING MEADOWS IL 60008

Phone (708) 253-6020
FAX (708) 253-6054

WHO ARE WE?

We are an organization of parents, family members, providers, professionals, friends, and affiliated groups in 47 states who are involved with people in institutional settings, community living arrangements, or at home. We strongly believe that a spectrum of services must be available to meet the diverse needs of our M.R. population.

**WE ARE A STRONG VOICE
BEING HEARD
ACROSS THE USA
FROM
NORTH TO SOUTH
EAST TO WEST.**

HISTORY

VOR was incorporated in 1983 by a group of Illinois parents in response to proposed federal legislation that would have phased out all larger facilities by withdrawing eligibility for Medicaid funding. VOR was instrumental in defeating that 6 year initiative. Today there are new directions that could eliminate small community homes as well as larger facilities.

PURPOSE

Our general purpose is to act as a resource for families with mentally retarded members. We provide information, support, and advocacy services according to individual and group needs. We keep public officials, legislators, and the general public informed about issues which will affect the mentally retarded. We seek to create a wholesome and productive attitude about a variety of residential models and support services which will best suit the needs of each mentally retarded person and his/her family.

OUR ON-GOING ACTIVITIES INCLUDE:

- Participation in panel and media discussions to bring information to the general public about mentally retarded people.
- Testimony before Federal, State, and local governmental bodies regarding the problems of the retarded.
- Publication of a Quarterly Newsletter.
- Advocacy on behalf of groups and individuals in residential, community, or home settings.
- Interaction with other parent organizations who work with the retarded.

WE INVITE YOUR SUPPORT

THERE IS STRENGTH IN NUMBERS



VOICE OF THE RETARDED

An Association of Individuals and Parent Groups working for Persons with Mental Retardation

A not-for-profit corporation under the laws of the State of Illinois

5005 Newport Drive, Suite 108 • Rolling Meadows, IL 60008 • (708) 253 - 6020 phone

(708) 253 - 6054 fax

SUMMER 1993

HELLER V. DOE: SUPREME COURT RECOGNIZES SPECIAL NEEDS OF RETARDED AND RIGHTS OF PARENTS TO PARTICIPATE

On June 24, 1993, the United States Supreme Court issued a decision in the case of Heller v. Doe which will be welcomed by all parents and guardians who are responsible for the care, placement and maintenance of retarded persons in residential treatment facilities. Because of the importance of the case, the Voice of the Retarded filed a brief in the case as an amicus curiae (friend of the court). With very little time, Bill Sherman, chairman of the VOR's Law Committee, worked around the clock and over weekends to prepare VOR's brief. Bill's position in the brief on the two crucial issues before the Court was upheld, one by a 5-4 majority and the other by a 6-3 majority of the justices.

The case is very significant because in it the Supreme Court recognizes that states can have an easier procedure for approving placement of the retarded in residential facilities than is required to commit the mentally ill. Because the case arose under the specific and unusual provisions of Kentucky law, it may not have immediate application in other states. Most states consider that placements for the retarded differ from commitments of the mentally ill. Unfortunately, because of the previous federal court cases contesting the Kentucky laws, that state had to consider placements of the retarded as though they were "involuntary commitments" similar to the mentally ill. In the face of this mandate from the federal courts, the Kentucky legislature tried to make it easier to obtain approval of the "commitment" of a retarded person.

Under Kentucky's laws, to justify a placement in an institution there must be a finding that the mentally retarded person is a danger to self or others, can benefit from treatment in a facility, and the placement is in the least restrictive alternative for the person. To make it easier to meet these tests for the mentally retarded, the Kentucky legislature declared that the burden of proof for placement of the retarded was to be "clear and convincing evidence", rather than "evidence beyond a reasonable doubt" as was required for the mentally ill. It is obviously easier to prove something by "clear and convincing evidence" than "beyond a reasonable doubt" - the latter is the same standard as the law requires for convicting a person of a crime.

(cont'd pg 11)

THE PRESIDENT'S MESSAGE.....

It's been an outstanding year!

VOR has gained national recognition. Our membership, both organizational and individual, continues to grow. We have, through our actions in the U.S. Supreme Court and The Washington Initiative July 12 - 16, achieved status as a viable achieving national advocacy organization dedicated to voluntary service on behalf of Americans with mental retardation.

Two new board members were elected at the June 12, 1993 meeting in Arlington Heights. Caroline Walsworth, of Arlington Heights, IL was elected a Director and Treasurer. Marilyn Straw, of Waukee, IA was elected a Director. VOR is fortunate to have the support of these dedicated parents and active advocates in their states.

This issue of our newsletter is dedicated to sharing our success with you all - our supporters - and extending our thanks to the many persons who contributed countless hours and weeks to help us establish credibility for VOR. We are the only national non-publicly funded, non-profit, non-provider corporation in the country serving people with mental retardation and their families.

I want to take this opportunity to thank the 72 selfless delegates from 19 states who participated at their own expense in the Washington Initiative. VOR was able to advise the U.S. Congress and the White House that our people with mental retardation who are "out-of-sight and out-of-mind" are indeed a population that must be included when long term care plans are considered as part of National Health Care Reform.

- Polly Spare, President

IN THIS ISSUE.....

WHAT THE SUPREME COURT DECISION MEANS..... page 1

THE PRESIDENT'S MESSAGE..... page 2

VOR HEALTH CARE POSITION STATEMENT..... page 3

THREE REACTIONS TO THE WASHINGTON TRIP.... page 5

REPORT: THE WASHINGTON INITIATIVE..... page 7

THE NATION'S PRESS..... page 8

PATTI SHAPEN WINS SPECIAL OLYMPICS HONORS. page 10

VOR POSITION ON NATIONAL HEALTH CARE REFORM.....

Because mental retardation lasts from birth to death, VOR believes that a major goal of health care planning must be **assurance of long-term care and treatments**, so that American families will not be impoverished and destroyed by the burden of home-care.

Today, U.S. health care delivery to our disabled population--projected by A.A.R.P. to be 8.9 million by the year 2000--is financed by Medicaid, Medicare and private insurance. This includes about 250,000 persons with developmental disabilities who reside in state and privately operated care/treatment facilities for mentally retarded persons.

Financing for this population provides:

- **SKILLED ACTIVE TREATMENT** for persons with severe or profound mental retardation.
- **INTERMEDIATE ACTIVE TREATMENT** for persons who are moderately or mildly mentally retarded and/or are dually diagnosed.
- **CUSTODIAL CARE** for persons with mental retardation often residing in nursing home environments. Typically custodial care provides assistance with eating, dressing, bathing and mobility.

CUSTODIAL CARE MUST NEVER BE THE ONLY LONG TERM CARE OPTION

Persons with severe and profound mental retardation need skilled care. These are people who have mental ages of infants and young children. Some are subject to life threatening seizure disorders and other neurological impairments. They can be afflicted with physical ailments and be wheelchair bound, medically fragile, blind, deaf or any combination of these disabilities. Others suffer from Autism, Prader Willi, Pica, Cerebral Palsy, etc.

Survival for some of these people often requires a variety of medical skills and intervention provided 24 hours a day by technically trained staff. Life sustaining and technological equipment as necessary supports, must be available in specialized residential facilities.

WHAT MUST BE DONE

Experience clearly indicates the need for:

- An array of facilities, public and private, large and small.
- Reasonable choice of vendors of service with parental concurrence.

- Enhanced and enforced quality assurance standards.
- Better self-discipline within professional groups (doctors, lawyers, etc).

Controlled expenditures by:

- Standardizing costs of medical procedures without presenting disincentives to continued medical advancements.
- Simplifying administrative and claim procedures.
- Eliminating malpractice damages and supporting tort reform.

SOURCES OF FINANCING FOR LONG TERM CARE

- Better-administered Medicaid/Medicare or an equal or better social insurance program.
- Elimination of Medicaid/Medicare fraud.

NOTE: Cost projections must be actuarially sound.

SOCIETAL SAVINGS

An investment in appropriate mental retardation care:

- Enhances family stability.
- Minimizes catastrophes.
- Reduces homelessness.
- Improves community acceptance.
- Helps to prevent losses by poor supervision, poor training and low pay.
- Contributes to reduction of costly litigation.
- Reduces prison populations.
- Offers new treatment options (cocaine babies, and fetal alcohol syndrome victims).
- Improves the quality of life for millions of people.

REGRESSIVE POLICIES WITH DISASTROUS CONSEQUENCES.....

The loss of federal and state funds for long term care (ICE/MR) for persons with mental retardation is a real threat in current health care negotiations. Parents, family members and friends, are urged to act immediately to prevent this from happening.

Join VOR today! Ask family members and friends for their support. Alert your state and federal legislators of the need for quality long term care for persons with mental retardation. Legislators need to know the dire consequences of loss of funding and how it would affect you and your family members.

PARTICIPANTS CRITIQUE THE WASHINGTON INITIATIVE.....

From: Carolyn Cowans
Parent-Guardian Association
of Arlington Developmental Center
Memphis, TN

Parents and family members of mentally retarded persons generated tremendous energy on Capitol Hill during the week of July 11, when we met with members of Congress and Legislative Aides on behalf of long-term care for persons with mental retardation.

The Congressional officials and their aides were impressed by the effort of VOR. They expressed appreciation at hearing the concerns from the families. Many of them did not realize the fragile conditions and special needs of our loved ones.

VOR did an outstanding job organizing The Washington Initiative. I hope this effort will be repeated. We must keep our concerns before Congress and support VOR as it continues to advocate on our behalf.

From: Mark Fitzpatrick
Parent Association for the
Retarded of Texas
Dallas, TX

The spontaneous decision to join VOR in Washington, D.C. has permanently changed my involvement with the issues that confront us as parents and family members of a severely retarded individual. Being a newcomer amongst the more experienced participants was a revealing education. Discussions about the trend toward deinstitutionalization were as alarming as the successful activities of parent groups and individuals to confront these threats were encouraging.

Our meetings with congressional members and their legislative aides were generally cordial and informal. We expressed our concerns about possible changes in Medicaid funding and the reported emphasis by the Task Force on home-based services. They said that little was known of the Plan, and in every instance reassured us that our special-needs population would not be forgotten.

Until our participants began to explain the trends at the state level, however, the decision-makers knew little of the conflicts between institutions, community and home-based services. And only then did they begin to become aware of our vulnerability.

Being in a position to communicate this vulnerability to persons of influence is both an empowering and a sobering situation. Understanding the challenges that exist has given me the desire to do what I can to secure the public resources that my son and all mentally retarded persons need.

VOR is a beautiful example of the desire and hard-earned experience we as concerned individuals can focus into a powerful group effort. This latest Washington trip succeeded in many ways, and there is much follow-up work to be done. The trip was exciting, fun and very satisfying. I'm proud to now be an active member of VOR.

From: Lex Wells
VOR California State Coordinator
Wildomar, CA

When VOR asked that members come to Washington, D.C. on July 10th to discuss our concerns with our Congressmen on how the new health care reform plan would affect the mentally retarded, California formed a group of six members. Our California representatives were Dennis and Lex Wells from Fairview Developmental Center, Helen Hawkins from Sonoma Developmental Center, Joe Romozi and Doug Fratt from Lanterman Developmental Center, and David Swain from Camarillo. These six delegates contacted two Senators and 51 Congressmen.

I am very happy to report that as of July 25, 1993 I have personally heard back from Senator Boxer and 6 Congressmen.

VOR and its top staff were very instrumental in getting us an appointment at the White House with Carol Rasco, President Clinton's Domestic Policy Advisor, and I felt that this was one of the biggest breaks on letting the President know of our concerns.

All of our parent organizations in California would like to thank VOR and its staff for making this opportunity occur. Communications today are so important and if we are not united and stand together to form strength for our cause, then we will never conquer our problems. VOR must do what no organization has ever done before and this is encourage growth and gain in strength and numbers. We, in California, stress that all of you ask your friends to join VOR - as we are going to do - so that we can protect our loved ones during these difficult times.

PLAN TO JOIN US FOR WASHINGTON INITIATIVE PHASE II!
LATE FALL "93" date to be announced

REPORT ON THE WASHINGTON INITIATIVE.....

Seventy-two VOR advocates for long term care traveled from 19 states to Washington DC at their own expense, to meet with over 300 legislators and staff members. Ten met at the White House with Carol Rasco, Domestic Policy Advisor to the President. Additional meetings were held to discuss long term care with the National Catholic Conference, the General Board of Church and Society of the United Methodist Church, the American Association of Retired Persons, and the American Federation of State, County and Municipal Employees.

In spite of the 98 degree temperature, the reception accorded VOR was enthusiastic and positive. VOR's position paper on long term health care was given to every legislator and staff member visited. A basis for continued sharing of ideas has been established, so that when the health care bill is introduced, VOR reaction will be considered.

Many Capitol Hill offices have received little information about the proposal. However, there is a consensus that families of persons with mental retardation will only be given a choice between \$500 per month Home and Community based Medicaid Waiver, OR individual, state-defined payments for long term care services/home based paid for by federal block grants.

To prove eligibility, each individual will have to show deficits in at least three activities of daily living. IT IS POSSIBLE THAT ONLY A FRACTION OF THOSE PRESENTLY ELIGIBLE FOR MEDICAID MAY PASS THE NEW TESTS, EVEN THOUGH A COGNITIVE ABILITY MEASURE MAY BE ADDED.

VOR plans to return to Washington DC late in the year, and will be in touch with the membership about this. Meanwhile, VOR has been asked to send its concerns directly to the White House, as well as to the U.S. Congress.

It is also important that state legislators and officials be informed by VOR members and their friends about the need for long term health care.

Parent power was very evident in Washington DC this month, but we've just begun the long road to inclusion of our most disabled population in the long term health care reform package.

HERE'S WHAT THEY REPORT IN THE NATIONAL PRESS.....

CASH/PCR News Release (CA) 6/8/93: The statewide association of parents whose children reside in California's seven state developmental centers has asked court permission to intervene in a sweeping lawsuit that could jeopardize future care for up to 2,000 developmental disabled Californians. Attorneys for CASH/PCR have petitioned the San Francisco Superior Court to let the group intervene in the 1990 class-action suit titled Coffelt v. DDS.

The Hartford Courant (CT) 5/27/93: The biggest state government overhaul in 15 years would begin in one month under the plan approved Wednesday by the Senate, which turned aside an attempt to postpone it for a year. The legislation, which was sent to the House, would combine five agencies that run social and health programs into two new departments that are expected to give better service at lower cost.

Illinois Issues (IL) 6/93: Clear plans finally exist to guide the department (of Mental Health and Developmental Disabilities) future. Especially exciting is the idea that a broad range of people is taking part in hashing out the stakeholders - consumers, parents, patients who are living full lives.

Misericordia Newsletter (IL) 5/93: Three years ago, Misericordia opened the Greenhouse Inn, a restaurant offering its customers a delicious lunch menu and affording the residents of Misericordia valuable work opportunities as waiters and waitresses, bus persons, and kitchen assistants. At about the same time, Misericordia's staff was encouraging residents such as Joan to go out and look for jobs in the community. Joan has been working part time at a local veterinary hospital for nearly three years now.

Detroit News (MI) 5/23/93: The head of the nation's Social Security Administration said he is "deeply troubled" by reports of widespread exploitation in Michigan's private care homes and will investigate complaints that disability checks are being misused.

