

President's Message

Last year my son, Zachary, lost his job. He had worked for a local department store for close to two years stocking shelves and helping customers. Zachary is mentally retarded. This job provided him with social interaction and a sense of purpose; it defined him as a contributor to society in his mind.

The pay was low and he worked only 20 to 25 hours a week, but it was enough for him to buy his favorite CD's and an occasional lunch at McDonald's. His job coach was great, his boss liked him, and all the other employees liked him.

We had finally weaned him off all medication. He was happy. His mother and I were happy for him. Since he had been on numerous medications to control his behavior, we had never thought this achievement would be possible. We had tried just about everything at one time or another. Nothing seemed to work, but now he was finally free of all medication. He was calm and mellow.

Then he was fired.

Zachary's job coach had been on vacation. His replacement didn't have the same rapport with Zachary and couldn't read him as well. There was an incident with an employee, a report was written, the boss was notified, and that was the end of it. At least that's what we thought at the time.

But the employee's husband filed a police report. Was it because most people think indi-

viduals with mental retardation are dangerous? Was that the reason?

To this day I am not sure why the report was filed, but it was enough to get Zachary fired. His boss didn't want to jeopardize his position with the company. That was understandable. And since no formal complaint was entered at the courthouse, the filing didn't warrant any action from the police.

The person filing the complaint didn't take that next step. Why bother? Zachary had been fired. End of story, problem resolved. The dangerous "retard" had been removed from the work site.

It took six months to find a new job for Zachary. In the meantime he became depressed. He lost a lot of weight. He started repeating phrases over and over, as if it gave him some type of relief. He felt bad and looked bad.

***His job coach was great, his boss liked him, and all the other employees liked him ...
Then he was fired.***

Without a job his world became boring. He had no purpose. He didn't meet new people. All social interaction had been reduced to a monthly dance in Northampton. There was nothing for him to do.

President, cont.

Having been laid off myself, I could easily empathize with what he was going through. He was depressed because he had lost his job. He was constantly reminded of this every time he went out for groceries because the department store where he had worked was next to the grocery store. In fact, because he had to pass the department store to go anywhere, he was reminded of his failure every time he left his house.

Zachary went back on medication for depression and behavior problems. It seems to have helped. After he started another new job delivering parts for an automotive store, he began to laugh more and he appeared to be more relaxed. He has been working for about four months now. Life for him is looking a lot better.

What about the person who filed the police report? That person would never know the results of his actions. Would it have made a difference? I don't know.

Many people don't come into contact with individuals with mental retardation. The attitudes in the community are learned. They are

learned from parents and friends who have only the negative and sensational stories to talk about regarding people with mental retardation.

There are many "good" stories, but "good" stories don't make interesting conversation. Attitudes concerning people with mental retardation will not change unless we actively show they can be safe contributors to our society.

How do we do this? We can encourage our local businesses to employ people with mental retardation. Many are already doing so. We need to thank them and let them know we shop at their stores because of this practice. *Big Y* and *Stop and Shop* actively employ people with mental retardation. I encourage you to talk to the managers of these stores and thank them for their participation in breaking down the attitudinal barriers that prevent people with mental retardation from achieving their full potential.

Jonathan Hallett
President



Testimonial Dinner In Honor of Ben Ricci

The Friends of Ben Ricci are planning an evening of recognition for this extraordinary individual who has devoted his life to advocating for those with mental retardation.

Have you made your reservations yet for this important event? If not, please see page 9 of this issue for more information, and mail your check today.

- What? Dinner Honoring Ben Ricci
- Where? Chez Josef Banquet House
176 Shoemaker Lane
Agawam MA
- When? Thursday, May 3
Cocktail Hour at 6 PM
Dinner at 7 PM
- Cost? \$50 per person

Please see detailed menu and ticket information on page 9.

Also, please see the tributes to Ben in our special feature to this special man on pages 7 and 8 of this issue of *Advocacy Network News*.

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*.

We are an all-volunteer advocacy group of concerned parents and guardians. As a united group we have influence over the Department of Mental Retardation and its contracted vendors. As individuals your voice can hardly be heard, but as a member of *Advocacy Network* your voice is heard throughout the Commonwealth.

As a member you have exclusive access to a number of dedicated advocates who can break down the walls of bureaucracy to get action on problems that negatively affect people with mental retardation. You get help when you need it, but membership is required to receive these services.

Without independent oversight and review, as provided by *Advocacy Network*, our government will make decisions that affect people with mental retardation based on what officials think is correct, not what the families, friends, and guardians know to be correct. *Advocacy Network* is your voice and your organization that can and will represent you.

