

## Greetings from Our New President

Please allow me to introduce myself as the newly-elected president of *Advocacy Network*. To all our membership and friends, I say “Hello.” Serving as president is a first for me, but I used to be a board member under Ben Ricci’s leadership, and can assure you that Ben taught us the power of pure advocacy. We all know the task of advocating for someone dear to our hearts is never-ending. But when we unite, we can use our power to make changes for the better.

I am legal guardian for my brother Jack. He grew up at home until he was eighteen, when Mom had a stroke. Dad and I were forced to place Jack at Belchertown State School. He is a *Ricci Class* member.

Jack now lives in a good home on Ohio Avenue in West Springfield, close to family. But even a “good” home needs constant vigilance. The power I get from *Advocacy Network* helps me to be smart when advocating for his rights. That is why I have returned to the board.

I experienced a real treat last summer. While vacationing on Cape Cod, I was invited to join the Special Olympics in Orleans, where a fine group of commercial fishermen took the Olympians for a day of saltwater sports fishing out of Rock Harbor. I was on *The Roxy*, a boat captained by Tom Hayes, along with three young gentlemen who were experienced fishermen. They caught over 60 fish! This was the 24th year for the Cape Cod Special Olympics, and I hope to be on board for the 25th cel-



**Attorney Beryl Cohen (seated, center) reviews legal issues in his Boston office, with *Advocacy Network* President Sheila Paquette and Board Member Ted Wysocki.**

eboration. I was so impressed with the dignity of that event. Amazing, what persons who care can do!

On a different note, members of our Board met with Attorney Beryl Cohen in Boston in July. Beryl assured us he will be honored to remain on retainer to support all of our legal issues.

During our Board’s August meeting at Holyoke Community College, we received Individual Service Plan (ISP) training from Don LaBrecque, of the Department of Mental Retardation. I hope you all know about this most important document. The ISP is the governing plan for all the services your son, daughter, brother, or sister receives. If you need

help, or a knowledgeable person to be at your annual ISP meeting, please write to us at the address on the mailing page of this newsletter, or send an e-mail to [adnetnews@hotmail.com](mailto:adnetnews@hotmail.com), and we will respond.

*Advocacy Network* is alive and well, ready to continue to support all persons who are developmentally challenged.

I invite you to attend our next Board meeting at Holyoke Community College at 6 p.m., on April 4.

Please introduce yourself when you come.

*Keep the Faith!*

—*Sheila Paquette*

## Our Mission

**A** *dvocacy Network*, originally incorporated in 1954 as the Friends of Belchertown, is an all-volunteer group of concerned parents, relatives and guardians of persons afflicted with mental retardation. Since they cannot speak for themselves, our mission is simply to promote and protect the health, human rights and safety of our relatives and friends who are impaired by mental retardation.

In 1993, under the leadership of Dr. Benjamin Ricci (author of *Crimes Against Humanity*) and Attorney Beryl Cohen, *Advocacy Network* fought a successful battle in U.S. Federal Court in Boston to force improvements in care for the state's mentally retarded citizens served by the Massachusetts Department of Mental Retardation and its privately contracted vendor agencies. The resulting Consent Decree issued by Judge Joseph L. Tauro in this landmark class action included creation of the Individual Service Plan (ISP), a legally binding process that provides input from family members and guardians in the care of their loved ones.

Under our vigilance, the ISP remains intact as the most important tool to safeguard the welfare of those with mental retardation. The membership and Board of Directors of *Advocacy Network* remains dedicated to this cause.



**Advocacy Network Board of Directors confer with Attorney Beryl Cohen (seated center) in Boston. Standing, left to right, are Gail Orzechowski, Everett Kosarick, President Sheila Paquette, and Richard Gowen. Seated beside Attorney Cohen is Ted Wysocki.**

### *Advocacy Network Board of Directors*

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# Important Information About ISPs

**W**hat is the ISP? How is it developed? How are guardians involved in the process?

These and many more questions about Individual Service Plans were discussed with Don LaBrecque at a recent Board meeting of *Advocacy Network*. Don works for the DMR Office of Learning and Development out of Monson.

He shared part of the ISP training workshop that is administered to employees. We know that a successful plan requires ideas and involvement from as many concerned people as needed. That would include the individual, his or her family members, guardians, and any other person with an interest in the individual.



