

Advocacy Network News

*Fall Membership Drive
Please Renew Now!
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Effective Advocacy -- Our Only Service

November/December 2002

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President's Message

In the Mission of *Advocacy Network*, Your Voice Counts

Among those who act to protect the rights of persons with mental retardation, **Advocacy Network** stands tall. As an all volunteer organization, our only purpose is to protect the health, safety, and rights of individuals with mental retardation. We act to help assure that our most vulnerable citizens are safe from exploitation, poverty, abuse, unnecessary dangers, neglect, and misguided political agendas that put them at risk. As we act against these negatives, we simultaneously move toward securing positive outcomes in the form of better care, education, decent clothing and shelter, and opportunities for all to enjoy their lives to the best of their abilities.

Improving the Quality of Life

We act to improve the quality of life for those with mental retardation. We do this wherever we find people with mental retardation who are in trouble, or where there are opportunities to help better their lives. If someone has tattered clothing, we act to make sure that person has proper clothing. If someone is destitute, we act to correct that inequity. If someone wants to learn to cook, we support such interests as we are able. When we find a pattern of inequity throughout the Common-

wealth in the provision of mental health care, we fight for parity for mentally retarded people who feel pained from needless and extreme stresses. In these and in other ways, we work to make sure that the people we serve are not short-changed on their services, are treated respectfully, and have the best opportunities to preserve and to enjoy their lives.

There are many ways we protect the rights of those who cannot effectively speak up for themselves. We act through influencing the Department of Mental Retardation to support needed programs; through the courts when we have no other alternative; through the legislature to bring about protective laws; through the Individual Service Plan (ISP) to assure that necessary services are provided; through the media to bring matters of concern to the public's attention; and through raising money to pay our expenses. The list goes on.

*It volunteers
advocating for
retarded persons*

President, cont.

Members of **Advocacy Network** annually put in hundreds to thousands of hours of volunteer time in this quest to do the right thing for those with mental retardation. We receive no salaries or benefits for these initiatives. Our satisfaction comes from doing the right thing. But there is another value. If we do not speak up for those who cannot do so for themselves, each of us risks awakening one day faced with a handicapping physical crisis. Then, having no one to advocate for us, we'd become forgotten and left to suffer alone. So by collectively acting to protect those mentally retarded persons who cannot effectively protect themselves, we act for the general good of all.

As valued members of **Advocacy Network**, both your presence and your support are essential. We thank you for this participation. The Massachusetts Legislature and Department of Mental Retardation officials know that you are available to write letters, make phone calls, and exercise your right of petition to support your sons, daughters, brothers, sisters, relatives, and friends with mental retardation. This is a powerful message with great value. Without your presence, our uphill climb would be far steeper and the future misted with clouds of greater uncertainty. To this end, we welcome your ideas, observations, and support.

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In the months ahead, we will continue our usual responsibilities of directly serving persons with mental retardation and working with their families, friends, and guardians to make positive changes. Beyond that, your Board of Directors has authorized me to send the

following letter to Commissioner Gerald Morrissey, outlining areas of opportunity for positive change.

– Dr. Bill Knaus
President



Advocacy Network Board Seeks DMR Actions

[Re-printed below is the text of a letter from the Advocacy Network Board of Directors to Gerald Morrissey, Commissioner of the Massachusetts Department of Mental Retardation]

September 24, 2002

Gerald Morrissey, Commissioner
Department of Mental Retardation
500 Harrison Ave
Boston, MA 02118

Dear Commissioner Morrissey:

The Massachusetts Department of Mental Retardation serves approximately 4000 *Ricci Class* members and 25,000 non-class members. Following the 1974 Consent Decree, the Department has a special relationship with the plaintiffs representing the class, and a legal responsibility to assure that the services it provides to class members are consistent with the intent of the Consent Decree.

In light of this special responsibility, and the simultaneous responsibility of the Department to serve non-class members effectively, the agency has undertaken a Strategic Planning process to – among other things – improve and measure the delivery of services.

