

Withdrawal/Redaction Sheet

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DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
001. letter	From Carole L. Sherman re: VOR (2 pages)	07/09/93	P6/b(6)

COLLECTION:

Clinton Presidential Records
Domestic Policy Council
Carol Rasco (Meetings, Trips, Events)
OA/Box Number: 4592

FOLDER TITLE:

Voice of the Retarded 7-12-93 2:00 p.m.

rw147

RESTRICTION CODES

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

- P1 National Security Classified Information [(a)(1) of the PRA]
- P2 Relating to the appointment to Federal office [(a)(2) of the PRA]
- P3 Release would violate a Federal statute [(a)(3) of the PRA]
- P4 Release would disclose trade secrets or confidential commercial or financial information [(a)(4) of the PRA]
- P5 Release would disclose confidential advise between the President and his advisors, or between such advisors [a)(5) of the PRA]
- P6 Release would constitute a clearly unwarranted invasion of personal privacy [(a)(6) of the PRA]

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

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RR. Document will be reviewed upon request.

Freedom of Information Act - [5 U.S.C. 552(b)]

- b(1) National security classified information [(b)(1) of the FOIA]
- b(2) Release would disclose internal personnel rules and practices of an agency [(b)(2) of the FOIA]
- b(3) Release would violate a Federal statute [(b)(3) of the FOIA]
- b(4) Release would disclose trade secrets or confidential or financial information [(b)(4) of the FOIA]
- b(6) Release would constitute a clearly unwarranted invasion of personal privacy [(b)(6) of the FOIA]
- b(7) Release would disclose information compiled for law enforcement purposes [(b)(7) of the FOIA]
- b(8) Release would disclose information concerning the regulation of financial institutions [(b)(8) of the FOIA]
- b(9) Release would disclose geological or geophysical information concerning wells [(b)(9) of the FOIA]

THE WHITE HOUSE

July 13, 1993

Dear Polly,

I am so pleased I had the opportunity to meet the group representing VOR yesterday. I consider it the first in a series of conversations I hope we will have through the years. My best regards to all of you —

Barbara L. Bush

orig : CHR (in attached file)
xc : Christine Keenan

POSITION OF VOICE OF THE RETARDED
ON
NATIONAL HEALTH CARE REFORM

Voice of the Retarded, founded in 1983 and with members in 47 states, is a not-for-profit organization representing families with mentally retarded members. VOR supports the concept that a variety of services are required to meet the long-term health care needs of mentally retarded persons.

July 1, 1993

For more information contact:
James Enrietto, Administrator
VOICE OF THE RETARDED
Tel: 708-253-6020
Fax: 708-253-6054

or

Polly Spare
President
Tel: 215-348-4059
Fax: 215-348-4029

MAJOR VOR CONCERN IS
FOR LONG TERM CARE AND TREATMENT
FOR PERSONS WITH MENTAL RETARDATION

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 treatment 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 coverage. 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 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 wheel chair 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 option of vendors of service with parental concurrence.
- . Enhanced and enforced quality assurance standards.
- . Better self discipline within professional groups (doctors, lawyers, etc).
- . Basic dental care for persons of all ages.

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.

THE WHITE HOUSE

WASHINGTON

July 12, 1993

MEMORANDUM FOR CAROL RASCO, MIKE LUX AND CHRISTINE HEENAN

FROM: Debbie Fine

SUBJECT: Voice of the Retarded

Voice of the Retarded (VOR) is an advocacy group primarily made up of the parents of developmentally disabled individuals, although providers and professionals working with the disabled are also included in the membership. VOR describes its mission as supporting services that, "best suit the needs of each mentally retarded person and his/her family." This includes institutionalization for those who are severely disabled and more independent living services for others.

I would note that during the last year Mike Lux and I have worked closely with people with disabilities, and have never come across this group before. We have, however, worked particularly closely with The Arc, an advocacy group primarily of parents of the developmentally disabled who support home and community based care. Paul Marchand, Director of Government Relations for The Arc and Chair of the Consortium of Citizens with Disabilities, describes this group as one that advocates institutionalization of the developmentally disabled - rather than the more middle of the road way they describe themselves. According to Paul, the membership of this group is probably 5-7,000, spanning 10-15 states. (Voice of the Retarded would not tell me their membership over the phone.)

My sense is that the philosophy of this organization leans toward earlier beliefs that institutionalization is the better option for developmentally disabled individuals, in contrast to today's prevalent belief in home and community based care. The latter is what the majority of disabled advocates support.

For your information, I have attached copies of the brochures of both the Voice of America and The Arc.

VOICE OF THE RETARDED *J.H. Lutz*5005 Newport Drive
Suite 108
Rolling Meadows, IL 60008

(708) 253 - 6020 - Phone

(708) 253 - 6034 - FAX/Phone

July 8, 1993

Ms. Carol Rasco
White House Domestic Policy Advisor
The White House
Washington, D.C. 20500

JUL 9 1993

Dear Ms. Rasco:

When I read the June 18, 1993 article about you in the New York Times I realized that you are in a unique position to help with the health care plans for the developmentally disabled. As the mother of a retarded son and daughter and president of this national organization I believe that one of the most tragic consequences of the current system is that it has often divided parents and set them against each other.

Some feel that all developmentally disabled people should be in small group homes integrated into a community. Others believe the severely disabled need the greater protection of a large campus-like facility.

Our organization believes that different levels of retardation require different levels of care and we therefore take a both/and rather than an either/or position on this question. The retarded are not all alike. Some can prosper well in the mainstream. Others will be easy victims, particularly those with fragile medical conditions, blindness, deafness, or a dual diagnosis of mental illness and mental retardation. Some will be a danger to themselves and others.

We have two requests. A group of parents from Minnesota prepared a 16 minute videotape that illustrates the position of those who want state operated large facilities for their adult children. We are enclosing it for your review. In addition, many of these parents are coming to Washington, D.C. the week of July 11 to advocate for long-term residential care for these severely disabled people. We would like you to meet with them while they are in the capital. Since time is short, we would appreciate a phone call to let us know your decision.