Your membership is an investment that funds our phone calls, transportation, and newsletter. We need your support. 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. To renew your membership, or to join us now, please clip and fill out the form below and mail it with your check to:



ADVOCACY NETWORK CHARITABLE TRUST

Membership Dues

January 1, 2001 to December 31, 2001

Please Print Clearly

— Supporting Membership \$50 — Life Membership* \$200 or more
— Membership \$20 — Benefactor** \$1000 or more
\$_____ Donation

*Payment can be spread over two years

**Payment can be spread over five years

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Last Name

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Telephone (_____) _____

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Thank you!

Sincerely, Jonathan Hallett
President

Vice-President's Message

Those Living in the Shadows Have a Pressing Need for Services

As mentally retarded individuals integrate into the community, many are likely to experience uncertainties, interpersonal challenges, disruptions in their lives because of high staff turnover, helplessness in their ability to take charge of their lives, and other conditions that can evoke chronic stress.

What lines of evidence suggest we have a critical situation? We have epidemiology studies that affirm a higher prevalence of mental distress among the mentally retarded. There is a high rate of "shadow conditions" among mentally retarded persons including anxiety, depression, impulse disorders, alienation, and other stressful conditions.

*In the shadows they suffer,
and few know.*

In the shadows they suffer, and few know. Most who live in this shadow world often experience emotional distress they cannot express. Shadow conditions ordinarily go unreported and untreated.

There is more to this tragic story. After the United Kingdom closed its facilities for the mentally retarded, officials found an increase in the incidence of behavioral, sleep, and other disorders among deinstitutionalized mentally retarded persons. California found a 70-percent increase in the death rate among the

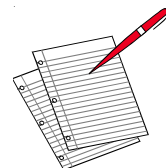
deinstitutionalized. Statistics in Massachusetts show a higher than expected death rate incidence among mentally retarded persons after they left the facilities.

We can attribute part of these stresses, behavioral disorders, and death rate increases to substandard community physical care, but many suffer because of shadow anxieties and other forms of undetected stress.

Stress is implicated in social difficulties and a long list of disease conditions including coronary heart disease, cancer, and gastrointestinal disorders. The evidence is compelling that persistent stress suppresses important aspects of a person's immune system, making the individual more vulnerable to opportunistic bacterial and viral infection. Much of this stress is unnecessary. There are many sound, tested psychological methods to help those mentally retarded persons who experience excess distress to leave the shadows and improve their chances for both good mental and physical health.

Because of the tremendous strides in the quality of care in Massachusetts' facilities, community-based programs have a long way to go to catch up. The time to start was yesterday. If we don't act soon, someone will have to pay the piper in the form of increased physical health-care costs.

**William Knaus
Vice-President**



What's In a Name?

Advocacy Network Opposes DMR Name Change

*“What’s in a name? That which we call a rose
By any other name would smell as sweet . . .
Romeo, doff thy name,
And for thy name, which is no part of thee,
Take all myself.”*

– *Romeo and Juliet*, Act II, Scene ii
William Shakespeare, 1594

In the famous balcony scene of William Shakespeare’s *Romeo and Juliet*, young Juliet Capulet urges her star-crossed lover, Romeo Montague, to discard his surname so the couple can spend their lives together, despite the fact that they come from long-feuding families.

Juliet wanted Romeo to drop his name because, in her family’s eyes, it carried a stigma beyond rapprochement.

Now, some 400 years later, the Massachusetts Department of Mental Retardation is researching a possible name change for much the same reason. The name is considered by some of the very people the agency serves to be offensive.

Last month, Alice Taverna, representing DMR’s State Advisory Council, told the **Advocacy**

and self-advocacy organizations nationwide to see what’s happening in other states where the mental retardation agency is considering, or has already made, a name change.

“The purpose of my subcommittee is to find out from other people who have been through similar circumstances the impact a change in name has had for them,” Taverna told the Board.

“The impetus has come from a groundswell of consumers who find the name [DMR] offensive; the department is trying to be responsive to them, which is appropriate, because it serves these individuals. It behooves the department to take a look at the idea.”

Mainly at issue is the use of the word

“retarded.” According to Taverna, many higher functioning persons afflicted with mental retardation feel it’s a negative label, especially when the word is used in an insulting context, such as when an individual is referred to as “a retard.”

But what are the alternatives? In places where a name

change has occurred or is under consideration, phrases such as “developmental services” or

“The impetus has come from a groundswell of consumers who find the name [DMR] offensive.”