To this end, we say that the higher level of services expected for the members of the class would best be the uniform standards for all mentally retarded persons who are served, and

President, cont.

that this should be reflected in the Strategic Plan. The reverse – watering down services of the class to equal that of non-class members – would be unacceptable. In support of your strategic planning effort, we sent you a draft of this statement circa February 2002 so that we could collaborate. We understand that the Strategic Plan goes beyond the items specified in that draft, such as determining eligibility. Our goal was to open a dialogue.

The Strategic Plan affords an opportunity to better implement the provisions of the Disengagement Order wherein the Commonwealth promised to provide equal or better care and treatment to members of the class relative to the services mandated under the Consent Decree. The **Advocacy Network** Board of Directors takes this opportunity to identify issues we believe further the intent inherent in the Disengagement Order which can be partially established through the Strategic Plan.

To this end, we assert the following expectations for members of the class, and for all mentally retarded people served by the Department:

3. The Department would best measure how well its vendor agencies deliver contracted services according to the vendor's purpose. For example, a residential treatment center would best be judged according to whether it delivers the services that it is entrusted to deliver. The residents of a home for people who work for pay would best be judged on related factors such as job coaching.

4. The Department would wisely produce a report of the quality of services provided by vendor agencies who serve at least one member of the class. This report could include a summary of numbers of DPPC complaints, the percentage of health-care visits, timeliness and safety of transportation, mortality rate, mental health consultations, psychotropic drug rates, staff turnover rate, job coaching, social skills programs, and other conditions that can enable guardians and competent mentally retarded people to make fact-based judgments as to vendor selection. Without competition among agencies based on published quality-of-care data, services predictably degenerate.

We insist that each person's Individual Service Plan (ISP) be consistent with the framework designed by Benjamin Ricci and ordered by Federal Judge Joseph Tauro.

1. We insist that each person's Individual Service Plan (ISP) be consistent with the framework designed by Benjamin Ricci and ordered by Federal Judge Joseph Tauro.

2. We strongly want to see that the Department's quality assurance measures – for such diverse matters as timeliness of transportation, designated education activities, soap in the bathroom, food available, medical services provided, and so forth – are objective, measurable, reliable, and meaningful.

5. We want to see evidence that the Department concentrates its training dollars to help staff develop skills useful for the care, safety, and security of people with mental retardation. This training might include lessons in "individual differences," so that staff receive instruction on:

- (a) expected levels of functioning for people with different degrees of mental retardation, and
- (b) how to recognize and utilize each person's functional skills to his or her advantage.

President, cont.

6. The Department would best anticipate the changing needs of an aging class-member population, as well as for others who are entering their geriatric years, and plan for secure environments suitable for the care of such people. These settings would wisely have medical services readily available on grounds, and be monitored by an unbiased organization.

7. It is an essential function for the Department to provide necessary special services for people with mental retardation who have co-occurring biological, cognitive, emotional, or behavior distress conditions, including substance abuse, behavioral disorders, phobias, depression, anxiety disorders, and other conditions that require specialized services. The Department seems especially weak in recognizing and providing for the mental health needs of the people it serves. As a partial step, the Department would wisely conduct periodic epidemiology studies to determine the prevalence of major physical and mental health factors, access to health services by Region and by Area, and treatment outcomes.

8. We ask that the Department endorse the use of scientifically supported mental health treatment methods as they apply to the care of those with mental retardation who require specialized mental health services. The Department may approve the use of clinical treatment methods that appear relevant to treating a certifiable behavioral or mental condition, providing the treatment is definable, the process measurable, and the outcome identifiable.

9. The Department would best assure that the rights of people with mental retardation be respected. No person with mental retardation should be caused to look foolish as a result of placement into social experiments without informed consent. Insofar as the Department endorses the Social Role Valorization model as its prime philosophy, and insofar as this is a social experiment, people served by the Department

should not be the involuntary subjects of the Social Role Valorization social experiment. Guardians and competent mentally retarded people need to know the risks associated with the experiment, and to sign off on the risks prior to participating.

The Department would best assure that the rights of people with mental retardation be respected.

10. Modifications and revisions in the regulations made between 1990 and 1998 would best be reviewed by an independent tribunal for the purpose of revising those that are ambiguous or that promote negative practices.