Louis Enoff, acting commissioner of Social Security, said he will examine why monthly disability checks continue to be sent to some Michigan caretakers who have records of exploiting residents in dangerous, illegal care homes, like the one on Detroit's Pingree Street where 10 people died in a fire last summer.

Mental Retardation Association Newsletter (MO) 6/93: The growing list of people who have severe mental retardation with multiple handicapping conditions and behaviors should be relieved, by providing ADDITIONAL group homes on state habilitation center grounds...There is a need for protective environments, such as state habilitation centers in Missouri, to accommodate the state's most vulnerable MRDD citizens, whose mental disabilities and behaviors make it impossible for them to live safely in the community.

The Commercial Appeal (MS) 5/30/93: A group home operated by the Warren Yazoo Mental Health Service in Vicksburg is being accused of physically abusing patients and of giving one patient's medication to another to keep the second patient quiet.

Meriden Record-Journal (NC) 7/6/93: ...Some are reluctant to talk to an outsider about the five local youths charged with raping a 19-year old mentally retarded woman over two nights last winter..."This is a very moral community where something like this is totally out of place," said...the pastor of Troutman Baptist Church...A friend of the woman's heard her discussing the incident and notified police. The woman - who a local psychologist says has an IQ of 70 and the social skills of a 5-year-old - told police several teens invited her to go to the movies on New Year's Eve. Instead, they took her to an apartment...

The Cincinnati Enquirer (OH) 6/29/93: When Kathleen and Timothy Carroll began adopting disabled children, they knew it was against the odds that all of them would lead long lives. But five of their 10 adopted children have died in the last nine months, alarming local authorities and devastating the family.

The deaths began Sept. 21 when Hannah Carroll, 6, who had Down's Syndrome, died after getting into some household bleach...On Oct. 19, 7-week-old Chloe, born with only a brain stem, died at a Columbus adoption agency where she was taken shortly after Hannah died. Noah, who was born to a drug-addicted mother and had a history of seizures, died at the Carroll home Nov. 15. A month later, Mary, 3, who was mentally retarded...was found dead in her bed. On June 14, Josiah, who had cerebral palsy and asthma, was found dead in his bed.

Ft. Worth Star-Telegram (TX) 5/28/93: The House approved a Senate human services bill yesterday that lacks a provision that would keep the Fort Worth State School open. It has been sent to Gov. Ann Richards, who is expected to sign it into law. Rep. Doyle Willis, D-Forth Worth, argued yesterday that a federal judge was bullying the Legislature into closing the school...The decision to close state schools in Tarrant and Travis counties is part of a settlement to end a 19-year-old lawsuit against the Texas Department of Mental Health and Mental Retardation.

The Herald (Provo, UT) 2/2/93: Mike Stewart, new director of the Utah Department of Human Services, told employees of the State Department Center Friday that he has no plans to close the institution. Stewart and Lt. Gov. Olene Walker had lunch at the center, then toured the facilities...

Deseret News (UT) 5/27/93: Foster parents of an 18-year-old mentally retarded woman who died in a March 3 garage fire have been charged with murdering her. John and Tonya Vosburgh of Layton were charged Wednesday in 2nd Circuit Court with one count of first-degree homicide, aggravated arson and filing a false insurance claim.

The Virginian-Pilot and Ledger-Star (VA) 5/17/93: Dogs have long been used to guide the blind and more recently to assist people with hearing impairments or other physical disabilities. But Austin and Bishop are the first participants in a local project that uses dogs to help people with mental retardation...Pilot, a golden retriever, is being trained to summon help when Austin suffers seizures. Bishop has autism in addition to mental retardation. His sheltie has been taught to sit down at curbs and not let his master cross the street until traffic has cleared.

PATTI SHAPEN WINS SPECIAL OLYMPICS HONORS

Patrice (Patti) Shapen, a 36-year-old resident of the Howe Developmental Center in Tinley Park, Illinois, was introduced by Sargent Shriver at a July 16 banquet in Orlando, FL commemorating the 25th anniversary of International Special Olympics. Three days later, Patti was honored as Grand Marshal of the Disney World parade, attended by 2,000 Special Olympics meeting participants. Patti was announced to all of the persons at Disney World and Epcot Center over the parks' loudspeaker system.

Patti has been a Special Olympics athlete for 25 years. She loves sports, including bowling, swimming, tennis, downhill skiing, basketball, softball, the standing long jump, and horseback riding. Her best bowling score is 153: a sensational statistic for a young lady who, early in life was never supposed to be able to lift her head, stand, sit or walk. Patti often rides her favorite horse, Smokey, at Friends of the Handicapped Camp near Tinley Park.

In 1980, Patti was a member of the Dixon Developmental Center basketball team that won the Illinois State Special Olympics championship.

Today, Patti has a Grand Marshal Certificate, photographs, a VCR film, and gifts from Disney World with which to remember her very special trip to Orlando in 1993.

In addition, Resolution #681 was introduced into the Illinois State Senate honoring Patrice Shapen and 16 other Illinois Special Olympians for 25 years of participation. The Resolution was introduced by Senator Aldo DeAngelis.

Most likely, Patti gets some of her enthusiasm for life from her mother, Hazel, Past President of the Howe Parents Association, a long-time member of Voice of the Retarded, and an active advocate in Illinois for persons with mental retardation.

The second thing the Kentucky legislature did was to give the parents and guardian of a retarded person the right to participate in the hearings regarding placement, and to appeal rulings they felt were not in the best interests of the retarded person. In other words, if someone was arguing against placement of a person in a residential facility, the parents or guardian could argue for it, and appeal if the placement was turned down.

After the State of Kentucky amended its law to apply these different kinds of treatment to placement proceedings for the retarded, the Legal Aid Society of Kentucky filed a class action suit in the federal district court in Kentucky and argued that giving different treatment to the retarded violated the rights of the retarded under the U.S. Constitution! This was the same organization that had previously gone to the federal courts to force Kentucky to consider the placement of the retarded as an involuntary commitment proceeding. The theory of the Legal Aid Society seemed to be that placement of the retarded is always an adversary proceeding and that parents and guardians are the last persons who should have any say in the matter!

The legal Aid Society was successful in having the federal district court strike down the two parts of the law that provided different treatment of the mentally retarded. The State Attorney General appealed, but the Court of Appeals for the Sixth Circuit affirmed the district court ruling. When the Supreme Court agreed to review the decision, President Polly Spare consulted the law committee and others and decided that VOR should file an amicus curiae brief to support the state of Kentucky. VOR feels that the placement of the retarded in residential facilities should not be treated as an involuntary commitment, as required in Kentucky. However, Kentucky's efforts to consider the special situation of the retarded deserved support, and it would be a bad precedent if the lower federal courts' decisions were upheld.

The decision of the Supreme Court in Heller v. Doe reversed the lower federal courts. The Court held that Kentucky could treat the mentally retarded differently under the law from the mentally ill, overruling the lower court decisions which held that the difference in treatment violated the Equal Protection and Due Process Clauses of the U.S. Constitution.

On the matter of standard of proof, the opinion of the majority, written by Justice Kennedy, said, in part:

"...Kentucky's basic premise that mental retardation is easier to diagnose than is mental illness has a sufficient basis in fact...

"This difference between the two conditions justifies Kentucky's decision to assign a lower standard of proof in commitment proceedings involving the mentally retarded...From the diagnostic standpoint alone, Kentucky's differential burdens of proof...are rational."

When it came to allowing parents and guardians to participate to appeal a determination regarding placement, the Court said:

"There is a rational basis also for the other distinction...that Kentucky allows close relatives and guardians to participate as parties in proceedings to commit the mentally retarded but not the mentally ill. ...By definition, mental retardation has its onset during a person's developmental period. Mental retardation, furthermore, results in 'deficits or impairments in adaptive functioning,' that is to say, 'the person's effectiveness in areas such as social skills, communication, and daily living skills, and how well the person meets the standard of personal independence and social responsibility expected of his or her age by his or her cultural group.' ...Based on these facts, Kentucky may have concluded that close relatives and guardians, both of whom likely have intimate knowledge of a mentally retarded person's abilities and experiences, have valuable insights which should be considered during the involuntary commitment process."

Given the close decision in the Supreme Court, it was quite possible that Bill Sherman's brief for the VOR, which was joined by many member groups who represent the interests of the retarded and their families, was persuasive to the majority in reaching its result. There were many national groups who joined in amici on the other side of the issue. It is interesting to note that those members of the Court usually considered the "conservatives"- Justices Kennedy, Scalia, Thomas, White and Chief Justice Rehnquist, decided to uphold the Kentucky law in both respects- Justice O'Connor joined them on the parents' right to participate. Justice Souter wrote the dissenting opinion and was joined by the more progressive or moderate justices, Blackmun and Stevens, on both issues. With Justice White leaving the Court, it is not known how Justice Ginsburg would view the question in this case should a similar issue arise in the future.

It is good that the court gave such strong recognition to the special situation of the retarded. In addition to all the other problems facing parents, relatives and guardians of the retarded, they do not need to be put in a procedural mire when seeking placement for their loved ones and wards.

But it is important to remember that state law is what gives the rights to parents and guardians to seek the best placement for the retarded. VOR and its members must be alert to efforts in the states or elsewhere to make the placement procedures more difficult, or to cut out the rights of parents and guardians. In the meantime, the Supreme Court's decision is very welcome, and should encourage us all to pursue the interests of retarded persons in obtaining residential placements that are best suited to their needs.

- Sam Golden, VOR Law Committee

Respondents

Samuel Doe, by his mother and next friend, Mary Doe, et al

Petitioner

Leonard E. Heller, Secretary, Kentucky Cabinet for Human Resources

Amici Curiae in Support of Respondents

- 1) The mental Health Law Project
- 2) The American Association on Mental Retardation
 - The ARC
 - The ARC of Kentucky
 - The Association for Persons with Severe Handicaps (TASH)
 - TASH of Kentucky
 - The American Association of University Affiliated Programs for the Developmentally Disabled
 - The American Orthopsychiatric Association
 - The Joseph P. Kennedy, Jr. Foundation
 - The American Civil Liberties Foundation

Amici Curiae in Support of Petitioner

- 1) Voice of the Retarded, et al (100 organizations)
- 2) The States of New Jersey, Indiana, Michigan, Minnesota, Nebraska, South Dakota, and Virginia

VOICE OF THE RETARDED

Send this portion with appropriate remittance.

Individual Membership - \$15.00 - Association Membership - \$150.

Contribution - \$25 \$50 \$100 \$500 other -

NAME _____
(Please print)

ADDRESS _____

_____ ZIP _____

PHONE _____

If Individual:

Relationship: Parent Sibling Relative Friend Legal Guardian Concerned Citizen

Retarded person resides at: State Facility Home Priv. Licensed Facility Community Living Arrangement

If Association Name _____

MEMORIAL TRIBUTE FUND

VOR MAINTAINS MEMORIAL FUND

This Memorial Fund is dedicated to advocacy for the benefit of developmentally disabled persons and their families.

Gifts have been received in memory of

- Norman K. Bailey
- Hilding V. Beck
- Kenneth Lowen
- Edward A. Malone
- Gerald A. McCarthy
- Joseph J. Muto
- Kathryn L. D. Nash

in honor of

Michael Siegel

Your Name _____

Your Address _____

City _____ State _____ Zip _____

_____ In Memory _____ Birthday _____

_____ Anniversary _____ Get Well Wish _____

_____ Other Occasion _____ Amount _____

In Honor of: _____

Please send acknowledgment to:

Name _____

Address _____

City _____ State _____ Zip _____

Please make checks payable to:
Voice of the Retarded

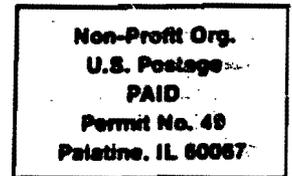
Mail form or letter to:

Voice of the Retarded
5005 Newport Drive, Suite 108
Rolling Meadows, IL 60008

Voice of the Retarded

5005 Newport Drive
Suite 108
Rolling Meadows, IL 60008

*An Association of Individuals and Parent Groups
working for Persons with Mental Retardation*



Clinton Presidential Records Digital Records Marker

This is not a presidential record. This is used as an administrative marker by the William J. Clinton Presidential Library Staff.

This marker identifies the place of a publication.

Publications have not been scanned in their entirety for the purpose of digitization. To see the full publication please search online or visit the Clinton Presidential Library's Research Room.

July: Disabilities

Pre-Employment Inquires: Avoiding Discrimination

A Guide for Managers and Supervisors



Office of Administration
Equal Employment Opportunity

THE WHITE HOUSE
WASHINGTON

September 30, 1993

MEMORANDUM FOR CAROL RASCO

FROM: Stanley S. Herr (x2372)

SUBJECT: COOPERATIVE U.S.-ISRAELI-PALESTINIAN INITIATIVE TO
CREATE A PALESTINIAN SERVICE DELIVERY SYSTEM FOR
PERSONS WITH DISABILITIES

I. Briefing papers attached:

1. Rothschild Report on Exploring Avenues for U.S.-Israeli-Palestinian cooperation in serving Palestinians with disabilities.
2. U.S.-Israel Memorandum of Understanding for Cooperation in the Fields of Social Services and Human Development.
3. Council of Jewish Federations (CJF), Summary of projects, organization, and specific contacts engaged in the U.S.-Israel Memorandum of Understanding (MOU).
4. CJF, MOU projects update.
5. Herr, Human Rights and Mental Disability : Perspectives on Israel, 26 Israeli Law Review 142 (1992) (table of contents).
6. MOU, Human Services Partnerships (brochure).

II. Background

There is a truly historic opportunity for the Clinton Administration to bring Palestinians and Israelis together for reconciliation and peaceful coexistence. Inspired by the President's remarks and the potential for joint ventures signaled by the Palestinian-Israeli accords, I requested and received your permission to explore the possibilities for encouraging and aiding disability services for the residents of the West Bank and Gaza. This effort is premised on the following assumptions:

- The universal desire of families to realize the potential of their members with disabilities and of such individuals to lead more productive and satisfying lives.
- The deep pools of expertise and leadership the U.S. possesses in both public and private sectors for building and improving disability services;

- The imminent transfer of responsibility for social services (including disability services) from the Israeli authorities to the Palestinians as envisioned by the Accords signed on September 13th on the South Lawn;
- Disability services as a highly favorable field and prototype for encouraging cooperative U.S.-Israeli-Palestinian efforts in light of the humanitarian interests at stake;
- The need for a series of concrete and immediate actions to demonstrate that the Clinton Administration will mobilize resources and technical assistance to make the Israeli-Palestinian peace deal "work";
- The ability to recruit capable, motivated partners from all sides who are willing to take risks for the benefit of the Palestinians with disabilities, the indirect benefit of Israelis with disabilities, and for a future in which Israelis and Palestinians can work together to prevent and relieve all types of disabilities, regardless of cause; and
- The President's strong interest in supporting moves toward peace and greater stability in a region sacred to Americans of many faiths.