**Donald LaBrecque, of DMR's Office of Learning and Development, presents an ISP workshop for *Advocacy Network* Board of Directors at Holyoke Community College. Seated is Board member Everett Kosarick.**

Don took us through the planning process, including Quality of Life issues, the ISP process overview, and the essential lifestyle planning component. We discussed the service coordinator's role, the individual's role, as well as the guardian's role.

One of the activities Don discussed revolved around a tear-shaped "diamond." We realize that

we are all unique people with positive and valuable characteristics. Often times, throughout our life, our diamond may start to be covered by experiences and messages from other people that might not be that positive. Some examples of this may be when we are ignored, called a name, or have our feelings negated. As time goes on, we may not be able to see the "diamond," and may actually forget that it is still there!

Don reminded us that we need to value ourselves and the individuals we support and care for, and to truly search beneath the layers of experiences to discover that diamond, and help it sparkle!

At the conclusion of our meeting, Don gave each one of us a "diamond" of our own to remember our evening.

A special *Thank You* to Don for sharing his time and information with us. And we encourage you, our readers and members, to contact *Advocacy Network* if you have any questions about the ISP.

—Erni Booth & Diana Booth Duff

## *Please Renew Today*

**Y**our dues dollars help us remain a strong voice for services for your relatives and friends with mental retardation.

Help us 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 on page 8, then mail it with your check to the address at the top of this page.

*Thank you!*

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# Looking for Help?

Caring for a family member or friend with mental retardation can be a great burden. When problems arise, sometimes you might not know where to turn for help.

*Advocacy Network* is currently assisting a guardian who came to us with a list of issues regarding his sister's care in a vendor-operated home. The gentleman was frustrated by a lack of response to a range of ongoing problems regarding medication, healthcare, transportation, finances, and human rights issues.

We are investigating these charges, and working with DMR to resolve the problems.

If you find yourself in a similar situation, a good place to start looking for answers is the with the Human Rights Officer and Advocate at the residence. Also ask to speak with the Human Rights Coordinator and Service Coordinator to address the issues at hand. (A list of phone numbers for DMR Human Rights Specialists follows on page 5, at the end of this article.)

Several members of our *Advocacy Network* Board of Directors also serve on the following Human Rights Committees and advisory boards in Central and Western Massachusetts:

telephone hotline—1-800-426-9009—operates 24 hours a day, seven days a week, including holidays.

And always remember that your ward's Individual Service Plan (ISP) is a *legal contract* to provide services for your relative or friend. In the case cited above, workers at the home said they had "no idea" what is in this woman's ISP, or even what an ISP is!

The ISP, designed by the late Ben Ricci, was hammered out in Federal Court before Judge Joseph L. Tauro, and remains a vital working document, defined in section 2.01 of the Code of Massachusetts Regulations (115 CMR), as: "**... a written plan of services or supports for an individual, which is developed, implemented, reviewed, and modified according to the requirements of the Department's regulations on individual service plans.**"

Section 6.20, paragraph (3) further states the following:

**Principles Governing Individual Support Planning.**

**(a) The following principles govern the planning and provision of supports by and through the Department:**

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***The Individual Service Plan  
is the most significant document  
in detailing the care prescribed for our family members and friends  
in the DMR system.***

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- Monson Developmental Center HRC
- Quabbin Valley HRC
- Pioneer Valley Homes HRC
- Hampden County HRC
- Commonwealth Community Services Advisory Board
- Western Massachusetts Regional Citizen Advisory Board

If you feel that a situation has been one of abuse, you may report it immediately to the Disabled Persons Protection Commission. The DPCC

- 1. respect for the dignity and rights of each individual;**
- 2. humane and adequate care and treatment;**
- 3. self-determination and freedom of choice to the person's fullest capacity;**
- 4. the opportunity to live and receive services in the least restrictive and most typical setting possible;**
- 5. the opportunity to undergo typical developmental experiences, even though such experiences may entail an element of risk; pro-**

vided, however, that the person's safety and well-being will not be unreasonably jeopardized; and 6. the opportunity to engage in activities and styles of living which encourage and maintain the integration of the individual in the community through individualized social and physical environments.

