

With All Due Respect

Since our last newsletter, a member of **Advocacy Network** called our helpline, seeking assistance. For confidentiality reasons, I'll call her Jane. This mother has a long history of dealing with the Department of Mental Retardation (now the Department of Developmental Services) in behalf of her son "Jim." Ben Ricci recounted one of those early incidents in his book, *Crimes Against Humanity*.

Many years ago, Jane lost custody of Jim, and the court appointed a guardian to make all decisions regarding his care. More recently, Jane had had a number of conflicts with the attorney who has now been Jim's guardian for quite some time, with staff at the privately operated home where Jim resides, and with DDS personnel. Without going into details, telephone contact and visits were among the main issues involved.

Jane said she had been bullied and intimidated by the legal guardian, house staff, and DDS. So she asked my wife Gail, who is also an **Advocacy Network** board member, and me to accompany her and a friend to an upcoming meeting of the involved parties. Jane said we should be prepared to be hollered at, verbally attacked, and treated disrespectfully, because that was how she and her friend had previously been treated. I said I doubted that anyone would act that way with **Advocacy Network** representatives present. After all, we had never even met any of the other individuals.

But when the meeting occurred at the area DDS office, that is exactly the scenario that played out. From the very outset, the attorney assailed the three of us. He questioned why Gail and I were even present, interrogating us like witnesses in a courtroom. He was condescending and demeaning toward Jane. It was a very hostile environment, with DDS officials exercising no control over the proceedings.

Session with the Commissioner

As a result, my wife and I requested an appointment with Elin Howe, Commissioner of the Department of Developmental Services, to lodge a complaint about how the session had been conducted. Assisting us was Colleen Lutkevich, Executive Director of COFAR, the Massachusetts Coalition of Families and Advocates, with which **Advocacy Network** re-affiliated a few years ago. When we met at the Commissioner's office in Boston, Deputy Commissioner Larry Tummino was also in attendance.

Our discussion was frank and cordial. Commissioner Howe said she had talked with the Area Director, and confirmed that the meeting we had experienced was antagonistic and disrespectful. In a follow-up letter she wrote: "... we expect that people would be treated in a professional manner in meetings such as the one you attended."

Since that session with Commissioner Howe, we have attended Jim's ISP meeting, again with

both Jane and Jim's legal guardian present. This meeting was conducted in a professional atmosphere. To his credit, the attorney guardian was civil, and has offered to continue communicating with us as representatives of **Advocacy Network**.

To be sure, serious disagreements remain in this case. But regardless of the fact that Jane no longer has custody of her son, she is still his biological mother, and a member of **Advocacy Network** with strong concerns.

Dealing with the bureaucracy of the Department of Developmental Services, its regulations and its contractors can be intimidating and emotionally draining. But remember that as a dues-paying member of **Advocacy Network**, you are not alone.

If you find yourself in a similar situation as the one we've described here, please do not hesitate to call the **Advocacy Network** helpline at 413-289-9030.

You deserve to be treated with respect.

—*Ed Orzechowski*

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Budget Battle Continues

Advocacy Network is working closely with COFAR, the Massachusetts Coalition of Families and Advocates, in the battle against privatization as Governor Patrick and DDS Commissioner Elin Howe seek to shutter state facilities for the developmentally disabled. In March, **Advocacy Network** participated in COFAR's annual "State House Stroll," part of a concerted lobbying effort in Boston to protest the announced closures of Monson, Templeton, Fernald (in Waltham), and Glavin (Shrewsbury) developmental centers, along with cuts to the Tufts Dental Clinic and the Disabled Persons Protection Commission.

As of this writing, several state legislators including Representatives Anne Gobi of Spencer, Todd Smola of Palmer, Rosemary Sandlin of Agawam, Brian Ashe of Longmeadow, Benjamin Swan of Springfield, and Christopher Donelan of Orange, have co-sponsored a budget amendment calling for a cost-benefit analysis to determine whether or not it actually would be less expensive to care for all the current residents of the above facilities in privately operated community homes. State Senator Steven Brewer of Barre is one of several co-sponsors of a similar bill in the Senate.

