

Advocacy Network **Board of Directors**

President

Dr. William Knaus, Longmeadow, MA

Vice-President

Richard Gowen, Palmer, MA

Chairman, Legislative & Legal Affairs

Dr. Benjamin Ricci, Amherst, MA

Treasurer

Frank Pietryka, Bernardston, MA

Secretary

Gail Orzechowski, Palmer, MA

Editor, *Advocacy Network News*

Edward Orzechowski, Palmer, MA

Board Members

Ernestine Booth, East Longmeadow MA

Roland Charpentier, Westborough MA

David Cowles, South Deerfield MA

Diana Duff, East Longmeadow MA

Jonathan Hallett, Sandy Hook CT

Robert Jurczyk, Ware MA

Everett Kosarick, Amherst MA

Gail Orzechowski, Palmer MA

Kathleen Pietryka, Bernardston MA

Virginia Ricci, Amherst MA

Walter Ronan, Springfield MA

and \$11-million in FY2002. As a result, hundreds of DMR employees have lost their jobs or taken early retirement, negatively impacting the Department's ability to properly care for its client population, which has remained relatively constant.

The loss of many psychologists, registered nurses, speech pathologists, audiologists, occupational therapists, physical therapists, service coordinators, sociologists, along with countless direct care and support staff has resulted in an alarming increase in case loads. The quality of service has severely eroded, approaching the horrible conditions that existed thirty years ago, when the *Ricci* parents undertook an historic class action suit against the Commonwealth of Massachusetts.

***"... there is a systemic failure to
provide services to class members ..."***

– Judge Joseph L. Tauro

Advocacy Network's attorney, Beryl Cohen, who represents the class at the former Belchertown State School, Fernald, and Monson, states to DMR Commissioner Gerald Morrissey:

"In accordance with Paragraphs 7a and 7C(1) of the Order of the United States District Court (Tauro, J.) of May 25, 1993, the plaintiffs, by their counsel hereby give notice that for reasons that the Defendants have substantially failed to provide Individual Support Plans in compliance with the Order and as described in the Order, and further that the Defendants are not in substantial compliance with the Order with regard to systemic issues, the plaintiffs hereby seek to reopen and restore the above-entitled case to the active docket and to move for enforcement of the Court Order."

Contact Us At:

Advocacy Network
P.O. Box 2071
Amherst MA 01004-2071

adnetnews@hotmail.com

413-256-1313

The State is trying to close down the Fernald School in Waltham to save money; however, *Advocacy Network* questions any such savings if the level of services – required by Federal Court mandate – are to be maintained.

To get around this issue, the Department of Mental Retardation is attempting to transfer the retarded from Fernald by ignoring the Individual Service Plan (ISP) process, effectively circumventing parental or guardian involvement. The ISP was a hard-won victory in Federal District Court. Now the Department is attempting to arbitrarily avoid it.

Governor Romney is attempting to balance his budget on the backs of the most vulnerable segment of our population – the retarded – who cannot speak for themselves. Alarmed parents are concerned that the hard-won gains achieved after a 30-year effort in Federal District Court are being severely eroded by his continuing insensitivity.

Massachusetts Association for Retarded Children (MARC) is supposed to represent the interests of Wrentham and Dever, has not been heard from to date.

The loss of the ISP process is unacceptable for the parents who are concerned for their loved one's programs. This alone is sufficient for the *Ricci Class* to urge their attorney, Beryl Cohen, to take proper action. In the meantime, employees of DMR continue to be over-worked, and concerned with the deterioration of the services they provide.

Wondering who is next to be axed does not make for high morale.

A CALL TO ARMS!!!

Advocacy Network, the group that filed and won the historic class action suite – a thirty-year odyssey – is now asking everybody who is concerned about our most vulnerable segment of Massachusetts' population to give generously to the cause, whether they are parent, sibling, friend of the retarded, or DMR employee.