– Alice Taverna,
State Advisory Council

cacy Network Board of Directors that she’s been charged with calling a variety of advocacy

“rehabilitation services” have cropped up. Or, says Taverna, at the very least, the words “people” or “individuals” have been incorporated into the agency’s title, for example, “Department of People with Mental Retardation.”

Taverna says she has been contacting ten to fifteen agencies nationwide, including some in California, Kentucky, Kansas, Vermont, Tennessee, the Carolinas, and Washington State.

“To a person,” Taverna reports of her survey, “they all said the name carried so much of a stigma – was so offensive – that they wanted the name changed if it already hadn’t been.”

The **Advocacy Network** Board of Directors, however, is unanimously opposed to changing the name “Massachusetts Department of Mental Retardation.” While recognizing that the word “retardation” can have adverse effects when used in a derogatory manner, Board members believe it nonetheless conveys a clear idea of the population being addressed, particularly to state legislators who handle the budget purse strings.

“Any name carries a stigma if people assign a negative connotation to it,” President Jonathan Hallett told Taverna, “so if we were to change it to ‘Developmentally Disabled,’ even that would eventually become a negative name.”

Advocacy Network

is also concerned that a softer, broader name could adversely affect funding for those afflicted with mental retardation, since terminology like “developmental disabilities” might spread funding over a wider population.

Board member Roland Charpentier, who also is an advocate with the Glavin group, says, “The current name of DMR gives the community at large a good sense of what people are being served. In essence, a name change would mean that resources now available to the retarded

would be stretched to include other people, thus reducing funding for persons with mental retardation.”

President Hallett concurs. “We clearly know, the Commonwealth clearly knows, and the legislators clearly know, when we talk about mental retardation, the type of person we’re discussing. ‘Developmental disabilities,’ as one of the proposed new labels, would lead to opening the door to all sorts of developmentally delayed conditions that may be transitory in nature.”

In a telephone interview following her meeting with our Board, Taverna said, “The people I’ve spoken with at state agencies where the name has been changed were very positive about it.”

She conceded, however, that a name change might bring about unforeseen problems. “Two persons I talked to suggested that when you do change the name, you should approach it very slowly because you can open a Pandora’s box. You need to know what you’re getting into.”

But President Hallett was adamant about **Advocacy Network’s** stand on the issue. “It’s a complete waste of time for the SAC to be examining a DMR name change when there are so many more significant issues, such as people



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-- Jonathan Hallett
Advocacy Network President

on the waiting list for services, people getting inadequate services, and DMR attempts at manipulation of vendors and families.”

Hallett concluded, “Mental retardation – while it may not be the greatest name – we all know what it means.” □

Keeping the Faith

A Testimonial Dinner

In Honor of Dr. Benjamin Ricci

On the evening of Thursday, May 3, *The Friends of Ben Ricci* will gather at Chez Josef in Agawam, Massachusetts, to pay tribute to an individual whose unceasing efforts have improved the lives of retarded citizens across the Commonwealth. Dr. Benjamin Ricci, the founder of **Advocacy Network**, known to most of us as “Ben,” will be honored for his lifetime of devoted advocacy for those who suffer mental retardation.

Featured speakers will be:

- “ Michael Dukakis, former Governor of Massachusetts
- “ Attorney Beryl Cohen, who successfully crafted the historic *Ricci vs. Greenblatt* 1972 class action suit, and who has served as **Advocacy Network** attorney for three decades
- “ Gerald Morrissey, Commissioner of the Massachusetts Department of Mental Retardation

Please look for more detailed menu and ticket information on page 9 of this newsletter. You may order your tickets by returning the form at the bottom of that page, along with your check payable to *Advocacy Network Charitable Trust* to:

The Friends of Ben Ricci
c/o Robert Jurczyk
27 Westbrook Avenue
Ware, MA 01082



Please order your tickets soon, as time is running short.

Below and on the following page you'll find testimonials from **Advocacy Network** members whose lives have been touched by the courage of this remarkable man. In all likelihood, if you are reading this newsletter, you have similar stories to share. If you'd like to have them placed in a scrapbook to be presented to Ben the evening of the dinner, and/or have them published in our next issue, please write to Ed Orzechowski at 4 Caroline Circle, Palmer MA 01069, or send an e-mail to edorz@massed.net or call 413-283-6012. Thank you!