Unlike the situation when we fought to close Belchertown State School because of the horrendous conditions that once existed there, parents and guardians involved with the above institutions today are fighting to keep them open. There are many reasons. First of all, they are pleased with the care their loved ones are receiving. The majority of residents are medically fragile, have lived in these Intermediate Care Facilities a good part of their lives, and evicting them could have dire consequences. Another very significant issue is that the Department of Developmental Disabilities lacks the capability of properly monitoring conditions in vendor-operated homes.

In addition, the state employees who are direct care workers at these facilities are better paid than their counterparts in privately operated settings. This means the turnover rate is lower, so staff have long-standing relationships with residents. And while direct care workers in private facilities are low-paid, many of the executives of the large vendors have six-figure salaries. For example, financial statements from 2008-2009 show that the president of Vinfen in the greater Boston area earned more than \$376,000, and the president/CEO of Seven Hills in Worcester received more than \$520,000 in compensation. These are taxpayer dollars that are being funneled into the private sector with very little oversight.

Dental Care Being Cut Back

Regarding dental care, the Tufts clinic serves more than 2,000 persons with developmental disabilities in the Boston area, individuals who would have great difficulty finding private dentists to treat them. Marilyn Meagher, president of the Fernald League, said, "Where will they go? These are extremely handicapped people. It is going to be very devastating for them." (*The Boston Globe*, March 22).

The Patrick administration has announced a plan to keep the Tufts University Dental Facilities

clinic at the Fernald Developmental Center in Waltham in operation for up to another year. But here in Western Massachusetts, the Amherst branch of Tufts Dental already closed in February, consolidating services at its location on the campus of the Monson Developmental Center.

According to Terry O'Hare, Area Director of DDS Central West, the Monson Tufts clinic was upgraded not long ago with state-of-the-art equipment.

"The hours at the Monson clinic are being expanded," O'Hare said, "to absorb the individuals transitioning from the Amherst site, and no change in service is anticipated."

Make That Call!

Do you know who your state legislators are? If not, call us at **413-289-9030** and we'll find out. No matter what stage the budget discussion is in, it never hurts to contact your Representative and Senator to ask them to support funding for the care of your loved one. Phone calls, letters, and e-mails all work. But you have to make your voice heard. Remember Ben Ricci's signature motto: "*Keep the Faith!*"

Let Advocacy Network Help You

Advocacy Network maintains a telephone help line, U.S. Post Office box, e-mail address, and Internet website. If you need assistance with care problems, help with an ISP (Individual Service Plan), navigating DMR regulations, or any other needs, please don't hesitate to contact us.

We're here to help you!

You Can Reach Us At:

Advocacy Network

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413-289-9030

DDS Releases Funeral Policy

You may recall from our last issue that **Advocacy Network** had requested, then more than two years prior, a copy of the funeral planning protocol being used by the Department of Developmental Services. Terry O'Hare, Director of the DDS Central West Region, has since supplied that document. It includes sections titled: Planning for Final Arrangements, Services Available through the Department of Transitional Assistance, and Pre-Paid Burial Arrangements. [The complete document follows this article.]

According to O'Hare, the "Funeral Planning Document" is now being distributed to guardians and families, most often in person. Your loved one's Service Coordinator should be able to provide it, especially when reviewing the Individual Service Plan (ISP).

As a parent or guardian, it is important for you to know that the stated policy does not include the following significant section of DDS Regulations pertaining to an option for guardians to have funeral expenses deducted in advance from the individual's monthly Charges for Care:

Section 3.06: Charges for Care – Department Facilities

(6) Adjustment to Charges. If an individual who has necessary expenses but does not have sufficient funds to pay for these expenses in a particular month, the monthly fee-payor charge may be reduced by an amount that will enable the individual to pay such expenses. Expenses deemed necessary may include, but are not limited to, the following:

3.06(6); (g) Funeral related payments and expenses of the individual;

In addition, with the aging population of *Ricci Class* members, we remain concerned that **Advocacy Network** is still not informed about the passing of individuals in a timely manner. We would like to pay our proper respects, to let our membership know about these deaths, and to update our records.