Yours sincerely,

Polly Spore
Polly Spore
President

Phone 215-348-4059
or 202-638-1616 after Friday July 9

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

Non-Profit • Tax Exempt • Voluntary

**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.

VOICE OF THE RETARDED



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

Send this portion with appropriate remittance.

Individual Membership - \$15.00 - Association Membership - \$150.
Contribution - \$25 \$50 \$100 \$500 other -

NAME _____

(Please print)

ADDRESS _____

PHONE _____

ZIP _____

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 _____



INTRODUCTION TO THE ARC

What is The Arc?

"The Arc" is the new name of a 42-year-old organization known for many years as the Association for Retarded Citizens of the United States.

It is the nation's largest volunteer organization solely devoted to improving the lives of all children and adults with mental retardation and their families. The association also fosters research and education regarding the prevention of mental retardation in infants and young children.

The Arc's name change is the result of a vote by delegates attending the organization's 42nd annual national convention in Portland, Ore., in October 1991. Members, chapter leaders, young parents and people who have mental retardation had become increasingly uncomfortable over careless, inappropriate and too-frequent use of the label "retarded." The word therefore became unacceptable in the association's name.

The new name carries a tag line of explanation: "a national organization on mental retardation." As affiliated chapters change their names to "The Arc," each will have a localized tag line reflecting objectives and/or services.

Who is The Arc?

The Arc is people - people with mental retardation and other disabilities, parents and other family members, and friends of people with mental retardation and professionals who work with them. The Arc is essentially a grass roots organization formed in 1950 by a small group of parents and other concerned individuals. Today there are 140,000 members and 1,200 state and local chapters across the nation. The National Headquarters is in Arlington, Texas, and The Arc's Department of Governmental Affairs is in Washington, D.C.

Mission Statement

The Arc, a national organization on mental retardation, is committed to securing for all people with mental retardation the opportunity to choose and realize their goals of where and how they learn, live, work and play.

The Arc is further committed to reducing the incidence and limiting the consequence of mental retardation through education, research, advocacy and the support of families, friends and community.

Through the successful pursuit of quality and justice, The Arc will provide leadership in the field of mental retardation, and develop necessary human and financial resources to attain its goals.

Why does The Arc exist?

The Arc works to provide more than 7.2 million Americans having mental retardation and related disabilities with services, including employment, training, education, independent living and other opportunities to reach their greatest level of personal fulfillment and potential. The Arc also exists because people with mental retardation need help to ensure that their rights as citizens of this country are protected.

What are some of the current activities of The Arc?

Projects of The Arc's Department of Research and Program Services target a wide range of needs of children and adults who have mental retardation. Here are some current and recent efforts, which also include prevention initiatives:

- Gathering and disseminating information to foster services that support people who have a family member with mental retardation;
- Helping people with mental retardation understand and avoid the human immunodeficiency virus, which causes AIDS;
- Assisting businesses in complying with provisions of the Americans with Disabilities Act;
- Educating prospective parents about preventing some causes of mental retardation, particularly Fetal Alcohol Syndrome;
- Helping young adults with mental retardation realize their full potential as happy, productive citizens.

In addition, two long-term projects, the National Employment and Training Program (NETP) and the Bioengineering Program, continue to garner success and recognition. Since 1966 NETP has helped more than 47,000 adults with mental retardation find jobs. The 10-year-old Bioengineering Program has captured national awards for its achievements in applying today's technologies to help children and adults with mental retardation and other disabilities enjoy greater independence.

In advancing its mission, The Arc also works with:

- organizations and coalitions tackling similar objectives;
- the nation's policymakers, to protect rights and improve services;
- the public at-large, to educate all people about mental retardation and its prevention.

Because of its knowledge, resources and commitment, The Arc has more than 100 publications and videos which are available to anyone needing information on research, employment, prevention, family and organizational issues.

What is the structure of The Arc?

The state and national components of the organization are the products of the local chapters and work to serve the chapters in conducting activities which are statewide and national in scope.

Volunteer-driven in policy and direction, a national board of directors is headed by a president, senior vice-president, secretary and treasurer. Their decisions and goals are carried out by a staff.

How is The Arc supported?

The Arc is a 501(c)(3) nonprofit, tax-exempt corporation and derives its support primarily from its membership, government grants and project grants from foundations.

Corporate donations are generated through sponsorship programs of The Arc, through employee contributions and corporate promotions. Additional support is provided through the association's co-sponsorship of Affinity credit card and long-distance telephone programs, in which the participation of supporters triggers company contributions to The Arc.

The Arc also participates in the Combined Federal Campaign Overseas in which federal employees and members of the armed services contribute to some 50 national voluntary health organizations.

Individuals may also contribute to The Arc through general donations, tributes and memorials, matching gift programs of participating companies, and through planned gifts such as wills, trusts, life insurance, securities and/or appreciated property.

The Foundation of The Arc of the United States was established in 1988 to support future operations and special programs of The Arc. A \$4 million endowment fund is a goal designed to provide a permanent financial base for The Arc.

How can I get more information about The Arc?

The best way of getting current, up-to-date information about The Arc and its activities as well as the latest news in the mental retardation field is by becoming a member. Members automatically receive *The Arc Today*, the association's national newspaper, six times a year.

All local and state chapters receive *The Arc Now* monthly, another resource of news and information, and *The Arc's Government Report*, which is published twice monthly and offers a detailed examination of governmental activities touching the lives of people who have mental retardation.

How can I become involved in The Arc?

You can find most local chapters of The Arc listed in the white pages of the phone book. Since chapters are still in the process of changing their names, they may be listed locally as "Association for Retarded Citizens" or "ARC" if not "The Arc."

If you cannot find a local chapter, a membership application appears at the end of this flyer. When you return it with a dues payment of \$15, you will become a member of The Arc at the national, state and local levels and be advised of your closest chapter.

Chapters differ in their services and interests, offering a diverse array of activities and opportunities for becoming involved with the lives of children and adults with mental

retardation and their families. There are many successful parent support groups. Citizen advocacy and self-advocacy programs, recreational activities, public education efforts and employment programs also are available through many local chapters. It is likely that your talents and skills are needed by a chapter in your community.

How can I contribute to The Arc?

