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Disabled - Voice of the Retarded

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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.

The Arc

Q&A

*a national organization on mental retardation*

# 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 Tommorrow"

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 Box 300649**
**Arlington, TX 76010**
For more information please call:
(817)261-6003/FAX (817)277-3491/TDD (817)277-0553

Revised February 1992

Plans to "abandon long term"
(because Medicaid will be ending)

# 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

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 Spare
President

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

## 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

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 feceral 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 fac ies.

## 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 STRENG H IN NI ERS**





Make checks payable