“We parents must pay attention to this continued erosion of services, if our hard-won

victory in Federal District Court is to be retained”, stated Dr. Benjamin Ricci, principal plaintiff in the original and historic class action suit.

“We are asking each of you loyal followers to dig a little deeper this year.”

– Dr. Benjamin Ricci

“Although we work for free, there are unavoidable legal costs to remain in court,” Ricci said. “We are asking each of you loyal followers to dig a little deeper this year. Those of you have allowed your membership to lapse, please think hard about whether you would like conditions for your loved one to become degraded to intolerable conditions again.”

“A generous donation to help us prevent this from happening is not only appreciated, but vitally needed”, stated Dr. William Knaus, president of *Advocacy Network*. Donations can be sent to *Advocacy Network*, PO Box 2071, Amherst, MA 01004-2071.”

What Can You Do?

As a member of *Advocacy Network*, or as a reader of this newsletter, you have the power to help reverse the course of these proposed budget cuts that would so adversely affect the lives of our relatives and friends with mental retardation.

Here's what you can do now:

1. Renew your membership in *Advocacy Network*, or join us now. Please see page 8 for info.
2. Ask a relative or friend to consider joining us. There is tremendous strength in numbers.
3. Make a donation to *Advocacy Network*. Join our Honor Roll of Donors listed on page 7.
4. Include *Advocacy Network* in your will or estate plan.
5. Call, write, or e-mail your legislators and Governor Romney. See page 6 for details.

Proposed State Budget Reductions Jeopardize Care For Mentally Retarded

Advocacy Network is taking steps to assure that the mandates of our federal Class Action lawsuit of 1973 and the Final Court Order of 1993 to protect our relatives and friends are not being ignored.

According to *Advocacy Network* Attorney Beryl Cohen, the Department is attempting to circumvent the ISP (Individual Support Plan) which permits input from family members and guardians regarding care for the retarded.

“DMR has recently created a Placement Planning Process for the displacement of all current residents at the Developmental Centers at Fernald, Glavin, Hogan, Monson, Templeton, and Wrentham ... [which] circumvents and denies to family members and guardians the timely opportunity to invoke an Appeal Process, and Informal Conference, a Fair Hearing, and Judicial Review as guaranteed by the ISP,” Cohen stated in an April 6 correspondence to DMR Commissioner Gerald Morrissey.

Attorney Cohen also charges the Department with re-writing ISPs “... in the absence of family members, guardians, and team member professionals, with the purpose of intentionally

reducing costs, services and supports to residents ...

“Since the announcement in February 2003 by Governor Romney of his intention to close Fernald, DMR has taken steps directed at restricting the information describing service needs including clinical information and social work assessments that are included in Individual Support Plans,” said Cohen.

Regarding further budget slashing proposed by the Governor, Cohen said, “It is particularly troubling that the FY05 budget proposes to cut resources for clinical supports in community settings at the very same time that the Romney administration is moving to close the Fernald Developmental Center.”

Continued severe budget cuts mean increased caseloads for service providers, already stretched too thin.

“Of the nearly 1200 individuals currently resident in the facilities, nearly 75% of those individuals have been diagnosed with either profound or severe mental

“ ... since it has been announced that all of the existing Developmental Centers will be closed during Governor Romney’s term in office, there is no approved plan to accommodate the impact of necessary multiple moves and disruption, which will occur to the daily lives of the residents and their families.”

– Advocacy Network Attorney, Beryl Cohen

retardation,” Cohen said.

“At Fernald alone,” Cohen said, “approximately 90% of the residents are identified as profoundly or severely retarded. ... The staff reductions and inadequate efforts to fill the increased number of vacancies have directly resulted in increased caseloads for remaining staff, a lack of necessary supervision, and inappropriate reliance upon floating staff to cover professional and direct care responsibilities.”

And the impact of budget cutting and facility closures extends beyond Fernald.

“Further, since it has been announced that all of the existing Developmental Centers will be closed during Governor Romney’s term in office, there is no approved plan to accommodate the impact of necessary multiple moves and disruption, which will occur to the daily lives of the residents and their families,” Cohen said.