III Conclusions

- The White House can and should stimulate a cooperative U.S.-Israeli-Palestinian Disability Services Project (hereinafter USIPDSP).
- A published report in the New York Times of Sept. 30, 1993, page 1 states that the U.S. will contribute \$500 million and states that Israel will contribute \$25 million as part of the \$2 billion in pledges over five years to Palestinian development for such matters as schools, health care, and poor relief. However, there is a strong risk that projects on disability services will be overlooked without some specific efforts of the types proposed below.
- The Rothschild Report outlines a practical, low-cost concept for planning a service delivery system for persons with disabilities (see item 1). It is based on consultations with an impressive array of responsible and knowledgeable Palestinian leaders.
- The U.S. government has existing vehicles and domestic resources for promoting a USIPDSP, including the Memorandum of Agreement between HHS, and its counterpart in the Israeli government, the

Ministry of Labor & Social Affairs, (see items 2, 3, 4 and 6).

- Federally assisted projects could mobilize additional U.S. experts with relevant knowledge and experiences, including the World Institute of Disability and the International Exchange of Experts in Rehabilitation (based at the University of New Hampshire).

- The Agency for International Development is currently funding disability projects, including an effective project in Prague that trains local leaders on how to develop modern, client-centered services and demonstrates model community-based residential programs (that project is spearheaded by Jerusalem-based experts whose experience could be tapped for the proposed USIPDSP).

- Stefan Rothschild is well-known as a respected professional with 15 years of experience in delivering services to persons with disabilities. Employed by the local parents' association for the mentally retarded (AKIM) in Jerusalem, he is in regular contact with Palestinian professionals in various disability fields and has consulted with Palestinian parents to support their efforts to improve the quality of care for their children. Of Scandinavian birth and training, he is familiar with the best service models in the U.S. and Europe. He was a U.S.-sponsored Hubert Humphrey Fellow at Johns Hopkins University in 1988, and developed the above-mentioned USAID disability project in the Czech and Slovak republics (1991 to present). He is willing to be a project coordinator, assuming a Palestinian (and possibly a U.S.) coordinator can be recruited and funding support can be obtained.

- Other private sector leaders in Israel and the U.S. have reacted very enthusiastically to a cooperative concept of this type, including :

- a. Professor Arik Rimmerman
Bar-Ilan University
Ramat Gan, Israel
disability advisor to the Israeli Ministry of Labor and Social Affairs.

- b. Heidi Goldsmith
CJF Coordinator, U.S.-Israel Memorandum of Understanding, Washington

- c. Terry Perl
Executive Director, CHIMES

(one of Maryland's largest non-profit disability service networks, which also operates CHIMES-Israel under contract with the Israel government).

d. Marvin Kivitz
CEO, The Elwyn Institute
(one of the nation's oldest residential programs in this field which also operates disability programs in both the Jewish and Arab sectors of Jerusalem).

e. Arnold H. Packer
Director, SCANS/2000 Project
Institute for Political Studies
John Hopkins University in Baltimore
(a former assistant Secretary of Labor in the Carter Administration with useful contacts here and in Israel).

●My own background for assessing the value of and potential for a USIPDSP comes from a Fulbright Senior Fellowship in Jerusalem and Tel Aviv in 1990-1991, a World Institute of Disability Fellowship in 1993, and various other domestic and international disability empowerment experiences since 1970. (see item 5)

IV. Action Steps

●As you mentioned, you can share this proposal with the Assistant for National Security and through him seek consultation from his staff and relevant internationally oriented federal agencies.

●We can try to convene a meeting in Washington to identify sources of financial, logistical, and technical support from leaders in and out of government (e.g. HHS, Ed., NIDRR, AID, State, CJF, University of Rochester, University of Minnesota/Bar-Ilan University Joint Disability Project, New Israel Fund, and Palestinian counterpart groups and exchanges).

●Most importantly we can be a catalyst for the type of dialogue that people like Stefan Rothschild have started with Palestinians who are now providing actual services or facing the challenges of planning a new service system. This means finding modest funds for initial planning conferences, needs assessments, training local leaders, and such first phase efforts. It also means finding ways that persons with disabilities can be part of the healing process for themselves and

between two peoples.

- As you have been doing in your presentations in Washington to domestic disability audiences (e.g. September 28-29th), we can inspire concrete people-to-people efforts so that people with disabilities can live in dignity and in peace.

Please advise me of your pleasure.

THE WHITE HOUSE

WASHINGTON

September 30, 1993

MEMORANDUM FOR CAROL RASCO

FROM: Stanley S. Herr (x2372) *SSH*

SUBJECT: COOPERATIVE U.S.-ISRAELI-PALESTINIAN INITIATIVE TO
CREATE A PALESTINIAN SERVICE DELIVERY SYSTEM FOR
PERSONS WITH DISABILITIES

I. Briefing papers attached:

1. Rothschild Report on Exploring Avenues for U.S.-Israeli-Palestinian cooperation in serving Palestinians with disabilities.
2. U.S.-Israel Memorandum of Understanding for Cooperation in the Fields of Social Services and Human Development.
3. Council of Jewish Federations (CJF), Summary of projects, organization, and specific contacts engaged in the U.S.-Israel Memorandum of Understanding (MOU).
4. CJF, MOU projects update.
5. Herr, Human Rights and Mental Disability: Perspectives on Israel, 26 Israeli Law Review 142 (1992) (table of contents).
6. MOU, Human Services Partnerships (brochure).

II. Background

There is a truly historic opportunity for the Clinton Administration to bring Palestinians and Israelis together for reconciliation and peaceful coexistence. Inspired by the President's remarks and the potential for joint ventures signaled by the Palestinian-Israeli accords, I requested and received your permission to explore the possibilities for encouraging and aiding disability services for the residents of the West Bank and Gaza. This effort is premised on the following assumptions:

- The universal desire of families to realize the potential of their members with disabilities and of such individuals to lead more productive and satisfying lives;
- The deep pools of expertise and leadership the U.S. possesses in both public and private sectors for building and improving disability services;

- The imminent transfer of responsibility for social services (including disability services) from the Israeli authorities to the Palestinians as envisioned by the Accords signed on September 13th on the South Lawn;
- Disability services as a highly favorable field and prototype for incurring cooperative U.S.-Israeli-Palestinian efforts in light of the humanitarian interests at stake;
- The need for a series of concrete and immediate actions to demonstrate that the Clinton Administration will mobilize resources and technical assistance to make the Israeli-Palestinian peace deal "work";
- The ability to recruit capable, motivated partners from all sides who are willing to take risks for the benefit of Palestinians with disabilities, the indirect benefit of Israelis with disabilities, and for a future in which Israelis and Palestinians can work together to prevent and relieve all types of disabilities, regardless of cause; and
- The President's strong interest in supporting moves toward peace and greater stability in a region sacred to Americans of many faiths.

III. Conclusions

- The White House can and should stimulate a cooperative U.S.-Israeli-Palestinian Disability Services Project (hereinafter USIPDSP).
- A published report in the New York Times of Sept. 30, 1993, page 1 states that the U.S. will contribute \$500 million and states that Israel will contribute \$25 million as part of the \$2 billion in pledges over five years to Palestinian development for such matters as schools, health care, and poor relief. However, there is a strong risk that projects on disability services will be overlooked without some specific efforts of the types proposed below.
- The Rothschild Report outlines a practical, low-cost concept for planning a service delivery system for persons with disabilities (see item 1). It is based on consultations with an impressive array of responsible and knowledgeable Palestinian leaders.
- The U.S. government has existing vehicles and domestic resources for promoting a USIPDSP, including the Memorandum of Agreement between HHS, and its counterpart in the Israeli government, the

Ministry of Labor & Social Affairs, (see items 2, 3, 4 and 6).

- Federally assisted projects could mobilize additional U.S. experts with relevant knowledge and experiences, including the World Institute of Disability and the International Exchange of Experts in Rehabilitation (based at the University of New Hampshire).

- The Agency for International Development is currently funding disability projects, including an effective project in Prague that trains local leaders on how to develop modern, client-centered services and demonstrates model community-based residential programs (that project is spearheaded by Jerusalem-based experts whose experience could be tapped for the proposed USIPDSP).

- Stefan Rothschild is well-known as a respected professional with 15 years of experience in delivering services to persons with disabilities. Employed by the local parents' association for the mentally retarded (AKIM) in Jerusalem, he is in regular contact with Palestinian professionals in various disability fields and has consulted with Palestinian parents to support their efforts to improve the quality of care for their children. Of Scandinavian birth and training, he is familiar with the best service models in the U.S. and Europe. He was a U.S.-sponsored Hubert Humphrey Fellow at Johns Hopkins University in 1988, and developed the above-mentioned USAID disability project in the Czech and Slovak republics (1991 to present). He is willing to be a project coordinator, assuming a Palestinian (and possibly a U.S.) coordinator can be recruited and funding support can be obtained.

- Other private sector leaders in Israel and the U.S. have reacted very enthusiastically to a cooperative concept of this type, including :

- a. Professor Arik Rimmerman
Bar-Ilan University
Ramat Gan, Israel
disability advisor to the Israeli Ministry of Labor and Social Affairs.

- b. Heidi Goldsmith
CJF Coordinator, U.S.-Israel Memorandum of Understanding, Washington

- c. Terry Perl
Executive Director, CHIMES

(one of Maryland's largest private non-profit disability service networks, which also operates CHIMES-Israel under contract with the Israel government).

d. Marvin Kivitz

CEO, The Elwyn Institute

(one of the nation's oldest residential programs in this field which also operates disability programs in both the Jewish and Arab sectors of Jerusalem).

e. Arnold H. Packer

Director, SCANS/2000 Project

Institute for Political Studies

Johns Hopkins University in Baltimore

(a former assistant Secretary of Labor in the Carter Administration with useful contacts here and in Israel).

- My own background for assessing the value of and potential for a USIPDSP comes from a Fulbright Senior Fellowship in Jerusalem and Tel Aviv in 1990-1991, a World Institute of Disability Fellowship in 1993, and various other domestic and international disability empowerment experiences since 1970. (see item 5)

IV. Action Steps

- As you mentioned, you can share this proposal with the Assistant for National Security and through him seek consultation from his staff and relevant internally oriented federal agencies.
- We can try to convene a meeting in Washington to identify sources of financial, logistical, and technical support from leaders in and out of government (e.g. HHS, Ed., AID, State, CJF, University of Rochester, University of Minnesota/Bar-Ilan University Joint Disability Project, New Israel Fund, and Palestinian counterpart groups and exchanges.
- Most importantly we can be a catalyst for the type of dialogue that people like Stefan Rothschild have started with Palestinians who are now providing actual services or facing the challenges of planning a new service system. This means finding modest funds for initial planning conferences, needs assessments, training local leaders, like first phase efforts. It also can mean finding ways that persons with disabilities can be part of the healing process for themselves and

between two peoples.

● As you have been doing in your presentations in Washington to domestic disability audiences (e.g. September 28-29th), we can inspire concrete people-to-people efforts so that people with disabilities can live in dignity and in peace.

Please advise me of your pleasure.

SEP 28 '93 08:15 AKIM JERUSALEM 972 2 663805
THIS FAX CONTAINS 5 PAGES!

1

Jerusalem, September 28, 1993

To Professor Stanley Herr
218 Old Executive Building
Washington DC 20050
U.S.A.

"There are many wounds that need to be healed - the group of the needy is large - I welcome your initiative"

Seri Nusseibah
Orient House, Jerusalem
September, 27, 1993

Dear Stanley,

Re: exploring avenues for U.S.-Israeli-Palestinian cooperation in providing assistance to a Palestinian service delivery system for persons with disabilities.

Your preliminary request to explore the possibilities for developing a proposal supporting the establishment of a Palestinian service delivery system for persons with disabilities has met with positive responses.

Background

In view of the new agreement between Israel and the P.L.O. to mutually recognize one another's fundamental right to self-determination and to implement Palestinian autonomy initially in Gaza and Jericho and later in additional areas of the West Bank, the current proposal aims at facilitating the establishment of a basic service delivery system for persons with disabilities in Gaza and in the West Bank.

The basic parameters of the current proposal entails an exchange of Palestinian, American, Israeli and other international expertise and to engage in a dialogue on all aspects of service delivery to persons with disabilities. It has been the first aim of the current proposal to solicit Palestinian endorsement of the initiative.

The current text does not reflect the result of a full or systematic screening of all potential partners to a project in the area of service delivery to persons with disabilities. It is rather an exploratory attempt to tap attitudes of potentially interested persons and to assess the timeliness of preparing a proposal.

Activities and goals:

1. To identify Palestinian partners, (organizations, professionals and family members) who are interested in promoting the development of a Palestinian service delivery system.

2

2. To identify, through personal interviews and field visits, current needs and priorities and to establish an agenda for Palestinian service delivery.

3. To facilitate the development of a Palestinian service delivery system by making international expertise available in Gaza and the West Bank and also to promote Palestinian professionals to visit American, Israeli and other service delivery systems.

4. To make funding available for developing a limited number of locally adapted service models which, if successfully implemented, might be replicated in additional locations.

Activities

The following contacts were made:

1. Dr. Seri Nusseibah - Head of the Palestinian Technical and Advisory Committee. The Committee which was established two years ago has engaged in planning for diverse aspects of the Palestinian autonomy, namely, environmental issues, the organization of the police, social development. At this point the Committee is drawing up the structure and functions for a future Palestinian government. Dr. Nusseibah declared his willingness to facilitate the implementation of all aspects of the current proposal.

2. Nadim Sheiban - Social Worker, 15 years Director of the Social Welfare Bureau in East Jerusalem of the Municipality of Jerusalem, Hubert Humphrey Fellow to the US in 1988-1989.

3. Dr. Mohamad Abu Zaid - a medical doctor with extensive experience in working for non-governmental, voluntary associations in the West Bank. Dr. Abu Zaid has been active in maintaining contacts with Israeli representatives of the "Peace Now Movement" all through the years of the intifadah and expresses an interest in inter-cultural affairs.

4. Ms Naila Rabah - Administrative Director of the Al Nahda Rehabilitation Center for the Disabled in Ramallah, West Bank.

5. Mr Ismail Amira - Mass Communication specialist trained at New York Institute on Technology and at the Cleveland State University between 1974-1986.

6. Mr Misalach Elchayat - Chairman of the Central Parents' Committee in Jerusalem.

7. Mr Omar Kabha - Senior Special Education Teacher currently directing two community based living arrangements for persons with mental retardation in East Jerusalem.

3

8. Lill Ruth Sarras - Director of the Jerusalem based Swedish Organization for Individual Relief.

Impressions and Results

The recent agreement between Israel and the P.L.O. has not yet been in existence long enough to enable a clear definition of the new possibilities for cooperation. However, all Palestinians above expressed a keen interest in exploring cooperative efforts. In talking to the Palestinians a strong feeling of satisfaction with the agreement was expressed and they conveyed the view that the opponents to peace in the Palestinian camp were a small minority. However, in the majority camp too, there are many sub-groups representing different political, social, economical and other orientations. Future efforts to support Palestinian self rule will need to include a representative cross-section of persons. For the Palestinians, the agreement with Israel signals the beginning of taking on the difficult challenges of establishing their own institutions. The transition from being an internationally, only partially recognized, popular, political and military movement opposing Israeli occupation to being a responsible governing entity will be long and difficult. The international political and military affiliations chosen by the Palestinian leadership in the past were not always beneficial in the long run and there exists a lot of clogged-up frustration in all camps about wasted time and efforts. Behind the experiences and memories of years of animosity, an undercurrent of careful optimism about the future is clearly discernable.