Ben Ricci is a man with vision, hope and perseverance. He fought the State of Massachusetts in the '70s to put a stop to the injustices Belchertown State School students were suffer-

ing -- the inhuman living conditions, the lack of human care, love and contact, the dungeon-like conditions. In a time when not many dared speak out, Ben saw the injustices being committed and forced society and state leaders to take a

long, hard look at what was going on. He made us look at ourselves and how we treat one another.


Honor Ben? You bet, we should honor him! A commemorative dinner to express thanks to the man who has done so much for so many seems insignificant when you measure it against the many people Ben has assisted, and the lives he has touched over the years.

-- *Kathy Pietryka,*
Barnardston MA



Ben, you have been a mentor to me and my family, supporting my son John throughout the many years, being there for us. Although my husband Al passed away in 1994, I know he, too, would like to thank you for all you have done. I feel blessed to have you in my life, and call you my dear friend.

-- *Erni Booth,*
East Longmeadow MA



The testimonial for Ben is much deserved and long overdue. He has helped mentally retarded citizens and their guardians one at a time, and by the thousands in the *Ricci* court case. It is difficult to imagine an individual who has had a greater and more

positive impact on the lives of the mentally retarded than Ben Ricci.

-- *Richard Gowen,*
Palmer MA



Ben has been so many things to me. When I first became a member of **Advocacy Network**, I saw Ben as a leader who could move mountains to help the retarded. He exhibited strength that I had never before encountered.

Ben also had no fear. He wasn't afraid to stand alone for the people he cared for so dearly.

As I continued to attend meetings, Ben turned into a teacher. He taught me how to deal with problems I met regarding my sister's care, and not to be afraid.

I always knew I could count on Ben if I ran up against situations I couldn't resolve myself. All those times I left a message at his home for guidance, he never failed to return my call. And he would also check back with me later to make sure the problem had been taken care of permanently.

Ben was also a friend and still is. There has never been a time when our conversation ended that Ben didn't say, "Keep the faith!" Those three words have become very important to me. I carry them with me to every meeting I

attend concerning my sister. Ben has given me the faith to continue to advocate for the retarded wherever I am. He is truly a giant among men.

-- *Gail Orzechowski,*
Palmer MA



Living in the same town as Ben extracted a price, and a reward. I accompanied Ben to many an ISP meeting for others, assisting distraught or frustrated parents who were being denied adequate services for their disabled child. His presence always changed the dynamics. Solutions would soon follow.

Ben was indefatigable. I have accompanied him to innumerable court sessions, visits to the State House, DMR meetings over the past 25 years, and I hit only a fraction of his activity. We always left early in the morning and arrived at the Boston Common Garage before the morning commute . . . and some people thought that he actually lived in Boston. I needed toothpicks to prop up my eyelids.

Every time I go to my son's annual meeting, I thank Ben Ricci for giving me the tool of the ISP, and the courage to become my son's guardian. Without that I would be naked, and my son deprived.

-- *Everett Kosarick*
Amherst MA

Dear Friend,

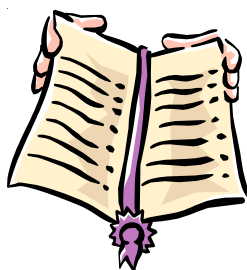
We invite you to join us in recognizing Ben Ricci for his 30 years of dedicated and effective advocacy for the mentally retarded. **The Friends of Ben Ricci** are planning a dinner and testimonial to express our thanks to him for his efforts on behalf of all mentally retarded citizens. The event is scheduled for Thursday, May 3, 2001 at Chez Josef Banquet House, 176 Shoemaker Lane, Agawam, MA. Dinner will be served at 7:00 P.M., with a 6:00 – 7:00 P.M. cocktail hour preceding the meal. The cost for this event is \$50 per person.

We look forward to seeing you and all of Ben's friends at Chez Josef, where we can personally greet him and show our appreciation for his many contributions to the cause of the mentally retarded.

Please, take a moment right now to complete the bottom portion of this announcement and mail it with your check payable to **Advocacy Network Charitable Trust** to:

The Friends of Ben Ricci
 c/o Robert Jurczyk
 27 Westbrook Avenue
 Ware, MA 01082

Thank you!
The Friends of Ben Ricci



Dinners	# of meals	Amount
<i>Roast Prime Rib of Beef, Au Jus</i>	_____	_____
<i>Boneless Breast of Chicken Supreme</i>	_____	_____
<i>Baked Boston Scrod</i>	_____	_____
<i>Portabello Mushroom Ensemble (vegetarian)</i>	_____	_____
Total	_____ @ \$50 ea.	Total _____

Name _____

Address _____

City/State/Zip _____

Phone Number _____

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to honor Ben Ricci