There are several ways you can support The Arc's services and programs, such as:

- A general contribution - to support the work of all;
- Restricted gift - to support a particular interest, program fund or research project;
- Designated gift to support a particular program or service area of The Arc;
- Tribute gift in honor of a friend or loved one;
- Memorial gift in memory of a friend or loved one;
- Bequest of cash, securities, life insurance or property;
- Planned gift through a will of cash or property;
- Contribution to the Foundation of The Arc.

More information regarding any of these giving programs is available through the Department of Resource Development at National Headquarters, P.O. Box 300649, Arlington, Texas 76010, or use the telephone numbers listed elsewhere in this flyer.

For further information on how to join The Arc in its mission, please send the following information on...

- membership
- publications
- The Arc and mental retardation
- The Foundation of The Arc and its programs

I am interested in the following planned giving brochures...

- "Gifts Made Outright Now"
- "Gifts of Appreciated Property"
- "Reflecting on Tomorrow"

Yes, I want to support The Arc's efforts...

- My introductory membership fee of \$15 is enclosed.
- A donation in the amount of \$ _____ is enclosed.
- A donation in the amount of \$ _____ is enclosed in memory of _____
- A donation in the amount of \$ _____ is enclosed in honor of _____
- Other _____

Name _____

Address _____

City _____ State _____ Zip _____

Telephone (____) _____ Daytime
(____) _____ Evenings

Make checks payable to The Arc and return to:

The Arc
National Headquarters
P.O. Box 300649
Arlington, TX 76010

For more information please call:
(817)261-6003/FAX (817)277-3491/TDD (817)277-0553

Revised February 1992

- Fight for choice

- XIX }
Medicare } fraud? look at this in health care reform

- Publicly funded groups -
lawsuits affect parental involvement

- Plans to abandon LTC, i.e. XIX

NO. 92-351

IN THE
SUPREME COURT OF THE UNITED STATES

October Term, 1992

LEONARD E. HELLER, SECRETARY,
KENTUCKY CABINET FOR HUMAN RESOURCES,

Petitioner.

V.

SAMUEL DOE, BY HIS MOTHER AND NEXT
FRIEND, MARY DOE, ET AL.

Respondents.

On Writ of Certiorari To The
United States Court of Appeals
For The Sixth Circuit

BRIEF OF VOICE OF THE RETARDED (VOR), ET AL.
AS AMICI CURIAE IN SUPPORT OF PETITIONER

William F. Sherman
Attorney for
Voice of the Retarded

504 Pyramid Place
221 West Second St.
Little Rock, AR 72201
(501) 372-3148

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**VOR IS DEDICATED
TO
THESE PRINCIPLES**

- A more cautious approach to the downsizing and deinstitutionalization of large facilities for developmentally disabled persons.
- Program design based on individual need.
- Choice of residential and rehabilitative services and supports.
- Empowerment of families.
- Federal/state standards of quality assurance measurable in terms of consumer happiness, freedom from harm, training, programmatic continuity and quality of life.
- Independent monitoring of all programs.
- Continuing education of federal/state officials and the general public as to the diversity of the population of persons with mental retardation.
- Research into causes, prevention and treatment of mental retardation.

VOICE OF THE RETARDED



FOUNDED 1983

**5005 NEWPORT DRIVE
SUITE 108
ROLLING MEADOWS, IL 60008**

**PHONE (708) 253-6020
FAX (708) 253-6054**

**JAMES ENRIETTO
ADMINISTRATOR**

VOICE OF THE RETARDED

Send this portion with appropriate remittance.

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

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

NAME _____
Individual member or association member (Please print)

ADDRESS _____

PHONE _____ ZIP _____

FAX _____

If Individual:

Relationship: Parent Sibling Relative Friend Legal Guardian Concerned Citizen

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

Make checks payable to VOR.

WHO ARE WE?

- VOR is a national not-for-profit advocacy organization that strongly favors a variety of services and supports to meet the long-term care/rehabilitation needs of persons with mental retardation.
- VOR members in 47 states include parents and families of mentally disabled persons, providers, professionals, friends and affiliated groups. Membership is open to all who share our concerns.
- VOR opposes the rush toward mainstreaming all persons with mental retardation.
- VOR is a resource for related health care data, federal/state court actions, and national/state legislation.
- VOR maintains a speakers bureau and is listed as expert in the national Broadcast Interview Source.
- VOR has a 21-member board of directors, whose officers are:

President:
 Polly Spare, Doylestown, PA

Vice Presidents:
 Terry Turner, New Orleans, LA
 Warren Snow, San Diego, CA

Secretary:
 Bill Whetham, Des Plaines, IL

Treasurer:
 Caroline Walsworth, Arlington Heights, IL

HISTORY

VOR was incorporated in 1983 by a group of parents in response to proposed federal legislation to phase out larger facilities for persons with mental retardation by withdrawing Medicaid funding.