Establishing an agenda for service delivery to persons with disabilities is not the first priority for the Palestinian leadership, but it is one they recognize as having significant human importance. The persons that were interviewed in preparing for this paper were very appreciative of the present initiative and declared their readiness to engage in the exploration of ways to cooperate in resolving the many problems faced by persons with disabilities in the West Bank and Gaza. There are indications that several other initiatives for cooperative efforts in related areas are in the making, notably by the Israeli Ministry of Health and by the Palestinian Medical Relief Committee.

There are hundreds of private organizations in the West Bank and Gaza whose activities focus on helping people with disabilities. Many of the organizations were established during the intifadah in order to provide support for the Palestinian victims of the belligerencies. The services generally provided are institutional in character rather than community based. The organizations are generally dependent on donations to cover their operating costs. The municipalities do not, as a rule, take responsibility for delivering or for financially supporting service delivery for persons with disabilities. Two immediate concerns were expressed by the Palestinians: a. There are indications that funds made available to many private organizations in the past are not

4

forthcoming at this point. E.g. it is not clear to Ms Rabah of the Al Nahda Rehabilitation Center in Ramallah if and how the salaries for her workers will be paid this month, b. Since the first stage of the autonomy plan includes only Gaza and Jericho, there is fear that all resources will be channelized to these areas at the expense of the rest of the areas populated by Palestinians. If this observation will prove to be correct many existing services may be destroyed before the new structures are established which would hamper efforts at benefitting from continuity, and thus to facilitate a smooth transition into the new service delivery system.

Recommendations

1. To appoint two (or three) coordinators, one Israeli and one Palestinian, (and one American), whose main task would be to implement the current proposal.

2. To prepare a workshop with participants from the U.S., Israel and Palestinians on the topic of The Future Palestinian Service Delivery System For Persons With Disabilities. The purpose of the workshop, which was suggested by Mr Seri Nusseibah, would be to:

a. Outline the key questions that need to be addressed by the Palestinian leadership in order to facilitate the establishment of a service delivery system.

b. Define the operative agenda for the future Palestinian service delivery system.

c. To consult the Palestinian leadership on a suitable form of government to administer the needed services.

3. To develop a number of training programs in relevant areas of service delivery to persons with disabilities for Palestinian academics, professionals, family representatives, and direct service personnel.

4. To support the establishment of a small number of basic models of support services such as, home care, respite care, community based living arrangements, creating job training opportunities and developing a recreational program adapted to the needs of various age groups.

The details of items 3 and 4 above need further elaboration which could take place in conjunction with the workshop (item 2 above) or even prior to the workshop.

Tangible support needs to be provided soon in order to substantiate the high expectations created by the current movement towards peace in the Middle East.

Prepared by: Stefan Rothschild

"stan2"



MEMORANDUM OF UNDERSTANDING BETWEEN THE
DEPARTMENT OF HEALTH AND HUMAN SERVICES
OF THE UNITED STATES OF AMERICA
AND THE
MINISTRY OF LABOUR AND SOCIAL AFFAIRS
OF THE STATE OF ISRAEL
FOR COOPERATION IN THE FIELDS OF
SOCIAL SERVICES AND HUMAN DEVELOPMENT

The Department of Health and Human Services of the United States of America and the Ministry of Labour and Social Affairs of the State of Israel,

Desiring to:

promote cooperation between their experts in the fields
of social services and human development,

obtain solutions to problems of mutual concern through
collaborative efforts, and

share and exchange information on research and
administration of programs and services,

Have agreed as follows:

1. To realize the benefits of cooperation pursuant to this Memorandum of Understanding (hereinafter referred to as the Memorandum), the Department of Health and Human Services and the Ministry of Labour and Social Affairs, hereinafter referred to as the Parties, agree to exchange information and to develop other cooperative activities as specified below, or as may be subsequently agreed upon.
2. Cooperative activities initiated under this Memorandum will be conducted on the basis of equality, reciprocity, and mutual benefit. Such cooperation may be implemented through: (a) exchange of delegations, professionals and specialists, to include study visits; (b) exchange of information, standards, regulations and procedures, to include publications and monographs; (c) organization of joint conferences, seminars, workshops and meetings; (d) development of collaborative projects or demonstrations; or (e) other forms of cooperation that may be agreed upon.
3. The financing of activities under this Memorandum shall be determined by agreement and is subject to the availability of funds and personnel and to the laws and regulations of the United States of America and the State of Israel. In general, each side shall bear the costs for its participation in projects and activities unless otherwise agreed upon.

4. Areas identified for possible cooperation are as follows:

- a. Adoption of children with special needs
- b. Community and in-home services for functionally impaired populations
- c. Innovative housing arrangements for the aged
- d. Intergenerational linkages
- e. Programs designed to reduce dependency
 - (i) work-related day care
 - (ii) in-home day care
- f. Social indicators
- g. Developmental disabilities
- h. Access to services by the handicapped
- i. Juvenile delinquency - prevention/rehabilitation
- j. Other areas as may be mutually agreed upon

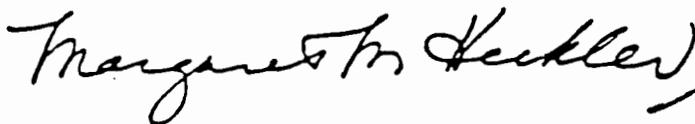
5. Overall coordination shall rest on the U.S. side with the Office of the Assistant Secretary for Human Development Services and on the Israeli side with the Department of International Relations of the Ministry of Labour and Social Affairs. The representatives of these agencies will meet as necessary to review the implementation of exchange and cooperation and to develop annual and future programs within the framework of this basic agreement. Both sides will designate coordinators for each cooperative activity that is undertaken. Coordinators shall serve as the initial points of contact for developing joint activities and responding to requests for information or exchange of materials.

6. This Memorandum shall enter into force upon signature and shall remain in force for a period of five years. It may be amended or extended by the written agreement of the Parties. Either Party may terminate this Memorandum after one hundred and twenty days written notification of its intention to do so.

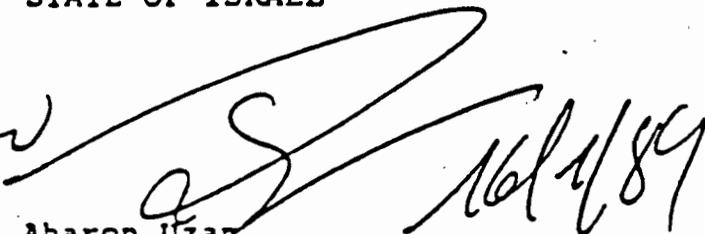
DONE at Washington, D.C., and Jerusalem, in duplicate in the English language.

FOR THE DEPARTMENT OF HEALTH
AND HUMAN SERVICES OF THE
UNITED STATES OF AMERICA

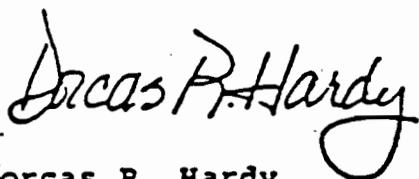
FOR THE MINISTRY OF LABOUR
AND SOCIAL AFFAIRS OF THE
STATE OF ISRAEL



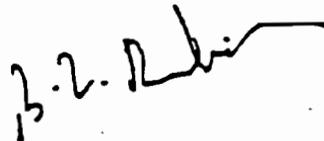
Margaret M. Heckler
Secretary
Date: 1/12/84



Aharon Uzan
Minister
Date:



Dorcas R. Hardy
Assistant Secretary
for Human Development
Services
Date: 1/16/84



Ben-Zion Rubín
Deputy Minister
Date: 16/11/84



U.S. - ISRAEL MEMORANDUM OF UNDERSTANDING

• COUNCIL OF JEWISH FEDERATIONS • 1640 RHODE ISLAND AVENUE, N.W. SUITE 500 • WASHINGTON, D.C. 20036 • 202/736-5860

September 21, 1993

Stanley Herr
Room 224
Old Executive Office Building
Pennsylvania Avenue
Washington, D.C. 20050

Dear Stanley,

It was good to speak to you. Congratulations on your current position.

Attached you will find the information you requested. I gave you minimal information at this point, and will give you more details on those projects, organizations, or specific people according to your interest.

I have also faxed my counterpart in Israel, Dr. Stephen Donshik, for further suggestions.

I look forward to speaking with you soon.

Sincerely,

Heidi Goldsmith
Heidi Goldsmith
Coordinator

U.S.- ISRAEL MEMORANDUM OF UNDERSTANDING

The U.S.- Israel Memorandum Of Understanding (MOU) in Social Services and Human Development is a formal agreement between the U.S. Department of Health and Human Services (HHS) and its Israeli counterpart, the Ministry of Labour and Social Affairs. The MOU was signed in 1984 for a five year period, renewed in 1989 for another five year period, and it is anticipated that it will be renewed again in 1994. The Council of Jewish Federations facilitates the implementation of the MOU, under a grant from HHS.

The aim of the MOU is the improvement of the delivery of social services in both countries through collaborative activities and the exchange of experts, technology, procedures, information, and programs. A wide variety of bi-national projects have taken place under the framework of the MOU over the past nine years, including many in the area of developmental disabilities. Below is a summary of activities that have taken place in this field:

University of Rochester School of Medicine and Dentistry (U.A.P.D.D.)/ Child Development Center of Soroka Hospital, Ben Gurion University of the Negev; Crisis Intervention for People with Dual Diagnosis. 1990- 1994. This program aims to improve community-based crisis intervention services for developmentally disabled children with psychiatric and behavioral disorders. Rochester's comprehensive home-based crisis intervention program is being adapted and expanded in Israel to include younger children and those residing in rural areas who have these multiple disabilities. The project examines the components of a successful intervention program including the obstacles to its implementation in different cultures and for different age groups. This project is especially significant because behavioral and psychiatric disorders are considered to be the leading barriers to community integration for people with developmental disabilities. Behavior crises is one of the principal threats to community integration.

U.S. Project Coordinator- Dr. Phil Davidson, U. of Rochester- 716-275- 2986

Dr. Davidson is also planning a bi-national conference for professionals involved in this field which will take place in the early summer in Israel.

Israeli Coordinator- Esther Goldstein, CDC of Soroka Hospital

Atlanta Shepherd Spinal Center/ Alyn Orthopedic Hospital (Jerusalem) Spina Bifida Project; 1987- 1991. The aim of the project was the development of a model to promote the social integration and independence of children with Spina Bifida and other developmental disabilities. The two institutions have similar demographics and both were in the process of setting up programs and services beyond the medical model by involving the families and communities of Spina Bifida patients. Alyn has extensive experience with children with disabilities; Shepherd with the rehabilitation of people with spinal cord injuries. Program components and testing instruments were jointly designed. Ongoing results were shared which provided a larger, more accurate data pool. The varied cultural perspectives on people with disabilities were shared, and often tested in the other country. In addition, through summer camp and residency programs, the Shepherd Spinal Center built upon Alyn's successful experience in establishing living arrangements for developmentally disabled people. The model developed through this joint project has now been emulated in other sites in both countries.

U.S. Contact: Judy Reinohl, Shepherd Spinal Center- 404-352- 2020
or David Sarnat, Atlanta Jewish Federation Executive
Director- 404- 873- 1661

Israeli contact: Tirzta Ilan, Chief Social Worker, Alyn Hospital

University of California, Santa Barbara/ Tel Aviv University Special Education Program; 1987- 1990. The two universities conducted a three year study to explore opportunities for persons with developmental disabilities to use computer technology for vocational rehabilitation, and a review of employment opportunities for these people. The project assisted developmentally disabled persons find employment while providing a pool of entry level employees for industry in both countries. As a result of the training they received (on software developed in Israel and translated into English), students showed a marked increase in self-confidence while the business community recognized the value and reliability of these students as employees. Papers, task analyses, and reports were prepared for dissemination.

U.S. Project Coordinator- Dr. Mel Semmel, UCSB- 805- 893- 3477
Israeli Coordinator- Dr. Malka Margalit, Tel Aviv U., School of
Special Education

Jewish Foundation for Group Homes of Washington, D.C./ Israel; 1989- Present. Funded by a private, family foundation, this program is an annual internship providing one Israeli an entry level position with JFGH. This is a unique opportunity to broaden his\ her expertise in the field of developmental disabilities for a period of one year. He/she lives at a JFGH group home and receives a modest hourly salary for his/her direct service care of individuals. The intern gains valuable experience which he/she

will bring back to colleagues in Israel, while enriching the Judaic atmosphere of the JFGH program.

U.S. Contact- JFGH Director (program was begun by the former director)- 301-984- 3839.

Chimes (Baltimore and Tel Aviv); 1992- present. Though not officially an MOU "project", the MOU has been consulting with Chimes Baltimore on their opening of Chimes, Israel. Upon the request of the Israeli Ministry of Labour and Social Affairs, which wants to test "privatization" of some of its programs and services. Chimes, Israel opened in 1992, assuming management of two programs (small institutions formerly managed by the Ministry) in the Tel Aviv area.

U.S. Contact- Terry Perl, Director of Chimes- 410- 521-1555.

Temple University, U.S. Department of Health and Human Services/ Israeli Ministry of Labour and Social Affairs; Conference on Developmental Disabilities. 1983. This was not an MOU project. In fact, this was a precursor to the MOU and one of the catalysts for the MOU. At this conference representatives of HHS and the Ministry agreed that an MOU would be of benefit to all.

U.S. Contact (he is also on the board which advises CJF on the implementation of the MOU): Dr. Ed Newman- 215- 635- 3190.

EXPERTS

In the past four years the following professionals in the field of developmental disabilities, in addition to those mentioned above, have been outstanding:

- 1) Dr. Herb Cohen- Einstein College of Medicine- 212- 430- 2440
- 2) Sister Bernadette Wynne, Director of the Helen Keller National Center- 111 Middle Neck Road, Sands Point, N.Y. 11050
There is now a Helen Keller Center in Jerusalem, but I'm not exactly sure what the connection is with the New York center. By the way, I haven't been in contact with her for two years.
- 3) Al Miller- Executive Vice President of F.E.G.S, the largest voluntary vocational training organization in the U.S., has done a lot of work with Israel, including building training institutes there. He is creative, always open to new ideas, has some flexible funds, and has a large program (New York based, at this time) for people with developmental disabilities. 212- 366- 8400.

4) Sheldon Bycoff, President of VINFEN Corporation in Boston, is keenly interested in a project with Israel, and is currently trying to develop one through a private consultant. VINFEN is a PVO which operates a comprehensive array of community-based residential, social service and mental health programs for "a diverse multicultural group of developmentally disabled, emotionally disturbed adults in over 70 sites". 617- 254- 7300.

ISRAELI ORGANIZATIONS

The following Israeli organizations are among the most appropriate to get involved with the initiatives under consideration:

1) The Child Development Center system in general. Dr. Celia Kozokov, Director of the CDC in Sfat, is outstanding, is very interested in a project that is "international", and has a good deal of experience in working with Arab families.

2) AKIM- especially in those cities in Israel where they actually provide services, not just "advocacy" (as has been the case in Tel Aviv until recently). My sources in Israel have told me that AKIM Jerusalem was recently taken over by a progressive organization, "SHEKEL".

3) The Aleh Center in Bnai Brak is supposed to be outstanding, (though I've only seen a video of it) with an open-minded, competent director- Dr. Diamond.