It would seem only fitting that the organization

whose members brought the *Ricci* lawsuit, and which continues to advocate for these individuals, their families and guardians, would be so notified.

But the Department cites privacy protection as the reason for not releasing such information, even when obituaries have been published in newspapers.

We learn about the passing of *Ricci Class* members only when we happen to catch them, often by word of mouth.

Below is the complete text of the DDS "Funeral Planning Document"

PLANNING FOR FINAL ARRANGEMENTS

Contemplating the arrangement of a loved one's funeral and final resting place can be very difficult. It is even more challenging to make these arrangements at the time of death in the midst of dealing with your family's loss and shared grief. Without advance guidance, surviving family members may wonder about the right or "expected" thing to do. Pre-arrangement can lend a guiding hand to help them and reduce some of the stress and uncertainty. It will also assure that the person's personal preferences are honored and that the service will reflect their beliefs, values and lifestyle. This document was prepared to help you and your loved one to think about and begin arranging for their final resting place.

When you are ready, where do you start? First, discuss with your loved one about their thoughts and feelings on a funeral service and as appropriate include other family members, friends and clergy. In your discussions, identify where the person would like to be buried and local funeral homes with whom you might wish to work. Many funeral homes offer a free consultative visit to explain their services and costs. Specific arrangements should then be developed with the funeral home you select. How do you pay for a funeral? In 2009, the average cost for a funeral in the United States was around \$8,000 to \$10,000*. Funeral costs can vary widely for similar products and services so there is value in exploring more than

one option. Two to consider are the Department of Transitional Assistance (DTA) funeral benefit and private pre-paid burial arrangements. MassHealth recipients who do not have sufficient resources to cover the cost of a funeral are eligible for a small funeral and burial benefit from DTA. If you desire more services than can be covered by DTA, and for those who may not have MassHealth, you may want to consider a pre-paid burial arrangement. Both of these options are explained in more detail below.

SERVICES AVAILABLE THROUGH THE DEPARTMENT OF TRANSITIONAL ASSISTANCE

Under Massachusetts law, the Department of Transitional Assistance (DTA) will pay up to \$1,100 for funeral and burial expenses that do not exceed \$1,500. This amount may, however, be reduced by whatever financial resources exist in the estate of the deceased individual. This benefit is available for people who receive EAEDC, TAFDC, and SSI, and is available to individuals with MassHealth who have less than \$1,500 in assets at the time of death. Expenses that are covered would include a casket, transportation of a casket, embalming, and a burial plot. Cremation is covered only when you or your loved one has stated a preference for cremation. Monuments are not covered in this benefit.

Funeral homes may not bill survivors any amount that exceeds the \$1,500 limit. Since DTA will only pay \$1,100 of the \$1,500 funeral, there is \$400 that still must be paid to the funeral home.

PRE-PAID BURIAL ARRANGEMENTS

An alternative to the DTA option is to prepay for a funeral of the person's choice. Working with the funeral home, you set up an *irrevocable account*. You or your family choose what you want, including the type of coffin and vault. If specific arrangements cannot be decided upon at the time the account is set-up, the funeral home may offer the option of putting funds into an irrevocable pre-need burial plan as a "cash advance" noting that specific arrangements will

be selected later. These decisions cannot be changed by anyone after the person's death. Pre-paying locks in the cost of the funeral against inflationary price increases. This pre-paid burial account must be binding and must assure that there is no access to the principal or interest earned by the deposit in order to qualify for exclusion as an asset through MassHealth. Funeral directors must give you as part of any discussion of pre-paid funeral arrangements a copy of the *Buyers' Guide to Pre-Need Funeral Arrangements* to help you in your decision-making.

There are several ways to fund an irrevocable trust. The money for the account can be paid all at once or in installments. The prepaid account can be set up through a trust account or an insurance account. In a life insurance policy, the benefit is assigned to the funeral home. If the life insurance does not increase enough over time to cover your funeral needs, the person responsible for the account must pay any extra funds needed. The individual's monthly Social Security benefit(s) can be used to pay for a pre-paid funeral plan as long as the person's other needs are currently being met. If the individual is living in a 24/7 staffed apartment, he/she may be eligible to receive a deduction(s) to the monthly charge for care bill for the payment(s) made to the pre-paid funeral account.