11. The Department would wisely conduct studies prior to laying off clinical staff to determine the effects such layoffs would have on the health and welfare of those who are served. Such studies would best be open to public review prior to the formulation of recommendations.

12. The Department would wisely look for opportunities to consolidate Regions and Areas for purposes of reducing needless duplication of effort and cost. Reducing redundancy in administrative staff can lead to increased efficiencies. Beyond that, situating Regional Offices in functional but empty buildings on facility grounds saves dollars that would otherwise be expended for rent. Dollars thus saved can be spent for direct services, which is the Department's prime function.

Sincerely,

– Dr. William Knaus, President
For the Board of **Advocacy Network**



Murder and Mental Retardation

The murder of a homeless man quickly implicated a retarded person. This is the only occasion that we've had experience with this sordid crime. But it was extensively covered in the *Springfield Republican* [Aug 16, 2002], *Greenfield Recorder*, and *Boston Herald*.

The retarded persons do not appear to have been former residents of Belchertown State School, or members of the *Ricci Class* in the historic and precedent-setting class action suit in Federal Court, Boston. This is strictly a legal matter and we must allow the process to unfold. We shall remain involved. Service-Net, the vendor agency involved, will undergo our Board members' scrutiny.

Budget cuts have impacted the Department of Mental Retardation, and may be a factor in Service Net's failure to meet the needs of the perpetrator [and victim?] of this senseless crime. The negative publicity bodes ill for all persons with retardation. This alarms us.

Impact of Shrinking Budgets

How will shrinking budgets affect *Ricci Class* Members? This issue will require careful monitoring. The number of complaints reaching my ears from parents and relatives has been increasing of late. [Remember, you can reach us at any time at (413) 256-1313. Leave a message – Verizon is now providing us with messaging services.] I have met with our lawyer, Beryl Cohen, several times of late, and we are studying the possibilities of returning to Federal Court. If you are experiencing difficulties with your vendor or the Department, please let me know.

Time to Renew Your Membership

Advocacy Network has been "lying low" for the past couple of years. We have not asked for dues. While the fiscal situation in the Commonwealth has now become challeng-

ing, we must not allow the legislature to balance the budget on the backs of the retarded again. Court action requires money. Thus we are asking you to mail in your 2003 dues as soon as you are able to.

Thank you for your support!

– Ben Ricci
Chairman, Legal and Legislative Matters

Advocacy Network **Seeks COMECC Funding**

It is that time of year – COMECC time at the University of Massachusetts in Amherst. COMECC stands for the *Commonwealth of Massachusetts Employees' Charitable Campaign*.

The UMass retired faculty group, of which I am a lifetime member, has been alerted by Professor Arthur Clinton. He has sent to each of us a short, timely reminder to participate in COMECC. I am certain our response will be timely, as well as effective.

Of course, my favorite charitable group, one with a long history of effective advocacy, is **Advocacy Network**. We are listed under the COMECC campaign as **685602 Advocacy Network**. Those of us who have volunteered with **Advocacy Network** for many years will deeply appreciate your support.

You can also assist us by phoning or communicating with members of UMass faculty and staff to ask them please to consider their contribution for **685602 Advocacy Network**, and by thanking them for their support!

I ask for your full support and cooperation. *Thank you!*

– Ben Ricci, Professor Emeritus, Retired
UMass/Amherst

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Advocacy Network Needs You

Is it important in today's world to maintain an organization that advocates for people with mental retardation and their respective families, friends, and guardians? Your response to this question, in the form of membership, will determine the future existence of *Advocacy Network*.

Check your mailing label to see if you have paid dues for this year. If not, please help us to continue to be your advocacy group by renewing your membership now, or by joining as a new member. Please clip and fill out the form below and mail it with your check to the address at the top of this page. *Thank you!*

ADVOCACY NETWORK CHARITABLE TRUST

Membership Dues

January 1, 2003 to December 31, 2003

Please Print Clearly

— Supporting Membership \$50 — Life Membership* \$200 or more
— Membership \$20 — Benefactor** \$1000 or more
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*Payment can be spread over two years

**Payment can be spread over five years

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Thank you!