4) Yad Sarah- Easily one of the most logical organizations for what you have in mind. As you probably know, they are a Jerusalem-headquartered PVO whose original purpose was the free loan of medical equipment. By now they serve a varied population, including Arabs, have branches in over 60 locations in Israel, including in Arab villages, and most of their "staff" is volunteers. Contact: Judith Intract or the Director, Uri Lupoliansky. 43 HaNevi'im Street, Jerusalem.

5) Dr. Sam Raz, Director of the Variety Center in Jerusalem. This new multi-million dollar center for children also houses part of Dr. Reuven Feuerstein's programs. I'm sure you know Dr. Feuerstein, and his work with people with developmental disabilities using his "Instrumental Enrichment" techniques.

6) Last, but not least, the Joint Distribution Committee. Dr. Paul Gitelson, who you probably know, is dedicated and worth consulting with.

7) Avraham Lavine, Director of International Relations for the Ministry of Labour and Social Affairs, would likely know what organizations there are which serve people with developmental disabilities in the "territories". His fax is: 011-972-2-731640. His direct phone line is: 011- 972-2-708130 or 708129.



U.S. - ISRAEL MEMORANDUM OF UNDERSTANDING

21 COUNCIL OF JEWISH FEDERATIONS • 1640 RHODE ISLAND AVENUE, N.W. SUITE 500 • WASHINGTON, D.C. 20036 • 202/736-5860

To: Stan Herr
From: Heidi Goldsmith
Date: September 22, 1993

A few additions to the enclosed information which I faxed you last night:

1. Dr. Diane Bryen's phone number is 215- 204- 6037 at Temple University.
2. I would add to the list of Israelis the name of Yitzchak Berman, who works in the Ministry of Labour and Social Affairs in Jerusalem- at the national level. He's a "doer", has a lot of experience with international projects, is a former American with a good sense of humor and good sensitivity. Phone: 011- 972- 2- 708346.
3. According to my colleague at CJF in Israel, Stephen Donshik, the organization "Shekel" which I mentioned already, is directed by Clara Feldman. They provide services to Jewish, Arab, and Palestinian sectors of Jerusalem.
4. Stephen also said that Elwyn has expanded their services over the past few years, and also have programs for Israeli Arabs and Jews and Palestinians. Avi Ramot is the Director.

I look forward to your reactions, and to seeing what develops.

GOVERNMENT PERSONNEL EXCHANGE PROGRAM

September 1992. Chaim Pozner, Director of Personnel and Social Services at the Israeli Ministry of Labour and Social Affairs (MLSA), met with top officials of the Administration for Children and Families at HHS to compare the social services provided to refugees and new immigrants in Israel and the United States. Pozner explained that new immigrant social services in Israel are not separated from the services provided to the general citizenry. Israel believes this hastens the integration process of the immigrants into society. Integration programs there currently emphasize language and cultural adaptation before employment.

December 1989. Deputy Assistant Secretary Givens spent 5 days in Israel meeting with staff of the MLSA, and studying Israeli social service organizations and practices.

March 1986. Arieh Garber, then Acting Director of the MLSA Division of Personal and Social Services worked in Washington, D.C., with Office of Human Development Services (OHDS) for several months.

1985-1987. Byron Gold, an analyst with the Administration On Aging, was assigned by OHDS to work with the MLSA in Israel.

MOU-Related Activities

BI-NATIONAL QUARTERLY CONFERENCE CALLS BETWEEN HHS AND MLSA. Initiated in early 1990, these calls are an integral component of the open communication between the two government agencies. They are invaluable tools in maintaining the high level of commitment required for the success of the MOU.

PRINCIPAL DEPUTY ASSISTANT SECRETARY, ADMINISTRATION FOR CHILDREN AND FAMILIES, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES. Donna Givens visited Israel in December, 1989, accompanied by CJF MOU Coordinator Heidi Goldsmith, to meet with Israeli social welfare policy-makers and practitioners. Her visit also allowed both countries to forge an agreement on mutual priorities and collaborations for the near future. Department of Health and Human Services Secretary, Dr. Louis Sullivan, visited Israel in January, 1990. He praised the aims and accomplishments of the MOU and pledged continued HHS commitment.

MEMORANDUM OF UNDERSTANDING - US DEPARTMENT OF LABOR / ISRAELI MINISTRY OF LABOR AND SOCIAL AFFAIRS, NOVEMBER 1986. The two government agencies signed an MOU in the field of labor, which pledges cooperation in the following areas: Employment and Training, Labor-Management Relations, Occupational Health and Safety, Research and Statistics, Labor Standards, Occupational Rehabilitation, Women's Affairs, and others as mutually agreed upon. This was an indirect outcome of the MLSA's agreement with HHS in social services.

LABOR CONFERENCE, NOVEMBER 1987. The first major project under the MOU between the U.S. Department of Labor and the MLSA, a three-day conference attracted American and Israeli labor leaders from the public and private sectors. Organized by the Council of Jewish Federations and funded by the Department of Labor, the State of Israel, and the Federation Employment and Guidance Service of New York, the focus was primarily on issues of occupational health and safety, collection and use of labor statistics, and employment and training. Presenters from both countries shared problems, techniques, and plans for the future via formal presentations and working group sessions. Two volumes of the proceedings and the papers presented have since been published.



U.S. - ISRAEL MEMORANDUM OF UNDERSTANDING

Item 4

21 COUNCIL OF JEWISH FEDERATIONS • 1640 RHODE ISLAND AVENUE, N.W. SUITE 500 • WASHINGTON, D.C. 20036 • 202/736-5860

MOU PROJECTS UPDATE: MAY 1993

Projects in Progress

* **UNIVERSITY OF ROCHESTER SCHOOL OF MEDICINE AND DENTISTRY (U.A.P.D.D.) / CHILD DEVELOPMENT CENTER OF SOROKA UNIVERSITY HOSPITAL, BEN GURION UNIVERSITY OF THE NEGEV; Crisis intervention for people with Dual Diagnosis, 1990-1993.** This program aims to improve community-based crisis intervention services for developmentally disabled children and adults with psychiatric and behavioral disorders. Rochester's comprehensive home-based crisis intervention program is being adapted and expanded in Israel to include younger children and those residing in rural areas who have these multiple disabilities. The project examined the components of a successful intervention program including the obstacles to its implementation in different cultures and for different age groups.

The project is especially significant because behavioral and psychiatric disorders are considered to be the leading barriers to community integration for people with developmental disabilities. Behavior crises is one of the principle threats to maintaining these persons in community-based residential care. Ben Gurion University epidemiologist, Dr. Ilana Shoham, is spending this year on sabbatical at the University of Rochester in New York to help evaluate the project's successes thus far. Several professional papers are being prepared that will disseminate information about the program to a broader audience.

* **WAYNE STATE UNIVERSITY'S MERRILL PALMER INSTITUTE, LUTHERAN FAMILY AND CHILDREN'S SERVICE / HEBREW UNIVERSITY; Foster Care Monitoring System, 1992-1995.** Lutheran Family and Children's Service, with the assistance of Wayne State University, is adapting Hebrew University's computerized foster care monitoring system. The computerized system is based on a model that combines structural and systematic monitoring of each child with the aggregation of this information across the whole system. The system, developed on a national level in Israel and now mandated there, is being modified and expanded for the U.S. foster care system.

The U.S. and Israeli foster care systems differ slightly in terms of the intensity of contact between adults and children, some regulations, length of time in care, and the kinds of problems facing biological families. Wayne State is facilitating the adaptation of the Israeli system, in light of these barriers.

* **UNIVERSITY OF ARIZONA AT TUCSON AND YAQUI AMERICAN INDIAN TRIBE, TUSCON, ARIZONA / HUBERT H. HUMPHREY INSTITUTE OF SOCIAL ECOLOGY AT BEN GURION UNIVERSITY OF THE NEGEV AND THE BEDOUIN COMMUNITY OF RAHAT; Youth Dropout Prevention, 1992-1995.** Collaboration is underway to implement a program on youth dropout prevention among the Pasqua Yaqui Indian Tribe in Tucson, Arizona and the Bedouin community of Rahat in Israel. The project is being conducted in consultation with the Hubert H. Humphrey Institute of Social Ecology at Ben Gurion University of the Negev and the American Indian Graduate Center of the University of Arizona. The three primary components are: 1) culturally appropriate teaching, 2) after-school programming to stimulate young people's interest in school and careers, and 3) counselling parents on the importance of education for their children. Representatives of the two tribes and the two universities have visited each other, designed the program, and are in the first phase of implementation. A survey in both communities is being conducted to gauge third and sixth graders' self-esteem and long-range goals.

* *Distinguishes projects which received full or partial funding from the U.S. Department of Health and Human Services*
An agreement between the U.S. Department of Health and Human Services and the Israeli Ministry of Labour and Social Affairs

"RESIDENTIAL EDUCATION AS AN OPTION FOR AT- RISK YOUTH - LESSONS FROM THE ISRAELI EXPERIENCE;" At- Risk Youth, 1993 - PRESENT Israel's 60+ year old residential education system (which includes the Youth Aliyah village system and other residential education centers) is being examined for replication in the U.S. for at-risk youth. In January, 1993, 25 leading American Youth At-Risk practitioners, policymakers, academicians, and funders visited Israel to evaluate the efficacy of replicating the system or components of it in the U.S. They agreed these centers should be an option available for economically and socially disadvantaged youth in America.

On April 22, a follow-up conference was held in Washington, D.C. to introduce the Israeli system to a larger audience. Participants generated a list of recommendations for "next steps" in this initiative which are being prioritized and will soon be acted upon. The National Council of Jewish Women, F.E.G.S., and the National Jewish Community Relations Advisory Council have been primary players in this project, along with the CJF MOU Office.

APPALACHIAN EDUCATIONAL LABORATORIES / GIMMEL FOUNDATION; Teachers as At-Risk Youth Workers in Rural Areas 1992 - PRESENT The Gimmel Foundation in Israel has developed an innovative model of service integration in which local teachers are trained as para-professional social workers within their communities utilizing health, education, and social service agencies to assist at-risk children. Teachers, due to their already established credibility within the community and families, are well suited to identify children with at-risk factors. The program intends to improve access to health and human services as well as empower families to address their future health and human service needs. The Appalachian Educational Laboratory, is adapting this program in an Appalachian community - Philippi, W.V.

JEWISH FOUNDATION FOR GROUP HOMES OF WASHINGTON, D.C. / ISRAEL, 1989 - PRESENT. Funded by a private, family foundation with program development assistance from CJF, this annual internship program provides one Israeli an entry level professional position with the Jewish Foundation for Group Homes. This is a unique opportunity to broaden his/her expertise in the field of developmental disabilities for a period of one year. This person lives at a JFGH and receives a modest hourly salary for his/her direct service care of individuals. The intern gains valuable experience which he/she will bring back to colleagues in Israel, while enriching the Judaic atmosphere of the JFGH program.

BOSTON / JERUSALEM SOCIAL SERVICES PROFESSIONALS EXCHANGE, 1992 - PRESENT A group of children at-risk professionals from the Jerusalem municipality spent one week in Boston in October, 1992. The group visited Boston area social service agencies for children. In June, 1993; a group of Boston area social service directors will visit human service providers in exchange.

Completed Projects

* **ATLANTASHEPHERDSPINAL CENTER / ALYN ORTHOPEDIC HOSPITAL SPINA BIFIDA PROJECT, 1987-1991.** The aim of this project was to develop a model to promote the social integration and independence of children with Spina Bifida and other developmental disabilities. The two institutions have similar demographics and both were in the process of setting up program services beyond the medical model by involving the families and communities of Spina Bifida patients. Alyn has extensive experience with Spina Bifida patients specializing with children. The Shepherd Spinal Center excels at the rehabilitation of people with spinal cord injuries. Program components and testing instruments were jointly designed. Ongoing results were shared which provided a larger, more accurate data pool. In addition, through summer camp and residency programs, the Shepherd Spinal Center built upon Alyn's successful experience in establishing independent living arrangements for developmentally disabled persons.

* **LOS ANGELES / JERUSALEM FRAIL ELDERLY PROGRAM, 1987-1991.** The cooperative cities program between the municipalities of Los Angeles and Jerusalem was facilitated by the Jewish Federation Council of Greater Los Angeles. The first phase of the program was a survey and examination of community-based services in both cities for frail and economically disadvantaged elderly through a series of exchanges of information about policies, innovative programs, challenges in delivering care to ethnically diverse communities, and the needs of both cities' elderly populations. The second phase was a demonstration project utilizing neighborhood volunteers to work with frail elderly in such culturally diverse communities as L.A.'s predominantly Hispanic, largely Black, Watts' community, Israel's Jewish West Jerusalem and Arab East Jerusalem.

Volunteers provided a variety of services such as friendly visits, personal care, meals-on-wheels, as well as informed clients about government benefits not previously known to them. The network of volunteers proved to be a cost-effective complement to professional services as well as expedited the delivery of care for the elderly in under-serviced areas. The project successfully demonstrated that multi-ethnic professional linkages can be established and maintained when addressing problems common to all communities. The Jerusalem Department of Human Services and the municipality of Los Angeles are now funding the project as new parts of their respective budgets.

* **UNIVERSITY OF CALIFORNIA, SANTA BARBARA / TEL AVIV UNIVERSITY SPECIAL EDUCATION PROGRAM FOR DEVELOPMENTAL DISABILITIES, 1987-1990.** The two universities conducted a three year study to explore opportunities for persons with developmental disabilities to use computer technology for vocational rehabilitation and a review of employment opportunities for persons with developmental disabilities. The studies were designed to: 1) match individual skills with tasks in demand in the high-tech sector, and 2) utilize computer technology in ways which compensate for possible cognitive limitations of persons with developmental disabilities. The project assisted developmentally disabled persons to find employment while providing a pool of entry level employees for industry in both countries. As a result of the training, students have shown a marked change in self-confidence while the business community has recognized the value and reliability of these students as employees. Papers, task analyses, and reports were prepared for dissemination.

ELI CHILD ABUSE PREVENTION MODEL, 1989 - 1991 This project developed a crisis intervention model suitable for an abused child. This model was based on therapeutic techniques appropriate for the unique needs of children in crisis. Set in an Israeli crisis intervention center, the study involved intensive contact with a large number of abused children in various stages of crisis. Dr. Hanita Zimrin, Project Director for Eli, has presented her findings at many conferences in the U.S., including those sponsored by HHS.

* **KANSAS CITY / HAIFA EDUCATION PROGRAM, 1986-1989.** This program, supported by a grant from HHS and facilitated by the Jewish Federation of Greater Kansas City, was an exchange between the University of Kansas, the Kansas City-based Juniper Gardens, and the University of Haifa. The project involved the Israeli replication of "active learning" through peer tutoring, a technique developed in Kansas. Israeli children in various settings, using this technique, experienced significant improvement in their academic performance. Behavior problems also decreased. This program proved, through the use of a diverse student population, that the "active learning" methods used are effective regardless of socioeconomic and cultural conditions. Dr. Rolider, a renowned professor of behavioral science from the University of Haifa, trained Kansas City-area professionals on the methods of using behavior modification with self-injurious adolescents.