We encourage you to consider both of these alternatives when you begin your planning with the funeral home. Once arrangements have been made, or at least, initiated, inform the service coordinator who will help to ensure that all the necessary information is documented in the appropriate places so that the plans and wishes you prepare with your loved one are followed.

* Information regarding individual funeral homes, services provided and associated costs is available from the Funeral Consumer Alliance of Western Mass (www.funeralconsumerswmass.org) and the Funeral Consumer Alliance of Eastern Mass (www.fcaemass.org)

Advocacy Network Honor Roll of Donors

Our deep gratitude to all listed here, and to those who wish to remain anonymous, for your support of persons afflicted with mental retardation. Our late friend Ben Ricci exhorted all of us to *"Keep the Faith!"* Each of your generous contributions, no matter the amount, helps us to carry on his mission of advocating for those who cannot speak for themselves.

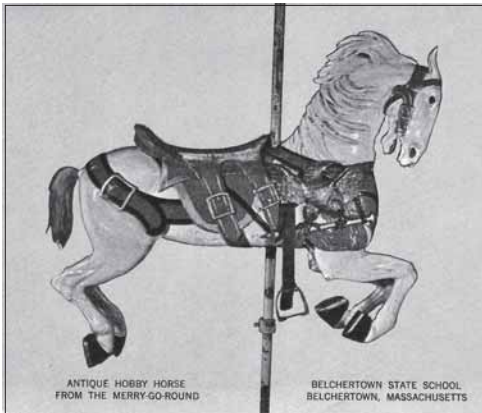
Thank you all for your support, your compassion, and your generosity!

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Mia Deanne Fiorello, Danvers
Flenoid Washington, *Ricci Class*, Feeding Hills MA
Paul Yeskie Jr., Northampton MA

Carousel Trust Fund Grants Awarded



The Belchertown State School Carousel Trust Fund Board in February awarded just over \$8,000 in grants. According to **Advocacy Network** Board member Richard Gowen, who also serves on the Carousel Trust Fund Board, 68 applications were received for this round of funding. The Board granted 48 of those requests.

Money for the Belchertown State School Carousel Trust Fund is generated through interest gleaned from investments since the fund was originally established, prior to the closing of the state school. With the current poor economy, available funds have

been down. While the maximum amount awarded to any individual is set at \$400, the average grant this year was about \$170.

The grants pay for items not otherwise covered by the Department of Developmental Services or provider agencies, such as vacations or trips to visit family members. Other activities funded this year included memberships to YMCA's, Weight Watchers, and classes in computer training, martial arts, and swimming.

The Carousel Trust Fund Board will again be accepting applications later this year. Please contact your loved one's Service Coordinator or DDS Area Office for specifics. And, of course, if you have questions, you may call the **Advocacy Network** Help-Line at 413-289-9030.

We'd Love to Hear from You!

In an effort to keep our database current, we have been calling the phone numbers of some of our **Advocacy Network** members, just to check in with you. Sometimes people move and circumstances change.

We're also looking for feedback from our members. For example, is your loved one's ISP up to date? Are the goals being met? Is he or she learning something new? Are the proper services being provided? If not, can we help?

A recent Board discussion focused

on the pros and cons of Do Not Resuscitate (DNR) orders. A DNR is a legally binding document which states that resuscitation should not be attempted if a person suffers cardiac or respiratory arrest. Do you have a DNR on file for your loved one?

If you would like to respond to any of the above questions, or if your mailing address, phone number, or other information has changed, please let us know by calling the **Advocacy Network Help-Line** at **413-289-9030**. Thank you!

Please Renew Today

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

We know these difficult times, so we have not increased *Advocacy Network* dues. But with so many serious state budget cuts being discussed, it is essential that we stay vigilant.

Help us continue to be your advocacy group by renewing your membership now, by becoming a new member, or by making a new donation.

Please clip the form on page 8, and mail it with your check to the address at the top of the page.

Thank you!

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