Dr. Benjamin Ricci of *Advocacy Network* concurs with the need to consider returning to court. “Our attorney, Beryl Cohen, is petitioning Judge Joseph Tauro that the systemic DMR problems merit attention,” Ricci said. “The ISP (Individual Service Plan) that we won in court is being challenged, and a lot of parents who don’t understand the force of the ISP are giving up too

President’s Message

You are the eyes and ears of the judge. It is important that you take an active role into looking into conditions with your own relatives, those for whom you are guardians, and the people living alongside them. Look at whether or not the services being provided meet your expectations and standards.

Look beyond the window dressing to examine what’s actually happening. Your awareness plays an important role in helping us to assure that Judge Tauro’s Disengagement Order is being implemented, and that the ISPs are solid.

Don’t be intimidated by people in positions of authority within DMR to accept less, and don’t be fearful that if you say anything the

much. And all the budget cutting means the mentally retarded are being given less help than they really need, which puts them at risk.”

According to *Advocacy Network* President, Dr. William Knaus, there are a number of reasons to press the court issue. “People with mental retardation living in the community are not at all adequately monitored,” Knaus said. “Those who also suffer from co-occurring forms of mental distress such as depression, anxiety, and substance abuse are grossly underserved.”

Knaus also expressed concern over the integrity of the ISP. “The numbers of people who are not receiving adequate Individual Service Plans under the Court Disengagement Order appears alarming. Substituting what the Department calls ‘support for services’ seems to be nothing other than a means of giving lip service to what they’re required to do,” Knaus said.

As you know, court proceedings are costly, and your renewed membership in *Advocacy Network* and/or generous donation will help fight this battle. Please renew your membership now, or send your contribution today. On behalf of our relatives and friends afflicted with mental retardation, thank you!

people for whom you are responsible will be hurt. They will be hurt even more through fear, and the way you conquer fear is through action. Decide what’s right and proper. Pursue that, and work with the *Advocacy Network* Board of Directors to see that sufficient funding is provided for professional services, healthcare, and adequate oversight.

If we don’t work together to stop this erosive process from continuing, then we’re going to face a situation that’s far worse than what Ben Ricci observed in Belchertown in the late 1960s and early ’70s.

– Dr. William Knaus
President



Contact Governor Romney, Your State Senator and Representative

One of the best ways to have a positive influence on the life of your relative or friend with mental retardation is to contact Governor Romney, your state senator and representative directly. Write a letter, make a phone call, send an e-mail. Here's a suggested brief message:

Recent budget reductions for the Department of Mental Retardation are adversely affecting the well-being of Massachusetts citizens with mental retardation. I care very much about the way my (son/daughter/friend, etc.) is being treated, and I hope you do, too. Please do everything in your power to assure that the DMR budget retains the funding required under the Order of United States District Court (Judge Joseph Tauro) of May 25, 1993.

Or offer your own personal message of the need for adequate funding to provide direct care services for your relative or friend. A personal account can be very effective.

Governor Romney may be contacted at:

**State House
Office of the
Governor
Room 360
Boston, MA 02133**

Phone: **(617) 725-4005**

e-mail: **Governor.Romney@state.ma.us**

U.S. mail: **State House
Boston MA 02133**

The switchboard at the State House will direct your phone call to the office of your own Senator or Representative.

Main number: **(617) 722-2000**

Complete listings of e-mail addresses, room numbers, and phone numbers for Massachusetts senators and representatives are available online.

Go to: **www.mass.gov** and click on **State Senators** or **State Representatives**.

Don't hesitate. It's easy, and politicians respond when constituents speak in a united voice.