* **DEPARTMENT OF HEALTH AND REHABILITATIVE SERVICES OF FLORIDA / JOINT DISTRIBUTION COMMITTEE (BROOKDALE INSTITUTE OF GERONTOLOGY AND ADULT HUMAN DEVELOPMENT), 1987-1989** The Florida Department of Health and Rehabilitative Services tested the efficacy of a system developed by Brookdale, whereby quality and appropriateness of care in congregate living settings and nursing homes for the elderly are evaluated using a "tracer" method. A "tracer" is a well-defined and frequently occurring problem which has a known treatment, such as hypertension, vision and hearing difficulties, and mobility problems. The basic assumption in this method is that the manner in which care is provided for these "tracers" is an indicator of the quality of care as a whole in the congregate housing and nursing home facilities. Meanwhile, Brookdale tested an altered tracer approach in which tracers are utilized by staff other than doctors and nurses.

The evaluation method has been shared with evaluators throughout the U.S. by way of conference presentations and professional papers. This "tracer" method has now been established as a standard method for congregate housing evaluation throughout Israel and been adopted by many communities in the U.S.

* **UNIVERSITY OF MICHIGAN / BEN GURION UNIVERSITY, 1988.** A cooperative research venture between the American and Israeli institutions studied the improvement of community self-help by analyzing self-help groups and developing models for an "ideal" support group. The work focused on two self-help groups in the United States (Parents of Children with Cancer and Parents of Murdered Children) and Israel (Families of Mentally Ill Children and Families of New Immigrants). Project evaluators found that in both countries such groups are similarly structured, but this structure must be adapted to fit the parameters of local social service systems. Success of such groups is largely dependent on the expectations people bring to them.

Government Exchanges

U.S.I.A. SECOND WORLDNET CONFERENCE, SEPTEMBER 1992. An international satellite broadcast on Child Abuse Prevention and Treatment took place between representatives of U.S. Department of Health and Human Services (HHS), the National Center on Child Abuse and Neglect, the Director of Social Services in Prince George's County, Maryland, representatives of the Israeli Ministry of Labour and Social Affairs (MLSA), and the Director of ELI-Israel Association for Child Protection. The conference utilized the broadcast facilities of the U.S. Information Agency. Discussions gave a historic perspective on government action concerning Child Welfare, the status of legal action taken to combat child abuse in each country, and programs being developed to ensure early intervention into families and better prevention of abuse and neglect.

U.S.I.A. WORLDNET CONFERENCE, NOVEMBER 1990. HHS and MLSA took part in an international satellite broadcast entitled, "Volunteering By and For the Elderly." Experts from both countries shared their experiences on the subject -- an area of priority under the MOU.

USE OF DATA IN SOCIAL SERVICE EVALUATION, MARCH 1989. This seminar, co-led by two Israeli experts and two HHS representatives, was held at HHS. Israel produced a report of the proceedings.

COMPUTERIZATION STUDY TOUR, 1986. A delegation of officials from the MLSA visited the U.S. to observe and analyze developments for computer systems in social services and to exchange views for the planning and implementation of such services in Israel.

Item 5

HUMAN RIGHTS AND MENTAL DISABILITY: PERSPECTIVES ON ISRAEL

*Stanley S. Herr**

- I. *Introduction*
- II. *International Standards*
- III. *Recent Developments in Israel*
 - A. *Context*
 - B. *Rights to Special Education*
 - C. *Rights to Developmental Services*
 - D. *Individual Rights*
- IV. *Taking Disability Rights Seriously*
 - A. *Assessing the Israeli Experience*
 - B. *The Case for Human Rights Initiatives*
- V. *Conclusion*

I. *Introduction*

The human rights of persons with mental disabilities represents a frontier area for legal protection. The content and means of enforcing their rights have become topics of both scholarly and popular concern. For two decades, the international community has grappled — somewhat fitfully — with the human rights norms that should guide nations in their care and treatment of these vulnerable groups. International concern has focused not only on problems of arbitrary detention and cruel, inhumane or degrading treatment, but on issues of institutionalization, sterilization, and a broad array of education, treatment and welfare services.

In many countries, obsolete legislation and service delivery models have hindered the realization of both negative and affirmative (“positive resource claims”) human rights.¹ As devalued and marginalized citi-

* J.D., D. Phil. (Oxon.); Associate Professor, University of Maryland School of Law; Senior Fulbright Scholar, Bob Shapell School of Social Work, Tel Aviv University and The Faculty of Law, The Hebrew University of Jerusalem, 1990-1991. For their insights and hospitality, I especially thank Dean Mordechai Kremnitzer, Head of School Shimon Spiro, Celia Fassberg, Neta Ziv Goldman, Kenneth Mann, Arik Rimmerman, Stefan Rothschild, Amos Shapira and Dan Shnit.

¹ See L. Henkin, *The Age of Rights* (1990) 2; P. Morris, *Put Away: A Sociological Study of Institutions for the Mentally Retarded* (1969).



THE PRESIDENT'S COMMITTEE ON
EMPLOYMENT OF PEOPLE WITH DISABILITIES

1331 F STREET, N.W., WASHINGTON, D.C. 20004-1107
(202) 376-6200 VOICE (202) 376-6205 TDD (202) 376-6219 FAX

orig: CHR
re: New name
let's
discuss
in
our
meeting
next week
CHR

CHAIRMAN
JUSTIN DART

file

September 20, 1993

SEP 22 RECD

Ms. Carol Rasco
Assistant to the President
Domestic Policy
The White House
Washington, D.C. 20500

Dear Ms. Rasco:

Thank you so much for meeting with my colleague Dale Brown to discuss disability policy. You requested a letter from our agency outlining a program through which the Clinton Administration could provide model leadership for the harmonious implementation of a major civil rights law - the Americans with Disabilities Act (ADA).

ADA is the foundation for fulfilling the promises of the Declaration of Independence and the Constitution to 43 million persons with disabilities who form our nation's poorest, most isolated, and dependent minority. Almost 70% of employable Americans with disabilities are out of work.

ADA is the world's first comprehensive civil rights law for people with disabilities. It is a landmark in the evolution of humanity. After an eternity of outcast status, poverty and early death, people with disabilities are declared full members of the human race. For the first time they will have a real opportunity to move from charity and welfare, from institutions and isolated back rooms, to become employees, consumers, taxpayers and welcome participants in their communities.

Some anti-civil rights lobbyists say that ADA is going to be costly for business, that it will bankrupt small business. They say businesses will be forced to pay salaries for unqualified employees and enormous costs to make facilities accessible, and that they will be overwhelmed by litigation.

The truth is that ADA specifically states that no business will have to employ a single person who is not the best qualified candidate for the job, that no business will have to spend a single penny that it can't afford to spend on renovating facilities or providing special accommodations. The truth is that 88% of the accommodations for employees with disabilities cost less than \$1,000-; 69% less than \$500-; 50% less than \$50; 31% nothing. The truth is that the predicted avalanche of litigation has not

occurred. People with disabilities want jobs, not lawsuits. The truth is that it costs America almost \$200 billion per year in public and private payments to exclude millions of Americans with disabilities from the productive mainstream. The implementation of ADA will cost a fraction of one percent of that amount.

President Clinton has said, "I am strongly committed to full implementation and enforcement of the ADA, because I believe that our entire nation will share in the economic and social benefits that will result from full participation of Americans with disabilities in our society."

First let me say that the President and his Administration have already made a good start toward model implementation. He has made repeated and firm pledges to implement ADA. He has appointed some magnificent pioneers of disability rights and ADA to serve in his administration: Judy Heumann, Marca Bristo, Bob Williams, Bob Simpson, Max Starkloff and many more. He has included people with disabilities in the decision making process. On July 27th he conducted an historic first face-to-face Presidential dialogue with leaders of the disability community. Attorney General Janet Reno has also met disability community leaders to discuss ADA, has made firm pledges to enforce the law, and has announced increases in ADA technical assistance funds and the number of staff attorneys assigned to implementation. Your request for this letter is another good example of positive ADA action.

RECOMMENDATIONS

Following is a skeleton outline of suggestions for positive ADA action by the Clinton Administration. This is not a plan for an hypothetically "ideal" approach, but rather a listing of actions which we know are practical in the current financial, political and personnel reality.

1. PERSONAL ACTION BY THE PRESIDENT

Most important is visible leadership by the President personally.

- He should make brief mentions of ADA and the rights of people with disabilities as a high priority - in public speeches, talk shows, TV, radio, PSAs, videos, to various groups. In most cases a sentence or a phrase will suffice, or simply listing people with disabilities among those whose rights and economic/employment situation must be improved. Special attention should be given to

brief, positive mentions when the President addresses groups with major potential to provide positive leadership for voluntary compliance with ADA: business; labor; architects; lawyers; builders; state and local government; media. The upcoming focus on health care reform will offer numerous opportunities for the President to mention that his program will go a long way toward keeping the promise of ADA to millions of Americans with disabilities whose lives are severely limited by the present discriminatory systems.

- There should be systematic inclusion of people with disabilities in Presidential events, in Washington and local areas, just as there is systematic inclusion of other minorities - on stage - at receptions, lunches, dinners, photo ops, etc.

- There should be followup face-to-face meetings with disability rights leaders. Every time this occurs the word goes within a few days to the disability community and the federal leadership that disability issues are important in America. Consciousness is refocused from the trivial to the central thrust of policy; there is increased motivation to act. One such meeting could deal with health care reform. The 43 million people with disabilities, their families, service providers and advocates will be valuable allies in the struggle for responsible action.

- There should be systematic recognition of people and organizations - in and out of government - that voluntarily comply, or effectively promote voluntary compliance. There could be a form letter for the President's signature, photo ops, mentions in speeches to groups, etc. The President's Committee could staff a small disability community committee that would screen recommendations from entities such as EEOC, DOJ, the Consortium for Citizens With Disabilities (CCD), the Disability Rights Education and Defense Fund (DREDF), the National Council of Independent Living (NCIL), the National Council on Disability (NCD), DNC, the Access Board and state groups and pass them to the White House. My agency could also promote local, state and national awards for positive ADA action.

- The great things the President is doing for ADA and disability rights should be given much more publicity. His positive attitude toward people with disabilities, if properly communicated, will serve as a dynamic model for the nation. For example the appointment of Bob Williams to head the Administration on Developmental Disabilities at HHS has the potential for major media

coverage. He is probably the first non-verbal person in history to hold a major Federal position.

2. THE PRESIDENT AND THE AGENCIES

The President should send a memo to all agencies emphasizing the need to make every Federal entity a visible model of creative accommodations for people with disabilities, and an aggressive advocate for voluntary compliance with ADA. He should follow up with ongoing brief mentions of ADA and disability rights at cabinet and staff meetings and in written communications. He could issue an Executive Order calling for an action plan to bring Federal programs into harmony with the spirit of ADA (a draft coordinated by ADA author Bob Silverstein has already been submitted).

Appropriate entities within every agency should be mandated to coordinate and promote ADA implementation: the employment and promotion of qualified people with disabilities; modifications to facilities and systems that enable employees, clients and visitors with disabilities to participate fully; the unique ways that the particular agency can communicate the message of voluntary compliance to the public.

Attorney General Janet Reno is a natural choice to lead the ADA charge for the Administration at the cabinet level; she has already started to do this, and brilliantly. But we need all Administration leadership fully involved. Likewise the DNC should encourage all Congressional, State and local candidates and organizations to do the same. Civil rights for people with disabilities should become part of the litany of the President's Administration and of the politics of his party.

3. EDUCATING THE PUBLIC ABOUT ADA

No law has ever been successful without citizen knowledge and citizen enforcement. The White House and DOJ should strongly encourage all entities with ADA enforcement and education responsibilities and potential to move aggressively to promote voluntary compliance, by making all impacted persons and organizations aware of their rights and obligations, and of how to fulfill those rights and obligations efficiently and economically. Public programs operated under existing and special funding, private efforts and the media have raised public awareness of ADA from 18% to 41% during the past two years. But there are still millions who are not aware. Effective training programs like those

funded by DOJ and EEOC and operated by DREDF, should be continued and expanded. Reliable information sources should be given the resources to answer inquiries.

ADA education through secondary and higher education would be effective in the long run. This would require modest funding in some cases, but in many instances could be accomplished through existing staff and resources. Every major Federal agency has enormous power to disseminate information through existing channels. The National Council, the President's Committee, DOJ, EEOC, The Access Board and appropriate private entities could cooperate to provide models of informational materials.

4. ADA LITIGATION

While all parties to potential ADA litigation should be encouraged to achieve negotiated solutions, there must be aggressive legal action when conscious, blatant violations continue after positive negotiations have failed. We simply do not have the staff and funding to investigate and prosecute every violation of ADA in a thorough and timely manner, but vigorous, well publicized prosecution of selected flagrant violators can send a powerful message.

5. A NATIONAL POLICY TO IMPLEMENT ADA

The Administration should develop a detailed long range national policy to implement ADA, and to keep the clearly implied promise of ADA - that people with disabilities will be fully empowered as equal participants in the productive mainstream. After Marca Bristo is confirmed as Chair of the National Council on Disability, that entity could gather a select group of disability community leaders, members of the Clinton administration and of non-governmental organization and to draft such a policy: "Keeping the Promise - From ADA to Empowerment."

6. WHITE HOUSE MEETING ON ADA

After the initial months of intense Presidential focus on the health care reform program, the President could host an ADA meeting in or near the White House for representatives of business, architects, labor, lawyers, state and local government, and the disability community. There could be a progress report by White House staff, the Attorney General, other appropriate officials and disability community leaders, and a positive statement by the

President. There could be special recognition for entities that had been models of positive compliance (A. G. Reno did this last July 26th). Such meeting might be held around next July 26th, the fourth anniversary of the signing of ADA, when employers of 15-25 persons will be required to comply. An option to give it double impact would be to issue an advance announcement of it which expressed the President's support for full, voluntary compliance with ADA. The logistics of this event could be handled by the National Council, the President's Committee, and a consortium of entities.

7. ADA SENSITIVITY TRAINING

Appropriate Administration and private disability rights entities could also cooperate to form teams that would put on brief, punchy, ADA sensitivity orientations meetings for key departments in the White House and other agencies. These could include brown bag lunches that would infringe on very little working time. Our agency could provide logistical support.

DISCUSSION:

COST: Most of the recommendations in this letter can be implemented simply through better utilization of existing resources and staff. My agency, for example, could contribute its share of staff time, supplies, printed materials, meeting space, teleconference sponsorship, etc. Excellent publications already exist, and could be edited to communicate to particular constituencies. Funding could be provided within budgets by reallocation of resources in larger agencies, and by Congress.

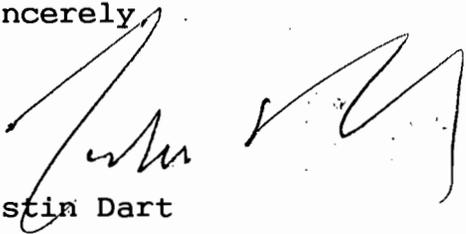
PERSONNEL: Effecting change in government always requires establishing a critical mass of knowledgeable, motivated leadership. This Administration is developing a critical core of people who have already demonstrated ability and willingness to do everything in this plan: The President, the Attorney General, Secretary Shalala, yourself, Mike Lux, Debbie Fine, Bob Boorstin, Paul Miller, Judy Heumann, Marca Bristo, Bob Simpson, Bob Williams, Rick Douglas and many others. Secretaries Cisneros and Pena have cooperated with the disability community in the past. Secretaries Brown and Reich have backgrounds which suggest that they might be receptive. DOJ and EEOC have good people in place. Congress people like Tom Harkin, Steny Hoyer and Bob Silverstein are making major contributions. People outside of government like Pat Wright, Fred Fay, Paul Marchand, Bob Sevigny, and Tony Coelho are already

playing key roles. What remains is to facilitate nomination and confirmation procedures to get the President's team in place, to focus and to systematize efforts, and to find a person to orchestrate those processes. That person could be you, or a person designated through your suggestion. One or more ADA knowledgeable staff could be detailed to help you.