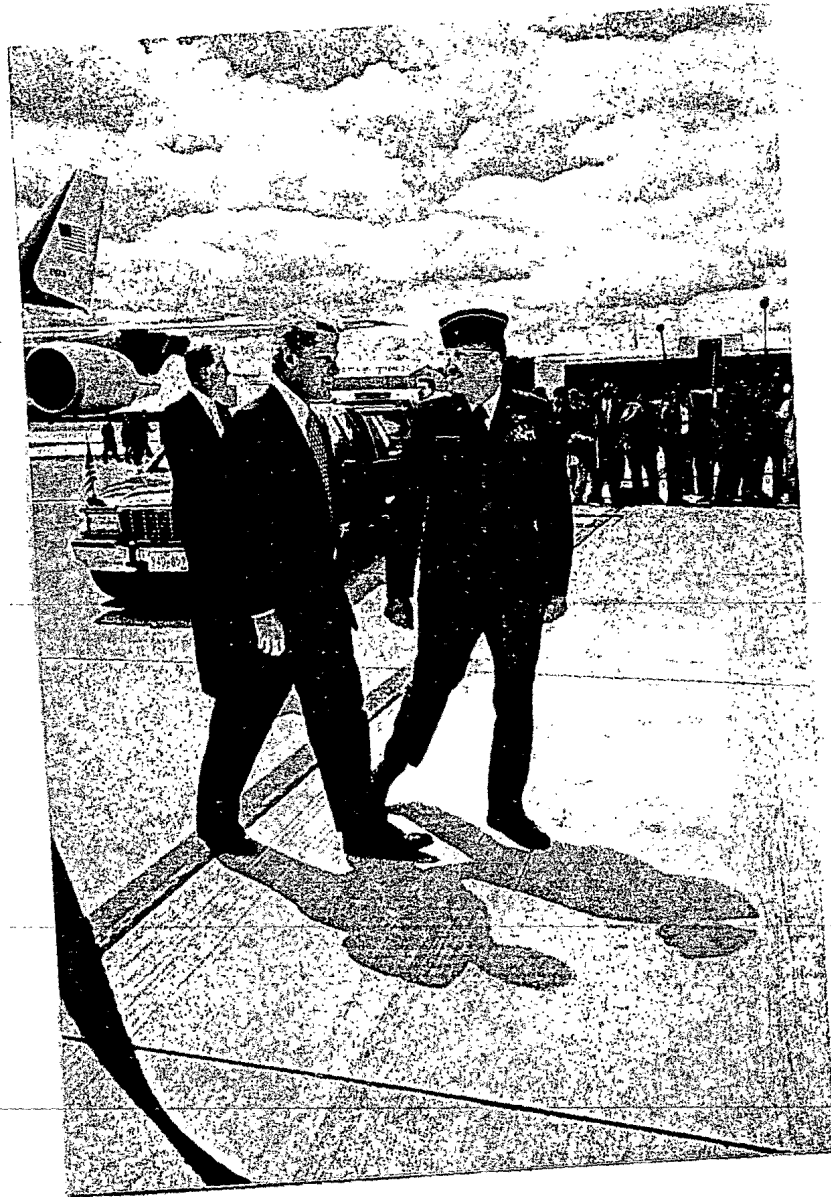
Today, new initiatives threaten to eliminate small community homes, as well as larger facilities.

PURPOSE

VOR provides information, support and advocacy services according to individual and group needs. We keep public officials, legislators, and the general public informed about issues which affect persons with mental retardation. We support alternatives in residential living and rehabilitation systems which best suit the individual needs of a person with mental retardation and his/her family.

ACTIVITIES INCLUDE:

- Testimony before federal, state, and local governmental bodies regarding the problems of retardation.
- Advocacy on behalf of groups and individuals in residential, community or home settings.
- Cooperation and interaction with other parent organizations which share our concerns.



Milwaukee WI.

1993.

By Mike Sullivan
Clinton Campaign
Driver - Motorcade

Dear President Clinton
I want to be in
your next Campaign
& will take time
off to do so!

1993

Milwaukee, WI.

Pres. Clinton Visit.

Mike Sullivan - Clinton
Campaign & Attorney
for Vice of Retiree

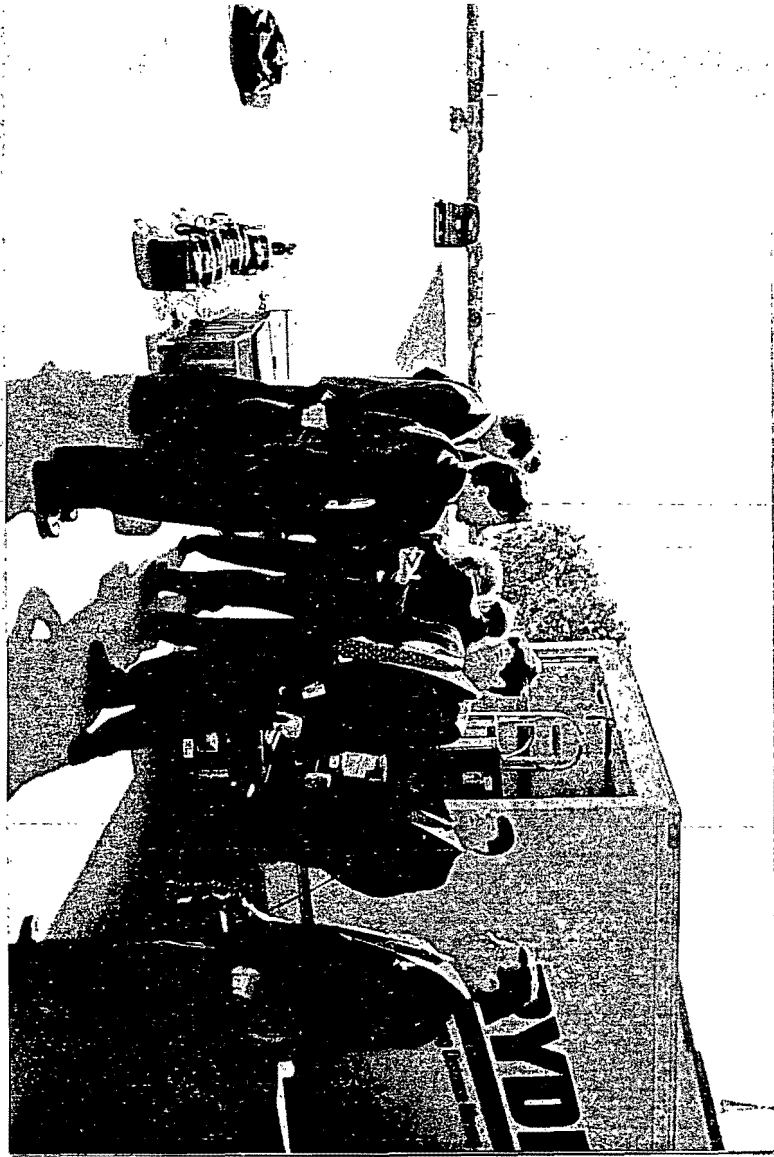


Milwaukee, WI.