Make no mistake about it. From our perspective, the Individual Service Plan is *the most significant document* in detailing the care prescribed for

our family members and friends in the DMR system.

You can access further ISP information, and complete DMR regulations, online at:

[www.lawlib.state.ma.us/cmrr.html](http://www.lawlib.state.ma.us/cmrr.html)

Of course, if you have questions, you may also contact *Advocacy Network* by e-mailing us at [adnetnews@hotmail.com](mailto:adnetnews@hotmail.com), or by sending us a letter to the Post Office address on the mailing page of this newsletter.

In the near future, we hope to establish a website with further contact information.

## Human Rights Contacts

### DMR Office for Human Rights

500 Harrison Avenue  
Boston, MA 02118  
Phone 617-727-5608

### Central/West Region

Martin Rachels  
413-284-5006  
800-328-3123 x5006

### Central/West Facilities

Monson Developmental Center  
Mary Ann Trzcinski  
413-283-3411 x543

### Glavin Regional Center

508-845-9111 x189

### Templeton Developmental Center

978-939-2161 x2212

### Northeast

Richard Salandrea  
Hogan Regional Center  
978-774-5000 x528

### Southeast

Maureen Pereira  
508-866-5000 x325  
Wrentham Developmental Center  
508-384-1625

### Metro

Ana Diaz  
**Hogan Regional Center**  
978-774-5000 x541

## DPPC Hotline

Report Incidents of Suspected Abuse

by calling the

**Disabled Persons Protection Commission**

24 hours - 7 days a week,

including holidays

**1-800-426-9009**

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# In Memoriam

**Walter A. Ronan** of Springfield, a longtime member of *Advocacy Network*, passed away in July at the age of 73. For the past ten years, Walter served on our Board of Directors. Walter, a U.S. Army veteran, was buried in the Massachusetts Veterans' Cemetery in Agawam. The Board extends its sympathies to Walter's family, and thanks Walter for his service to his country and to *Advocacy Network*.

**Zoa "Dodie" Marie Chapman Halpin**, of Granville, passed away in January. She was 76. Having retired in 1998 from Friends of the Retarded in Westfield, she had served more than a decade as counselor and caregiver. *Advocacy Network* is saddened by the loss of this truly dedicated individual. "Dodie" was an exemplary caregiver.

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## Announcements

### The Legislature

There are two proposals before the Massachusetts Legislature this year that would impact the Department of Mental Retardation and the mentally retarded. Both were initially filed last year.

The first would require that any person seeking employment with DMR to have a national criminal background check.

The other would change the title of DMR to the "Department of Developmental Services." *Advocacy Network* is concerned that such a change might expand the number of persons served by the department, thus diluting services.

### The Department

DMR will present its 23rd annual Human Rights Conference on Tuesday, June 12, at the DCU Center in Worcester. This year's theme is "Making a Difference." Keith Jones, a community and disability activist and entrepreneur, will be the keynote speaker.

According to a DMR brochure, the conference

will include "Strategies, stories and inspirations for how affirming, promoting and protecting human rights can make a difference in people's lives."

DMR also offers an ongoing series of training workshops through its Learning Matters program. Although most are geared for staff training, "Rights Parents & Guardians Need to Know" is designed for parents and guardians of persons with mental retardation.

For more information about either this workshop or the Human Rights Conference, call Martin Rachels at 413-284-5006 or 800-328-3123, extension 5006.

### National Guardianship Association

The National Guardianship Association promotes standards for excellence in guardianship, and provides a wealth of information for guardians and families, including rights of individuals under guardianship, matters of ethics and confidentiality, medical treatment, and finances.

More detailed information is available on the NGA website at [www.guardianship.org/](http://www.guardianship.org/)

# Advocacy Network's Honor Roll of Donors

*Advocacy Network* thanks all donors listed here, and those who wish to remain anonymous, for your generous contributions in support of persons afflicted with mental retardation. We warmly welcome and deeply appreciate every donation, no matter the amount. Our late friend Ben Ricci exhorted all of us to "**Keep the Faith!**" Each of your gifts helps us to carry on his mission of advocating for those who cannot speak for themselves. **Thank you all for your support, your compassion, and your generosity!**

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continuing support!***



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***Thank you!***