I realize that this is an ambitious plan, and that not all of it can be implemented at once. I suggest a meeting or teleconference among Dale, you, myself and members of our advisory group to discuss priorities and concrete action. I will soon be replaced by the President as Chair of PCEPD, but it would be a privilege to continue to work with you and your colleagues on this historic project. The successful implementation of ADA will be the foundation for a revolution in the quality of the lives of billions of humans in generations to come. Failure is unthinkable.

I am deeply grateful for your personal leadership for people first change. Please let me know if there is any way I can be of service to you or the President.

Sincerely,

A handwritten signature in black ink, appearing to read "Justin Dart", written over a horizontal line.

Justin Dart

NOTE: I would like to acknowledge the assistance of several distinguished disability community colleagues in writing this letter - Nancy J. Bloch, Executive Director, National Association of the Deaf; Marca Bristo, the President's nominee to Chair the National Council on Disability; Dale Brown, The President's Committee; Jay Centifanti, Chair, the National Forum on Psychiatric Disability; Dr. Fred Fay, National Co-Chair, Clinton-Gore disability constituency campaign; Dr. I. King Jordan, President, Gallaudet University; Paul Marchand, the ARC and Chairman, the Consortium for Citizens with Disabilities; Oral Miller, Director, American Council of the Blind; Fred Patterson, Vice President of Johnson & Johnson; Bob Silverstein, Director, the Senate Subcommittee on Disability Policy, author of the final version of the ADA; Bob Simpson, the President's nominee to head

vocational rehabilitation; Tony Young, Director, Residential and
Community Support Services, National Association of Rehabilitation
Facilities.

rasco.sl

READY, WILLING, ENABLE, Inc.

SUMMARY OF ACCOMPLISHMENTS

Incorporated as a 501(c) 3 Nonprofit organization, 1991

Expanded cablecasting from thirty cities to more than 100 cities and towns in Massachusetts, in less than three years.

Cited Business Week as "an intriguing accommodation resource".

Commended by the President of the United States George Bush for making an "outstanding achievement in community service".

Featured at the 1992 International Conference on Volunteer Administration and the 1993 Points of Light Foundation's National Community Service Conference, as well as state-wide conferences sponsored by disability groups.

Presented nationally-known celebrities and spokespersons as guests on the television program, such as Patricia Neal, Anthony Shriver, and Chris Burke.

Highlighted over 80 products and services and addressed major issues affecting persons with disabilities and their families, in the ongoing television series, including:

long-term care, stroke, deafness, blindness, pain, environmental controls, telephone relay services, fashions for persons with disabilities, accessible recreation, computerized assistive devices, independent living skills, employment assistance and accessible housing information.

Alan Langer featured as keynote speaker and workshop presenter in state and national conferences.

Finalist in the national Hometown-USA Video Festival, 1992 and 1993. Recipient of grant support from New England Telephone, the Island Fund of New York Community Trust, and others.

THE WHITE HOUSE
OFFICE OF DOMESTIC POLICY

CAROL H. RASCO
Assistant to the President for Domestic Policy

To: _____

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: _____

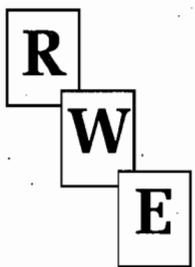
Send copy to (original to CHR): _____

Schedule ? : Accept Pending Regret

Designee to attend: _____

Remarks: _____

APR 25 REC'D



April 20, 1994

Ready,
Willing,
ENABLE, Inc.

Carol H. Rasco
Assistant to the President
Office of Domestic Policy
1600 Pennsylvania Avenue, NW
2nd Floor West Wing
Washington, D.C. 20500

Dear Ms. Rasco:

Although we did not meet at the Annenberg Washington Program last week, I thoroughly appreciated your presentation which bespoke the combination you represented so well: the concerned and caring parent of a child with a disability and the resource professional who is addressing the larger issues from a basis of real understanding.

I believe you were not present for the CAST presentation which opened the program, but my son was one of the pioneer trainees shown on video with whom that remarkable organization has been working. They are prototypes of the thousands of other young people with disabilities who potentially will benefit from the research and development coming about as a result of CAST's work and that of others in the field.

I write to thank you for your involvement in this important area of domestic policy concern and also to pick up on something you stated from the platform at the Annenberg:

As I thought I understood it, you said that your office did sometimes hear from corporations and foundations interested in learning of innovative programs in the disabilities arena that they might investigate for possible funding. I would want you to be aware of a program in Massachusetts that has made an extraordinary impact in its first three years, a fully-credentialed 501(c)3 organization, Ready, Willing, Enable, Inc., which is dedicated to improving the ability of persons with disabilities to become full participants in society. The corporation's premier project is an ongoing television series, *Ready, Willing, Enable!* supported by volunteer and donated personnel and contributions, which is currently carried on more than 100 community stations and sponsor networks in Massachusetts.

Co-founded and co-produced by Alan Langer, a quadriplegic businessman and former actor -- who also is the anchor person on the program -- *Ready, Willing, Enable!* is meeting the needs of disable viewers and their families, by growing popular demand. This use of technology is also contributing to the improvement of education, and already has involved classroom-linked programs in its series.

Carol H. Rasco
Page 2

I am taking the liberty of sending a packet of information on Ready, Willing, Enable, Inc. for your resource files. As co-founder and secretary of the nonprofit corporation, I will be happy to respond to any inquires about the organization or the television program we produce.

Thank you for the opportunity to share this information with your office.

Sincerely,



Joanne H. Patton
Vice-President/Secretary

JHP:lb
Enc.

READY, WILLING, ENABLE, Inc.

- WHAT:** A private, non-profit organization with the mission of helping people with disabilities enhance the quality of their lives through education, example and support.
- WHO:** Established by Alan Langer, who has MS, and Joanne Patton, the parent of an adult with special needs. Together, they saw a critical need to provide information to people with disabilities, to their families and to the community.
- WHEN:** Formed in 1990, RWE, Inc. was formally incorporated in April, 1991.
- HOW:** Information is the primary tool of RWE, Inc. and today this information is distributed through a series of television programs called "Ready, Willing, Enable!", cablecast on community access systems on over 100 Massachusetts cities and towns.
- WHERE:** RWE, Inc is based in Massachusetts, providing a focal point to connect with the myriad of resources in the country. The mailing address is:
- RWE, Inc.
P.O. Box 1339
Marblehead, MA 01945

**President: Alan Langer, Marblehead, MA,
Vice President/Secretary: Joanne Patton, Hamilton, MA,
1-800-RWE-5656**

What They're Saying About READY, WILLING, ENABLE!

"Perhaps the most intriguing accommodation resource...a new cable television program entitled, 'Ready, Willing, Enable!'"

BUSINESS WEEK

"...Langer and Binsfeld have teamed up to make a difference in the lives of others."

BOSTON GLOBE

"New cable production helps break down...barriers."

BEVERLY TIMES

"Very good quality and content. Very informative...people have called and said that they like it."

CABLEVISION SYSTEMS, Peabody, MA

"RWE serves an underserved segment of the population."

MEDFORD COMMUNITY CABLEVISION, Medford, MA

"Ready, Willing, Enable! certainly plays an important function in informing and serving the needs of the disabled community."

David H. Rose, Executive Director
CENTER for ASSISTIVE SPECIAL TECHNOLOGY

"You and your program together...will go a long way in helping us educate the community surrounding disabilities."

William Olubodun, Director of Services to the Deaf
NORTHEAST INDEPENDENT LIVING PROGRAM, INC.

"Education and changing people's attitudes is a process. We appreciate your effort in helping us toward change."

JoAnne Maynard, Special Education Instructor

"...I wish to congratulate you for...filling the unmet need of bringing disability awareness to the public."

Lorraine Greiff, Assistant Director
MASSACHUSETTS OFFICE ON DISABILITY

READY, WILLING, ENABLE![®]

THE TELEVISION PROGRAM OF DISABILITY RESOURCES AND ISSUES

VIDEOCASSETTES TO ORDER

The following videos from the *Ready, Willing, Enable!* (RWE!) television series may be ordered as single programs or in four-show packages. Please consult the attached order form for details.

SHOW #1: Host Alan Langer introduces *Ready, Willing, Enable!* Guests discuss the independent living program. An accessible symphony orchestra concert is featured. Alan and co-producer Joanne Patton discuss disabilities terminology. 28:31

SHOW #2: Academy Award-winning actress Patricia Neal tells about her stroke and the founder of a stroke support group talks about family needs in the face of a stroke. 29:22

SHOW #3: Guests describe the Very Special Arts program. The state-wide Architectural Access Board's functions are discussed. An environmental control system is demonstrated. 28:50

SHOW #4: A high school disability awareness program is examined. A jazz artist in a wheelchair is interviewed at a concert for mentally challenged adults. 28:00

SHOW #5: An organization specializing in locating assistive devices for people with disabilities is introduced. Alan talks with two architects about adapting residential and public buildings. Deaf Awareness Week is discussed with a representative of the independent living program and his ASL interpreter. 29:35

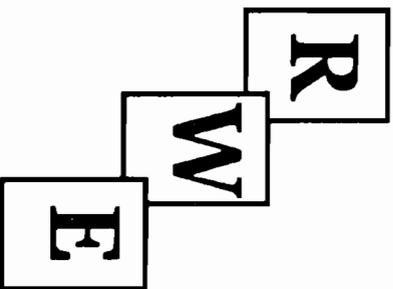
SHOW #6: Representatives from a State Attorney General's Office and a State Office on Disability talk about the effect of Americans with Disabilities Act. A computer training center for persons with disabilities is visited. 29:00

SHOW #6A: Representatives of *Business Week* magazine talk about a special issue focusing on disabilities and employment. A video from the Long Term Care Coalition focuses on the need for a long term care program. 28:35

SHOW #7: A support organization for people who have chronic pain is introduced. A designer of clothing for persons with disabilities show some samples and discusses needs. A representative of Canine Companions for Independence talks about the program and demonstrates how it works. 28:00

SHOW #8: Exercises for people in wheelchairs are demonstrated. Adaptive technologies for computer users are displayed. Worksite adaptations that accommodate persons with disabilities are shown and discussed. 29:50

SHOW #9: Lisa Binstfeld, a new co-host who is blind, is introduced. A vocal text reading device for people who are visually impaired is demonstrated. Anthony Shriver describes "Best Buddies" a program he founded which pairs college students with mentally challenged people. 27:58



Ready,

Willing,

ENABLE, Inc.

Program information:

RWE, Inc.
P.O. Box 1339
Marblehead, MA 01945
(617) 631-9013

Video distribution:

RWE! c/o PCS
650 Asbury Street
South Hamilton, MA 01982
1-800-RWE-5656

SHOW #10: A marathon runner who had a stroke when she was just 21 talks about her experience. A Vocational Rehab. Manager who runs forums on disability issues discusses the concept. A fledgling foundation which helps persons with disabilities is introduced. 26:20

SHOW #11: A rehabilitative program for people with disabilities using horseback riding is examined and the founder interviewed. A telephone relay system for people with hearing impairments is demonstrated and discussed. 29:40

SHOW #12: The Americans with Disabilities Act and the employment of people with disabilities is discussed with an occupational therapist, a national authority on the ADA. Two business leaders whose companies hire people with disabilities share their experiences. 28:30

SHOW #13: A former actress who was permanently injured by a drunk driver introduces segments from a play she's written about her experiences. The show features professional actors and interviews with the playwright and a representative of M.A.D.D. and the National Head Injury Foundation. 28:40

SHOW #14: The Shake-A-Leg organization offering sailing lessons and other physical activities to persons with disabilities is discussed. Television star Chris Burke helps RWE! recognize graduates of the McJobs work training program. 28:25

SHOW #15: RWE! visits a college which has made learning accessible to students with all types of disabilities. Heller An Shapiro of the John F. Kennedy Center discusses access to the arts, on-site at a New England theatre. 27:45

SHOW #16: Introducing the Assistive Technology Partnership, an organization designed to reach people with disabilities who typically "fall through the cracks" when it comes to finding and using assistive devices. The premier show of "The Accessible House" begins to document a house renovation for a person with a disability. (Part 1 of a six-part series). 26:46

SHOW #17: M.I.T. students demonstrate their business venture: barcode telephone grocery ordering for homebound persons; Alan & Lisa discuss disability semantics; Mike Scannell and Alan Langer continue "The Accessible House" series, part 2. 27:51

SHOW #18: Personnel consultant introduces job placement agency for persons with disabilities; Partnership with Disabled Youth: mentors and workshops help young adults with disabilities develop entrepreneurial job skills; "The Accessible House" series, part 3. 29:13

SHOW #19: Amputee describes new prosthetics and her amputee support services; Cooking Club and "Tasty Tapes" offering special kitchen techniques, equipment and recipes for persons with disabilities; "The Accessible House" series, part 4. 29:48

SHOW #20: Alan interviews real estate broker specializing in finding accessible housing for clients; Mike Scannell demonstrates new commercial van, specialized for passengers and drivers in wheelchairs and scooters; "The Accessible House" series, part 5. 28:39

SHOW #21: Non-verbal child demonstrates classroom "light talker" which enables him to communicate and participate with other students; "The Accessible House" series, part 6 - Alan and architect do final walkthrough in finished house. 27:21

SHOW #22: RWE producers and on-air hosts discuss disability etiquette; Mike visits public school which integrates disabled and non-disabled students successfully; Alan demonstrates his new motorized wheelchair; Lisa introduces her new guide dog to the audience. 28:30

SHOW #23: Environmental group joins able and disabled persons in cleaning up an area around Boston; video segment shows accessible bathtub design and modification possibilities, discussed with the designer; arts and crafts center for people with disabilities enters the marketplace. 28:46

SHOW #24: Woman advocates for people with disabilities, despite her own severe cerebral palsy; a town's accommodations to the ADA are examined with a town official; director of the Information Center for People with Disabilities discusses its work. 28:00

SHOW #25: Vietnam-disabled vet and state Commissioner for Veterans' affairs discuss problems and services for the veteran with disabilities; a revisit to the North Shore Music Theatre looks at its new hearing-assistive devices; "Anchor to Windward" -- a support organization for developmentally disabled adults toward independent living is introduced; Original quilts and bags for wheelchairs are described by their creator in her own wheelchair. 27:56

SHOW #26: Environmental control device is demonstrated by its developer; social service program benefiting persons with disabilities is described; attitudes toward disabilities are discussed by host Alan Langer and guest Archer O'Reilly, Director of Information Center for Persons with Disabilities. 28:30

SHOW #27: Two young amputee athletes prepare to run across the United States to raise awareness and funds for disability cause; director of career planning and work support program tells of ways to prepare persons with disabilities for the work world; World Disabled Sailing Championship features disabled sailors from eleven countries in competition. 27:50

SHOW #28: Sheltered work programs for people with disabilities are described; program for elders sponsored by area human services is shown; therapeutic massage is interview topic. 27:50

SHOW #29: Personal communications device for persons with speech or hearing disabilities is demonstrated; International Disabilities Council is described by two participants; New England Telephone's relay system and equipment giveaway are discussed. 29:00

SHOW #30: This program focuses on school systems that have developed or are creating programs for "inclusion" of children with disabilities. Newton's 17-year "Understanding Handicaps" program and the Melrose school system's fledgling efforts are featured. 28:15

SHOW #31: Charles Crawford of the Commission for the Blind explains his mission: The North Shore ARC tells about its educational puppets program operated by children; "Solutions For Accessibility" teaches how to make your home more accessible; an author with multiple sclerosis talks of the problems and successes involved in writing her book Undaunted Spirits. 28:12

SHOW #32: The program focuses on travel. Guests discuss wheelchair accessible taxis in Boston. A representative from a local travel agency specializing in assisting persons with disabilities tells about travel opportunities. A tourist with a disability shares his experiences about a cruise. A representative from the MBTA (Massachusetts Bay Transportation Authority) discusses "the Ride" and other Mass. transportation services. 29:00

To order tapes, please fill out the attached order form and return it to RWE c/o PCS, 650 Asbury Street, Hamilton, MA 01982. For further information call 1-800-RWE-5656.