Ellen
By Mike Sullivan
Clinton Campaign
& Attorney Mike
Sullivan for
VOR. Voice of the
Antifuck -

Ellen - hope to
say "hi" to you
at next Campaign -
If you & Wes heard
we'll find stop
by it in Milwaukee

Michael Dean - 11:30 am
June 1-1993



Ben Austin

Spain, Mex, etc

June 1-1993

June 1-1993

MEMORANDUM

TO: U.S. Senators and Representatives, and their staffs

FROM: William F. Sherman
Attorney at Law

SUBJECT: Issues regarding the developmentally disabled

DATE: July 9, 1993

1. As you might remember, I represented the Arkansas state-wide parents' group (AHDCR) in Baldrige v. Clinton, which was dismissed by Judge Woods, to the enormous joy and relief of the parents (about 1,000 in number) I represent. Advocates for Human Development Center Residents in Arkansas and similar groups in all states have endured for many years the attacks upon our larger public facilities for developmental disabled persons. The challenges have been constant. It grieves us that we must look forward to many years of meeting the continuing attacks in the courts, legislative bodies, and other governmental agencies of our country (advisory and decision-making). Many groups which are initiating the actions to effect public policy changes are supported directly by public funds, which has created substantial unfairness to people interested in preserving the centers.

2. I am now serving as law committee chairman for Voice of the Retarded (VOR), the Chicago-based organization which has done so much to challenge the de-institutionalization contentions of groups favoring closure and down-sizing of our larger public facilities. VOR is a rapidly growing organization which has as members most public developmental centers, individual parent organizations, coalitions of parent groups, private residential facilities (both large and group home programs), and thousands of individual members in 48 states. VOR exists today because no other organization represents the needs of developmental center residents and their families.

3. Our members, parents and relatives throughout the country are exhausted by the barrage of assaults upon our centers, which we honor as we do other basic institutions in the society - churches, schools, and public facilities. Our group supports the expansion and improvement of community support systems for disabled people. However, many community activists (most of whose disabled relatives would never be considered qualified for admission to the larger facilities), express no appreciation or concern for the needs of our children. We do not oppose the civil rights movement for disabled people. It should be recognized however that most people seeking greater opportunities in employment and community housing and in the work place are not people who would qualify for admission to a human development center.

4. President Bush announced that 47 million Americans would benefit from the Americans with Disabilities Act passed in 1990. Most families of developmental center residents do not think the ADA benefits them or their disabled loved ones at all, although they do appreciate that there are benefits for many other people. The last Developmental Disabilities Act passed by Congress, in its preamble, stated that there were 3 million developmental disabled persons in the country.

5. By law, persons with developmental disabilities have one or more of four different disabilities: mental retardation, epilepsy, autism, and cerebral palsy. Persons with mental retardation are now included within one of four broad categories, based upon the severity of mental impairment: mild, moderate, severe, and profound. Statistics show a basic division of the percentages of those within each of the four categories as follows: mild 90%, moderate 6%, severe 2-1/2%, and profound 1-1/2%. Most of those persons still residing in our larger congregate facilities are severely or profoundly retarded. Most of those with higher levels of mental retardation still residing in the larger facilities have other disabilities which make it difficult for them to function in the larger society.

6. Most of the people now residing in human development centers are "at risk" when they are living in the society at large. Many are at risk because they do not recognize the dangers existing there. My own twenty-three year old, disabled son has been injured far more at home than while living at Arkadelphia HDC. Last winter, he sustained a serious fall at home. He suffered abrasions and lacerations on his hand and abdominal area, but was not seriously hurt. He could have been severely injured or killed. This incident was reminiscent of the time when he lived with us full time. Briefly out of our sight, he walked into the street and sat down. We were shocked to find him there with a car stopped two feet away blaring its horn. There were hundreds of such incidents when he lived at home, from swallowing objects to cutting himself on sharp edges. Supporting him at home became an exhausting challenge, which was reason enough to justify his admission to an HDC. But more importantly, he has learned at Arkadelphia HDC things we could never teach him. In addition to the structural support systems there, he has access to training and treatment opportunities which he would not have at home.

7. When I first became active in the national and state controversy, I thought advocates for de-institutionalization were simply ignorant of the realities. It has been a chilling, shocking revelation to me and my family to learn that many of the advocates, usually professionals and families of people with different or lesser impairments, are actually willing to accept the dangers for our most severely afflicted people in the

community. They make such statements as "life is not worth living if it is in an institution" and "in the balance between freedom of the community and isolation and segregation of institutions, we must have the freedom of community." It is becoming recognized - what many families have recognized all along - that community living arrangements are for some people far more restrictive than the larger facilities, which is the basis for a new revelation in the DD field called "paradigm." Many advocates are now saying that only living in private residences is acceptable (with families or in foster care) for disabled people. Nothing better illustrates our contention that the de-institutionalization movement in this nation has been filled with deception and misrepresentation than this new concept of "paradigm change," which means simply "model or pattern." The new model is to send the disabled people from residential care facilities, large and small, to their homes, and if their parents cannot accept them or are no longer living, send them to foster care.

7. I am enclosing for your information copy of an amici curiae brief which I wrote to the United States Supreme Court in the Heller, recently decided. I send it only for the information it provides. The views expressed reflect the positions of virtually all families whose disabled families reside in the larger centers. In a period of seven days when I was writing this brief, 103 parent organizations nation-wide requested to join the brief as amici. There was not adequate time to make contact with many other groups, which have since indicated they would have joined also.

8. The U.S. Supreme Court in its decision delivered on June 25, 1993 resoundingly affirmed the rights of parents to participate in proceedings concerning their disabled children. The Court accepted the position argued by VOR; the Court denied arguments made by many old-line advocacy groups in our nation which took the other side of the issue.

FAX COVER SHEET

TO: OFFICE OF ASSISTANT TO PRESIDENT FOR DOMESTIC POLICY

ATTN: ROSALYN KELLY

FAX # 456-2878

FROM: CAROLE LYNN SHERMAN

VOICE OF THE RETARDED

ONE (1) PAGE IN ADDITION TO COVER SHEET

TO: OFFICE OF ASSISTANT TO PRESIDENT FOR DOMESTIC POLICY

ATTN: ROSALYN KELLY

FROM: CAROLE LYNN SHERMAN

JULY 12, 1993

RE: VOICE OF THE RETARDED MEETING WITH CAROL RASCO MONDAY,
JULY 12, 2:00 P.M.