Benjamin Ricci's just-published book

CRIMES AGAINST HUMANITY

is now available at the following online bookstores:

www.iuniverse.com

www.amazon.com

www.barnesandnoble.com

www.borders.com

ISBN 0-59566163-7 hardcover \$37.95

0-595-30398-6 paperback \$27.95

The next issue of

Advocacy Network News

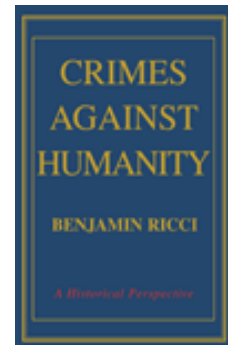
will focus on this impor-

tant work, a chronicle of

our landmark federal court

lawsuit and related history of Belchertown

State School.



You may also order through local bookstores.

Advocacy Network's **2004 Honor Roll of Donors**

Advocacy Network could not continue to function without your financial support. We are an all-volunteer organization, funded by the dues and donations of individuals who care about the well-being of the mentally retarded. Our Board of Directors thanks both the people listed below, and those many others who wish to remain anonymous, for their generous donations during 2004.

On behalf of all those who suffer from mental retardation, ***thank you all for your generosity!***
The following individuals contributed beyond the basic membership fee:

Arnold Anderson, Glastonbury CT
Lucy Wilson Benson, Amherst MA
Benjamin and Anna Delmonico,
West Springfield MA
Julie Guthrie
Frances Jones Highsmith,
Fort Akinson WI
Paul Leveillee, Woodridge IL
Rita Lively, Colrain MA
Lisa Mocera,
Bridgewater State College
Nicholas and Margaret Ruggeri,
Pittsfield MA
Dr. David Rush, Cambridge MA
Frances Saed
Dana Snyder, Amherst MA
Bernice Spitzer, Rockville MD
James Watt Jr., Wilmington MA
Lauren and David Wolff, Feeding Hills MA

Corporate Matching Gifts

Mass Mutual, Springfield MA
UnumProvident, Chattanooga TN

In Memoriam Gifts

Frederick and Judith Biegner,
North Kingstown RI
in memory of
Thomas Paul Andrews

Nancy and Mark Kitz,
West Hartford CT
Barbara and Philip LaFrance,
Taunton MA
Bruce and Barbara Lawson,
Feeding Hills MA
Ms. Josephine Navach,
Riverside RI
Charles and Donna Rounds,
West Springfield MA
Cosimo and Claire Serio,
Easthampton MA
Mary and Leborio Serio,
Northampton MA
all above in memory of
Constance Lownds

William McCarron, Ludlow MA
in memory of
Peg McCarron

Dr. and Mrs. Benjamin and Virginia Ricci,
Amherst MA,
in memory of Jack Leaman

Dr. and Mrs. Benjamin and Virginia Ricci,
Amherst MA,
in memory of father of Linda Bisi

Ms. Mary Lou Stankiewicz, Spencer MA
in memory of
Rhoda Ann Stankiewicz

ADVOCACY NETWORK
P.O. BOX 2071
AMHERST MA 01004-2071

Non Profit Org.
US Postage
PAID
Permit No. 129

Membership and Donations Form

Your dues dollars help us remain a strong voice for services for your relatives and friends with mental retardation. Please help us to continue to be your advocacy group by renewing your membership now, by becoming a new member, or by making a donation.

Please clip and fill out the form below, then mail it with your check to the address at the top of this page. *Thank you for your continuing support!*



ADVOCACY NETWORK CHARITABLE TRUST

Membership Dues
January 1, 2004 to December 31, 2004

Please Print Clearly

___ Membership \$20

___ Life Membership* \$200 or more

___ Supporting Membership \$50

___ Benefactor** \$1000 or more

\$ _____ Other Donation

*Payment may be spread over two years

**Payment may be spread over five years

___ Yes, you have permission to list my name and town on the Honor Roll of Donors page

___ Please do not include my name and town on the Honor Roll of Donors page

Mr. & Mrs. Mr. Mrs. Ms. Other

First Name

Initial

Last Name

No. Street

City

State

Zip

Telephone ()

Check #

___ Check here if above address differs from mailing label

Thank you!