Ready, Willing, Enable! is a television program about disability resources and issues, produced by Ready, Willing, Enable, Inc., a not-for-profit 501(c)3 organization, in cooperation with Continental Cablevision, Inc.

MAIL IN YOUR ORDER TODAY!

READY, WILLING, ENABLE![®]

CASSETTE ORDER FORM

Item and Quantity	Price	Total
SINGLE SHOW # _____ (Each show on a single cassette)	\$9.95 per single cassette	_____
4 SHOW PKG. #'s _____ (Any 4 shows on a single cassette)	\$29.95 (25% discount)	_____
	Sub-total	_____
	Sales tax (5% MA residents only)	_____
	Shipping & Handling (\$3.50 per cassette)	_____
	TOTAL PAYMENT	_____

Address to send cassettes to:

NAME _____

ORGANIZATION _____

STREET _____ TEL. NO. _____

CITY _____ STATE _____ ZIP CODE _____

Mail this order form to:

**RWE! Cassette Series, RWE! c/o PCS, 650 Asbury Street,
Hamilton, Massachusetts 01982**

Program information:

RWE, Inc.
P.O. Box 1339
Marblehead, MA 01945
(617) 631-9013

Video distribution:

RWE! c/o PCS
650 Asbury Street
South Hamilton, MA 01982
1-800-RWE-5656

***Ready, Willing, Enable!* has featured:**

A.B.O.V.O.
Adaptive Rehabilitation Technologies
ADD-TECH
Architectural Access Board
Best Buddies
Businessweek Magazine
Canine Companions for Independence
CAST (Center of Applied Special Technology)
Clothing for persons with disabilities by Tricia's
Eastern Middlesex Human Services
Ellenrobin Productions
Gateway Crafts
Hotwatt, Inc.
Independent Living Center of the North Shore
Information Center for Persons with Disabilities
M.A.D.D.
MBTA
Mass. Commission for the Blind
Mass. Commission for Persons with Disabilities
Mass. Office on Disability
Mass. Rehabilitation Commission
McJobs
Mirror Bond Company
New England Telephone
North Shore Music Theatre
Northern Essex Community College
Outdoor Explorations
Project Triangle
Quartet Technology Inc.
Sailing for the Disabled
Shake-A-Leg
Special Friends
Statler Gilfillen Architects
Stroke support group
Stylus Innovation
Theracise
Travel agency for persons with disabilities
Uniting People in Pain
Very Special Arts Massachusetts
Windrush Farm
Work Stations Inc.
WorkTech
Wellbridge Center
Xerox Imaging Systems
and more!

Taking the mystery out of disability

Show offers information, enlightenment

By GAIL LEACH
Times staff

Alan Langer frowned as he described the steps leading up to the restaurant he and his wife had picked for dinner.

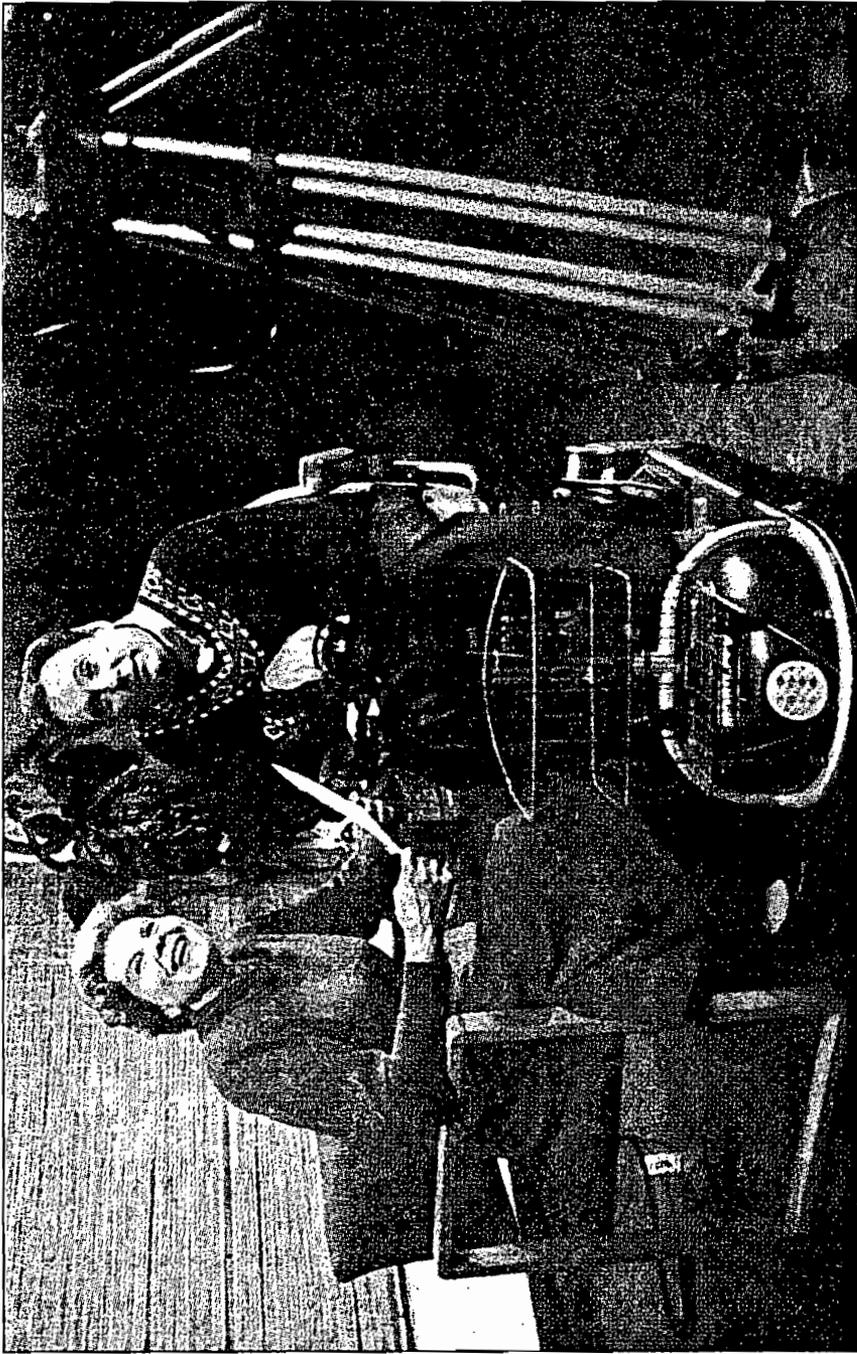
"We had called ahead of time to ask if the restaurant had access for people with disabilities," said Langer, who is paralyzed from the shoulders down. "And they said they did. Obviously they didn't."

His wife went in to ask why the restaurant had given them wrong information.

"They figured they could just carry my wheelchair up the steps," said Langer, 53, shaking his head slowly. "My wheelchair weighs 250 pounds without me in it and costs about \$11,000," he said, adding he wants no one to handle it. "This wheelchair is my life."

It's this type of problem Langer tries to fight with his cable television show "Ready, Willing, Enable!" which airs on community access stations in 100 cities and towns in New England, including most on the North Shore.

The show, which he co-produces with Joanne Patton of Hamilton, focuses on informing disabled people that there are services for them, whether it's a wheelchair accessible business or a business that assists visually impaired people. It also provides support and information on products.



Mark Tetrault photo

Alan Langer and Joanne Patton work on the set of "Ready, Willing, Enable," a cable television show about people with disabilities. Produced in Marblehead, the program airs on more than 100 cable television stations across New England.

"We deal with attitudes. So many people have myths about disabled people," Langer said while sitting in his office in his Marblehead home. "The show tries to point out that everyone has a disability. If you wear glasses then you have a disability too."

Patton said that when developing the show, produced in Marblehead, he realized there was something missing from the mass media.

"There was really nothing ongoing on television" regarding people with handicaps, Patton said. The program is designed to "demystify disabilities," he added.

While the 2-year-old show is seen in some community access stations in New England, Langer hopes to broaden that appeal with a \$10,000 grant awarded to the private, non-profit Ready, Willing, Enable Inc. by the

Island Fund at the New York Community Trust.

Langer said he will use the money to produce a pilot program to market to national stations. "We'll try to sell the show to stations like Lifetime, Discovery and PBS," Langer said. "We'll see if they will sponsor it."

With that type of national exposure, Langer hopes to change the way people see disabled people.

Program, page A10

• Program on disabilities

Continued from page 1

ple view those who are disabled.

Occasionally during the interview, Langer answered the ringing phone with the help of a mouth stick. The stick let him press the button on the phone, which he can speak into and listen to through a headset. The mouth stick also helped him punch the keys on his computer terminal.

Langer knows that people with disabilities need the kind of information he can provide. He also believes television is the best way for them to get it.

"There are newsletters by groups like the (Muscular Dystrophy Association), but it's important to get the information on television. That has the biggest impact," Langer said.

Langer estimates there are 43 million disabled Americans. "That's not even counting their families or friends who would likely accompany them to restaurants or stores," Langer said. "So, it's important to provide this service. There is a tremendous audience out there."

And, he said, that audience needs to know there are products geared toward it.

"My wheelchair can be controlled by my chin, it can raise up nine inches and the seat can lean back, so my hair can be washed like most people do when they get their hair cut," Langer said. "My computer can also be controlled by my voice. But most people wouldn't know those types of products are out there."

The magazine-format, half-hour show attempts to bring that information to people. The show has three or four segments and some are filmed in different locations.

"Not everyone who works on the show is disabled," said Langer, who is the co-host. "We have had a blind co-host and another with cerebral palsy."

The show also features on-air reporting. "So far we've produced 23 shows and 60 guests have appeared and we've covered a wide range of topics," said Langer, who was a professional stage actor in New York during the 1950s and 1960s.

Langer said he plans to have an upcoming segment

on scuba diving for disabled people. And someone will demonstrate showers that are designed for people in wheelchairs.

"We show people a disability doesn't mean you have to stay home," Langer said. "Instead we focus on the abilities of people. We want people to stop labeling and look at what that person can do."

And like a lot of other people, Langer enjoys eating out.

"My wife and I went to a restaurant for dinner and the guy who showed us the table looked at my wife and asked her where I would sit," Langer said. "I looked at him and I answered I would sit over there and pointed to a side of the table."

"Even though I had answered him and showed I'm a thinking individual, he looked at my wife again and told her that wasn't the best place," Langer said. "That can be maddening."

Langer has gotten that type of treatment for some time.

More than 20 years ago, Langer noticed numbness and tingling in his hands and feet. But it wasn't until 1979 when he was diagnosed with Multiple Sclerosis. The disease forced Langer to walk with a cane, but in 1985 he had to start using a wheelchair.

"Now, I can't walk or use my hands," Langer said. But that doesn't stop him from taking an active role in Ready, Willing, Enable Inc.

In fact, Langer and Patton are taking part in the Points of Light Foundation workshop in Florida this week. They will present a workshop on disability access at the 1993 National Community Service Conference.

"I enjoy doing things everyone else does," said Langer, who has two daughters. His youngest daughter recently graduated from Syracuse University.

"I buy clothing and groceries. I like to go to the mall and buy Christmas presents. I like to buy gadgets for my house," Langer said. "And I should be able to do those things."

(Ready, Willing, Enable' airs on Peabody's channel 11 at 7:30 Friday and on Beverly's channel 3 at 6 p.m. Wednesday. Check local cable listings for other times.)

ANNOUNCING!

READY, WILLING, ENABLE!

A Community Access Television Program!

THE SHOW FOCUSES ON PRODUCTS, SERVICES, ISSUES AND FUN FOR PEOPLE WITH DISABILITIES AND THEIR FAMILIES.

THE PROGRAM'S PRODUCERS, JOANNE PATTON AND ALAN LANGER, SAY "THIS IS FOR EVERYONE, EVEN IF YOU DON'T HAVE A DISABILITY."

All too often if you have any disability, be it a hearing difficulty, mobility impairment, visual difficulty or even just reduced capabilities associated with getting older, finding the products and services you need is next to impossible. People assume that you no longer are interested in such things as music, theatre, the arts, good food and good conversation.

WELL WE DON'T BELIEVE IT!

READY, WILLING, ENABLE!

Brings you news and information about new and unique products and services that can help you remain independent. We highlight places to go and things to see that are designed for easy access, so that you, as well as your family can enjoy them together.

**YOU HAVE A VOICE THAT SPEAKS FOR YOUR NEEDS
AND A FRIEND THAT LISTENS TO YOU**

READY, WILLING, ENABLE!

CONTACT YOUR LOCAL CABLE STATIONS FOR DATES AND TIMES

If your town doesn't carry RWE!, write us at:
P.O. Box 1339, Marblehead, MA 01945
or call 1-800-RWE-5656

**LIST OF ALL TOWNS AND CITIES IN MASSACHUSETTS VIEWING
"READY, WILLING, ENABLE!"**

Amesbury
Andover and North Andover
Arlington
Avon
Barnstable
Bedford
Beverly
Billerica
Boxford
Brewster
Brockton
E. Bridgewater
W. Bridgewater
Brookline
Burlington
Byfield
Cambridge
Cambridge Community
Chatham
Chelmsford
Cohasset
Danvers
Dennis
Dracut
Eastham
Easton
Essex
Framingham
Georgetown
Gloucester
Greenfield
Groveland
Hamilton
Hanover
Hanscom
Hanson
Harwich
Haverhill
Hingham
Holbrook
Hull
Ipswich
Lawrence
Lexington
Lynn
Lynnfield
Malden

Manchester
Marblehead
Medford
Merrimack
Methuen
Middleton
Milford
Needham
Newburyport
Norwell
Northborough
Orleans
Peabody
Plymouth
Provincetown
Raynham
Reading
Revere
Rockport
Rowley
Salem
Salisbury
Saugus
Shrewsbury
Scituate
Somerville
South Hampton, N.H.
Stoneham
Stoughton
Swampscott
Tewkesbury
Topsfield
Truro
Wakefield
Walpole
Watertown
Wellfleet
Wenham
Westborough
West Newbury
Wilmington
Whitman
Wilmington
Winchester
Winthrop
Woburn
South Yarmouth
Yarmouth