Following are the ten (10) participants at our meeting:

Carol L. Sherman	Arkansas
Carolyn Cowans	Tennessee
Mike Sullivan	Wisconsin
Carolyn Walsworth	Illinois
Marty Pratt	Illinois
Louise G. Underwood	Kentucky
Polly Spare	Pennsylvania
George O'Donnell	Wisconsin
Alexine Wells	California
Sandra L. Held	Louisiana

P6/b(6)

Thank you for your cooperation.

VOICE OF THE RETARDED

5005 Newport Drive
Suite 108
Rolling Meadows, IL 60008

(708) 253 - 6020 - Phone

(708) 253 - 6054 - FAX/Phone

July 8, 1993

Ms. Carol Rasco
White House Domestic Policy Advisor
The White House
Washington, D.C. 20500

Dear Ms. Rasco:

When I read the June 18, 1993 article about you in the New York Times I realized that you are in a unique position to help with the health care plans for the developmentally disabled. As the mother of a retarded son and daughter and president of this national organization I believe that one of the most tragic consequences of the current system is that it has often divided parents and set them against each other.

Some feel that all developmentally disabled people should be in small group homes integrated into a community. Others believe the severely disabled need the greater protection of a large campus-like facility.

Our organization believes that different levels of retardation require different levels of care and we therefore take a both/and rather than an either/or position on this question. The retarded are not all alike. Some can prosper well in the mainstream. Others will be easy victims, particularly those with fragile medical conditions, blindness, deafness, or a dual diagnosis of mental illness and mental retardation. Some will be a danger to themselves and others.

We have two requests. A group of parents from Minnesota prepared a 16 minute videotape that illustrates the position of those who want state operated large facilities for their adult children. We are enclosing it for your review. In addition, many of these parents are coming to Washington, D.C. the week of July 11 to advocate for long-term residential care for these severely disabled people. We would like you to meet with them while they are in the capital. Since time is short, we would appreciate a phone call to let us know your decision.

Yours sincerely,

Polly Spore
Polly Spore
President

Phone 215-348-4059
or 202-638-1616 after Friday July 9

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

Non-Profit • Tax Exempt • Voluntary

Call & tell
this woman
I have very
limited time
wk. of 11/15 because
I'm leaving the
next week
for Hamp's
surgery.
Offer her
a time or
two of no
more than
30
minutes
some
morning
9 or
later.

JUL 9 1993

5 Page

MESSAGE BY FAX TO: CAROL RASCO
DOMESTIC POLICY ADVISOR TO THE PRESIDENT
FAX NO. 202-456-2878

FROM: CAROLE L. SHERMAN



DATE: JULY 9, 1993

RE: REQUEST FOR MEETING WITH NATIONAL HEALTH
CARE ADVISORY BOARD MEMBER/MEMBERS
REGARDING LONG TERM CARE FOR SEVERELY
RETARDED CITIZENS

DEAR CAROL,

I AM SENDING ALONG A MEMO OF INTRODUCTION FOR YOUR USE.
THANK YOU FOR YOUR CONSIDERATION IN ARRANGING A MEETING. I
WILL BE HAPPY TO COME TO ANY MEETING ALONE; OR, IF IT IS
APPROPRIATE, I WOULD LIKE TO BRING SOME FRIENDS WHO ARE
ACTIVE IN VOR.

I HAVE TOLD ONLY BILL AND THE PRESIDENT OF VOR (POLLY SPARE
OF PA) OF THIS REQUEST.

7-9-93
6:20 pm

Carol

Carole Lynn faxed this to
me and asked that I fax it on
to you.

F.Y.I.

Jerry

Withdrawal/Redaction Marker

Clinton Library

DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
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001. letter	From Carole L. Sherman re: VOR (2 pages)	07/09/93	P6/b(6)
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**This marker identifies the original location of the withdrawn item listed above.
For a complete list of items withdrawn from this folder, see the
Withdrawal/Redaction Sheet at the front of the folder.**

COLLECTION:

Clinton Presidential Records
 Domestic Policy Council
 Carol Rasco (Meetings, Trips, Events)
 OA/Box Number: 4592

FOLDER TITLE:

Voice of the Retarded 7-12-93 2:00 p.m.

rw147

RESTRICTION CODES

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

- P1 National Security Classified Information [(a)(1) of the PRA]
- P2 Relating to the appointment to Federal office [(a)(2) of the PRA]
- P3 Release would violate a Federal statute [(a)(3) of the PRA]
- P4 Release would disclose trade secrets or confidential commercial or financial information [(a)(4) of the PRA]
- P5 Release would disclose confidential advise between the President and his advisors, or between such advisors [a)(5) of the PRA]
- P6 Release would constitute a clearly unwarranted invasion of personal privacy [(a)(6) of the PRA]

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

PRM. Personal record misfile defined in accordance with 44 U.S.C. 2201(3).

RR. Document will be reviewed upon request.

Freedom of Information Act - [5 U.S.C. 552(b)]

- b(1) National security classified information [(b)(1) of the FOIA]
- b(2) Release would disclose internal personnel rules and practices of an agency [(b)(2) of the FOIA]
- b(3) Release would violate a Federal statute [(b)(3) of the FOIA]
- b(4) Release would disclose trade secrets or confidential or financial information [(b)(4) of the FOIA]
- b(6) Release would constitute a clearly unwarranted invasion of personal privacy [(b)(6) of the FOIA]
- b(7) Release would disclose information compiled for law enforcement purposes [(b)(7) of the FOIA]
- b(8) Release would disclose information concerning the regulation of financial institutions [(b)(8) of the FOIA]
- b(9) Release would disclose geological or geophysical information concerning wells [(b)(9) of the FOIA]

EDITOR'S NOTEBOOK/Bernard Rimland, Ph.D.

Community, my foot!

The LAPD, autism, and residential alternatives

Many months have passed since the vicious unprovoked beating of motorist Rodney King by members of the L.A. Police Department first appeared on our TV screens. Most of us have seen the replays so often that we can summon them to our mind's eye without the benefit of electronic equipment.

The Rodney King affair unleashed a storm of public outrage and protest. Calls for reform were widely heard and many suggestions for improving police accountability, in Los Angeles and elsewhere, were made. Some reforms have been adopted. Despite the highly emotionally charged situation, there were, so far as I know, no calls for the total abolition of the Los Angeles Police Department, nor the abolition of other police departments elsewhere, where similar incidents have since surfaced. It is widely understood and accepted that even though there are instances of abuse, police departments perform an important and necessary social function, and the good they do far outweighs the bad.

Contrast the above situation with what has occurred during the past several decades with regard to "mental" institutions. Historically, people with serious mental incapacities such as schizophrenia, severe retardation, or autism were left to wander the streets of cities and towns, defending themselves as best they could from attack by others, scrounging food from wherever they could find it, including the gutter, trying to find shelter from cold and snow. To create a safe and humane environment for these unfortunate individuals, society created asylums—places of safety and refuge—far

ilions everywhere, and a concerted effort to get patients out of institutions into what is euphemistically called "the community."

The deinstitutionalization movement took hold with a vengeance. Countless thousands of people who are unable to cope with the problems of survival in a harsh and uncaring society were dumped into the streets, or into small, privately run facilities, under the supposed protection and care of a large number of expensive, but inadequate and ineffective, "community mental health centers."

Deinstitutionalization proved to be a cure worse than the disease. At least five books have been published in the past three years detailing its tragic consequences. Seymour Sarason of Yale University, one of the leaders of the deinstitutionalization movement in the U.S., describes these efforts in his recent autobiography, *The Making of an American Psychologist*. He concludes that the most serious professional mistake of his life was his advocacy of deinstitutionalization. (I tip my hat to you, Dr. Sarason. Few of us have the courage and integrity to own up to our mistakes.)

As the legions of poorly fed, physically and mentally ill homeless persons on our streets attest, moving people out into that wonderfully warm and nurturing mythical "community" wasn't necessarily a bright idea. Some of the institutions they left were excellent places; others were terrible. Some of the community places they were moved to were excellent; others were terrible.

If abuse and neglect are going to occur, they can occur far more easily and more secretly in small group homes in the com-

parison at all. I am aware of institutions where real community, caring people, long term relationships, exist in abundance.

Community once implied human relatedness. Now it refers merely to an urban area. Community living—with no other options—is an ideology pushed with religious fervor by the sanctimonious but misguided Association for Persons with Severe Handicaps (TASH). I read with grim amusement the complaint in their most recent newsletter: "Although persons with severe disabilities have been living in the community physically for some time, they have not generally been participating in the shared life of those communities." What shared life? Community, my foot!

Let us not be misled by the warm fuzzy feeling that the word "community" is intended to instill. Let us not be misled into the feeling of abandonment and neglect that the word "institution" has come to connote. I am in touch with literally thousands of parents of autistic children and adults throughout the world. Many of these children are maintained in healthy, happy, and to them and their parents, satisfying environments on farms and ranches and in institutions, public and private, that parents do not want to see closed or abandoned.

While many, perhaps most, urban group homes are excellent, I disagree strongly with those who insist that urban group homes must be the only residential option. I favor the existence of a variety of options to fit different family and individual needs and preferences. We need not only urban group homes but rural residences,

Terry or Mary-Mara Rasco 501 663 9278

P. 01

JUL 09 '93 06:21 EXOTIC 375-4752

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P. 4

7

Community, my foot!

The LAPD, autism, and residential alternatives

Many months have passed since the vicious unprovoked beating of motorist Rodney King by members of the L.A. Police Department first appeared on our TV screens. Most of us have seen the replays so often that we can summon them to our mind's eye without the benefit of electronic equipment.

The Rodney King affair unleashed a storm of public outrage and protest. Cries for reform were widely heard and many suggestions for improving police accountability, in Los Angeles and elsewhere, were made. Some reforms have been adopted. Despite the highly emotionally charged situation, there were, so far as I know, no calls for the total abolition of the Los Angeles Police Department, nor the abolition of other police departments elsewhere, where similar incidents have since surfaced. It is widely understood and accepted that even though there are instances of abuse, police departments perform an important and necessary social function, and the good they do far outweighs the bad.

Contrast the above situation with what has occurred during the past several decades with regard to "mental" institutions. Historically, people with serious mental incapacities such as schizophrenia, severe retardation, or autism were left to wander the streets of cities and towns, defending themselves as best they could from attack by others, scrounging food from wherever they could find it, including the gutter, trying to find shelter from cold and snow. To create a safe and humane environment for these unfortunate individuals, society created asylums—places of safety and refuge—far better than living the life of homeless and despised vagrants on the streets. Many of these institutional asylums did a wonderful job. Others did a very poor job, and permitted terrible abuse and neglect of the residents to occur.

Along came television. Guess what? The public was not treated to the spectacle of clean, well-fed and well-treated mental patients basking in the sun or participating in exercise classes in well-equipped gyms. Instead the public was shown the worst of the "snake pits," *Christmas in Purgatory*, and the horrible revelations about patients' lives at Willowbrook, were presented to national audiences. This of course is to be expected, and is in fact a good thing, because it exposed problems that required reforms and led to the establishment of state and federal guidelines. But it gave a very distorted picture of the true situation. How much national media coverage would have been given to secretly videotaped images of LAPD officers helping little old ladies

across the street? The exposés of neglect and abuse at some institutions led to an indiscriminate smearing of the reputations of all institu-

tions everywhere, and a concerted effort to get patients out of institutions into what is euphemistically called "the community."

The deinstitutionalization movement took hold with a vengeance. Countless thousands of people who are unable to cope with the problems of survival in a harsh and uncaring society were dumped into the streets, or into small, privately run facilities, under the supposed protection and care of a large number of expensive, but inadequate and ineffective, "community mental health centers."

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As the legions of poorly fed, physically and mentally ill homeless persons on our streets attest, moving people out into that wonderfully warm and nurturing mythical "community" wasn't necessarily a bright idea. Some of the institutions they left were excellent places; others were terrible. Some of the community places they were moved to were excellent; others were terrible.

If abuse and neglect are going to occur, they can occur far more easily and more secretly in small group homes in the community than they can in a major institution with many other people present. Group homes can come and go very rapidly. Some last many years, others last only months. It is not unknown for the residents of such homes to be left on the street when the owner of the facility decides that he or she can no longer tolerate the stress of trying to find enough semi-qualified, minimum-pay, high-turn-over workers to care for the residents.

The word "community" needs careful examination. It derives from "common," and implies a degree of coherence, shared interests and concerns that is today rarely found in urban environments. The word "community" conjures an image of a white-haired grandmotherly lady at one's door, asking, "Can you use this freshly baked apple pie? We just have too many apples this year." When was the last time this happened in your neighborhood? Many group homes in the U.S. are located in places that would be better described as urban jungles than communities. I am aware of group homes in areas that are so dangerous that the social workers will visit them only in pairs—on those rare occasions when there is any su-

perision at all. I am aware of institutions where real community, caring people, long term relationships, exist in abundance.

Community once implied human relatedness. Now it refers merely to an urban area. Community living—with no other options—is an ideology pushed with religious fervor by the sanctimonious but misguided Association for Persons with Severe Handicaps (TASH). I read with grim amusement the complaint in their most recent newsletter: "Although persons with severe disabilities have been living in the community physically for some time, they have not generally been participating in the shared life of these communities." What shared life? Community, my foot!

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While many, perhaps most, urban group homes are excellent, I disagree strongly with those who insist that urban group homes must be the only residential option. I favor the existence of a variety of options to fit different family and individual needs and preferences. We need not only urban group homes but rural residences, such as farms and ranches. And we need institutions—good, well-run institutions—for some of our sons and daughters.

I believe that with the proper technology, all kinds of residential facilities can be run in safe and responsible ways. Both small group homes and large institutions could be monitored frequently by randomly scheduled surprise drop-in visits from inspectors who are employed by advocacy groups, rather than by the organization running the group home or institution. Monitoring by electronic surveillance provides another means of protection.

Last year we published in ARRI (4/3) an editorial titled "The Non-Urban Alternative," in which we advocated the availability of farm and ranch residences for autistic individuals, such as Bittersweet Farms or Rusty's Morningstar Ranch. For many months afterward, and even to this day, we receive enthusiastic letters from parents who want that option available for their children when they are no longer here to care for them. That rural option, the urban group home option, and the state institutional option should all be available so families can exercise freedom of choice.

The Boston Globe

FRIDAY, MARCH 26, 1993

'Home' for my mentally retarded son

PHYLLIS HARLOW

There is something terribly wrong with our state's policy toward serving the mentally retarded. Instead of being driven by the needs of individual clients and their families, it is fueled by the antigovernment sentiments of rigid ideologues. They are that large, state-operated institutions must be closed so that the money can be used for smaller, community-based facilities. It sounds nice, and indeed, some people can be served effectively this way. But the Weld administration's policy fails to consider the needs of severely handicapped individuals for whom group homes are inappropriate or simply unavailable.

My 37-year-old son Clifton is profoundly retarded and autistic. He has lived at the Paul Dever School in Taunton since age 9 except for a brief period in 1985. That year, ignoring my better judgment, I allowed Cliff to leave Dever for a vendor-run residence not far from our home.

After six months he had lost a lot of weight and the seizures to which he's prone were more frequent, sometimes followed by comas of up to 10 hours. His neurologist believed Clifton was dying. "We used to call it dying of a broken heart," he told me. "He's given up hope."

Cliff was returned to Dever on a stretcher. He lived for a year in the infirmary, where he gained 25 pounds. His seizure activity declined. He was allowed to wander the halls and play as he chose. He was at "home." The neurologist recommended that he not be moved again.

I wish I could feel confident that the doctor's recommendations will be followed. But I can't. I have seen the Department of Mental Retardation memos that talk

about closing the Dever School in September 1995. I know parents — many of them elderly — who are being asked to agree to move their sons and daughters. But why? Is it really in the client's best interest? Or is it simply part of the administration's determination to turn over more and more government services to private contractors?

Look what happened in California when the state turned over almost its entire system of care for the mentally retarded to private providers. An examination in 1989 and 1990 by the Los Angeles Times found "a widespread pattern of lethal neglect, physical and sexual abuse and financial exploitation of retarded people living in privately run facilities throughout the state."

I support the Dever School because it has an experienced, professional and devoted staff whose members know the clients and how to care for them. It is a safe, clean and modern facility with the medical resources and equipment that my son requires. Large windows look out onto beautiful surroundings and let in abundant sunshine. It is a stable and invaluable resource for my son. If he is forced to move, there is a real question as to whether he could survive.

Services for the mentally retarded shouldn't be seen as an "either-or" situation. Some individuals are able to live and function well in a community setting, but others need and deserve the care provided by state-run schools. As the Los Angeles Times noted in an editorial following its reports, "Honoring a general commitment to community care is not a good reason to ignore the fact that for some individuals state hospitals are more suitable."

Phyllis Harlow is the president of the Dever Association for the Retarded.

P6/b(6)

June 28, 1993

Mrs. Carol H. Rasco
Irene Apartments, No. 309
Chevy Chase, MD 20815

Dear Carol:

Enclosed is copy of a letter sent today to Hillary requesting a meeting with her and/or a member of her health care committee the week of July 12. I would appreciate your seeing that my request is not "lost".

Bill and I, as are most parents of profoundly retarded children, are most anxious to convey to those planning our nation's health care our concerns about our disabled children's future care. We are active members of VOR (Voice of the Retarded) and feel that parents/family members with our particular concerns have not been heard.

Your assistance would be appreciated.

Best,

As ever,



Carole L. Sherman

P6/b(6)

cc: Mrs. Hillary R. Clinton

P6/b(6)

June 28, 1993

Mrs. Hillary R. Clinton
1600 Pennsylvania Avenue
The White House
Washington, D.C. 20500

Dear Hillary:

I will be in Washington Sunday, July 11 - Tuesday, July 13, and I write to request a meeting with you and/or a member of your health planning committee. If possible, I would like to bring several friends and the purpose of our meeting would be to express our concern for our severely disabled children.

I am an active member of the Voice of the Retarded (VOR). VOR is, to my knowledge, the only nationwide advocacy group which is concerned for the welfare of our developmentally disabled population who are most impaired.

I look forward to your reply.

With all good wishes,

Very truly yours,

Carole L. Sherman

P6/b(6)

P.S. I am sending a copy of my letter to Carol because of time constraints, and not knowing if you would receive this.

cc: Mrs. Carol H. Rasco ✓